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6 HEARING:

7 LEGISLATIVE PROPOSALS TO SUPPORT

8 PATIENTS AND CAREGIVERS

9 WEDNESDAY, FEBRUARY 14, 2024

10 House of Representatives,

11 Subcommittee on Health,

12 Committee on Energy and Commerce,

13 Washington, D.C.

14

15

16 The Subcommittee met, pursuant to call, at 10:01 a.m.,

17 in Room 2123 Rayburn House Office Building, Hon. Brett

18 Guthrie [Chairman of the Subcommittee] presiding.

19 Present: Representatives Guthrie, Burgess, Latta,

20 Griffith, Bilirakis, Bucshon, Carter, Dunn, Pence, Crenshaw,

21 Joyce, Harshbarger, Miller-Meeks, Obernolte, Rodgers (ex

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22 officio); Eshoo, Sarbanes, Cardenas, Ruiz, Dingell, Kuster,  
23 Kelly, Barragan, Craig, Schrier, Trahan, and Pallone (ex  
24 officio).

25 Also present: Representatives Cammack; Tonko and  
26 Castor.

27 Staff present: Kate Arey, Digital Director; Sarah  
28 Burke, Deputy Staff Director; Nick Crocker, Senior Advisor  
29 and Director of Coalitions; Kristin Fritsch, Professional  
30 Staff Member; Grace Graham, Chief Counsel; Sydney Greene,  
31 Director of Operations; Rebecca Hagigh, Executive Assistant;  
32 Nate Hodson, Staff Director; Tara Hupman, Chief Counsel;  
33 Daniel Kelly, Press Assistant; Patrick Kelly, Staff  
34 Assistant; Alex Khlopin, Staff Assistant; Emily King, Member  
35 Services Director; Chris Krepich, Press Secretary; Molly  
36 Lolli, Counsel; Karli Plucker, Director of Operations  
37 (shared staff); Carla Rafael, Senior Staff Assistant; Emma  
38 Schultheis, Clerk; Catilin Wilson, Counsel; Lydia Abma,  
39 Minority Policy Analyst; Shana Beavin, Minority Professional  
40 Staff Member; Keegan Cardman, Minority Staff Assistant;  
41 Tiffany Guarascio, Minority Staff Director; Una Lee,  
42 Minority Chief Health Counsel; Katarina Morgan, Minority

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43 Health Fellow; and Andrew Souvall, Minority Director of  
44 Communications, Outreach and Member Services.  
45

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46           \*Mr. Guthrie. The subcommittee will come to order.  
47 Before I recognize myself for opening statement, I know that  
48 we all got the news this weekend that our chair is going to  
49 do other things, and we \_ and I will tell you it is  
50 absolutely a pleasure to serve with you as chair. I know  
51 all of us don't get a chance to say that, but I have the  
52 microphone now so I will. And it is just an honor and your  
53 leadership of this committee has been wonderful. I think  
54 both sides of the aisle will say that you have been a great  
55 leader.

56           I know we haven't all disagreed on everything \_ agree  
57 with both sides. I agree with you.

58           [Laughter.]

59           \*Mr. Guthrie. But I would say that \_ that was a good  
60 save, wasn't it? A good save. But I know that I think  
61 everybody here, I speak for everyone, is that what a class  
62 act you are \_

63           \*The Chair. Thank you.

64           \*Mr. Guthrie. \_ and how much you are going to be  
65 missed. And I know \_ I am sure, Anna, do you want a minute  
66 since we have \_ before we kick off?

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67           \*Ms. Eshoo. Thank you, Mr. Chairman. Well, the news  
68 that went out over the weekend, Madam Chairwoman, I think  
69 really took all of us back, it wasn't something that anyone  
70 anticipated. You have served in the House for 20 years, two  
71 decades, six years on Energy and Commerce.

72           [Applause.]

73           \*Ms. Eshoo. At the beginning of this Congress, we  
74 celebrated the first woman in the history of this committee  
75 to become the Chairwoman, and that historical fact will  
76 remain.

77           [Applause.]

78           \*Ms. Eshoo. That historical fact will remain. So we  
79 wish you everything good, that God will continue to bless  
80 you, your family. Thank you for your leadership of this  
81 committee. Thank you for your friendship. We have the rest  
82 of this year \_

83           \*The Chair. That is right.

84           \*Ms. Eshoo. \_ so let's get more done.

85           \*The Chair. That is right. For sure.

86           \*Mr. Guthrie. Absolutely.

87           \*Ms. Eshoo. Yeah. Thank you. Thank you, thank you.

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88           \*Mr. Guthrie. We are going to keep charging forward.  
89    So thank you, and again thank you for your class and  
90    everything.

91           So now we will begin opening statements for members and  
92    I will recognize myself for five minutes.

93           Thank you to our witnesses for being before the  
94    subcommittee today. The bills in front of us today are  
95    designed to promote greater and improve access to care for  
96    Americans and their families. There are also \_ they are  
97    also complementary to our work on lowering healthcare costs  
98    for all Americans that we have worked together bipartisan  
99    moving forward with that. We are considering legislation  
100   that will continue programs to detect, to diagnose, and to  
101   treat chronic diseases and health conditions at earlier  
102   stages, improve the quality of life for individuals with  
103   disabilities, help ensure Americans in rural communities  
104   have access to lifesaving care, and provide additional  
105   resources to assist in the development of cutting edge  
106   treatments for debilitating health conditions.

107           Today's hearing will help inform our policy making as  
108   we explore how current programs are working and if any gaps

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109 that exist may be addressed to improve the quality of life  
110 for millions across the country. For example, my bipartisan  
111 bill, H.R. 7218, the Billing Our Largest Dementia  
112 Infrastructure for Alzheimer's Reauthorization, or BOLD,  
113 Act, will \_ would continue programming to ensure individuals  
114 living with Alzheimer's have access to the highest quality  
115 of healthcare while building on efforts to identify and  
116 diagnose the disease sooner.

117         The BOLD Reauthorization Act also includes educational  
118 resources for caregivers to help ease the challenges for  
119 those caring for the loved ones with this vicious disease.  
120 These continued investments are more \_ even more important  
121 now that we have treatment to slow the progression of  
122 Alzheimer's and will help to ensure patients and their  
123 families have more time together. And I say that as one who  
124 just lost my mother-in-law to that disease in October. I  
125 would like to thank Representative Tonko for leading this  
126 legislation with me and I look forward to working to get  
127 this important bill reauthorized this year.

128         Another crucial bill we are considering today is the  
129 Charlotte Woodward Organ Transplant Discrimination

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130 Prevention Act that is led by Representatives Cammack and  
131 Dingell, which will prohibit healthcare providers and other  
132 entities from denying or restricting an individual's access  
133 to organs \_ to organ transplants solely on the basis of the  
134 individual's disability. This bill is on work we did last  
135 week led by Chair Rodgers who has been a champion for  
136 individuals with disabilities by passing the Protected  
137 Healthcare for All Patients Act out of the House of  
138 Representatives to ensure individuals with disabilities are  
139 treated fairly and are able to access the treatments they  
140 need.

141 We will also consider the DeOndra Dixon INCLUDE Project  
142 Act which will authorize current programs at the NIH to  
143 continue cutting edge research on Down Syndrome and address  
144 gaps in current research initiatives. The INCLUDE Project  
145 will continue to facilitate improved coordination across NIH  
146 and build upon research that will improve the quality of  
147 life for those living with Down Syndrome.

148 Other bills being considered today are designed to  
149 improve access to care for individuals in rural communities  
150 as well as diagnose potentially fatal yet treatable chronic



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151 diseases such as heart disease and certain cancers. The  
152 SIREN Reauthorization Act led by Representative David Joyce  
153 will continue providing resources for rural emergency  
154 medical providers to ensure they can maintain their  
155 essential services.

156 H.R. 7189 will reauthorize programs to help address  
157 gaps in care for individuals with congenital heart disease.  
158 Efforts like this have helped to ensure over 90 percent of  
159 kids who are diagnosed with congenital heart disease live  
160 well into adulthood. Many of the bills we are considering  
161 will promote greater access to care, facilitate earlier  
162 detection, diagnosis, and interventions, and help  
163 individuals live longer and healthier lives.

164 Thank you to all my colleagues who have worked hard to  
165 get the legislation before us today. I appreciate all of  
166 our panelists for being before us today and I thank  
167 everybody for their leadership in working on these policies.

168 [The prepared statement of Mr. Guthrie follows:]

169

170 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

171

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172           \*Mr. Guthrie. And I will yield back. And the chair  
173 will now recognize the ranking member, Ms. Eshoo, for five  
174 minutes for questions \_ or for opening statement, sorry.

175           \*Ms. Eshoo. For opening statement. Thank you, Mr.  
176 Chairman, and good morning, colleagues, and Happy  
177 Valentine's Day to everyone. It was always a wonderful  
178 celebration in our household because it was my mother and  
179 father's wedding anniversary.

180           So today the subcommittee will consider 19 bills to  
181 authorize critical public health programs that support and  
182 improve the health and wellbeing of children, of adults, and  
183 of caregivers. I am so pleased the majority of the bills,  
184 18 of the 19 bills, that we are taking up today are  
185 bipartisan. Each bill before us today supports individuals  
186 and families at the most vulnerable times in their lives.

187           I am sure most members of our subcommittee, I think all  
188 members of this subcommittee, have experienced at least one  
189 if not more of these vulnerable moments in their lives. I  
190 have and so have most Americans. Emergencies involving  
191 children are terrifying, most especially for their parents.  
192 The Emergency Medical Services for Children Reauthorization

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193 Act, led by Representative Castor, gives parents peace of  
194 mind by reauthorizing the only federal program dedicated to  
195 enhancing medical care for children during an emergency.

196 Representative Cardenas's Lifespan Respite  
197 Authorization Act supports people who serve as the primary  
198 caregiver for an aging or sick loved one. Being an unpaid  
199 caregiver is physically and mentally exhausting.  
200 Reauthorizing this program will ensure caregivers get a  
201 temporary break.

202 Finally, the SHINE for Autumn Act, introduced by  
203 Representatives Castor and Kelly, closes gaps in stillbirth  
204 data, research, and awareness to ensure every mother can  
205 have a healthy pregnancy and life with their baby. So many  
206 Americans experience one of these vulnerable moments each  
207 day. If someone you love was facing health challenges or in  
208 trouble, I think each one of us would go to the ends of the  
209 Earth to help them. We should give families confidence that  
210 when they seek out help, these programs will be there for  
211 them.

212 Together these bills bring us closer to the goal of  
213 quality healthcare for all Americans and show the vital

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214 importance of federal agencies such as the CDC and HRSA.  
215 Our seven witnesses, and thank you for being here today,  
216 will explain what people in these moments need and how these  
217 bills can help. I look forward to hearing your  
218 recommendations for how Congress can maintain and improve  
219 these essential programs.

220

221

222 [The prepared statement of Ms. Eshoo follows:]

223

224 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

225

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226           \*Ms. Eshoo. I now would like to yield the remainder of  
227 my time to Congressman Tonko. He leads three bills before  
228 our subcommittee today which offer crucial resources to  
229 detect Alzheimer's Disease early, reduce risks, and support  
230 the caregivers who take care of their loved ones.

231           \*Mr. Tonko. Thank you, Ranking Member Eshoo, for  
232 yielding, and I thank you and Chair Guthrie for your focus  
233 on Alzheimer's in today's hearing, and I thank you all \_  
234 thank all of our witnesses for their expertise and their  
235 insight shared this morning. Special thanks to Dr. Joanne  
236 Pike, CEO of the Alzheimer's Association and CEO of the  
237 Alzheimer's Impact Movement for joining us today and for the  
238 terrific work that you do and the great leadership you  
239 provide.

240           I am honored to be in the fight to end Alzheimer's. I  
241 have carried many of the bills for the organization and  
242 proud of that fact. As was indicated, many families have  
243 been impacted by this disease. I know so many in our  
244 community and around the Nation who are suffering from this  
245 disease and whose families carry a heavy burden indeed.

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246 Alzheimer's is the most common form of dementia and is  
247 unfortunately growing and growing fast. Unfortunately, one  
248 in three seniors dies with Alzheimer's or another dementia.  
249 In 2023, Alzheimer's and other dementias cost our Nation an  
250 estimated 345 billion dollars. It is something that we  
251 should be very noteworthy of.

252 Ever since my first days in Congress, I have pushed for  
253 strong action to support those living with Alzheimer's by  
254 driving medical research, federal coordination, early  
255 detection, and public health infrastructure, and of course  
256 support for caregivers. I invite all of my colleagues here  
257 to support NAPA Reauthorization, BOLD Reauthorization, and  
258 the Alzheimer's Accountability and Investment Act to  
259 continue our fight against Alzheimer's and to support the  
260 millions of Americans living with this devastating disease.

261 Again, I thank the ranking member for yielding, and  
262 together let's provide much needed hope.

263 [The prepared statement of Mr. Tonko follows:]

264

265 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

266

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267           \*Mr. Tonko. Thank you, and I yield back.

268           \*Mr. Guthrie. The gentleman yields back to the  
269 gentlelady and the gentlelady yields back, and I will now  
270 recognize the chair of the full committee, Chair Rodgers,  
271 for five minutes for her opening statement.

272           \*The Chair. Thank you, Mr. Chairman. First, just let  
273 me say thank you to all of you, to the chair, to the ranking  
274 member, to my colleagues, to the extraordinary staff given  
275 my announcement last week. What \_ I am blessed. I am  
276 blessed. And it has been a tremendous blessing to lead this  
277 committee, just extraordinary. I can testify that being the  
278 chair of the House Energy and Commerce Committee, the best  
279 committee on Capitol Hill, is the best position in the  
280 House, and it has been a privilege and honor for me to lead.

281           And I will just say, you know what, we are going to  
282 finish strong. We have a whole year ahead of us and we have  
283 a lot of work to do, and I look forward to working with all  
284 of you on important issues, including the issues that are  
285 before us today, the bills before the Health Subcommittee.  
286 So just a big thank you everyone.

287           I have said it many times and I will continue to say

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288 that this committee is extraordinary because it has a rich  
289 history of plowing the hard ground necessary to legislate  
290 and it means coming together to get things done, to get  
291 results. And I am proud of our efforts so far this  
292 Congress, like the Lowering Cost, More Transparency Act,  
293 which are fundamental to driving down the cost of care and  
294 fixing our broken healthcare system.

295         And today we are focusing on 19 bipartisan bills that  
296 support patients, caregivers, and healthcare providers.  
297 Specifically, we will examine proposals to help improve our  
298 understanding of various diseases, disabilities, chronic  
299 conditions, and stillbirths. We will look at legislation to  
300 continue support for emergency medical services and  
301 healthcare providers, to reauthorize respite care resources  
302 for family caregivers, and to prevent organ transplant  
303 candidates from being denied a transplant based solely on  
304 having a disability.

305         I look forward to hearing from our witnesses today,  
306 thank you for being here, about the importance of these  
307 programs. I especially am excited to be moving forward on  
308 the DeOndra Dixon INCLUDE Project Act of 2024 that I have



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309 introduced alongside with Representative Diana DeGette, Tom  
310 Cole, Rosa DeLauro, and Eleanor Holmes Norton, and I expect  
311 all of you to cosponsor this bill. Anyway.

312 [Laughter.]

313 \*The Chair. You all know that my mission here has been  
314 to improve the lives of individuals with disabilities, and  
315 that is why I am proud to champion this bill that would  
316 provide important congressional oversight and direction for  
317 the INCLUDE Project at the National Institutes of Health.  
318 It was established by a congressional directive in 2018,  
319 INCLUDE, and it is also known as the Investigation of Co-  
320 Occurring Conditions Across the Lifespan to Understand Down  
321 Syndrome Project, and it conducts research on critical  
322 health and quality of life needs for individuals with down  
323 syndrome throughout their lives.

324 And at the time INCLUDE was established, down syndrome  
325 was among the least funded genetic condition at NIH despite  
326 being the most common chromosome abnormality. So I just  
327 wanted to underscore how important it was that Congress took  
328 action to make sure that down syndrome was a priority at  
329 NIH. The individuals with down syndrome are affected by

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330 many of the same diseases and conditions that we are  
331 examining across the board.

332         The good news is that individuals with down syndrome  
333 are living longer than ever, but they are developing  
334 Alzheimer's or dementias like at a hundred percent. There  
335 is no case of an individual with down syndrome being \_  
336 having a tumor cancer, yet they have a higher likelihood of  
337 juvenile leukemia. And so when we are looking at research  
338 that benefits those with down syndrome, we also have the  
339 potential as we continue to focus on the 21st chromosome and  
340 some of the specific issues related to those with down  
341 syndrome that will benefit millions of people who battle  
342 these other conditions, whether it's Alzheimer's, cancer,  
343 heart conditions, that are not just \_ that are common but  
344 hardly limited to people with down syndrome. So this is  
345 bipartisan legislation directing NIH to continue this  
346 important work on down syndrome research to help everyone  
347 with down syndrome and their families.

348         And, you know, I will just say once again we have a lot  
349 of work ahead of us. These are important bipartisan bills,  
350 and I look forward to continuing to work with each one of

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351 you over the rest of this Congress to continue to improve  
352 the lives of the people that we have the honor and privilege  
353 of representing all across this country.

354       A big thank you again to the witnesses for traveling,  
355 for being here today, sharing your insights and expertise.  
356 We look forward to your testimony.

357       [The prepared statement of The Chair follows:]

358

359 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

360

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361           \*The Chair. And with that, I yield back.

362           \*Mr. Guthrie. Thank you. The chair yields back. The  
363 chair will now recognize the ranking member of the full  
364 committee, Mr. Pallone, for five minutes for an opening  
365 statement.

366           \*Mr. Pallone. Thank you, Chairman. I want to start by  
367 praising Chair Cathy Rodgers, who is of course the first  
368 woman to chair the Energy and Commerce Committee in its more  
369 than 200-year history. Cathy, I really enjoyed working with  
370 you over the years, but especially the last three years as  
371 you served both as ranking member and as \_ now as the chair.  
372 I think you have made a lot of progress in this committee's  
373 effort to accomplish things, including this year, the  
374 bipartisan legislation to lower healthcare costs and  
375 increase transparency in hospital pricings.

376           And, you know, I \_ it just \_ you are leaving \_ I still  
377 don't want you to leave, but I always say that and then  
378 nobody listens to me. But, you know, it is going to be a  
379 big loss for Congress and this committee, and \_ but I don't  
380 want to dwell on it too much because we still have the rest  
381 of the year and we can still accomplish a lot so \_

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382           \*The Chair. That is right. We got to get it on the  
383 President's desk.

384           \*Mr. Pallone. Exactly. So I am going to leave it at  
385 that for today and talk about our work today which is to  
386 consider 18 bipartisan bills to reauthorize and create  
387 several important public health programs.

388           This subcommittee will hear from a diverse panel of  
389 expert witnesses representing families affected by mental  
390 health, trauma, and discrimination, and I am pleased that we  
391 will be discussing H.R. 6839, the Cardiomyopathy Health  
392 Education Awareness Research and Training in Schools Act, or  
393 the HEARTS Act, which I introduced in December. The HEARTS  
394 Act will save lives by increasing awareness of cardio \_  
395 cardiomyopathy and helping prepare schools to deal with  
396 cardiac emergencies when they occur.

397           When I announced the introduction of this bill, I was  
398 drawn by members of two New Jersey families that each  
399 tragically lost a young son to this condition during high  
400 school sporting events. The legislation directs the  
401 Secretary of Health and Human Services to develop guidelines  
402 on the placement of automated external defibrillators, or

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403 AEDs, in schools and to provide resources to help schools  
404 create and implement a cardiac emergency response plan. And  
405 the use of AEDs during a cardiac emergency increases the  
406 chance of survival from five percent to over 50 percent,  
407 which could save up to 40,000 lives each year.

408       Aside from the HEARTS Act, there are many bills before  
409 us today that reauthorize important public health  
410 initiatives. I will start with the need to reauthorize  
411 several autism spectrum disorder programs as autism is one  
412 of the fastest growing developmental disorders affecting one  
413 in 36 children in our Nation. Today we will hear the impact  
414 of three important bills to extend funding for family-led  
415 organizations to help children with special healthcare  
416 needs. The bills reauthorize crucial research, training,  
417 and monitoring for autism research until 2029 and  
418 reauthorize respite care provided to children and adults  
419 with special needs.

420       Another challenge before us is helping Americans with  
421 Alzheimer's Disease. We know an estimated 6.7 million  
422 Americans over the age of 65 are living with Alzheimer's  
423 dementia and it is the fifth leading of cause of death for

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424 people 65 and older. We will discuss three bills that will  
425 support continued coordination of federal planning to  
426 promote healthy, aging \_ well to promote \_ I said healthy,  
427 aging, and bolster the national Alzheimer's project and  
428 support early detection, diagnosis, and dementia caregiving.

429 We are also discussing legislation that would provide  
430 support to our Nation's healthcare providers who have  
431 experienced unprecedented levels of stress and burnout that  
432 was only exacerbated by the COVID-19 pandemic. Today we  
433 will hear directly from a family who has turned tragedy into  
434 lifesaving relief for our healthcare professionals by  
435 creating a program to implement evidence based strategies to  
436 reduce and prevent suicide, burnout, and substance use  
437 disorders among those who are on the front lines of patient  
438 care. And we will also examine bills to reauthorize grant  
439 funding for improving emergency medical services in rural  
440 areas, supporting our poison control grant program, and  
441 providing states with access to services and support for  
442 people with traumatic brain injuries, and we will discuss  
443 bipartisan bills to support a broad variety of public health  
444 initiatives focused on stillbirth, down syndrome, and cancer

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445 screenings for women.

446           So there is a lot going on today, all very positive,  
447 and I look forward to hearing from our witnesses about the  
448 impact these programs have on the American people and our  
449 overall public health infrastructure.

450           [The prepared statement of Mr. Pallone follows:]

451

452           \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

453



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454           \*Mr. Pallone. So with that, Mr. Chairman, I yield back  
455 the balance of my time.

456           \*Mr. Guthrie. The gentleman yields back. That  
457 concludes members' opening statements. We will now go to  
458 our witness opening statements, and I will introduce each  
459 witness and I will call on you one by one to \_ for your five  
460 minutes.

461           So Dr. Andy \_ our first witness will be Dr. Andy Shih,  
462 Chief Science Officer of Autism Speaks; Mr. Corey Feist, Co-  
463 Founder and CEO, Dr. Lorna Breen Heroes Foundation; Dr.  
464 Joanna (sic) Pike, President and CEO of Alzheimer's  
465 Association; Dr. Gordon Tomaselli, Former President of the  
466 American Heart Association; Ms. Michelle Whitten, President,  
467 CEO, and Co-Founder of Global Down Syndrome Foundation; Mr.  
468 Randy Strozyk, President of American Ambulance Association;  
469 and Dr. Christina Annunziata, Senior Vice President of  
470 Extramural Discovery Science, American Cancer Society.

471           So thank you all for being here. You will have five  
472 minutes for your opening statement. Four minutes into your  
473 opening statement \_ you will see a green light for \_ to  
474 begin with, and after four minutes a yellow light, and it

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475 gives you a signal you got a minute left, and when you see  
476 the red light, it is time to wrap up. So we appreciate you  
477 all being here and we will begin by recognizing Dr. Shih for  
478 five minutes for your opening statement.

479

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480 STATEMENT OF ANDY SHIH, PHD, CHIEF SCIENCE OFFICER AUTISM  
481 SPEAKS; COREY FEIST, JD, MBA, CO-FOUNDER AND CEO, DR. LORNA  
482 BREEN HEROES FOUNDATION; JOANNE PIKE, DRPH, PRESIDENT AND  
483 CEO, ALZHEIMER'S ASSOCIATION, MARILYN AND STANLEY M. KATZ  
484 DEAN, EMERITUS AND PROFESSOR OF MEDICINE, ALBERT EINSTEIN  
485 COLLEGE OF MEDICINE, ADJUNCT PROFESSOR MEDICINE, JOHNS  
486 HOPKINS UNIVERSITY SCHOOL OF MEDICINE; MICHELLE WHITTEN,  
487 PRESIDENT, CEO, AND CO-FOUNDER, GLOBAL DOWN SYNDROME  
488 FOUNDATION; RANDY STROZYK, PRESIDENT, AMERICAN AMBULANCE  
489 ASSOCIATION; AND CHRISTINA ANNUNZIATA, MD, PHD, SENIOR VICE  
490 PRESIDENT OF EXTRAMURAL DISCOVERY SCIENCE, AMERICAN CANCER  
491 SOCIETY

492

493 STATEMENT OF ANDY SHIH, PHD

494

495 \*Dr. Shih. Thank you, Mr. Chairman. Good morning.  
496 Happy Valentine's Day to all members of the committee.  
497 Thank you, Chairman Guthrie, Ranking Member Eshoo, Chairman  
498 \_ Chair McMorris Rodgers, and Ranking Member Pallone, and  
499 all members of the committee for holding this hearing, for  
500 inviting me to testify on the Autism CARES Act of 2024. I

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501 would also like to thank Representative Chris Smith and  
502 Representative Henry Cuellar for their leadership  
503 introducing this important bill.

504 I am Dr. Andy Shih, Chief Science Officer for Autism  
505 Speaks, a national nonprofit organization dedicated to  
506 creating an inclusive world for people with autism  
507 throughout their lifespan. We do this through advocacy,  
508 services, support, research, and advances in care.

509 This committee has long recognized the urgent need to  
510 invest in autism research and training programs to ensure  
511 better care and wellbeing for autistic people. The Autism  
512 CARES Act is a remarkable example of how bipartisan  
513 collaboration can propel progress.

514 The most recent data indicates one in 36 children and  
515 one in 45 adults are on the autism spectrum in the United  
516 States. Like everyone else, each autistic person has unique  
517 strengths and challenges. Over the past two decades, we  
518 have seen a fundamental change in our understanding of  
519 autism and, most important, acceptance of autistic people.

520 At the same time, in large part due to research that  
521 the Autism CARES Act has funded \_ funded, we have a much

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522 clearer picture of the significant disparities that autistic  
523 people experience in terms of access to quality healthcare,  
524 daily life support and services, and employment  
525 opportunities. We know that autistic people struggle with  
526 myriad of co-occurring health conditions at a much higher  
527 rate. For example, about three-quarters of autistic  
528 children have one or more mental health conditions.  
529 Inextricably linked to these challenges are that many of  
530 these inequities that exist within our society are  
531 exacerbated for people with autism, which can often lead to  
532 poorer outcomes.

533       To be sure, we have come a long way. Around 30 years  
534 ago the NIH was spending less than 10 million dollars a year  
535 on autism research and autism was thought to be  
536 extraordinarily rare. Since the first version of the Autism  
537 CARES Act was signed into law, we have seen tremendous  
538 progress. The Autism CARES Act has been the single greatest  
539 driver of autism research investment and training programs  
540 for future health professionals who serve autistic people  
541 led to countless advancements in our understanding of autism  
542 from biology of condition to the medical complexity that

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543 affect autistic individuals at much higher rates.

544 Through support of clinical and community-focused  
545 program, Autism CARES Act ensures this knowledge reaches all  
546 families through improved services, personalized  
547 interventions, and toolkits for autistic-specific  
548 challenges. This work has formed the critical foundation  
549 for moving forward. With reauthorization of the Autism  
550 CARES Act, we will build on the progress made to close the  
551 significant gaps that remain to \_ for too many autistic  
552 people and ensure that every autistic person is able to  
553 reach their full potential. This includes investing in more  
554 research focused on the daily life challenges of autistic  
555 adults and improving our understanding of autism and aging,  
556 such as the elevated risk for dementia and heart disease.

557 It includes furthering research on how to reduce  
558 disparities in autism diagnoses and access to services,  
559 includes ensuring that we are researching how to best  
560 support autistic people who are non-speaking or may need  
561 additional communication support. It includes investing in  
562 more research in how we can best meet the healthcare and  
563 safety needs of autistic people who require 24-hour care,

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564 may struggle with harmful behaviors, and so much more.

565 I would just close with this thought. With increasing  
566 autism prevalence rate coupled with much greater acceptance  
567 of autism in our Nation, it is likely each of you knows  
568 someone, a loved one, a friend, neighbor, constituent who is  
569 on the autism spectrum. I would guess that if each of you  
570 turned to speak with a colleague next to you, they \_ that  
571 the individual experience, the strengths and challenges of  
572 the autistic person you are thinking of, would be very  
573 different.

574 As you move towards reauthorizing and enhancing the  
575 Autism CARES Act, I urge you to keep these individuals in  
576 mind. Let's work to ensure that they, along with millions  
577 of others on the spectrum, live the best life possible.

578 Thank you again for this opportunity to testify. I  
579 look forward to your questions.

580 [The prepared statement of Dr. Shih follows:]

581

582 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

583

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584           \*Mr. Guthrie. Thank you for your opening statement.

585           And, Mr. Feist, you are recognized for five minutes for  
586 your opening statement.

587



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588 STATEMENT OF COREY FEIST, JD, MBA

589

590 \*Mr. Feist. Hello, my name is Corey Feist. I am the  
591 CEO and Co-Founder of the Dr. Lorna Breen Heroes Foundation.  
592 It is great to see you all again.

593 Our mission is to reduce burnout of health  
594 professionals and safeguard their wellbeing and job  
595 satisfaction. Thank you to the chair and ranking member for  
596 the opportunity to address you all today, and to this \_ and  
597 for this committee's working in the last Congress to pass  
598 the Dr. Lorna Breen Healthcare Provider Protection Act.

599 While there has been much progress made since I sat in  
600 this seat just a couple years ago, there are still millions  
601 of health workers who are tirelessly working to save lives,  
602 yet often at great personal risk because of how the  
603 healthcare system operates. I stand before you as the voice  
604 of 22 million health workers urging you to reauthorize the  
605 Dr. Lorna Breen Healthcare Provider Protection Act, H.R.  
606 7153. This legislation aims to combat suicide, burnout, and  
607 the mental health challenges among health workers. I want  
608 to extend a special thanks to Representatives Kiggans, Buddy

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609 Carter, Debbie Dingell, and Susan Wild, as well as Senators  
610 Tim Kaine and Todd Young for their commitment to championing  
611 this cause.

612         Addressing burnout necessitates a dual approach:  
613 individual support and systemic change. Individual support  
614 programs act like pressure on a bleeding wound, that wound  
615 of burnout, essential for immediate relief. However, true  
616 healing requires addressing the root cause of the bleeding,  
617 the environment of care. Systemic efforts such as reducing  
618 administrative burdens on health workers are imperative to  
619 long-term relief.

620         In 2021 I shared the tragic story of my sister-in-law,  
621 Dr. Lorna Breen, the inspiration around our foundation.  
622 Today rather than sharing Lorna's story, I want to share  
623 stories of those who have reached out to us in response. In  
624 just the last two week since the reintroduction or the  
625 introduction of H.R. 7153, thousands of health workers have  
626 written you all as representatives sharing poignant stories.

627         Retired nurse Tammy Brown shared the heartbreaking loss  
628 of her husband Moe, an orthopedic surgeon, to suicide,  
629 underscoring the urgency of ending the stigma around seeking

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630 mental health. Tammy's message to you, "This loss is  
631 enormous, tragic, and could have been prevented if he  
632 wouldn't have feared punishment and stigma of needing help  
633 at a very stressful time in his life. This should never  
634 happen again.''

635 A veteran nurse highlighted the importance of  
636 accessible counseling, emphasizing its positive impact on  
637 both professional and personal life. These stories  
638 illustrate the critical need for comprehensive mental health  
639 support in the healthcare sector.

640 One particularly tragic story is that of Tristin Kate  
641 Smith, a 28-year old nurse who died by suicide. Before her  
642 death, Tristin left a message which said, "Ever since I was  
643 young I expressed an interest in healthcare and becoming a  
644 nurse, so I began my study. I gave my heart, my body, and  
645 my mind to you. I no longer feel like you care about me or  
646 the people you say you serve. When we dare to think we are  
647 finally getting the love and support we deserve, we get a  
648 pizza party and free pens for the healthcare heroes. I so  
649 desperately want to continue to help people, but I cannot  
650 stay in this abusive relationship any longer. Each day you

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651 ask me to do more with less.'

652 Tristin's experience is not isolated. In fact, female  
653 nurses are eight-and-a-half times more likely to die by  
654 suicide than the general female population.

655 In October of 2023, the CDC issued their vital signs  
656 report which underlines the mental health crisis within the  
657 healthcare workforce with significant increases over the  
658 past few years in burnout, intent to leave, and harassment.  
659 Further alarming statistics indicate that over the past few  
660 years there has been a significant exodus from the nursing  
661 workforce with nearly 900,000 registered nurses intending to  
662 leave by 2027.

663 Coupled with the impending surge in the elderly  
664 population by almost 50 percent in the next 10 years, this  
665 amplifies the urgency around this impending healthcare  
666 crisis. Who is going to take care of all of us?

667 The Dr. Lorna Breen Healthcare Provider Protection Act  
668 is a vital step and has catalyzed the change in supporting  
669 and protecting the healthcare workforce. 103 million in  
670 funding has supported 44 health organizations in  
671 implementing this work, however that represents less than

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672 one percent of health workers and one percent of the  
673 hospitals in this country.

674 Additional resources funded the Impact Wellbeing  
675 Campaign which provides health leaders evidence-informed  
676 solutions to reduce burnout. Hospital leaders need guidance  
677 in doing this work. This Act's reauthorization focuses on  
678 reducing administrative burdens, recognizing the need to  
679 address this burnout and this bleed at its root cause. This  
680 is not merely policy, it is vital to our healthcare delivery  
681 supply chain.

682 Thank you for your time, consideration, and support.

683 [The prepared statement of Mr. Feist follows:]

684

685 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

686

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687           \*Mr. Guthrie. Thank you for your opening statement.

688 Thank you for all your work.

689           Dr. Pike, you are recognized for five minutes for

690 opening statement.

691

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692 STATEMENT OF JOANNE PIKE, DRPH

693

694 \*Dr. Pike. Chairs McMorris Rodgers and Guthrie,  
695 Ranking Members Pallone and Eshoo, and members of the  
696 subcommittee, my name is Joanne Pike, and I am the President  
697 and CEO of the Alzheimer's Association and CEO of the  
698 Alzheimer's Impact Movement. Thank you for the opportunity  
699 to testify today to discuss four key laws that have been  
700 instrumental in prioritizing our Nation's response to the  
701 growing impact of Alzheimer's on over six million Americans  
702 and their 11 million caregivers.

703 The Association and AIM are proud to support the NAPA  
704 Reauthorization Act, the Alzheimer's Accountability and  
705 Investment Act, the BOLD Reauthorization Act, and the  
706 Lifespan Respite Care Reauthorization Act. We are grateful  
707 to the subcommittee and the champions leading these  
708 bipartisan bills for their timely consideration. Congress  
709 must reauthorize these laws now to ensure our country  
710 continues to advance policies that improve the lives of  
711 people living with dementia and their caregivers.

712 I also want to take an opportunity to thank all of the

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713 advocates behind me in the room today and those watching  
714 nationwide, especially those living with dementia or mild  
715 cognitive impairment, by sharing your stories, by advocating  
716 in your communities. You are giving everyone living with  
717 dementia the courage to do the same. You inspire all that  
718 we do to achieve our vision of a world without Alzheimer's  
719 and all other dementia.

720         As too many of us in this room know, Alzheimer's is a  
721 progressive fatal brain disease. We need to continue our  
722 commitment to think boldly, dream bigger, and step up to  
723 deliver a future in which no one is left behind. Not in  
724 prevention, or diagnose, or treatment, or support, or care,  
725 or cures.

726         In 2011, Congress passed the bipartisan National  
727 Alzheimer's Project Act, also known as NAPA, resulting in  
728 the landmark national plan to address Alzheimer's Disease.  
729 The national plan continues to drive meaningful change,  
730 creating and implementing strategies to address Alzheimer's  
731 and other dementia. NAPA also led the creation of the  
732 Advisory Council on Alzheimer's Research, Care, and  
733 Services, which I am currently serving. Simply put, the



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734 landscape has changed as a result.

735         For the first time, people living in the early stages  
736 of Alzheimer's have FDA approved treatments that slow  
737 disease progression. In fact, more treatments and  
738 diagnostics are in the pipeline than ever before. While the  
739 national plan has clearly driven enormous progress, we still  
740 have much work to do.

741         The bipartisan NAPA Reauthorization Act would extend  
742 this important work through 2035 and modernize the law to  
743 reflect strides the field has made in understanding the  
744 disease, such as including a new focus on healthy aging and  
745 reducing risk factors. Reauthorizing NAPA ensures the  
746 continuity of vital initiatives fostering advancements in  
747 understanding treatment and care for individuals living with  
748 Alzheimer's Disease and other dementia.

749         The 2015 Alzheimer's Accountability Act complements  
750 NAPA's efforts by ensuring the NIH receives the funding and  
751 resources essential to making meaningful research progress  
752 in the fight against Alzheimer's. The law requires the NIH  
753 to annually submit a bypass budget, an estimate of the  
754 investment needed to reach the research goals of the

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755 national plan. This annual bypass budget has been a crucial  
756 blueprint for Congress, enabling historic increases in  
757 Alzheimer's research, investments, and leading to a more  
758 than seven-fold increase in Alzheimer's funding at NIH over  
759 the past decade.

760         These increases have enabled groundbreaking  
761 advancements, including improved blood biomarker test  
762 accuracy. Blood biomarker tests will revolutionize the  
763 detection of Alzheimer's allowing for earlier, more  
764 accessible, and accurate diagnoses and the ability to track  
765 how people are responding to treatment. This progress must  
766 continue.

767         Reauthorizing this law through the bipartisan  
768 Alzheimer's Accountability and Investment Act will reinforce  
769 Congress's commitment to prioritizing the resources needed  
770 to address the challenges posed by Alzheimer's and other  
771 dementia. The bill would ensure NIH continues to submit an  
772 Alzheimer's annual bypass budget to Congress and the  
773 President through 2035.

774         The Alzheimer's community is also grateful to Chairman  
775 Brett Guthrie and Congressman Paul Tonko for their

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776 leadership on the 2018 Building Our Largest Dementia  
777 Infrastructure for Alzheimer's Act, also known as the BOLD  
778 Act, and recent efforts to reauthorize this important law.  
779 The BOLD Act has enabled communities nationwide to implement  
780 public health strategies that promote brain health, address  
781 dementia, and support people living with dementia and their  
782 caregivers.

783         The BOLD Act is set to expire this year. The  
784 bipartisan BOLD Reauthorization Act of 2024 would ensure  
785 this important work continues in communities across the  
786 country. It is vital that Congress passes this bill. Doing  
787 so will help further population level improvements, achieve  
788 higher quality of life for those living with the disease and  
789 their caregivers, and reduce associated costs.

790         Finally, we thank the subcommittee for considering ways  
791 to help support caregivers of people living with chronic  
792 conditions such as Alzheimer's and other dementia through  
793 the Lifespan Respite Care Program which continues to play a  
794 crucial role in helping support caregivers and enhancing the  
795 overall quality of life for people with chronic conditions  
796 or disabilities. Reauthorizing this program is essential

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797 for sustaining a supportive infrastructure to help alleviate  
798 caregiver stress and enhance care quality for people with  
799 chronic conditions.

800 The swift enactment of these four bipartisan bills will  
801 enable further strides in understanding, treating, and  
802 ultimately preventing Alzheimer's and other dementia. We  
803 have so much to be excited about and hopeful about. We know  
804 many of us personally how important these advancements are  
805 for real people, our families, our friends, and our  
806 neighbors.

807 I appreciate the opportunity to testify before you  
808 today and look forward to answering any questions you may  
809 have.

810 [The prepared statement of Dr. Pike follows:]

811

812 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

813

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814           \*Mr. Guthrie. Thank you for your opening statement and  
815 I appreciate it.

816           Dr. Tomaselli, you are now recognized for five minutes  
817 for opening statement.

818

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819 STATEMENT OF GORDON TOMASELLI, MD

820

821 \*Dr. Tomaselli. Thank you, Chairman Guthrie, Ranking  
822 Member Eshoo, and members of the Health Subcommittee of the  
823 Committee on Energy and Commerce. Thank you for this  
824 opportunity to testify on behalf of the American Heart  
825 Association, now celebrating its centennial year.

826 My name is Gordon Tomaselli, and I am a cardiologist  
827 and an expert in the field of sudden cardiac death. You  
828 have my CV, but briefly, I am the Emeritus Dean of the  
829 Albert Einstein College of Medicine and a Professor of  
830 Medicine at Einstein and at the Johns Hopkins School of  
831 Medicine. I am a former president of the AHA, and I have  
832 been proudly among the organization's 40 million supporters  
833 for more than 30 years.

834 Although my interest in cardiovascular disease and  
835 science was codified early in my training, personal  
836 connection to that disease galvanized my clinical track. At  
837 the age of 49, my mother, who was suffering from  
838 cardiomyopathy, experienced a cardiac arrest. She was  
839 resuscitated but continued to suffer from life limiting

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840 heart failure. She underwent cardiac transplantation which  
841 allowed her to enjoy nearly two decades of full life.

842 Today, I am pleased to testify about the ways in which  
843 your bills under consideration, namely the Cardiomyopathy  
844 Health Education Awareness Research and Training in the  
845 Schools Act of 2023, or the HEARTS Act, and the Congenital  
846 Heart Disease \_ Congenital Heart Futures Reauthorization Act  
847 of 2024 would improve the health and safety of students  
848 afflicted with congenital heart disease.

849 First, a story as a bit of backdrop for my remarks  
850 today, and I refer you to the two photographs in front of  
851 me. On what started as a regular day, Megan Etheridge and  
852 her husband were working from home and their two kids were  
853 at school. Megan's phone rang and she was told that her  
854 son, Collin, had fainted after running up the stairs at her  
855 middle \_ as his middle school. That is pretty concerning,  
856 but the school said he thought he would d be \_ they thought  
857 he would be okay.

858 A few minutes later the school called again. Things  
859 were not okay. Fortunately, this story has a happy ending,  
860 but Collin had fainted and had a cardiac arrest and wasn't

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861 breathing. Collin's school had gone above and beyond in  
862 school safety. The school had created a cardiac emergency  
863 response plan, and easily accessible automatic external  
864 defibrillator, or AED, and staff who were trained and ready  
865 to perform CPR and use the AED. Today Collin is doing well  
866 and his parents have gotten the opportunity to see him grow  
867 up.

868           The American Heart Association thanks Ranking Member  
869 Frank Pallone, Jr. for his work to champion the HEARTS Act  
870 which will improve the safety of our schools and ensure  
871 students, faculty, staff, and others are prepared to respond  
872 quickly and effectively to a cardiac arrest in classrooms  
873 and on playing fields. The legislation requires HHS to  
874 coordinate with CDC to develop educational materials and  
875 resources on cardiomyopathy, a leading cause of disability  
876 and sudden death among young people. It also calls for  
877 guidelines regarding the placement of AEDs in school, the  
878 establishment of the cardiac arrest emergency plans, as well  
879 as information on CPR training.

880           In addition to the HEARTS Act, the American Heart  
881 Association strongly urges Congress to pass the bipartisan



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882 Access to AED Act which would authorize critical resources  
883 needed to implement many of these lifesaving policies.  
884 Today more than 350,000 individuals in the United States  
885 experience an out of hospital cardiac arrest, with only one  
886 in ten surviving. Up to 23,000 of these are lethal events  
887 in children under the age of 18, many of them with  
888 cardiomyopathy or other congenital heart diseases, making  
889 these preventable tragedies the leading cause of death for  
890 high school athletes.

891 For every minute without CPR, a cardiac arrest  
892 patient's chances of survival drops by 10 percent. The  
893 average arrival time of emergency medical services is seven  
894 minutes. Lay responders are often truly the first  
895 responders and they need more CPR training and better access  
896 to AEDs to save lives. Evidence shows that in cardiac  
897 arrest emergencies where people are close by, AEDs used  
898 beforehand, before EMS arrival, patients survive  
899 meaningfully two-and-a-half times more likely than those who  
900 did not receive the same care prior to EMS arrival.

901 Despite AEDs being proven as lifesaving devices, only  
902 20 states currently require AEDs to be placed in schools.

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903 Even fewer states have programs to help schools purchase  
904 these devices. The HEARTS Act, together with the Access to  
905 AEDs Act, would fill these gaps. Ideally all school staff  
906 should be trained in First Aid, CPR, and AED use.

907 This February as we observe the national \_ we observe  
908 Heart Month, the American Heart Association is working to  
909 turn a nation of bystanders into a nation of lifesavers so  
910 that everyone everywhere is prepared and empowered to become  
911 a vital link in the chain of survival and provide CPR and  
912 AED. We hope that you will join this nation of lifesavers  
913 as well as your constituents.

914 The American Heart Association is also pleased to  
915 support the Congenital Heart Futures Reauthorization Act and  
916 we thank Congressman Gus Bilirakis for sponsoring this bill.  
917 It is a crucial piece of bipartisan legislation that  
918 addresses the pressing need for continued funding and  
919 research into congenital heart disease. This legislation  
920 builds upon the initial Congenital Heart Disease Future Act  
921 of 2010, a pioneering effort to allocate resources  
922 specifically for congenital heart disease research and data  
923 collection. This reauthorization act emphasizes the need to

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924 advance congenital heart disease research and awareness by  
925 further enhancing biomedical research at NIH, expanding  
926 public health research and data collection at CDC, and  
927 raising the public awareness of congenital heart disease  
928 throughout the patient's lifespan.

929 I thank you for the opportunity to offer my perspective  
930 today and for your continued leadership to improve  
931 cardiovascular health and wellness. The written and oral  
932 statements reflect my views and that of the American Heart  
933 Association and not necessarily those of Johns Hopkins  
934 University or the Albert Einstein College of Medicine. I  
935 look forward to your questions.

936 [The prepared statement of Dr. Tomaselli follows:]

937

938 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

939

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940           \*Mr. Guthrie. Thank you. Thank you for your opening  
941 statement.

942           The chair will now recognize Ms. Whitten for five  
943 minutes for your opening statement.

944

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945 STATEMENT OF MICHELLE WHITTEN

946

947           \*Ms. Whitten. Chairman Guthrie, Ranking Member Eshoo,  
948 Chairwoman Rodgers, and members of the committee, thank you  
949 for the opportunity to testify at today's hearing. My name is  
950 Michelle Sie Whitten, and I am the Co-Founder, President,  
951 and CEO of the Global Down Syndrome Foundation and the  
952 mother of two, including Sophia, a vivacious 20-year old  
953 sophomore at Regis University who happens to have down  
954 syndrome.

955           People with down syndrome are born with three copies of  
956 Chromosome 21 instead of two. This extra chromosome results  
957 in a radically different disease profile whereby people with  
958 down syndromes are highly predisposed to certain diseases  
959 and highly protected from others. For example, people with  
960 down syndrome are the largest population with a genetic  
961 predisposition to Alzheimer's Disease. By studying people  
962 with down syndrome, we can help our loved ones with the  
963 condition and potentially help millions of others who suffer  
964 from Alzheimer's.

965           Half or more of people with down syndrome are born with

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966 congenital heart defects, are predisposed to autoimmune  
967 disorders and to certain blood cancers. Conversely, they  
968 are highly protected from developing solid tumor cancers  
969 such as breast cancer or prostate cancer.

970 In the 1980s, the average lifespan of a person with  
971 down syndrome was 28 and today it is 60, but that is still  
972 16 years behind the general population. And, unfortunately,  
973 for those in rural areas and for black people with down  
974 syndrome, preliminary studies indicate a substantially  
975 shorter lifespan.

976 Down syndrome is a complex condition and research needs  
977 that involve almost every one of NIH's 27 institutes and  
978 centers. Fortunately, our bipartisan congressional  
979 champions, Chair Rodgers and Representatives Rosa DeLauro  
980 and Tom Cole, recognize the impact down syndrome research  
981 could have on millions of Americans. They increased federal  
982 funding and urged NIH to initiate a trans-NIH or NIH-wide  
983 effort called INCLUDE, Investigation of Co-Occurring  
984 Conditions Across the Lifespan to Understand Down Syndrome.  
985 Global is forever grateful to these fierce advocates.

986 There is no doubt that the creation of INCLUDE is

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987 increasing lifespan and improving health outcomes in those  
988 with down syndrome. Since fiscal year 2018, INCLUDE has  
989 provided 556 unique awards from 18 different NIH institutes  
990 and 11 institutes participating in down syndrome research  
991 for the very first time. Just consider some of the  
992 progress. Because of INCLUDE, we now have 12 down syndrome  
993 clinical trials, but more is needed. Because of INCLUDE, my  
994 daughter and the 450,000 people with down syndrome in the  
995 U.S. are starting to have the opportunity to participate in  
996 Alzheimer's research, and INCLUDE has established a  
997 groundbreaking data coordinating center led by Dr. Espinosa  
998 where all scientists have open access to research across all  
999 the NIH institutes.

1000 Global has long advocated for down syndrome centers and  
1001 recently INCLUDE has put out a request for proposal for the  
1002 very exciting and transformative down syndrome clinical  
1003 cohort coordinating centers, DS4C, and centralized biobank.  
1004 The DeOndra Dixon INCLUDE Project Act of 2024 to authorize a  
1005 trans-NIH model for down syndrome research would ensure that  
1006 multiple NIH institutes will collaborate and coordinate  
1007 research planning, funding, and sharing and disseminating of

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1008 research results.

1009           Global is so moved that our sponsors are paying tribute  
1010 to our beloved global ambassador and Quincy Jones  
1011 Exceptional Advocacy awardee DeOndra Dixon, an accomplished  
1012 self-advocate who tragically passed away in 2020 at the age  
1013 of 36. This legislation honors her and all individuals with  
1014 down syndrome.

1015           I also want to express Global's support for the  
1016 Charlotte Woodward Organ Transplant Discrimination  
1017 Prevention Act which would prohibit healthcare providers and  
1018 matching entities from discriminating against patients who  
1019 need organ transplants solely based on disability. This  
1020 bill highlights the importance of a need for auxiliary aids  
1021 and services, a support system to assist with post-operative  
1022 care and the need for reasonable modifications to policies  
1023 and procedures to make organ transplant systems and  
1024 facilities more accessible to those with disabilities.

1025           In addition, we want to share our support and  
1026 appreciation for Chair Rodgers's bill, the Protecting  
1027 Healthcare for All Patients Act, which bans all federal  
1028 health programs from using discriminatory measures such as



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1029 the quality adjusted life gears to deny or restrict medical  
1030 coverage for patients with down syndrome or other  
1031 conditions. It is important that this applies to all  
1032 government health programs and not just Medicare.

1033 While there is still much work to do \_ to be done for  
1034 us to close the gap on lifespan and health outcomes for  
1035 those with down syndrome and other intellectual  
1036 disabilities, the momentum continues to build for people  
1037 with down syndrome who are entering a new era where they are  
1038 respected citizens. Authorizing the INCLUDE Project ensures  
1039 our dedicated researchers can continue to work to reduce  
1040 health disparities, elongate life, and improve health  
1041 outcomes, not only for people with down syndrome but for  
1042 everyone.

1043 Thank you again for the opportunity to testify today,  
1044 and I look forward to your questions.

1045 [The prepared statement of Ms. Whitten follows:]

1046

1047 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

1048

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1049           \*Mr. Guthrie. Thank you for you testimony.

1050           The chair will now recognize Mr. Strozyk for five

1051 minutes for questions \_ opening statement.

1052

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1053 STATEMENT OF RANDY STROZYK

1054

1055           \*Mr. Strozyk. Good morning, Chair Guthrie, Ranking  
1056 Member Eshoo, members of the House Energy and Commerce  
1057 Subcommittee on Health, and the full committee Chair  
1058 McMorris Rodgers and Ranking Member Pallone.

1059           I am incredibly honored to be here today to provide  
1060 testimony on several legislative proposals on today's agenda  
1061 that speak to the importance of emergency medical services  
1062 across our healthcare system. My name is Randy Strozyk. I  
1063 have the great honor of being the President at the American  
1064 Ambulance Association, a trade association that represents  
1065 organizations providing both 911 service and vital ground  
1066 interfacility transports across our Nation.

1067           In addition, my day job is I am the Senior Vice  
1068 President of Operations at American Medical Response and  
1069 Global Medical Response, the largest provider of ground  
1070 ambulance services in the United States. I have also been  
1071 in EMS for 40 years now, and today listening to the various  
1072 testimonies each of the members \_ or representatives here  
1073 today touched my life and members of our community who

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1074 provide EMS.

1075           The American Ambulance Association and members of all  
1076 EMS providers, public or private, serve as the healthcare  
1077 safety net for our communities and play a critical and  
1078 unique niche role in responding to hurricanes, floods,  
1079 fires, and other disaster situations. EMS providers respond  
1080 24 hours a day, seven days a week for those in need, and put  
1081 simply, we are there for all Americans when they call for  
1082 help every day.

1083           In the interest of time today, I will be speaking on  
1084 four bills and representing those. Each of these bills have  
1085 strong support from national organizations that are behind  
1086 them, and for time, I will avoid going through the long  
1087 list.

1088           But one that is really critically important to America  
1089 today is House Resolution 4646, the SIREN Reauthorization  
1090 Act. Across America, much of EMS is provided to rural  
1091 America by volunteer and not-for-profit and public entities.  
1092 Funding for these entities is always difficult and a  
1093 challenge either because of limited tax spaces or small  
1094 communities. But as we found during COVID, these programs

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1095 and these systems were a critical part of delivery of  
1096 healthcare.

1097 At 2:00 in the morning in the middle of rural America  
1098 when you needed help and dialed 911, they came and they  
1099 provided service. In addition, new challenges arose for  
1100 these various rural services where they had to provide  
1101 transportation across to larger tertiary facilities. Many  
1102 of these services are provided by volunteers.

1103 In addition, they are now being impacted by both the  
1104 epidemic of opioids and increased levels of mental  
1105 healthcare that is requiring additional levels of training.  
1106 We call on the support for the this and we are very pleased  
1107 to thank Representative David Joyce and Debbie Dingell for  
1108 making \_ bringing this bill forward and the importance of  
1109 it.

1110 Next, one that has \_ all of us as parents and  
1111 grandparents are very supportive of is the Emergency Medical  
1112 Services for Children Reauthorization Act, House Resolution  
1113 6960. In my 40 years as an EMS provider, early days as a  
1114 paramedic, we have seen the change in healthcare for  
1115 children from treating them as small adults to truly what

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1116 they are, they are a unique group of citizens and caregivers  
1117 that need a special level of education and opportunity to  
1118 receive the proper care.

1119 We have trained our EMTs and paramedics to have new  
1120 skills to understanding the level of care recognize not only  
1121 the levels of injury and need for tertiary care, but we  
1122 brough that level of training forward to rural hospitals and  
1123 then to make that determination to take that to \_ forward to  
1124 community and large hospitals and the many children  
1125 hospitals. This has been incredibly important and we have  
1126 seen a tremendous increase in outcome in efficacy, level of  
1127 care, and positive outcomes. As a grandparent, I can't  
1128 support this more. Great thanks to Representatives Carter,  
1129 Castor, John Joyce, and my representative, Kim Schrier, for  
1130 introducing this act.

1131 My third today is the Reauthorization of the Traumatic  
1132 Brain Injury Program, House Resolution 7208. We have  
1133 learned through time that the treatment, identification, and  
1134 follow-up of treatment of traumatic brain injury is a  
1135 critical factor in the return to \_ of quality of life by  
1136 patients who have suffered these injuries. Research and

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1137 education has taught us how to better protect our student  
1138 athletes, how to protect citizens post-accident, and use  
1139 this as a means of bringing not only what we have learned  
1140 from our military experiences but to bring care forward.  
1141 And continued research on the issue of treatment of  
1142 traumatic brain injury will be critical.

1143         There is an interesting analogy of a poll here is that  
1144 motorsports has become an important part of training and  
1145 education. NASCAR, Indy car, IMSA are all involved very  
1146 distinctly in finding and identifying means of taking care  
1147 of this.

1148         And finally, I want to speak to the amendment of Public  
1149 Health Service Authorization for Poison Control Centers. As  
1150 a parent, I totally understand the importance of this \_  
1151 these centers across America have become a critical part of  
1152 our system of providing care to citizens. And as it grows  
1153 in exposure to opioids and so forth, these centers are a  
1154 treasure to all of us who provide care and to parents every  
1155 day who need to call for this help.

1156         I have appreciated my time today, and I will finish  
1157 very quickly by saying we will be coming forward to the

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1158 committee to talk future on funding for EMS across our  
1159 country, which is at risk, as we have \_ cost have risen, and  
1160 then finally to talk about how we are going to inquire and  
1161 bring on new members to provide EMS to our country \_ for our  
1162 country for our staffing and workforce issues.

1163 I appreciate your time, and I am 56 seconds over.

1164 [The prepared statement of Mr. Strozyk follows:]

1165

1166 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

1167



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1168           \*Mr. Guthrie. Well, thank you for your testimony \_ or  
1169 your testimony.

1170           And, Dr. Annunziata, you are now recognized for five  
1171 minutes.

1172

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1173 STATEMENT OF CHRISTINA ANNUNZIATA, MD, PHD

1174

1175           \*Dr. Annunziata. Thank you. Good morning, Chairman  
1176 Guthrie, Ranking Member Eshoo, and members of the  
1177 subcommittee. I am Christina Annunziata, Senior Vice  
1178 President of Extramural Discovery Science for the American  
1179 Cancer Society, and I am pleased to be here today to express  
1180 strong support of the American Cancer Society and our  
1181 affiliate, the American Cancer Society Cancer Action Network  
1182 for the Screens for Cancer Act and the Women Lung Cancer  
1183 Research and Preventive Services Act. Passage of these two  
1184 bills could have a critical impact on reducing the burden of  
1185 cancer for women in our country.

1186           Breast and lung cancer are the leading causes of cancer  
1187 incidents and mortality in women. In 2024, 970,000 women  
1188 will hear the word you have cancer, including 310,000 new  
1189 cases of breast cancer, 111,000 new cases of lung cancer,  
1190 and 13,000 new cases of cervical cancer among women. Also  
1191 in 2024, 288,000 women will lose their lives to cancer,  
1192 including 42,000 deaths from breast cancer, 59,000 deaths  
1193 from lung cancer, and 4,300 deaths from cervical cancer in

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1194 women.

1195           We also know that cancer does not affect everyone  
1196 equally and there are differences among women themselves and  
1197 between women and men. For example, despite historically  
1198 lower smoking rates than men, women still make up half of  
1199 all lung cancer cases and deaths. Compared to men, women  
1200 have slightly higher proportion of lung cancers that are not  
1201 attributed to factors like smoking, and while lung cancer is  
1202 higher for men overall, in the younger population of ages 35  
1203 to 54, the cancer incidence is higher in these younger women  
1204 than for their male counterparts. And this is also a fact  
1205 not fully explained by smoking status.

1206           With respect to breast cancer, the death rate for black  
1207 women is 40 percent higher than for white women, despite  
1208 lower breast cancer incidence rates in black women. Similar  
1209 disparities occur in cervical cancer where the death rate  
1210 for black women and Native American women are 65 percent  
1211 higher than for white women. And according to the recently  
1212 released American Cancer Society Facts and Figures Report,  
1213 cervical cancer is actually increasing in incidence in women  
1214 ages 30 to 44.

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1215           Women who are underinsured or uninsured are less likely  
1216 to get the recommended screening for breast and cervical  
1217 cancer resulting in a greater risk at being diagnosed at  
1218 later more advanced stages of disease than women who are  
1219 insured. And the more advanced stages of cancer require  
1220 more intense treatments and carry a higher risk of death  
1221 from the cancer.

1222           These two pieces of legislation can change those facts  
1223 and reduce the number of women who suffer and die from  
1224 cancer in the United States. The Screens for Cancer Act  
1225 reauthorizes the National Breast and Cervical Cancer Early  
1226 Detection Program through 2028 and gives greater flexibility  
1227 to grantees to implement innovative, evidence-based, early  
1228 detection and screening interventions to reach women  
1229 eligible for the program.

1230           The American Cancer Society Cancer Action Network has  
1231 long advocated for this screening program because it is the  
1232 gold standard for providing breast and cervical cancer  
1233 screening, diagnostic tests, treatment referral services to  
1234 women who have limited incomes and are uninsured or  
1235 underinsured. Funding for the program helps address

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1236 inequities in breast and cervical cancer screening and  
1237 diagnosis, especially for people who are geographically  
1238 isolated and for those who belong to racial and ethnic  
1239 groups that are disproportionately impacted by these  
1240 cancers.

1241         The program has been highly successful, having provided  
1242 15 million screening exams to more than six million eligible  
1243 people and detecting more than 75,000 breast cancers, 24,000  
1244 pre-malignant breast lesions, as well as 5,000 cervical  
1245 cancers, and 235,000 pre-malignant cervical lesions since  
1246 its inception in 1991. Simply put, without this program,  
1247 more women would be diagnosed with breast and cervical  
1248 cancer at later stages leading to unnecessary suffering and  
1249 premature death. Passage of the Screens for Cancer Act is  
1250 necessary to ensure continued and timely access to vital  
1251 breast and cervical cancer screenings which help reduce the  
1252 unequal cancer burden.

1253         In my role at the American Cancer Society, I lead an  
1254 interdisciplinary team of scientists to identify and fund  
1255 the most innovative and promising research to end cancer as  
1256 we know it for everyone. The Women and Lung Cancer Research

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1257 and Prevention Services Act calls for the same scientific  
1258 process through an interagency collaboration to review and  
1259 identify opportunities for research on women with lung  
1260 cancer, including evaluating environmental and genomic  
1261 factors contributing to lung cancer in women and advancing  
1262 new technologies for prevention, risk assessment, diagnosis,  
1263 and treatment. This type of cutting edge research tied with  
1264 evidence-based public education campaigns can truly turn the  
1265 tide on women and lung cancer.

1266 So thank you for this opportunity to testify today and  
1267 express our strong support for the Screens for Cancer Act  
1268 and the Women and Lung Cancer Research and Preventive  
1269 Services Act. We urge you both to pass these bills as  
1270 quickly as possible to end cancer as we know it for  
1271 everyone. Thank you.

1272

1273 [The prepared statement of Dr. Annunziata follows:]

1274

1275 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

1276

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1277           \*Mr. Guthrie. Thank you, Dr. Annunziata. Thank you  
1278 for your opening statement. And now that concludes all of  
1279 our opening statements. We will go to members' questions,  
1280 and so I will begin by recognizing myself for five minutes  
1281 for questions

1282           And, Dr. Pike, I focused on the BOLD Infrastructure for  
1283 Alzheimer's Act before and focused on it because my \_ I saw  
1284 my mother-in-law care for her father, and over the last  
1285 couple of years or a little longer, see my family \_ my wife  
1286 and her siblings care for her as she \_ and I think that was  
1287 the biggest burden when she realized what was happening to  
1288 her, that she knew what she had to do for her father, what  
1289 it was going to put on her family. So it is important that  
1290 we address it in every way possible. And she passed away in  
1291 October.

1292           But in reauthorizing the BOLD Infrastructure for  
1293 Alzheimer's Act for another five years, this will ensure our  
1294 constituents living with the disease, including 75,000  
1295 Kentuckians, can continue to benefit from initiatives under  
1296 BOLD that promote brain health, improve early detection and  
1297 diagnosis, and support people living with dementia.

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1298           So, Dr. Pike, could you describe some impactful real-  
1299 world examples that you have seen over the last five years  
1300 since BOLD was in action, and also would you suggest any  
1301 educational resources that you think may be helpful to  
1302 caregivers, providers, and patients that the reauthorization  
1303 bill can work toward providing?

1304           \*Dr. Pike. Thank you for your leadership, Chairman  
1305 Guthrie, in introducing the original BOLD Act and its much  
1306 needed reauthorization as well. The BOLD Act has proven to  
1307 be successful in \_ as a resource in implementing effective  
1308 Alzheimer's public health strategies in communities  
1309 nationwide. And since 2018, the CDC has established three  
1310 Alzheimer's public health centers of excellence and has made  
1311 66 awards to 45 state, local, and tribal public health  
1312 departments, including in your state of Kentucky.

1313           In Kentucky, for example, BOLD funding is increasing  
1314 the state's capacity to operationalize its Kentucky State  
1315 Alzheimer's Plan. Kentucky's initial investment in  
1316 Alzheimer's Disease and other dementia led to the creation  
1317 of a full-time state agency. The dementia services  
1318 coordinator staff position is also a catalyst that came from



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1319 your BOLD public health award. And in September 2023 the  
1320 Kentucky Department of Public Health was awarded funding to  
1321 develop strategic statewide strategies to address  
1322 Alzheimer's which is already allowing the state to support  
1323 the work of Kentucky's Office of Dementia Services.

1324 There are education programs, though, that come along  
1325 with that that focus on risk reduction, early detection, and  
1326 also healthcare system education as well. So there are  
1327 things that we can introduce long-term certainly, but things  
1328 that we know have been successful to move the needle on the  
1329 public health strategy for Alzheimer's. Thank you.

1330 \*Mr. Guthrie. Thank you. Thank you for that answer.

1331 Now, Ms. Whitten, would you discuss the various co-  
1332 occurring conditions individuals with down syndrome may have  
1333 and why it is critical to ensure that down \_ those with down  
1334 syndrome have equal access to approved therapies and  
1335 treatments?

1336 \*Ms. Whitten. Yes, absolutely. You know, we have  
1337 talked about Alzheimer's. You know, unfortunately, a  
1338 hundred percent of people with down syndrome will have the  
1339 plaques and tangles associated with Alzheimer's and an

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1340 estimated 70 percent will go on to get the dementia. This  
1341 is a really important population. Also cancer, there's  
1342 certain kinds of leukemia that are really up in people with  
1343 down syndrome. Autoimmune disorders really high up, well  
1344 over 50 percent.

1345       And then you \_ even autism, you know, my colleague here  
1346 from Autism Speaks, the recent American Academy of  
1347 Pediatrics guideline shows that it is not what it thought it  
1348 was in 2011, maybe two or three percent, it could be as much  
1349 as 30 or more percent of people with down syndrome also have  
1350 autism. They also are protected from certain kinds of heart  
1351 attacks, certain kinds of stroke, and as the Chairwoman  
1352 said, it is extraordinarily rare for a person with down  
1353 syndrome to suffer from a solid tumor.

1354       So this radically different disease spectrum really  
1355 requires a NIH-wide approach to research. In the past they  
1356 have done great work at the NICHD, but we can't just be  
1357 siloed in a child health and human services area. So this  
1358 trans-NIH approach really is not only going to help, you  
1359 know, nine million people with down syndrome worldwide, but  
1360 it stands to really help those people suffering from

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1361 diseases that have the co-occurring or where they are  
1362 protected from.

1363 I think it is important to note that where they are up  
1364 or down in diseases, those diseases represent 60 percent of  
1365 American deaths, so these are major diseases. So we are  
1366 very excited and so grateful for all of your support for  
1367 this important bill.

1368 \*Mr. Guthrie. Thank you. And I have just a few  
1369 seconds, I don't have enough for another question, but in  
1370 cardiac arrest, I \_ just an example why this is so  
1371 important. I had an \_ I was talking to my wife on the phone  
1372 one time, in Kentucky sometimes storms just pop up, it  
1373 doesn't even look like you could have one, but it happens.  
1374 And my wife \_ I heard the thunder, and she goes, wow, that  
1375 was really close.

1376 Turned out a kid about three houses down from us had  
1377 been struck by lightning and \_ which turns out to be a good  
1378 story, given that, is that the person he was with was  
1379 another young teenager who knew CPR from Boy Scouts. A guy  
1380 around the corner was an ambulance guy named Gary Madison  
1381 who is our \_ legendary in paramedics, just around the corner

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1382 heard it on his radio, and he immediately had a teenager  
1383 doing CPR, then a professional doing CPR. Life flighted to  
1384 Vanderbilt and is now living a \_ but if he hadn't have had  
1385 that kind of care \_ and I am out of time, so \_ but if he  
1386 hadn't had that kind of care \_ that is what is important,  
1387 that we try to get care as quickly as possible.

1388 And my time is expired. I will yield back and  
1389 recognize the gentlelady, the ranking member from California  
1390 \_

1391 \*Dr. Tomaselli. I would say that is an outcome that we  
1392 hope for in the American Heart Association, that something  
1393 like that doesn't turn into a tragedy.

1394 \*Mr. Guthrie. Yeah, immediate response is important.  
1395 So, Ranking Member.

1396 \*Ms. Eshoo. Thank you, Mr. Chairman, and I want to  
1397 thank each of the witnesses. You have given really such  
1398 important testimony. And to all of the advocates in the  
1399 hearing \_ in our hearing room today, you need to know that  
1400 you are the oxygen of all of these efforts.

1401 Before I came to Congress, I thought that Congress was  
1402 a proactive institution, and I don't know what got into me,

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1403 but I got here and quickly realized it is a reactive  
1404 institution, reacts to the voices of people from across the  
1405 country. So when I say that you are the oxygen of all of  
1406 these efforts, the \_ you move the needle every day, every  
1407 month, every year in all of these efforts, and we are all  
1408 really very, very grateful to you, and I am always mindful  
1409 that legislation doesn't move without you, so bravo to each  
1410 one of you.

1411 Mr. Feist, it is great to see you again. You were here  
1412 in 2021, you described that your late sister-in-law, Dr.  
1413 Lorna Breen, was afraid because she was convinced she would  
1414 lose her medical license if she asked for help, a fear that  
1415 ultimately contributed to her death. Your testimony, you  
1416 know, really outlined where we are in the country today. We  
1417 have 6,120 hospitals in the country but only like one  
1418 percent, the needle has moved like one percent. I am  
1419 grateful for the one percent, but at this rate the issue is  
1420 not going to be addressed.

1421 I don't know the following, and I would like to ask you  
1422 if you do. Do hospitals cover their doctors' insurance or  
1423 is it up to the doctors to \_

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1424 \*Mr. Feist. So \_

1425 \*Ms. Eshoo. \_ determine on their own what they buy?

1426 \*Mr. Feist. Which type of insurance are you speaking  
1427 of?

1428 \*Ms. Eshoo. Well, health insurance.

1429 \*Mr. Feist. Their health insurance, okay.

1430 \*Ms. Eshoo. Yeah.

1431 \*Mr. Feist. I didn't know if you meant malpractice  
1432 insurance.

1433 \*Ms. Eshoo. No, no.

1434 \*Mr. Feist. So lots of insurance out there. So, first  
1435 of all \_

1436 \*Ms. Eshoo. That is a whole 'nother issue.

1437 \*Mr. Feist. It is. By the way, I have Jennifer here,  
1438 Lorna's little sister. My wife is also here today with me.  
1439 I didn't acknowledge her in my remarks, but she is here.

1440 \*Ms. Eshoo. Well, thank you for being here.

1441 \*Mr. Feist. Happy Valentine's Day, honey.

1442 \*Ms. Eshoo. Thank you.

1443 \*Mr. Feist. Thank you so much for asking that. It is  
1444 really interesting. So the insurance that is covered by

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1445 physicians, if they are in \_ for their care, personal care,  
1446 is their employee. So if they are employed by a hospital  
1447 system, which a huge section of our physicians in this  
1448 country are \_

1449 \*Ms. Eshoo. That is why I am asking the question.

1450 \*Mr. Feist. \_ then, yes, they do not have a choice,  
1451 they are given the insurance. You are probably getting at  
1452 what their network of insurance \_ of providers are?

1453 \*Ms. Eshoo. Well, I would like to know if in fact the  
1454 hospitals \_ the doctors are insured through their employer,  
1455 the hospital, is mental health coverage part of it?

1456 \*Mr. Feist. It is. And importantly, what we \_

1457 \*Ms. Eshoo. I don't know how far we get with  
1458 administrative issues. I think they \_ that they \_ that  
1459 their insurance policy should cover mental health issues and  
1460 that it be private and not subject to the general gossip of  
1461 the hospital that Dr. Smith is receiving mental health  
1462 counseling.

1463 \*Mr. Feist. That is exactly right. So what you are  
1464 getting at is actually where they need to get care. Now  
1465 their employer defines who provides them the care, and in

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1466 most cases if you are a hospital system providing insurance  
1467 to your employees, you tend to not want to broaden the  
1468 network of options because you are kind of paying your  
1469 competitor to take care of your employees, if you will.

1470 In the mental health space, what you are speaking to is  
1471 exactly what we need to do. We need to broaden the networks  
1472 to make sure that physicians can seek care outside of the  
1473 hospital.

1474 \*Ms. Eshoo. Well, let me ask you this. Don't you  
1475 think in a reauthorization that this issue needs to be  
1476 addressed?

1477 \*Mr. Feist. Yes. Yes. So, I mean, if I may just for  
1478 a second. What we are talking \_ what you are talking about  
1479 is allowing the networks for the physicians to be able to  
1480 access outside of their institutions because of their  
1481 concern around confidentiality, and that is a \_ that is a  
1482 serious issue.

1483 \*Ms. Eshoo. Well, I think if it is confidential, it  
1484 really doesn't matter whether it is inside the institution  
1485 they are working at or outside, or do you think I am wrong  
1486 on that?



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1487           \*Mr. Feist. If you speak to the widow of Scott Jolly  
1488 from Utah, his only network option was in his hospital  
1489 system, and he was so burdened by the stigma of being  
1490 treated by his colleagues, he died by suicide.

1491           \*Ms. Eshoo. Okay. Well, my time has expired.

1492           \*Mr. Feist. Thank you.

1493           \*Ms. Eshoo. Thank you to each one of you.

1494           \*Mr. Guthrie. Thank you. The ranking member yields  
1495 back, and the chair will recognize the chair of the full  
1496 committee, Chair Rodgers, for five minutes for questions.

1497           \*The Chair. Thank you. I, too, want to thank everyone  
1498 for being here, all the advocates and the \_ and those that  
1499 have testified. We are covering a lot of ground today.

1500           I wanted to start with Mr. Strozyk, and recognizing you  
1501 are from Washington State and a WSU alum, I wanted to say Go  
1502 Cougs. But before I get to my question, I also wanted to  
1503 quickly take some time to congratulate Mr. Jacob Ambach from  
1504 Spokane, Washington for being recognized as one of this  
1505 year's distinguished Stars of Life honorees by your  
1506 organization, the American Ambulance Association. Mr.  
1507 Ambach saved the lives of five patients who suffered from

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1508 cardiac arrest last year, and if it had not been for his  
1509 work, the patients may not have survived. So we greatly  
1510 appreciate his service.

1511 Now, Mr. Strozyk, you mentioned in your written  
1512 testimony that EMTs and paramedics have experienced  
1513 increasing challenges when responding to mental health and  
1514 substance use disorder related calls. Would you just speak  
1515 briefly about some of the challenges and how the SIREN  
1516 Reauthorization Act would help improve patient care?

1517 \*Mr. Strozyk. Thank you, and I greatly appreciate the  
1518 words Go Cougs, so that has made my day.

1519 Chairwoman, across the country as the epidemic has  
1520 occurred with opioids, which we can always speak in terms of  
1521 major cities, be it Seattle, be it Spokane, be it Portland  
1522 where we have seen this across the country, as this has  
1523 spread into rural America, it is an environment that is  
1524 foreign. It is hard to imagine that your neighbor could be  
1525 overdosed on fentanyl and you are having to deal with this.

1526 In addition, mental health illness, as it has  
1527 progressed and been recognized across the United States,  
1528 requires an additional level of training and skill to handle

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1529 so that the patient is taken to the appropriate level of  
1530 care at the appropriate time. The difficulty as rural  
1531 America has seen the closure of hospitals and clinical  
1532 facilities, the ability to get these patients to that level  
1533 of care has challenged these systems.

1534 \*The Chair. Right. Okay.

1535 \*Mr. Strozyk. As an example in your district, when  
1536 they leave \_

1537 \*The Chair. Thank you.

1538 \*Mr. Strozyk. \_ Washtucna to go to \_

1539 \*The Chair. Yes.

1540 \*Mr. Strozyk. \_ Spokane, it is difficult.

1541 \*The Chair. Yeah. Thank you. Thank you very much.

1542 Ms. Whitten, you know, for all the advocates, I will  
1543 just \_ you know, we have a son now with down syndrome, he is  
1544 16 years old. And I will always remember when Michelle  
1545 brought in Sophia and \_ to introduce me to her daughter  
1546 early on, when he was first born, and just appreciate your  
1547 advocacy for many years. I am grateful for those who went  
1548 before me, as all advocates are. You know, we are all only  
1549 one diagnosis or car accident away from being in the same

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1550 position, and so it really makes a difference. And just so  
1551 grateful to you, Ms. Whitten, and your \_ all that you have  
1552 done, your passionate advocacy for individuals with down  
1553 syndrome.

1554         You outline some of the incredible accomplishments of  
1555 INCLUDE and what has happened at NIH since Cole was first  
1556 born and as we have come a long way. And it includes  
1557 research at WSU now, examining dementia in individuals with  
1558 down syndrome, related work to develop low-cost screenings  
1559 that detect dementia at early stages. This is certainly  
1560 going to help individuals with down syndrome get treatment  
1561 sooner.

1562         The DeOndra Dixon INCLUDE Project Act is going to  
1563 strengthen all of these activities and initiatives for many  
1564 years to come. And I wanted to ask if you would speak to  
1565 just what else NIH could be doing to further improve  
1566 INCLUDE's mission and purpose and also support the down  
1567 syndrome community.

1568         \*Ms. Whitten. Thank you so much. And, of course, your  
1569 leadership has been profound, right. We would \_ when my  
1570 daughter was born, the funding for down syndrome research

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1571 was 16 million. That was 20 years ago. And for 20 years,  
1572 it kind of floundered between 16 and 22 million. So again,  
1573 the leading cause of developmental delay, one of the least  
1574 funded genetic conditions. All sorts of reasons why that is  
1575 wrong.

1576 I would say \_ I also want to call out Mr. Frank  
1577 Stephens \_

1578 \*The Chair. Yes.

1579 \*Ms. Whitten. \_ who is behind me\_

1580 \*The Chair. Mm-hmm, yes.

1581 \*Ms. Whitten. \_ who has down syndrome who was at the  
1582 seminal hearing that Congresswoman Rosa DeLauro and  
1583 Congressman Cole had and from which INCLUDE sprung, right.  
1584 And I think Frank's testimony that \_ you know, he basically  
1585 said if you take away one thing, know this, I am a man with  
1586 down syndrome and my life is worth living. And the reason I  
1587 bring that up is because, you know, we are humans, we are  
1588 people, we are equal. We might be different, but we are  
1589 equal and we deserve a lot better.

1590 And in terms of what NIH could be doing, I think they  
1591 have got a beautiful structure through INCLUDE focusing on

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1592 clinical trials. We are still prevented from being \_  
1593 participating in many, many clinical trials, and so NIH,  
1594 working with FDA, working with advocacy organizations, we  
1595 need more people in clinical trials and we need more  
1596 clinical trials for people with down syndrome, right.

1597 For example, our big discovery that down syndrome is an  
1598 immune system disorder, right, and that a whole class of JAK  
1599 inhibitor drugs can actually stabilize their immune system  
1600 is huge, but it is not something you would do for a typical  
1601 person or a person without down syndrome. So that study.  
1602 And then, of course, DeOndra Dixon, I mean, she was a role  
1603 model not just for people with down syndrome, not just for  
1604 people who are black with down syndrome, just for all people  
1605 in the way she lived her life, and I think, you know, this  
1606 act really honors her and it allows her to really advocate,  
1607 you know, from up above \_

1608 \*The Chair. Mm-hmm.

1609 \*Ms. Whitten. \_ and make sure that people with down  
1610 syndrome are getting the research that they deserve at the  
1611 NIH and elsewhere. The other thing that they can do is more  
1612 RFAs like they are doing for transformational research and

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1613 then more medical research. You know, we want it to be  
1614 translational to people with down syndrome in our lives.

1615 \*The Chair. Thank you. Thank you just \_ again, thank  
1616 you for your advocacy. It has been because of the \_ because  
1617 of Frank Stephens's testimony and so many others who have  
1618 advocated that NIH is \_ has come a long way, the research,  
1619 and it is making a big difference in people's lives, and  
1620 this is just one example and much more to be done.

1621 Thank you, Mr. Chairman, I yield back.

1622 \*Mr. Guthrie. Thank you. The chair yields back. And,  
1623 Frank, would you just stand so everybody recognizes you  
1624 here? Because I don't know, if you are on the front row \_

1625 [Applause.]

1626 \*Mr. Guthrie. Thank you. Thank you for your advocacy.  
1627 The chair will now recognize the ranking member of the  
1628 full committee, Mr. Pallone, for five minutes for questions.

1629 \*Mr. Pallone. Thank you, Mr. Chairman. I wanted to  
1630 start by talking about the HEARTS Act and go to Dr.  
1631 Tomaselli. As I mentioned in my opening statement, I  
1632 introduced the HEARTS Act after the tragic death of two  
1633 young student athletes in New Jersey, and you are aware that

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1634 cardiomyopathy conditions affect approximately one out of  
1635 500 people. Though cardiomyopathy is relatively rare, it is  
1636 the leading cause of sudden cardiac death in children, which  
1637 is very troubling to me.

1638           So a few questions if you could. Dr. Tomaselli, what  
1639 does the data show about the impact of having access to AED  
1640 devices in schools administered by trained personnel?

1641           \*Dr. Tomaselli. Ranking Member Pallone, thank you so  
1642 much for the question. I would also add that there \_ in  
1643 addition to cardiomyopathy, there are a variety of other  
1644 conditions that are rare but when added together create a  
1645 situation where in fact cardiac arrest is a palpable event  
1646 in the community with often tragic outcomes.

1647           Now what the data show is that in out of hospital  
1648 cardiac arrests, the survival is really quite miserable.  
1649 However, if we have AEDs and if we have responders who are  
1650 nearby, the outcomes can be much improved. And a school is  
1651 a community where in fact it is geographically constrained,  
1652 there ought to be lots of \_ and if there \_ the AED Act is in  
1653 place, there ought to be a number of first responders who  
1654 are close by, and I suspect that the two-and-a-half fold



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1655 increase in meaningful survival in standard out of hospital  
1656 cardiac arrest would be even much better in schools if we  
1657 had AEDs and we had providers in those locations to provide  
1658 prompt treatment of sudden cardiac arrest.

1659       \*Mr. Pallone. Now what about cardiac emergency  
1660 response plans, why is that important for schools to have  
1661 and can it make a difference between life and death?

1662       \*Dr. Tomaselli. Right. So again, an important point,  
1663 again we are talking about a timeline here that is in minute  
1664 \_ seconds to minutes, not hours or days, so a response that  
1665 is prompt, a response that is coordinated is absolutely  
1666 essential to improve outcomes. And this is done in a way  
1667 most efficiently with a cardiac emergency response plan that  
1668 includes a team, a team that has leadership that is drilled,  
1669 that knows what to do, and in fact can overcome barriers  
1670 that people feel when they are approached \_ when they  
1671 approach a patient who has cardiac arrest.

1672       If you don't feel comfortable providing treatment, your  
1673 reluctance will increase. Having a cardiac emergency  
1674 response team and having training reduces that barrier to  
1675 providing care, and I think again will help to provide

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1676 prompt treatment for some cardiac arrest victims.

1677           \*Mr. Pallone. Then I wanted to ask you about raising  
1678 awareness because conditions like cardiomyopathy don't often  
1679 present symptoms until it becomes advanced. So how do we  
1680 help raise awareness about cardiomyopathy and disseminate  
1681 information to schools, or local health departments, or  
1682 health providers, how do we do that?

1683           \*Dr. Tomaselli. Yeah. So again, thank you. I think  
1684 this is a problem but also a mandate, and the mandate  
1685 includes some component of actually the patient knowing what  
1686 their own personal history is, what their family history is,  
1687 and being prepared because some of this is going to be  
1688 proactive, that is understanding who in your community is at  
1689 risk because they have congenital heart disease or they have  
1690 cardiomyopathy. But also reactive, and again links to the  
1691 AED programs and cardiac emergency response because even if  
1692 you know beforehand you don't know when a bad event may  
1693 occur.

1694           So being prepared to respond quickly but also  
1695 understanding who is at risk in your community can allow us  
1696 to better target where in fact defibrillators might be most

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1697 necessary. A related question that often comes up in this  
1698 context is that of screening athletes, screening athletes  
1699 for sports participation. And in fact, there is an ongoing  
1700 debate in the community about how this should be done. The  
1701 American Heart Association believes in a 14-element  
1702 screening protocol that includes personal history, family  
1703 history, physical examination, and others, and measurement,  
1704 for example, of blood pressures and cardiovascular  
1705 examination that can identify people who might need further  
1706 investigation.

1707         One of the components of this that is a debatable piece  
1708 of it is whether or not routine electrocardiography should  
1709 be a part of this. We don't believe it should be because of  
1710 the rarity of the disease and the frequency with which there  
1711 are non-specific findings on the electrocardiogram that  
1712 could lead to lots of expensive workup with no fruit at the  
1713 end of that path.

1714         So I think the two things are making sure that people  
1715 know their own personal family history, prospectively acting  
1716 on those histories, and being able to react quickly should  
1717 an adverse event occur.

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1718           \*Mr. Pallone. All right, thank you so much. Thank  
1719 you, Mr. Chairman, I yield back.

1720           \*Mr. Bucshon. [Presiding.] The gentleman yields back.  
1721 I now recognize Mr. Griffith for five minutes.

1722           \*Mr. Griffith. Thank you, Mr. Chairman, I appreciate  
1723 that. Ms. Eshoo talked about the need to provide  
1724 comprehensive mental health coverage for healthcare workers.  
1725 It is interesting that this week in the Richmond Times  
1726 Dispatch, that would be February 12th, I am just going to  
1727 read you the first two paragraphs. Dr. Trudy Shahady was  
1728 feeling burnt out. It was during the height of the pandemic  
1729 and three unvaccinated patients had died of COVID-19 in the  
1730 span of one week. She needed help she decided, so she  
1731 called a program that existed nowhere else in the country,  
1732 one that allows doctors to seek therapy without putting  
1733 their careers in jeopardy.

1734           This was a Virginia program. Virginia has been leading  
1735 and one of the programs they implemented and was a secure  
1736 subscription portal that healthcare workers can buy into.  
1737 This program allows health workers to seek discreet therapy  
1738 without a fear that they will lose their jobs or the mere

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1739 fact that they called in and asked for help and got help  
1740 would be used against them in every single malpractice case  
1741 brought up after that point. But with protocols in place \_  
1742 the program had protocols in place for reporting certain  
1743 instances. Over 8,000 workers in Virginia have taken  
1744 advantage of this program.

1745 Mr. Feist, what more can be done on top of  
1746 reauthorizing these important programs at the federal level  
1747 but won't hamper the state \_ what the states are trying to  
1748 do? Because obviously states are innovative sometimes.

1749 \*Mr. Feist. States are innovative. And let me go  
1750 beyond what Virginia is doing just to highlight it for the  
1751 committee, because Virginia really is leading the country.  
1752 No pressure on your other states, by the way. Their goal in  
1753 Virginia is to be the best place to take care of healthcare  
1754 \_ to take care of patients.

1755 And so this \_ the program you are speaking of is the  
1756 Medical Society of Virginia's Champion Safe Haven Program.  
1757 Last year the Virginia governor signed a new law into place  
1758 which puts every single licensed health worker in 62  
1759 different health professions. That is 500,000 licensed

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1760 health workers in Virginia now no longer have questions on  
1761 their licensing applications that talk about their prior  
1762 mental health treatment or diagnosis.

1763         This change that Virginia made, as I said, is  
1764 benefitting a half a million health workers and that is the  
1765 kind of leadership that we need to see across the country  
1766 when it comes to one of the two top barriers to accessing  
1767 mental healthcare that healthcare workers have. The first  
1768 is your license. The second is when you go to work for a  
1769 hospital and your credentials.

1770         It was actually pointed out that there is over 6,000  
1771 hospitals in this country. Well in the last year, in  
1772 addition to changing the law in Virginia, 75 percent of the  
1773 hospitals removed their questions from their credentialing  
1774 application. That is when you go to work at a hospital, you  
1775 need to be able to answer these questions, and they are  
1776 often overly invasive and drive this stigma.

1777         So what we are trying to do it get at the primary cause  
1778 of suicide of health workers and that is what others can do  
1779 is to really very, very artfully just take a look at those  
1780 questions that you are asking of your health workers and

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1781 recognize that in those questions you are creating  
1782 structural stigma that drives suicide, prevents mental  
1783 health treatment, and is one very important way that your  
1784 healthcare workers can feel valued and supported.

1785       \*Mr. Griffith. And the article also touches on the  
1786 high rates of suicide amongst our healthcare workers. Mr.  
1787 Chairman, I know the other side hasn't seen it, so I am  
1788 happy for it to be reviewed, but I would like to have that  
1789 article from the Richmond Times Dispatch entered into the  
1790 record if there is no objection. But give them a chance to  
1791 take a look at it first. We will pass that on down.

1792       \*Mr. Bucshon. Yeah, without objection.

1793       [The information follows:]

1794

1795       \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

1796

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1797           \*Mr. Griffith. I will now move to Mr. Strozyk. Thank  
1798 you so much, Mr. Feist.

1799           Calls to the poison centers across the country  
1800 increased by 82 percent from 2021 to 2022. In 2022 alone in  
1801 Virginia, there were more than 1200 calls into poison  
1802 centers for THC related incidences. I have legislation that  
1803 would attempt to create a regulatory framework for these  
1804 products because the FDA has dragged their feet in  
1805 addressing these products, leaving it to be kind of like the  
1806 Wild West out there. And it affects children, it affects  
1807 others, but it particularly is affecting young people who  
1808 don't \_ who buy this stuff at the convenience store and  
1809 think it is like candy because it comes in gummies.

1810           Have you had experience with your ambulances being  
1811 called to address CBD issues?

1812           \*Mr. Strozyk. We have had issues and calls related to  
1813 that. Specifically, you raise a very good point about the  
1814 issuance of candy, alternative administration of THC. This  
1815 has grown. Mom and dad have it at home, the young child  
1816 gets it, it is unknown, it is not regulated necessarily in  
1817 terms of dosages.



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1818           Equally and true is these modified medications or  
1819 modified therapeutics that you find at 7-11 or whatever, and  
1820 in some cases these have adverse effects. In the State of  
1821 Washington I believe two years ago, a gentleman  
1822 overconsumed, and I can't name the product, he went out  
1823 later on, shot two people. It was an incredibly tragic  
1824 event. And yet these things are not protected, they are on  
1825 the counter, they are not age regulated, and we have seen an  
1826 increase of effects by these.

1827           \*Mr. Griffith. Yeah, I appreciate it.

1828           My time is up. I have got lots of other questions I  
1829 will submit for the record, but I yield back.

1830           \*Mr. Bucshon. The gentleman yields back. I now  
1831 recognize Mr. Cardenas for five minutes.

1832           \*Mr. Cardenas. I would like to thank Chair Guthrie and  
1833 Ranking Member Eshoo for holding this hearing today, and I  
1834 would like to thank all of our witnesses for lending your  
1835 expertise and your opinions for this hearing today.

1836           I am glad to see so many critical programs discussed  
1837 today. I want to start by talking about uncompensated  
1838 caregivers who play a key role for our broader healthcare

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1839 ecosystem. In fact, 83 percent of help to all older adults  
1840 in the U.S. is from family, friends, or other unpaid  
1841 caregivers. This is an issue that touches so many families,  
1842 whether it is those who are blindsided by a devastating  
1843 diagnosis or those who are providing care to a loved one  
1844 with disabilities or debilitating illnesses.

1845 Providing a high level of care is a 24/7 job, and for  
1846 far too many, help is not on the way. That is why I am  
1847 grateful to be co-leading the Lifespan Respite Care  
1848 Reauthorization Act with my colleague, Rep. Molinaro. This  
1849 bill reauthorizes a program that offers a life raft for so  
1850 many who need a reprieve.

1851 My first question is for Dr. Pike with the Alzheimer's  
1852 Association. Can you talk a bit about what respite care is  
1853 and why it is so critical for caregivers and their patients?

1854 \*Dr. Pike. Thank you, Representative Cardenas. Every  
1855 day millions of American families are faced with unexpected  
1856 illness, disease, or disability, and with each situation, a  
1857 caregiver could be behind that individual. And one thing we  
1858 hear often is those are family caregivers that play a unique  
1859 role.

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1860           As I highlighted in my testimony, in the case of  
1861 Alzheimer's and dementia, there are six million individuals  
1862 living with Alzheimer's and 11 million of those caregivers  
1863 for this disease. Compared with caregivers with other  
1864 diseases, caregivers for those with Alzheimer's and other  
1865 dementia face unique challenges, stressors, and needs. The  
1866 Lifespan Respite Care Program recognizes that vital role of  
1867 caregivers and has a proven track record of supporting their  
1868 overall health and wellbeing by providing them with much  
1869 needed respite for their care responsibilities. Thank you.

1870           \*Mr. Cardenas. Thank you. In your testimony you note  
1871 that for patients with Alzheimer's or dementia especially, a  
1872 caregiver is provided an estimated 18 billion hours of  
1873 unpaid care just in 2022 alone. And what does this program  
1874 mean for those individuals who are working around the clock  
1875 to provide necessary care and how are these resources  
1876 particularly helpful for caregivers in medically underserved  
1877 communities?

1878           \*Dr. Pike. As I mentioned, those individuals caring  
1879 for someone with Alzheimer's or another dementia, they have  
1880 impacts that are related to emotional, financial, physical

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1881 difficulties that outweigh caregivers of other diseases or  
1882 have a increased burden on them. This type of program gives  
1883 them time, it gives them time to in essence recharge their  
1884 battery and be able to provide care in a way that is \_ that  
1885 is of higher quality within the home.

1886 For those that are underserved or in a underserved  
1887 community overall, this program is important from the  
1888 standpoint of being able to provide essential resources that  
1889 they may not have access to.

1890 \*Mr. Cardenas. Thank you. Mr. Chairman, I want to  
1891 make sure that \_ to mention the importance of legislation  
1892 that extends the Stop, Observe, Ask, and Respond to Health  
1893 and Wellness Training Program which will improve health  
1894 practitioner's ability to identify and support victims of  
1895 trafficking. Since I am almost going to be out of time, I  
1896 want to make sure that I submit for the record this  
1897 testimony called HEAL Trafficking Doc.

1898 \*Mr. Bucshon. Without objection.

1899 [The information follows:]

1900

1901 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

1902

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1903           \*Mr. Cardenas. Okay, thank you, Mr. Chairman.  
1904           With my time remaining I would like to ask Dr.  
1905 Tomaselli with the American Heart Association, Dr.  
1906 Tomaselli, in your testimony you note that fewer than 10  
1907 percent of adults with CHD are receiving recommended care,  
1908 that is congenital heart disease. Why is access to  
1909 appropriate services so inadequate and how will the  
1910 Congenital Heart Futures Reauthorization Act improve care  
1911 protocols?

1912           \*Dr. Tomaselli. Representative Cardenas, thanks \_  
1913 thank you for your question. I think there are a couple of  
1914 answers to that. One is failure to recognize that in fact a  
1915 patient does have congenital heart disease in the first  
1916 place. That is a minor \_ that is probably a minor piece of  
1917 all of this.

1918           But there may be, and I think this came up in another  
1919 question by another one of the representatives, there may  
1920 not be an adequate workforce to actually provide the care  
1921 for many of these patients, particularly in parts of the  
1922 country where specialized care is not available. I think  
1923 this really speaks to another mandate, and that is the

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1924 mandate of making sure that we have a team approach to the  
1925 care of these patients. Not every care provision needs to  
1926 be by a doctor, but there are highly trained and \_ nurse  
1927 practitioners, registered nurses, PAs, and others who are  
1928 part of a care team who can provide care under the direction  
1929 of a physician for these very specialized disorders.

1930           And we can also take advantage of what has happened  
1931 over the last couple of years with COVID-19 in telemedicine  
1932 and leverage telemedicine actually for provision of care in  
1933 places where it might not be readily available.

1934           \*Mr. Cardenas. Thank you. My time having expired, I  
1935 yield back, Mr. Chairman.

1936           \*Mr. Bucshon. The gentleman yields back. I now  
1937 recognize Mr. Latta for five minutes.

1938           \*Mr. Latta. Well, thank you, Mr. Chairman, and thank  
1939 you very much to our witnesses for being with us today. In  
1940 the United States we have the privilege to access many  
1941 cutting edge medical devices and pharmaceuticals. What was  
1942 once almost impossible to treat, such as Alzheimer's or rare  
1943 cancers now have hope due to American private industry  
1944 innovation.

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1945           Dr. Annunziata, I hope I pronounced that correctly,  
1946    advancements in our biopharmaceutical and medical device  
1947    industry have allowed us to detect cancer earlier and save  
1948    lives. Could you expand on how screening and early  
1949    detection more broadly are critical to reducing the burden  
1950    of cancer on patient and the healthcare system  
1951    [indiscernible] out there to save lives?

1952           \*Dr. Annunziata. Sure, absolutely. So screening and  
1953    early detection, it is \_ I will just put it this way. It is  
1954    much better to not get cancer than to get cancer. So the  
1955    screening and early detection allows people to identify  
1956    cancers at a pre-cancerous stage or before \_ or at a very  
1957    early stage of cancer.

1958           When cancer is diagnosed at an early stage, it is much  
1959    easier to treat, it is much less burden on the healthcare  
1960    system. So if cancers can be detected early, this would  
1961    make a huge impact. Cancers that are detected later require  
1962    much more chemotherapy, radiation, hospitalization, and put  
1963    a huge burden on the healthcare system.

1964           Also, people who are uninsured or underinsured will not  
1965    have access to those cares or will have difficult access to

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1966 those treatments. So the effect of cancer \_ or screening  
1967 and early detection has a huge impact on the American  
1968 population.

1969 \*Mr. Latta. Let me follow-up, because each year, you  
1970 know, we are getting closer to hopefully defeating cancer,  
1971 particularly breast cancer. In women between the ages of 50  
1972 to 74, access screening every two years, this reduces death  
1973 by about 26 percent. We all want to get that number to a  
1974 hundred percent up from 26. But what tools are out there  
1975 that can help achieve this goal today?

1976 \*Dr. Annunziata. So the tools that are out there, I  
1977 think the Screens for Cancer Act is something that can  
1978 really make an impact on the \_ on the approaching cancer and  
1979 preventing cancer in women who are uninsured or  
1980 underinsured. I think the amount of resources invested  
1981 there should be maintained and can really help decrease the  
1982 incidence of cancer and the detection at an early stage.

1983 \*Mr. Latta. Well, thank you.

1984 Dr. Pike, over 220,000 Ohioans suffer from Alzheimer's.  
1985 In addition, it is estimated that 6.7 million Americans 65  
1986 and older lived with Alzheimer's in 2023, and about one in



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1987 three seniors will die with Alzheimer's or another dementia.  
1988 You know, I am pleased to see that the reauthorization of  
1989 the BOLD Act was included in today's hearing. What else can  
1990 Congress do to eliminate this disease?

1991 \*Dr. Pike. Thank you. Congress continues to play a  
1992 critical role in the fight against Alzheimer's and other  
1993 dementia, and we are so pleased and grateful that Congress  
1994 continues to invest within the scientific progress that we  
1995 are seeing and the funding that NIH receives. Over the past  
1996 decade alone we have seen significant increases within that  
1997 research funding.

1998 And while we have a tendency to focus a great deal on  
1999 scientific progress, we also have to think about the reasons  
2000 why we do that. It is the families, it is the people, and  
2001 the ways that we can continue to contribute to support the  
2002 caregivers that are also supporting those living with  
2003 Alzheimer's. We have to consider the barriers these  
2004 families face in their daily lives like the caregiving  
2005 support that they need, increased access to early and  
2006 accurate diagnosis to support individuals who may have  
2007 concerns about their cognition, and certainly a more

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2008 coordinated high-quality care that we can provide within the  
2009 healthcare system.

2010 \*Mr. Latta. Well, thank you.

2011 \*Dr. Pike. Thank you.

2012 \*Mr. Latta. Dr. Strozyk \_ or Mr. Strozyk, excuse me,  
2013 despite not being federally legalized or approved by the  
2014 FDA, hemp-based THC is being added to a wide range of food  
2015 and beverage, often with packaging marketed to children.  
2016 Numerous reports have highlighted that calls to poison  
2017 control centers regarding cannabis have dramatically  
2018 increased around the country. In Ohio, for example, one  
2019 such report indicated that calls focusing on marijuana  
2020 edibles were up 115 percent from 2020 and experts expect  
2021 that number to continue to rise in Ohio since the Ohio \_  
2022 Ohio's new recreational marijuana law has been implemented.

2023 Given that many of these poison control calls involve  
2024 children, what should states and the Federal Government be  
2025 doing to ensure these products don't end up in the hands of  
2026 kids?

2027 \*Mr. Strozyk. Thank you, Congressman. I \_ you know,  
2028 as a parent and a grandparent, I think it is imperative that

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2029 rules be established and clearly be identified this is not a  
2030 \_ this is not a toy, this is not something that should not  
2031 be treated as any other medication, and for that matter the  
2032 assumption of \_ consumption of alcohol.

2033 So I think it requires both public education, public  
2034 knowledge, and public awareness of the effect that these  
2035 medication \_ these over the counter drugs, these legalized  
2036 drugs will have on children. It is not a short high, this  
2037 is significant overdosing for children, and I think public  
2038 awareness needs to be significant on this as well as  
2039 discussions of protection, containerization, and clearly  
2040 making everyone aware that access to this has a downside.

2041 That being said, you know, equally to your poison  
2042 control comment, we have seen an increase of children being  
2043 exposed to opioids because it is commonly about and we need  
2044 to educate everyone that our environment has become more at  
2045 risk today.

2046 \*Mr. Latta. Thank you. Mr. Chairman, my time has  
2047 expired, and I yield back.

2048 \*Mr. Bucshon. The gentleman yields back. I recognize  
2049 Mrs. Dingell for five minutes.

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2050           \*Mrs. Dingell. Thank you, Mr. Chair. I want to begin  
2051 by discussing the Charlotte Woodward Organ Transplant  
2052 Discrimination Prevention Act, which is legislation I am  
2053 leading alongside my friend, Rep. Cammack. Thank you, Rep.  
2054 Cammack, for your partnership on this important issue.

2055           This bill will prohibit discrimination against people  
2056 with disabilities in the organ transplant system by ensuring  
2057 eligible individuals are not declined a lifesaving  
2058 transplant based on their disability. The bill is named for  
2059 Charlotte Woodward who was an incredible young woman who was  
2060 born with down syndrome. It is fitting today is Valentine's  
2061 Day and National Donor Day since Charlotte received a  
2062 lifesaving heart transplant in 2012. She celebrated her  
2063 12th heart anniversary last month and has dedicated her life  
2064 to advocating for people with disabilities to receive equal  
2065 access. Charlotte is actually in the audience today.  
2066 Charlotte, would you just stand up and wave so everybody can  
2067 see you?

2068           [Applause.]

2069           \*Mrs. Dingell. Thank you. So she inspires all of us,  
2070 and I want to wish her a Happy Valentine's Day, and

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2071 everybody else, and I hope my colleagues will join me in  
2072 supporting this legislation.

2073 Ms. Sie Whitten, can you briefly explain why this bill  
2074 is so important to the disability community, and where is  
2075 discrimination most often appearing in the transplant system  
2076 decision making process?

2077 \*Ms. Whitten. Absolutely. You know, I am a mom of a  
2078 20-year old with down syndrome, and the idea that if she  
2079 were in need of an organ transplant and that she would be  
2080 denied solely because somebody read down syndrome, it would  
2081 be infuriating and also it is inhumane and unethical.

2082 So this legislation is really important. Even though  
2083 there are 40 states that have laws that are supposedly  
2084 preventing discrimination, there are still 10 states that  
2085 don't have it. In addition, the states that do have it, it  
2086 is not consistent in the way it is administered, it is not  
2087 consistent in the way that there is penalty if you break it,  
2088 and then how do you actually pursue, you know, with \_ now  
2089 with the Office of Civil Rights we have this pathway to  
2090 pursuing, you know, if you want to sue because you haven't  
2091 gotten it because people have been unethical.

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2092           So I think for all those reasons it is hugely important  
2093 that we pass this bill.

2094           \*Mrs. Dingell. Thank you.

2095           \*Ms. Whitten. And I am just so proud that we have a  
2096 person like Charlotte in our community \_

2097           \*Mrs. Dingell. It is wonderful.

2098           \*Ms. Whitten. \_ who is \_ has had that experience, and  
2099 I think naming it after her is beautiful. So I do think  
2100 this is going to make a huge difference \_

2101           \*Mrs. Dingell. Thank you.

2102           \*Ms. Whitten. \_ all across the board. Thank you.

2103           \*Mrs. Dingell. Great.

2104           Now I got a lot of bills here \_

2105           \*Ms. Whitten. Yeah, yeah.

2106           \*Mrs. Dingell. \_ so I am never going to get to all my  
2107 questions, but thank you.

2108           Now I want to turn to Dr. Lorna Breen Healthcare  
2109 Provider Protection Reauthorization Act, which is  
2110 legislation I am leading alongside Representatives Wild,  
2111 Carter, and Kiggans. This bill will reauthorize Dr. Lorna  
2112 Breen Healthcare Provider Protection Act which was

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2113 originally passed in 2022. I want to thank Mr. Corey Feist  
2114 for being here to share Lorna's story and reiterate why it  
2115 is critical we continue building on her efforts to support  
2116 the men and women who, as you write in your testimony, work  
2117 tirelessly to save other people's lives, often at their own  
2118 personal risk.

2119 Mr. Feist, can you elaborate \_ I am going to ask you to  
2120 do this quickly because I got one more bill to get to, too.  
2121 Can you elaborate on the lessons we have learned over the  
2122 past three years since the enactment of the Lorna Breen Act?

2123 \*Mr. Feist. Sure, and thank you so much for being a  
2124 cosponsor. To be brief, because I could take four or five  
2125 hours in answering that question, what I would say is one of  
2126 the things that we have learned is that the root cause of  
2127 the burnout of our physicians, nurses, and other health  
2128 workers can be tied to a number of things, but the primary  
2129 reason is the increased administrative burden that they  
2130 carry. When you think about the fact that over 50 percent  
2131 of a nurse's time and over 70 percent of a physician's time  
2132 is spent away from the bedside doing administrative work,  
2133 not only do I \_ would I argue that we don't have a

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2134 healthcare workforce crisis, we have a workforce doing the  
2135 wrong thing. They are the only ones trained to take care of  
2136 us and they are doing administrative work. So that is  
2137 driving burnout.

2138           The other thing that I would just say is that  
2139 healthcare leaders need to be given the tools now to help  
2140 focus on the impact of the work on the workforce not only  
2141 looking at patient care. Thank you.

2142           \*Mrs. Dingell. Thank you. I have more questions for  
2143 the record for you and I have a letter for the record I  
2144 would like to insert as well from FIGS, Mr. Chairman.

2145           \*Mr. Bucshon. Without objection.

2146           [The information follows:]

2147

2148 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

2149



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2150           \*Mrs. Dingell. Thank you. As co-chair, in my last  
2151 whatever seconds, of the Emergency Medical Service, or EMS,  
2152 Caucus, I care deeply about the EMS workers. They are often  
2153 the first to arrive at the scene of an emergency. They have  
2154 to quickly evaluate and determine the best course of action.  
2155 That is why I have introduced the SIREN Reauthorization Act  
2156 alongside Rep. Joyce. Housed within the Substance Abuse and  
2157 Mental Health Services Administration, SIREN grants grant  
2158 support in public nonprofit rural EMS agencies in their  
2159 efforts to train and recruit staff.

2160           I am going to ask Mr. Strozyk one question and do more  
2161 for the record. Do rural communities have the resources to  
2162 sufficiently recruit and retrain (sic) EMS personnel?

2163           \*Mr. Strozyk. They are doing their best but, no, there  
2164 is a shortage across the country both in terms of staffing,  
2165 resources, new/latest equipment, and ability to deal with  
2166 the closure of hospitals across America.

2167           \*Mrs. Dingell. Thank you. Mr. Chairman, I got several  
2168 other bills I wanted to speak on and I got more questions I  
2169 am going to submit for the record, but I look forward to  
2170 working alongside my colleagues to reauthorize many of these

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2171 important public health programs without delay. Thank you,  
2172 and I yield back.

2173 \*Mr. Bucshon. The gentlelady yields back. I recognize  
2174 Mr. Bilirakis, five minutes.

2175 \*Mr. Bilirakis. Thank you, Mr. Chairman, I appreciate  
2176 it, and this is really a great hearing. Thanks for holding  
2177 it.

2178 So again, H.R. 7189, the Congenital Heart Futures  
2179 Reauthorization Act of 2024, I have the \_ one of the  
2180 cosponsors, the lead cosponsor, and I want to thank my  
2181 colleagues again for co-leading, Soto, Carter, Schiff,  
2182 Salazar, and Cardenas. This critical legislation will  
2183 ensure the continued investments needed at HHS to understand  
2184 and assess the lifelong needs of congenital heart disease,  
2185 or CHD.

2186 Since this program was originally created, we have seen  
2187 the needs of patients living with CHD evolving over the  
2188 years. In the past you have heard me talk about Nicholas  
2189 Basken, who was born with congenital heart disease and  
2190 required heart surgery at just two days old. Well, I am  
2191 glad to report that Nicholas graduated from high school last

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2192 spring and is pursuing music writing. His decision to stay  
2193 in the Chicago area for college was certainly affected by  
2194 his access to adult congenital heart care.

2195 Other more rural areas, unfortunately, do not enjoy the  
2196 same access to adult CHD care, and this transition from  
2197 pediatric to adult care for CHD patients is a critical  
2198 period that requires specialized coordination of care,  
2199 especially that there are now more adults than children  
2200 living with congenital heart disease because of your great  
2201 work. And this isn't just in the rural areas where we have  
2202 a lack of adult congenital heart physicians, even in my  
2203 area, the Tampa Bay area, which is not considered rural.

2204 So, Dr. Tomaselli, I want to thank the American Heart  
2205 Association again for their support of H.R. 7189. Do you  
2206 have any suggestions for how we can expand and strengthen  
2207 the congenital heart program to focus on the unique lifelong  
2208 needs for adult congenital heart patients through workforce  
2209 development training measures, particularly when we know  
2210 there is a shortage of cardiac \_ cardiology care nationwide?  
2211 Now I know you addressed this, but I want to give you an  
2212 opportunity to expand upon that, sir.

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2213           \*Dr. Tomaselli. Representative Bilirakis, thank you  
2214 very much for the support of this bill. The American Heart  
2215 Association appreciates working \_ your work on this. And as  
2216 I \_ as you recognized, the workforce shortage is not unique  
2217 to this particular problem in cardiology, more in medicine  
2218 more generally.

2219           And I think, you know, there \_ one of the goals of some  
2220 of these bills is to provide education about some of these  
2221 conditions, and we find that actually getting into schools  
2222 and engaging people early on what needs to be done, for  
2223 example, in a cardiac emergency or what are the components  
2224 of these bills, allows us to draw in younger people who  
2225 might be interested but don't know it yet, that they might  
2226 be interested in a career in medicine or biomedical  
2227 research.

2228           So this legislation not only provides care, education,  
2229 and training to those providing care, but an opportunity and  
2230 a stepping stone for others who might want to be engaged to  
2231 get engaged. I also think it is really important to  
2232 recognize that regardless of the medical problem, team care  
2233 is essential in making sure that we not only recruit

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2234 physicians but we recruit other allied healthcare providers  
2235 who provide an important component of care, particularly at  
2236 the transitions, and oftentimes are the ones who are  
2237 following patients through that transition from childhood to  
2238 adulthood.

2239         And one other thing that I think is essential is that  
2240 really taking advantage of the fact that we can now  
2241 meaningfully do some things in telemedicine and actually  
2242 allow primary care providers or non-specialized providers  
2243 who are out in the community to communicate with the  
2244 specialists who might not be available immediately but would  
2245 be available to provide consultation and help with  
2246 management of patients. So I think this fully expands the  
2247 whole not only degree bearing providers for healthcare but  
2248 also expands the regions in which this care can be provided.

2249         So I think all of these things, and they are all  
2250 components of the two bills under consideration. And by the  
2251 way, the AED Access as well.

2252         \*Mr. Bilirakis. Thank you very much.

2253         Dr. Pike, I am thankful you are here. I have been such  
2254 a strong advocate for Alzheimer's patients, something that

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2255 is clear and really dear to my heart. My mom is suffering  
2256 from Alzheimer's Disease now, and a caretaker, as it has  
2257 been said, it is a really \_ what a burden on caretakers.

2258 I was proud to recently cosponsor Representative  
2259 Tonko's NAPA Reauthorization Act, which extends the National  
2260 Alzheimer's Project Act. And in fact we molded \_ we modeled  
2261 President \_ actually Representative Tonko and I modeled our  
2262 legislation, the National Parkinson's Plan, after the  
2263 Alzheimer's Plan due to its accomplishments.

2264 Can you provide specific examples of these successes,  
2265 how the National Alzheimer's Project has helped advance  
2266 Alzheimer's research and care and why this model has worked  
2267 at the federal level? So I know you don't have a lot of  
2268 time, but this is really important.

2269 \*Dr. Pike. It is important, and thank you for asking  
2270 the question. I will try to keep it brief. You know, the  
2271 NAPA Reauthorization is incredibly timely right now as we  
2272 look at the progress that we are making in this disease. We  
2273 have treatments for the first time. We have diagnostics  
2274 that are going through the pipeline, and part of that is  
2275 because of the seven-fold increase that we have seen in

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2276 research funding coming out of NIH over the last 10 years.

2277           Being able to coordinate across federal committees,  
2278 federal departments and agencies is incredibly important to  
2279 continuing that progress with the NAPA Reauthorization and  
2280 take what we have learned from the last decade of science,  
2281 including on risk reduction, and fold those new pieces of  
2282 information and new agencies into the act. Thank you.

2283           \*Mr. Bilirakis. Thank you very much. I guess I ran  
2284 out of time and went over. I apologize, Mr. Chairman. I  
2285 yield back the balance \_ whatever \_

2286           \*Mr. Bucshon. I will take it off your time for the  
2287 next hearing. No, I am just kidding. That is a joke. I  
2288 won't do that.

2289           The gentleman yields back. I recognize Dr. Ruiz, five  
2290 minutes.

2291           \*Mr. Ruiz. Thank you. Thank you, Mr. Chairman. As an  
2292 emergency medicine physician serving in a rural and  
2293 underserved area, I can attest to the urgent need for  
2294 programs that support emergency medical services, and as an  
2295 alumni of the great University of Pittsburgh affiliated  
2296 residency in emergency medicine where we basically do the

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2297 pre-hospital care research, I have a deep appreciation of  
2298 pre-hospital care.

2299 In the emergency room I have seen how the emergency  
2300 care that patients receive on the way to the hospital can  
2301 make a significant difference in patient outcomes, and in  
2302 some cases could be the difference between life and death or  
2303 even life with permanent disabilities. Providing emergency  
2304 services for patients in rural areas is challenging due to  
2305 factors like physical distance, workforce shortages, and  
2306 reimbursements that do not cover the costs of care.

2307 More work needs to be done to improve patient access so  
2308 we can ensure people are getting the emergency care they  
2309 need when they need it, and part of that objective includes  
2310 addressing workforce shortages and building up a robust and  
2311 skilled healthcare workforce. That is why programs that  
2312 help recruit and retain paramedics and emergency medical  
2313 technicians, EMTs, as well as ensure emergency responders  
2314 are equipped and trained to treat all individuals are vital.  
2315 And it is crucial that when necessary we reauthorize these  
2316 very programs.

2317 Look, I spent the Super Bowl Sunday watching the Super



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2318 Bowl at the CAL FIRE, Riverside County Fire Indio Station 80  
2319 with the folks from Station 80 and Station 87 to show them  
2320 my appreciation, and we are made from the same cloth. They  
2321 are incredible individuals who put their life on the line to  
2322 help others and to save lives. And while I was there, they  
2323 were called out to the field, and so Station 87 took it  
2324 because the captain of Station 80 was a big 49er fan and he  
2325 gave him a break. So you know how it goes.

2326           One of those programs up for reauthorization in H.R.  
2327 6960 is the Emergency Medical Services for Children's  
2328 Program. This program helps ensure children receive  
2329 appropriate healthcare during a medical emergency. Another  
2330 program being considered for reauthorization today is in  
2331 H.R. 4646, the Rural Emergency Medical Services Training  
2332 Program. This program focuses on recruiting and training  
2333 EMS personnel with a focus on addressing mental health and  
2334 substance abuse disorders.

2335           According to the National Rural Health Association,  
2336 four out of five counties, four out of five have at least  
2337 one ambulance desert. In fact, in certain parts of my  
2338 congressional district, the average EMS response time is one

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2339 hour. One hour, Dr. Bucshon. A person with a stroke, a  
2340 heart attack. One hour or more. This puts patients' lives  
2341 at risk. We must do better to ensure patient access.

2342 So, Mr. Strozyk, EMS plays an incredibly important part  
2343 in helping patients' access to care and connecting patients  
2344 to different care locations like local hospitals and  
2345 tertiary care. How can EMS be better utilized to reduce  
2346 delays in care?

2347 \*Mr. Strozyk. Well, thank you, Doctor. I think your  
2348 response in your testimony or reading of this is totally  
2349 correct. I think \_ here is an imperative point, and I just  
2350 used minor \_ one extreme example and it relates to the  
2351 cardiac issues we have been talking about. Early detection  
2352 of an infarction, transmission of that information to a  
2353 tertiary facility and the rapid transfer of that patient  
2354 from home either to an initial hospital or later to the  
2355 tertiary hospital where they can receive cardiac  
2356 catheterization, open heart procedures, whatever has a net  
2357 savings to America not only in terms of that person's life  
2358 but in terms of the downstream care.

2359 30 years ago it would not be thought of that a

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2360 paramedic from the scene would be sending \_ recognizing an  
2361 infarction and getting the patient quickly from the point in  
2362 time of onset of pain to needle time.

2363 \*Mr. Ruiz. Yeah.

2364 \*Mr. Strozyk. Today we have that in record levels.

2365 \*Mr. Ruiz. Yeah.

2366 \*Mr. Strozyk. Equally in turn is if we can find means  
2367 through programs there \_ whereby the EMS provider goes to  
2368 the scene, does an evaluation of a patient but doesn't  
2369 necessarily have to transport that patient to the most  
2370 expensive level of care, an emergency room, and can refer  
2371 that patient either to a freestanding clinic, take that  
2372 person to a freestanding clinic and/or provide them  
2373 additional access \_

2374 \*Mr. Ruiz. Yeah.

2375 \*Mr. Strozyk. \_ and resources to mental health.

2376 \*Mr. Ruiz. Let me \_ in my 10 seconds left \_

2377 \*Mr. Strozyk. Yes.

2378 \*Mr. Ruiz. \_ you know, I have been talking to a lot of  
2379 the paramedics, and EMT, and fire folks back in my district  
2380 and, you know, they are incentivized to take the patient to

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2381 the hospital, even when they don't have to, because the only  
2382 time they can get paid is by delivering patients to a  
2383 hospital. Now you know that there is patients who get  
2384 called for mental status changes, and the paramedics go  
2385 there, they realize they are diabetic, they didn't eat, they  
2386 are hypoglycemic, they give them their D50 or they give them  
2387 some snacks, they get better, they are fully awake, alert,  
2388 they are like, oh, it is done, they can stay home.

2389 They provide lifesaving care at the home and they don't  
2390 get reimbursed for that. That has to change and we have to  
2391 change it in this committee. They deserve better. Thank  
2392 you.

2393 \*Mr. Bucshon. Thank you. Agreed. The gentleman  
2394 yields back. I now recognize myself for five minutes.

2395 I was a cardiovascular and thoracic surgeon prior to  
2396 being in Congress. I personally operated on two patients in  
2397 my career who survived out of hospital cardiac arrest due to  
2398 AEDs, and in my practice we did all the screening echoes for  
2399 the college athletes at University of Evansville looking for  
2400 undiagnosed cardiomyopathy.

2401 Dr. Tomaselli, I appreciate your testimony and

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2402 expertise in cardiovascular related issues and support for  
2403 the HEARTS Act and the Congenital Heart Futures  
2404 Reauthorization Act. In your testimony you also discussed  
2405 the bipartisan Access to AEDs Act which seeks to increase  
2406 access to AEDs at K-12 schools and provide cardiac arrest  
2407 plan training. Would you quickly remind us how an AED is  
2408 used during a sudden cardiac arrest?

2409       \*Dr. Tomaselli. Thank you, Chairman Dr. Bucshon. We  
2410 speak at the American Heart Association of a chain of  
2411 survival, and that chain of survival includes five links.  
2412 The first two links are activating EMS, providing CPR, and  
2413 the third link is the AED, which is nothing more than a  
2414 computer that is hooked to a battery that has a couple of  
2415 patches that can do two things: record the cardiac rhythm  
2416 and deliver a shock.

2417       So we \_ these devices do an exceptional job at rhythm  
2418 interpretation and they are now designed in such a way that  
2419 there are voice prompts and they are very easy to use.  
2420 Training makes it even easier because people feel  
2421 comfortable with these devices. What they do is they detect  
2422 an irregular and fast heart rhythm and will deliver a shock

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2423 to correct it. Some of these devices also can detect a very  
2424 slow heart rhythm and deliver a lower energy shock to pace  
2425 the heart, to increase the heart rate.

2426 So again, it is important that this be included in a  
2427 total program of cardiac emergency response plan.

2428 \*Mr. Bucshon. Yeah.

2429 \*Dr. Tomaselli. But this is a critical piece of it.

2430 \*Mr. Bucshon. Agreed. I really want to \_ I want to  
2431 lean on \_ in on the training aspect of the bill and make it  
2432 clear in my view that, you know, lay people with no medical  
2433 training can use these devices if they can get over their  
2434 initial fear of using them. I mean, you know, in medical  
2435 school they always said when you respond to a code in the  
2436 hospital, first thing you do is take your own pulse. And  
2437 they say that because, you know, trained people can control  
2438 their emotion \_ help control their emotions and can respond  
2439 properly, and that includes lay people.

2440 So I recently was at an airport, believe or not, there  
2441 was a witnessed arrest in a bathroom, and when I \_ my  
2442 daughter kind of came out of the women's bathroom and said  
2443 something is going on in the men's bathroom. I went in

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2444 there and there was a airport security officer there  
2445 standing there not providing CPR and had not asked for an  
2446 AED, and I had to \_ I did CPR and then asked him for an AED.  
2447 I think it was out of fear and not proper training.

2448         So many public spaces already have these, and some  
2449 states even require schools to have AEDs, although the laws  
2450 aren't necessarily funded. In addition to access to the  
2451 device itself, why is it important to have a sudden cardiac  
2452 arrest plan immediately set in motion to save lives?

2453         \*Dr. Tomaselli. I think this is an \_ a fundamentally  
2454 essentially important here. If you have an AED but nobody  
2455 knows where it is and nobody is willing to use it, it  
2456 becomes an expensive piece of wall art that doesn't help  
2457 anybody. So having a cardiac emergency response plan does a  
2458 couple of things. It actually provides the therapeutic  
2459 treatment strategy for people and provides training so that  
2460 they feel comfortable doing things and not causing harm.

2461         It also allows for the entire team, and there is a team  
2462 of individuals who are responsible for this, to drill and to  
2463 train, like you would have a fire drill, so that when the  
2464 event happens, you know what to do and you know how to do

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2465 it. So I think these are important. And I think the two  
2466 bills, the HEARTS Bill and the Congenital Heart Disease  
2467 Bill, as well as the AED Bill, all provide educational  
2468 training for a number of these things and I think are  
2469 synergistic.

2470 In terms of what the Federal Government can do, I know  
2471 that a number of states are working on passing legislation  
2472 for CERP plans in schools. Some have mandates and \_ but  
2473 some are contingent upon other forms of funding \_

2474 \*Mr. Bucshon. Right.

2475 \*Dr. Tomaselli. \_ either from the Federal Government,  
2476 from grants, from donations. I think having the Federal  
2477 Government step up in the access to AEDs Act and these other  
2478 two bills will be \_ could I think help the states move this  
2479 to \_ move these initiatives forward, so thank you for your  
2480 support of these.

2481 \*Mr. Bucshon. Thank you. Thank you very much. I  
2482 would totally agree with that.

2483 Dr. Annunziata, thank you for being here and for your  
2484 partnership in fighting against cancer. Although part \_ not  
2485 part of today's hearing, I also want to highlight



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2486 legislation that I have with Congressman Yvette Clarke, the  
2487 PSA Screening for HIM Act, previously with Bobby Rush, one  
2488 of our former committee members, legislation to eliminate  
2489 the copay for at risk men to receive prostate cancer  
2490 screening, and this has been in the news recently with one  
2491 of our cabinet secretaries, as everyone knows.

2492         We know that screening cancer can save lives. Do you  
2493 think not having a copay and taking down financial barriers  
2494 to screening, for example, for prostate cancer with a PSA  
2495 for HIM Act could make a difference?

2496         \*Dr. Annunziata. Yes, absolutely. I mean, I think the  
2497 American Cancer Society Cancer Action Network supports the  
2498 PSA for HIM Act. There is many potential benefits of this.  
2499 As we know, prostate cancer survival rates increase when the  
2500 disease \_ survival rates increase when the disease is  
2501 detected early, so it is really essential to remove all  
2502 barriers to getting this prostate cancer screening test.

2503         The screening can help detect prostate cancer at an  
2504 early stage, often before signs are even present, before the  
2505 disease becomes more advanced.

2506         \*Mr. Bucshon. Yeah, my \_

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2507           \*Dr. Annunziata. And as I talked about in my previous  
2508 comments, this is really essential to improving the survival  
2509 of \_

2510           \*Mr. Bucshon. Thank you. My time is expired, but I  
2511 couldn't agree more.

2512           \*Dr. Annunziata. Sorry. Thank you.

2513           \*Mr. Bucshon. Thank you very much for those comments.  
2514 I now recognize Ms. Kuster for five minutes.

2515           \*Ms. Kuster. Great. Thank you, Chairman Guthrie, I  
2516 appreciate it. Thank you to our panel.

2517           I am pleased to see this committee is dedicating time  
2518 to reauthorizing these critical health programs, and the  
2519 list is impressive, supporting premature infants to funding  
2520 stillbirth research and prevention, and committing federal  
2521 resources to fight Alzheimer's Disease. This committee once  
2522 again is working to improve the healthcare system for  
2523 Americans all across our country.

2524           In my experience caring for my mother, she lived with  
2525 Alzheimer's Disease, I have seen firsthand how hard the  
2526 challenges of aging and caring for older adults can be on  
2527 families and caregivers. I am proud to cosponsor two bills

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2528 that will build on the progress that we have made in  
2529 Alzheimer's research and treatment over the last decade, the  
2530 Alzheimer's Accountability and Investment Act and the NAPA  
2531 Reauthorization Act.

2532 As we invest in new treatments and therapies, it is  
2533 more important than ever that we continue funding to detect  
2534 the disease early and that we do everything we can to  
2535 improve healthcare outcomes. So, Dr. Pike, could you share  
2536 some of the breakthrough research and technologies that  
2537 federal investment has made possible over the years?

2538 \*Dr. Pike. Thank you for the question, and I think  
2539 this is an incredibly important one. As I have mentioned  
2540 before, the Alzheimer's Accountability and Investment Act  
2541 really takes what we are hearing from scientists at NIH and  
2542 applying what they believe they need in order to make  
2543 advances against the NAPA Act, asking them how much  
2544 investment they need for the professional judgment budget in  
2545 order to make progress against what we are seeing.

2546 As a result of this, we have seen a seven-fold increase  
2547 in research funding over the last decade and we anticipate  
2548 that that need is going to grow as we continue to see

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2549 advances and the knowledge that we are learning out of the,  
2550 this research.

2551           One of the biggest things I would comment on from the  
2552 standpoint of what we are seeing and what has been invested  
2553 so far is on diagnostics and the important of diagnostics  
2554 within the process of identifying, identifying early, and  
2555 being able to move people into either care pathways, quality  
2556 care, or now that we have treatments that treat the  
2557 underlying biology of the disease, the importance of being  
2558 able to identify those individuals early. NIH funding, NIA  
2559 funding has led to some of those breakthroughs with blood  
2560 diagnostics in particular, efficient and effective ways to  
2561 diagnose Alzheimer's into the future.

2562           But the other side of that is it also identifies  
2563 individuals who may not be eligible for treatment. It gives  
2564 us more information about those dementias and gives us the  
2565 ability to provide better research on ways to create  
2566 pathways for treatments for those other dementias while also  
2567 getting individuals into treatment and improving the  
2568 treatments for those with Alzheimer's.

2569           \*Ms. Kuster. Very helpful. In your testimony you

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2570 mentioned the need to an updated national strategy to fight  
2571 Alzheimer's Disease. Could you briefly discuss some of the  
2572 changes to the advisory council that the NAPA  
2573 Reauthorization Act would make?

2574 \*Dr. Pike. I would highlight two specific areas, and  
2575 one \_ the first one I would highlight is because of the  
2576 increased knowledge that we are seeing around risk  
2577 reduction, the ability to add a sixth goal to the National  
2578 Alzheimer's Project Act on looking at risk reduction and  
2579 ways to reduce risk for Alzheimer's and other dementia.  
2580 That is number one.

2581 Number two is that it takes the knowledge that we have  
2582 seen over the last decade and includes more agencies from  
2583 the Federal Government, for instance like Social Security  
2584 Administration, FEMA, within the National Alz \_ within the  
2585 NAPA advisory committee in order to help coordinate the  
2586 outreach and the work that we do.

2587 \*Ms. Kuster. Great, thank you. Investing in advanced  
2588 diagnostics and innovative treatments is deeply personal to  
2589 me and many of my \_ the families of my constituents across  
2590 my district. I urge my colleagues to support reauthorizing

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2591 these important programs to fund continued research and  
2592 improve early screening, prevention, and treatment now that  
2593 it is available while we work to find a cure for  
2594 Alzheimer's.

2595 And with the remainder of my time, very briefly I will  
2596 turn to rural health. Question for Mr. Strozyk. How are  
2597 SIREN grants helping rural communities in New Hampshire and  
2598 across the country.

2599 \*Mr. Strozyk. Well, New Hampshire is an ideal state to  
2600 look at between your urban and your rural areas. It is \_  
2601 real quickly, it is training, it is education, it is  
2602 recruiting new community members to be part of their EMS  
2603 system. It is the purchase of AEDs and advanced cardiac  
2604 monitoring equipment. It is advanced levels of care, be it  
2605 air \_ advanced airway management for cardiac patients.

2606 But it is also working to develop new programs to \_ as  
2607 to Dr. Ruiz's point, where we can now not take the patient  
2608 to the most expensive means, that we can find means of  
2609 taking them home and taking care of them. So New Hampshire  
2610 has been very strong for that, and I will just \_ one quick  
2611 shoutout to your folks. New Hampshire has one of the finest

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2612 programs for recognition and treatment of opioid overdoses  
2613 by law enforcement, EMS, and community healthcare workers,  
2614 so thank you.

2615 \*Ms. Kuster. Thank you. Thank you very much, and I  
2616 will yield back.

2617 \*Mr. Guthrie. [Presiding.] Thank you. The gentle lady  
2618 yields back, and the chair will recognize Dr. Dunn for five  
2619 minutes for questions.

2620 \*Mr. Dunn. Thank you very much, Mr. Chairman. We have  
2621 a lot of commonsense proposals before us today that  
2622 represent our federal investment and commitment into the  
2623 wellbeing of our Nation. It is important when we  
2624 reauthorize these programs that we evaluate the changing  
2625 healthcare needs of our population. The SARS-CoV-2 pandemic  
2626 certainly identified some weak spots in our public health  
2627 infrastructure as well as left us with new challenges, for  
2628 instance, relating to mental health. Many public health  
2629 needs persisted, such as the need for early and accurate  
2630 cancer screening, an initiative that is near and dear to my  
2631 heart from my many years of medical practice.

2632 What has changed remarkably is the technology that is

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2633 now available to providers to detect cancer earlier, and in  
2634 spit of this, I have to say we are still seeing the  
2635 Preventive Services Task Force dragging their feet to  
2636 recognize the improvements in early diagnosis and thus they  
2637 end up obstructing access to early diagnosis.

2638 Dr. Annunziata, thank you for appearing with us today  
2639 on behalf of the American Cancer Society and also on behalf  
2640 of patients and doctors everywhere. Would you agree that  
2641 there are in fact vast benefits to patients and to the  
2642 healthcare system in terms of quality of life and total cost  
2643 of the system when cancer is detected in its early stages?

2644 \*Dr. Annunziata. Absolutely. It is better to detect \_  
2645 as I mentioned earlier, it is better to detect cancer early,  
2646 even when it is a pre-cancerous lesion, and this vastly  
2647 improves lives, yes.

2648 \*Mr. Dunn. So I think \_ I mean, so that is both \_ the  
2649 patients obviously benefit, but the costs to the system go  
2650 down. And I think there is another benefit that we talk  
2651 about less frequently, which is the benefit to all of  
2652 society in preserving human capital. You know, in my  
2653 opinion, we still fail to put enough emphasis on early and



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2654 accurate diagnosis of many potentially lethal diseases.

2655 I know the American Cancer Society is prioritizing  
2656 passage of H.R. 2407, a bill I cosponsor and led by  
2657 Representatives Hudson, Ruiz, Arrington, and Sewell, and  
2658 this bill will ensure that Medicare beneficiaries can  
2659 benefit from multi-cancer early detection blood test  
2660 screenings. Can you briefly tell the committee why this  
2661 bill is so important?

2662 \*Dr. Annunziata. Yes. So the Multi-Cancer Early  
2663 Detection Act, it will support Medicare paying for any  
2664 multi-cancer detection test. Multi-cancer detection tests  
2665 are moving forward and are currently available in the  
2666 network, but there are barriers to paying for that. So we  
2667 support \_ the American Cancer Society Cancer Action Network  
2668 supports removing that barrier to payment for this test.

2669 \*Mr. Dunn. I do, too. Thank you very much.

2670 Mr. Corey Feist, I appreciate your insights, I commend  
2671 your advocacy related to physician burnout. That is another  
2672 issue that is personal to me and that each of us here I  
2673 think care deeply about. You know, the \_ our physicians,  
2674 doctors and their staffs, are \_ you know, clearly they are

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2675 dedicated to their patients, they remain steadfast to the  
2676 oaths that they have taken, but this faithful commitment to  
2677 their patients can take a hard toll. The quotes you shared  
2678 in your testimony are a testimony to that fact.

2679           The SARS-CoV-2 pandemic exacerbated the plight of the  
2680 burnt-out healthcare workers, which is too often revealed in  
2681 heartbreaking stories like that of your dear sister-in-law,  
2682 Loran Breen. You mentioned that 44 organizations have been  
2683 able to take advantage of the Lorna Breen Act funds since  
2684 its implementation, although there is more work to be done.  
2685 I am supportive of the reauthorization of this program, H.R.  
2686 7153, which would do so.

2687           Would you please briefly share some of the creative  
2688 programs that you have seen that stand out utilizing the  
2689 Lorna Breen grant money?

2690           \*Mr. Feist. Thank you so much for your support of our  
2691 bill and healthcare workers such as yourself. It has been  
2692 amazing to see the work in a relatively short period of  
2693 time. If you think about the healthcare industry didn't  
2694 just get here overnight, it \_ as you say, healthcare workers  
2695 \_ there were about 40 percent of healthcare workers in this

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2696 country were burnt out going into the pandemic, and so it  
2697 was an exacerbation.

2698         What we have seen from the grant recipients is we have  
2699 seen different kind of categories of programs. So those  
2700 that were providing individual support to health workers are  
2701 improving mental health services, they are providing stress  
2702 and trauma support, and they are incorporating wellness  
2703 training into the just basic framework of the day to day in  
2704 life. And as you know as a physician, most of the  
2705 healthcare delivery focus in this country is on the patient  
2706 and it foregoes the impact of the work on the workforce.  
2707 And so these individual support programs have been critical  
2708 to holding pressure on this bleeding wound of burnout to  
2709 provide these workers these essential services.

2710         On the other side of the equation, that \_ you look at  
2711 the root cause of why the burnout is caused in the first  
2712 place. Many of these programs have gone to training  
2713 leadership. As we have discussed already, many leaders are  
2714 often focused so heavily on the patient care that they are  
2715 not even sure what they have the ability to do in their own  
2716 sphere of influence and control to impact the environment

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2717 that drives burnout in the first place, so leadership and  
2718 training has been key to these programs.

2719 Enhancing health worker solutions around reducing their  
2720 workload, their administrative burden. As we know, that  
2721 administrative burden continues to tick up and every  
2722 percentage that it ticks up decreases the amount of clinical  
2723 care that can be provided. So that has been huge. And then  
2724 there have been an ongoing \_ ongoing efforts to really try  
2725 to measure burnout and wellbeing. As you know, boards of  
2726 directors often look very closely at these key performance  
2727 indicators \_

2728 \*Mr. Dunn. I think we are dangerously over time here.

2729 \*Mr. Guthrie. Thanks, we are going to \_ yeah, the  
2730 gentleman \_

2731 \*Mr. Dunn. I don't want to \_

2732 \*Mr. Feist. Sorry about that.

2733 \*Mr. Guthrie. I didn't want to stop you, but the  
2734 gentleman \_

2735 \*Mr. Dunn. Thank you very much for your work.

2736 \*Mr. Feist. Yeah, sure, thank you.

2737 \*Mr. Dunn. I yield back.

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2738           \*Mr. Guthrie. I will recognize Ms. Kelly. She is now  
2739 recognized for five minutes for questions.

2740           \*Ms. Kelly. Thank you for holding today's important  
2741 hearing. Unfortunately, stillbirths affect one in 170  
2742 pregnancies, with over 20,000 babies born still every year  
2743 in the U.S. Nevertheless, what is more disheartening is  
2744 that studies show that nearly a fourth of these stillbirths  
2745 are preventable and the majority occur in what would  
2746 otherwise be considered low-risk pregnancies.

2747           Furthermore, certain groups, such as black women,  
2748 Medicaid recipients, and those living in rural areas share a  
2749 disproportionate burden of these lives lost \_ those lives  
2750 lost, highlighting the urgent need for targeted  
2751 interventions and equitable access to care. We have seen  
2752 other industrialized nations such as UK and Australia invest  
2753 in focused stillbirth education and prevention efforts would  
2754 significantly decrease their rates in just a few years.

2755           Dr. Pike, I know you have been talking a lot about  
2756 Alzheimer's, but I am going to go to your public health  
2757 background. I am proud to co-lead the SHINE for Autumn Act  
2758 with my colleagues, Reps. Kim, Castor, and Joyce. This bill

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2759 provides funding to bolster data collection, increase  
2760 perinatal pathology training, and disseminate educational  
2761 materials concerning stillbirths. This legislation is  
2762 crucial in addressing the gaps in research.

2763         From your public health background, do you have  
2764 thoughts as to why there are gaps in public health  
2765 surveillance data, such as stillbirth research, for example,  
2766 and how improving the research and data collection can help  
2767 us more aggressively decrease mortality in this country?

2768         \*Dr. Pike. Thank you, Representative Kelly, and I am  
2769 happy to offer my best response as a public health  
2770 professional, but want to acknowledge that stillbirth  
2771 prevention efforts are not my immediate expertise. So thank  
2772 you for acknowledging that.

2773         With that said, we know that two public health building  
2774 blocks are data and training, and being able to collect  
2775 data, share data, improve educational materials, increase  
2776 investment in research fellowships have generated positive  
2777 advancements across public health, including what we have  
2778 seen in Alzheimer's, the community. That is likely true  
2779 within the work that you are doing on this act as well.

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2780 Thank you.

2781           \*Ms. Kelly. Thank you. And, Mr. Strozyk, I have heard  
2782 from the ground ambulance service providers in my district  
2783 that they are struggling financially due in large part to  
2784 Medicaid payments that are significantly less, even with the  
2785 add-on payments, than their cost of providing vital medical  
2786 services. Since reform of the ambulance fee schedule is  
2787 likely still several years away, what happens if Congress  
2788 fails to extend the add-on payments at the end of this year,  
2789 and what more can we do to ensure that ground ambulance  
2790 service providers remain solvent until we reform the payment  
2791 system? And I even know finding ambulance drivers are \_ is  
2792 tough, too.

2793           \*Mr. Strozyk. Thank you, Congresswoman. I can't  
2794 imagine that if we cannot have the extenders passed what the  
2795 impact will be to a system that is already fragile and  
2796 having difficulties. Medicare for many, many years has not  
2797 met the direct cost and provision of service. This will  
2798 simply just place it as a more difficult position.

2799           Every month, every week we hear providers,  
2800 public/private, who may be that are struggling to survive,

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2801 and in some cases have had to reduce or \_ in service. We  
2802 are asking this committee and members of Congress in \_  
2803 before \_ as an interim sort of placement that we need not  
2804 only the extenders passed but an additional fee or funding  
2805 associated with that as an interim fix, for lack of a better  
2806 term, until such time as CMS completes the cost study and  
2807 comes forward with a true recognition that Medicare doesn't  
2808 cover the cost of service. Systems are at risk across our  
2809 country.

2810 \*Ms. Kelly. Thank you so much and thank you to all the  
2811 witnesses.

2812 And with that, I yield back.

2813 \*Mr. Guthrie. The gentleman yields back \_ I apologize,  
2814 we were discussing what was going on. Yields back, and the  
2815 chair will now recognize Mr. Carter. Mr. Carter is  
2816 recognized for five minutes.

2817 \*Mr. Carter. Thank you. I am down here in timeout so  
2818 you all focus down here. I appreciate it.

2819 Thank you all for being here. This is a very important  
2820 hearing. These are very important bills that we are  
2821 considering. And, you know, many of these bills, if not all



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2822 of these bills, are bipartisan. And I think when you look  
2823 at it, and I am a healthcare professional, a pharmacist,  
2824 and, you know, we all want the same thing in healthcare in  
2825 America. We want accessibility, affordability, and quality.  
2826 All of us, whether you are a Republican, Democrat, or  
2827 Independent, you want to accessibility, affordability, and  
2828 quality. That is what we want.

2829 That is why I am glad that we are having this hearing  
2830 today, particularly as it relates to children. And I have  
2831 got a bill here, a bipartisan bill, the Emergency Medical  
2832 Services for Children Reauthorization Act. It is extremely  
2833 important. All of us love our children. We want to make  
2834 sure that we are taking care of them, and what this bill  
2835 does is it reauthorizes grants that focus on addressing the  
2836 unique needs of children, and we know that they have unique  
2837 needs, particularly in emergency medical systems.

2838 You know, for nearly four decades now the Emergency  
2839 Medical Services for Children Program has been the only  
2840 federal grant program that specifically focuses on  
2841 addressing the needs of children in emergency medical  
2842 systems. That is why it needs to be reauthorized.

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2843           Mr. Strozyk, I wanted to ask you, can you explain the \_  
2844 how the needs of pediatric patients are different from  
2845 adults and why it is so important for local and community  
2846 hospitals to be ready to meet the needs of children?

2847           \*Mr. Strozyk. I think, and Dr. Schrier can attest to  
2848 this, children are not little adults, and the level of  
2849 training both at the EMS field, the first responders, be it  
2850 paramedic or EMTs, understanding the physiology, the level  
2851 of care that a child needs as well as recognizing that  
2852 children don't necessarily respond in the same way as an  
2853 adult was. I am not saying that we cry faster than a child  
2854 if we skin our knee, but these things do occur.

2855           Equally true is when that child is taken to a community  
2856 hospital, an initial level of care, it is that recognition  
2857 and training that is incredibly important by those  
2858 physicians and nurses at that facility to recognize that  
2859 that child may need tertiary level care. And in our state,  
2860 it is going to Children's Hospital Mary Bridge or wherever  
2861 it may be. We have grown this level of care over the last  
2862 few years, my last 40 years, from treating them as little  
2863 adults to really recognizing many \_

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2864 \*Mr. Carter. Right.

2865 \*Mr. Strozyk. \_ of these efficacies, including mental  
2866 illness, and enviro \_

2867 \*Mr. Carter. Exactly, exactly. Thank you for that.

2868 \*Mr. Strozyk. \_ and difficult environments.

2869 \*Mr. Carter. Extremely important point and I  
2870 appreciate you bringing that up. You know, I had the \_ as a  
2871 pharmacist, I dealt with nursing homes, geriatric patients,  
2872 so I had the other end of spectrum. But you are absolutely  
2873 right, with medications, they are not the same for children  
2874 as they are for adults or as they are for geriatrics, that  
2875 is why this is so very important, particularly when we are  
2876 talking about emergency situations.

2877 I want \_ because I want to get this in very quickly, I  
2878 am going to change and shift gears here and talk about  
2879 another bill that we have got here and that is the \_ I am  
2880 cosponsoring the National Alzheimer's Project  
2881 Reauthorization Act, and I believe that, Dr. Pike, you  
2882 discussed this in your testimony today. I am optimistic  
2883 about this and about the FDA approved treatments to slow the  
2884 progression of this awful disease.

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2885           As I mentioned, I worked in the geriatric world and I  
2886 have seen this, I have seen it firsthand, experienced it in  
2887 my family, as I think probably all of us have. You  
2888 mentioned that \_ Dr. Pike, you mentioned that the National  
2889 Alzheimer's Project Act has led to much of this great  
2890 progress that we have seen. Can you elaborate on how the  
2891 national plan has laid the foundation for these and future  
2892 scientific advances?

2893           \*Dr. Pike. Yes, and thank you for cosponsoring our  
2894 reauthorization act on this. Before 2011, there was no  
2895 cohesive national plan to address Alzheimer's Disease in  
2896 this country. Thanks to NAPA, the first ever national plan  
2897 to address Alzheimer's Disease was released 12 years ago  
2898 which focuses on the goals to promote rapid research on  
2899 Alzheimer's Disease, certainly on other dementia as well,  
2900 and improve the delivery of clinical care for services for  
2901 individuals who are living with dementia and also their  
2902 caregivers. It provides a roadmap of strategies with HHS  
2903 and its partner so that we can accelerate research.

2904           Within the last 10 years since we have been working  
2905 within the advisory council and the NAPA Act, we have

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2906 learned quite a bit as a result of this national investment.  
2907 This reauthorization gives us the opportunity to take that  
2908 knowledge and build on it, and make the updates to the NAPA  
2909 Act along with that. So, for instance, including risk  
2910 reduction. The infor \_ the science has \_ continues to  
2911 evolve on that and we learn more.

2912 \*Mr. Carter. Well, good. Thank you for that. And I  
2913 might add, I have been back and forth between a budget  
2914 committee hearing and this hearing, and the impact, the  
2915 fiscal impact that Alzheimer's is going to have in the  
2916 future on our budget here, that is another thing we need to  
2917 take into consideration. Not \_ I mean, the physical  
2918 effects, the effects it has emotionally on families, on the  
2919 caregivers and everyone else, yes, but the impact  
2920 financially it is going to have on our budget, that is  
2921 another thing we have to take into consideration, so thank  
2922 you for your work in this.

2923 Thank you, Mr. Chairman, and I yield back.

2924 \*Mr. Guthrie. Thank you. Thank you for raising that.  
2925 They say a trillion dollars by 2050.

2926 The chair will now recognize Dr. Schrier for five

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2927 minutes.

2928           \*Ms. Schrier. Thank you, Chairman, Guthrie, I \_ and  
2929 thank you to the witnesses today for speaking today on all  
2930 of these really important public health reauthorizations.  
2931 It was hard to figure out which one to talk about. I also  
2932 want to thank our Chairwoman Rodgers who is \_ who has  
2933 announced her retirement, and she has been a delight to work  
2934 with, especially being from Washington State.

2935           The Emergency Medical Services for Children  
2936 Reauthorization Act is near and dear to my heart. I am a  
2937 pediatrician and have seen in clinic how quickly a child can  
2938 become medically unstable. During training I worked in the  
2939 emergency department taking care of acutely ill or injured  
2940 patients, and however scary it can be when a child is in  
2941 dire straits, it is easier to manage these emergencies in  
2942 controlled settings, but first responders don't have that  
2943 luxury.

2944           They are the ones responding to the emergency in the  
2945 field, and taking of a child in distress is nerve-racking,  
2946 high stress, and high stakes, and EMS providers know that  
2947 children are not just little adults and they aren't all the

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2948 same size. Each one needs a different type of stethoscope,  
2949 and oxygen monitor, breathing tube, blood pressure monitor,  
2950 and each one requires a different dose of an emergency  
2951 medication in a crisis, so there is no automatic reflex with  
2952 a child.

2953 I would add to that that most of the people who are  
2954 providing emergency medical services take care mostly of  
2955 adults and they don't get as much practice with children,  
2956 and that is where we can help. So I am proud to co-lead  
2957 this reauthorization with Representatives Carter, Castor,  
2958 and Joyce. This program supports research, training, grant  
2959 funding, data collection that has resulted in better  
2960 emergency care and a decline in pediatric injury related  
2961 deaths by 40 percent since the program began in 1984.

2962 EMSC in Washington State has provided pediatric care  
2963 equipment throughout the state including pediatric pulse  
2964 oximeters and breathing tubes to EMS agencies who otherwise  
2965 would not be able to keep this equipment in stock.

2966 Mr. Strozyk, it is great to have you.

2967 \*Mr. Strozyk. Thank you.

2968 \*Ms. Schrier. A Washingtonian here testifying before

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2969 the committee. Before \_ for EMS providers who often have to  
2970 act in the moment quickly in order to save a life, can you  
2971 tell us how this program has helped them handle emergencies  
2972 and what gaps the program fills?

2973 \*Mr. Strozyk. Your district may be a great example of  
2974 a tale of two worlds. You live \_ half of your district is  
2975 in an incredibly urban place, Bellevue. You are within  
2976 minutes of tertiary care. The other half of your world in  
2977 Eastern Washington has vast areas where \_ communities there  
2978 but there are not hospitals, there are not advanced levels  
2979 of care.

2980 The training that exists and is ongoing today that  
2981 these first responders in rural portions of Washington,  
2982 across America is the difference. They are becoming  
2983 comfortable, they are becoming understanding, their ability  
2984 to use advanced levels of \_ as you said, airway management  
2985 and understanding that, recognition of diseases has been  
2986 incredibly important as well as recognition of where the  
2987 patient should go in terms of be it immediate evacuation by  
2988 air or whatever to a tertiary facility. This is \_

2989 \*Ms. Schrier. And that's right. We use airflight \_



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2990 \*Mr. Strozyk. Yes.

2991 \*Ms. Schrier. \_ in my district and they have to \_ you  
2992 know, part of the reason that these kids survive, and this  
2993 is why we have support from the Children's Hospital  
2994 Association, which I would like to submit, is that this  
2995 affects how children arrive to the emergency room and that  
2996 has so much to do with their survival. So I want to thank  
2997 you for your comments \_

2998 \*Mr. Strozyk. Thank you.

2999 \*Ms. Schrier. \_ and for being here.

3000 I also wanted to touch on pediatric \_ on provider  
3001 mental health. I am so happy that we are once again taking  
3002 up the important Lorna Breen piece of legislation because  
3003 doctors are trained to put their own feelings aside, and  
3004 work long hours, and not admit when they are having a mental  
3005 health crisis, and that is the culture of medicine, so I am  
3006 glad that we are doing all that we can to help save lives.

3007 I don't have much time left but, Mr. Feist, would you  
3008 like to talk just a little bit about this in the last 30  
3009 seconds remaining?

3010 \*Mr. Feist. Thank you for your support. Physicians,

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3011 nurses, pharmacists, every healthcare worker in this country  
3012 is experiencing a mental health crisis right now. CDC just  
3013 published a report in October that identified that among any  
3014 type of worker class, health workers have the worst mental  
3015 health right now, so reauthorizing this bill now sends a  
3016 signal and support that is much needed to address the  
3017 operational, cultural, and other mental health challenges  
3018 that our health healers have.

3019       You know, Buddy Carter was just in here, he is one of  
3020 the cosponsors, and he just said that it is critical,  
3021 everyone wants accessibility, affordability, and quality in  
3022 their care, but we can't have any of that unless we have a  
3023 healthy workforce.

3024       \*Ms. Schrier. That is right. And it is contributing  
3025 to the physician burnout we are seeing today.

3026       With that, I will conclude and yield back. Thank you.

3027       \*Mr. Guthrie. Thank you. Dr. Schrier yields back.  
3028 And your action on the document we will take at the end. On  
3029 the \_ if it is not on the documents list, we will consider  
3030 it with that. I think there is a documents list, so thank  
3031 you.

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3032           The chair will now recognize Dr. Joyce for five minutes  
3033 for questions.

3034           \*Mr. Joyce. Thank you for yielding, Mr. Chairman, and  
3035 thank you for our panel to being present here today. As a  
3036 doctor, I too am committed to ensuring the continued  
3037 effectiveness of federal resources that safeguard both  
3038 public health and public safety. When I first came to  
3039 Congress, I made it a priority to work on the healthcare  
3040 issues that matter most to Pennsylvania, which is why I am  
3041 pleased to see such an extensive list of bipartisan bills  
3042 before us for consideration today.

3043           Recently, I was proud to assist in introducing H.R.  
3044 7251, which would reauthorize funding for poison control  
3045 centers that play a critical role in providing expert  
3046 guidance and assistance to individuals and families facing  
3047 emergencies related to accidental poisonings and toxic  
3048 exposures. I would also like to thank lead Rep. Chavez-  
3049 DeRemer and co-leads Rep. Davis and Rep. Cherfilus-McCormick  
3050 for their work on introducing this important legislation.

3051           I am proud to stand alongside my colleagues in support  
3052 of the capacity of poison control centers to respond to

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3053 emergencies promptly and effectively, ultimately saving  
3054 lives. Poison control centers are staffed by highly  
3055 experienced staff with a wide range of knowledge on toxins  
3056 contained in everything from household cleaners to snake  
3057 bites and offer services to Americans in all of our 50  
3058 states. When seconds count, this wealth of knowledge can be  
3059 called upon to deliver accurate information in an emergency.

3060 As a member of this Energy and Commerce Health  
3061 Subcommittee, I am proud to be working on this issue. It is  
3062 imperative that we prioritize the reauthorization of these  
3063 essential centers to ensure that they remain equipped to  
3064 meet the needs of our communities.

3065 Mr. Strozyk, can you briefly discuss how these  
3066 organizations you represent with poison control are better  
3067 equipped today than they ever were before?

3068 \*Mr. Strozyk. Well first, it is \_ I would point out \_  
3069 thank you, Congressman, for your support. Poison control  
3070 centers are kind of the silent provider if you think about  
3071 it. It is an incredible resource we don't think about until  
3072 it is needed, be it physician level, be it EMS provider  
3073 level, be it a parent.

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3074 Database is a critical function of this that they have  
3075 developed as there are being ever increasing levels of  
3076 exposure to both chemicals or, and unfortunately to this  
3077 day, over the counter medications that should be regulated,  
3078 and/or street drugs. These systems allow citizens, EMS  
3079 providers, and physicians, and caregivers to make an  
3080 immediate contact to a resource that can provide information  
3081 that is incredibly critical, it is timely, and provides  
3082 direction for treatment and follow-up care that is needed.  
3083 It is a resource, an asset to our country that we many times  
3084 don't think about.

3085 When you say that \_ and you and I are old enough to  
3086 think of this. I think in the doc \_ Mr. Yuck sticker that  
3087 would \_ parents would put on containers and have young  
3088 children recognize if the green tag is on the container,  
3089 don't touch it. It has made a huge impact.

3090 \*Mr. Joyce. Thank you. I am also very pleased to see  
3091 this committee considering the Emergency Medical Services  
3092 for Children Reauthorization Act, which is a vital piece of  
3093 legislation aimed at children so that they receive the  
3094 appropriate care during medical emergencies. My colleague,

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3095 Dr. Schrier, just mentioned that children are not little  
3096 adults. I would like thank our lead sponsor, Rep. Carter,  
3097 and co-chair of the Children's Health Caucus, Rep. Castro  
3098 and Dr. Schrier, for their bipartisan work on this bill.

3099 The EMSC has been a necessary tool for our pediatric  
3100 health providers since it began in 1984 when I was an intern  
3101 in Baltimore and has helped in decreasing the pediatric  
3102 injury-related death rate since its inception by a  
3103 significant 40 percent.

3104 Mr. Strozyk, EMSC state funding has been used for the  
3105 purchase of specialized equipment and supplies to improve  
3106 how children are cared for following a severe accident or  
3107 during an illness. What other kind of specialized equipment  
3108 and supplies are unique to children?

3109 \*Mr. Strozyk. Well, if you think about it, everything  
3110 is smaller, be it airway management, be it cardiac  
3111 monitoring, the applications to use the monitor,  
3112 medications. There are therapeutics by which \_ called a  
3113 Broselow tape. You may recall that from your days where we  
3114 can put it down and make definitive decisions on dosages for  
3115 patients. There are warming equipment that is needed for

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3116 very, very young children, for neonates that need to be  
3117 protected.

3118           And then across this country we have developed some  
3119 very high-level technology of moving newborn patients and  
3120 young patients from primary care facilities to tertiary  
3121 facilities that have changed their life and allowed high  
3122 levels of recovery. Today we have units running around the  
3123 country that have levels of technology that are miniature  
3124 neonate units on the road. So all these things exist.

3125           And first and foremost we are training our EMS  
3126 providers to, as I said several times today and I will  
3127 repeat it again, children are not little people \_ not little  
3128 adults, that they are grown \_ that they have a special need.  
3129 And as a paramedic from the old days, a child was scary.  
3130 Today it is a critical part of the education program.

3131           \*Mr. Joyce. Mr. Strozyk, do you feel that innovation,  
3132 particularly medical device innovation that you just talked  
3133 about, allows for American children, American lives at risk  
3134 to be saved?

3135           \*Mr. Strozyk. Absolutely. Without a doubt we have  
3136 made an impact.

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3137           \*Mr. Guthrie. Thanks.

3138           \*Mr. Joyce. Thank you. My time has expired, and I  
3139 yield.

3140           \*Mr. Guthrie. Thanks. Dr. Joyce yields back. The  
3141 chair recognizes Mr. Sarbanes for five minutes for  
3142 questions.

3143           \*Mr. Sarbanes. Thank you very much, Mr. Chairman.  
3144 Thank you all for being here today. Very powerful testimony  
3145 on these important bills that we want to reauthorize that  
3146 can strengthen critical, primary, preventive, and emergency  
3147 healthcare programs.

3148           When I talk to the healthcare providers in my district,  
3149 and by the way, before I came to Congress I spent almost 20  
3150 years representing various healthcare providers, so it has  
3151 been an ongoing communication channel there for some time.  
3152 Two of the most pressing issues that come up over and over  
3153 again are healthcare workforce challenges, we have talked  
3154 about it today, and the mental and behavioral healthcare  
3155 crisis. And obviously these issues are not existing in a  
3156 vacuum, there is a lot of intersection between them.

3157           In Maryland we have especially seen this in the



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3158 pediatric mental health space where many children who have  
3159 sought acute care have been forced to remain in emergency  
3160 departments long after they are stabilized and ready to move  
3161 to more intermediate care settings, and this is mainly due  
3162 to the fact that there simply are not enough such settings  
3163 for them to move to, in part because of the longstanding  
3164 workforce shortages.

3165           Mr. Strozyk, what impact does this have on the quality  
3166 of care for children and the efficiency of the emergency  
3167 services system as a whole, if you could speak to that?

3168           \*Mr. Strozyk. Well, without a doubt across our Nation  
3169 with COVID we saw a significant impact to emergency  
3170 facilities, ED departments across the country, therefore it  
3171 was not uncommon to see 10 or more ambulances stacked upside  
3172 \_ outside a hospital ED with patients onboard waiting to get  
3173 admitted just to the ED, much less to have tertiary care  
3174 moving to the floor.

3175           In the case of pediatric patients needing to go to  
3176 higher levels of care, there are a limited number of beds,  
3177 there are a limited number of facilities. In return as  
3178 ambulances became backed up because they were \_ EDs were

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3179 filled up with patients and there were no bed space, that  
3180 delayed the transfer in some cases of patients needing to go  
3181 to tertiary care. I think, and I would be \_ I think it  
3182 would be an [indiscernible] statement today, if a patient  
3183 absolutely had to go, it was a life and death scenario, our  
3184 healthcare system made it happen, but it did delay the  
3185 delivery of transfer of patients under less acute  
3186 situations.

3187 And there \_ can't imagine anything worse for the  
3188 parents or the child to having \_ spending additional hours  
3189 in an emergency room when they really want their child to be  
3190 at the long-term care, be it the bed in the hospital  
3191 receiving care needed.

3192 \*Mr. Sarbanes. And a lot of these bottlenecks in the  
3193 whole system are traceable back, at least in part, to the  
3194 healthcare workforce shortages that we are seeing, because  
3195 obviously if you can't \_ if you can't resource different  
3196 things along the care spectrum, then you are going to have  
3197 those problems. So the workforce shortages coupled with  
3198 increased demand for healthcare services are further  
3199 straining already overworked and understaffed emergency

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3200 departments, that is leading to longer wait times for care  
3201 for all patients and more burnout of our healthcare  
3202 providers.

3203         Right now in Maryland, despite concerted efforts to  
3204 build pipelines and improve care that our governor, Governor  
3205 More has undertaken and our state agencies, Maryland has  
3206 some of the longest emergency room wait times in the Nation  
3207 actually. Something that we have been focusing on for the  
3208 last couple years like a laser.

3209         Mr. Feist, in your testimony you note the CDC's October  
3210 2023 vital signs report found that 46 percent of healthcare  
3211 workers experience frequent burnout and 44 percent intended  
3212 to look for a new job within a year. Those are really jaw-  
3213 dropping statistics and they make clear that as we work hard  
3214 to combat the broader mental healthcare crisis we are  
3215 facing, one in its own right among healthcare providers, and  
3216 you have talked about it today. And we know, for example,  
3217 why it is so important to reauthorize bills like the Dr.  
3218 Lorna Breen Healthcare Provider Protection Act.

3219         What I am curious about, just have a minute left, is  
3220 burnout as a concept, it is just getting \_ it is getting a

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3221 lot more focus, a lot more research behind it. Is there  
3222 kind of an emerging field that maybe burnout isn't sort of a  
3223 clinically defined condition yet? Maybe it is, I don't  
3224 know. But what is the data and research delivering to us  
3225 about this very specific topic of burnout and can it lead to  
3226 even more kind of out of the box creative thinking about  
3227 what the response should be for that particular situation?

3228 \*Mr. Feist. Absolutely. And thank you for your  
3229 support of our bill. What we need to remember is that  
3230 burnout is not a mental health condition. Burnout is an  
3231 occupational syndrome. It is impacted by \_ or it is driven  
3232 by the work environment. So a lot of the key to addressing  
3233 the root cause of burnout is to make the work environment a  
3234 better place.

3235 There are cultural issues, there are leadership issues,  
3236 but at the root cause of a lot of the burnout, in fact the  
3237 number one driver of burnout year over year, pre-pandemic,  
3238 during the pandemic, and post-pandemic is the increased  
3239 administrative burden that is placed on clinicians that take  
3240 them away from the bedside, that take them away from taking  
3241 care of patients and all of us. So what is emerging is this

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3242 is an operational redesign problem for the healthcare  
3243 industry to take on so that the workforce does not feel \_  
3244 does not burn out in the first place.

3245 \*Mr. Sarbanes. Thanks very much. I yield back.

3246 \*Mr. Guthrie. Thank you. The gentleman yields back.

3247 The chair recognizes Mrs. Harshbarger for five minutes.

3248 \*Mrs. Harshbarger. Thank you, Mr. Chairman. Thank you  
3249 all for being here today.

3250 I will start with Dr. Shih. Tennessee is home to one  
3251 of the 16 autism and developmental disabilities monitoring  
3252 network sites that are funded through the Autism CARES Act  
3253 authorization. And as the other pharmacist in Congress, I  
3254 have compounded many things for autistic patients over the  
3255 years. My question is, can you speak to why the information  
3256 derived from the network is so important both for  
3257 Tennesseans and the rest of the country?

3258 \*Dr. Shih. Thank you. Thank you, Representative, for  
3259 the question and for your support of the bill. So the ADDM  
3260 Network has been instrumental in terms of our \_ shifting our  
3261 thinking about autism in the United States. As Dr. Pike had  
3262 mentioned earlier, the two cornerstones of public health is

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3263 data and training, and until ADDM Network came into being,  
3264 we didn't have any data about autistic people in the United  
3265 States.

3266 In the decade since, we have been able to collect data,  
3267 longitudinal data as well as cross-sectional data about \_ of  
3268 our population, our community in the United States, and it  
3269 has told us where the needs are the greatest, where we are  
3270 seeing the greatest growth in terms of autistic population,  
3271 where the gaps are in terms of services, and more  
3272 importantly, what are the trajectory that we can expect from  
3273 these children.

3274 The other thing that ADDM data has really shown is to  
3275 highlight disparity that exists within the community and  
3276 between autistic people and neurotypical counterparts in  
3277 terms of their experience in the healthcare system. And so  
3278 we know that, for example, children of color tend to be  
3279 diagnosed much later than their white counterparts. Even  
3280 though that gap has closed and that ADDM data has really  
3281 shown us that, there is still obviously a lot more work to  
3282 do, and we think that data \_ the ADDM data will continue to  
3283 help us provide that monitoring ability to help us

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3284 understand whether or not the policy and program solution  
3285 that we are introducing are actually making a difference.

3286 \*Mrs. Harshbarger. Absolutely. You know, you talked  
3287 about the co-occurring health conditions with these autistic  
3288 patients and how they experience them at a higher rate, so I  
3289 guess further research can help us with all that, so \_

3290 \*Dr. Shih. Absolutely, yes.

3291 \*Mrs. Harshbarger. Yes, sir.

3292 Mr. Strozyk, you mentioned in your testimony a recent  
3293 Department of Veteran Affairs final rule that could  
3294 jeopardize our veterans' access to ground ambulance  
3295 services, and I guess my question is, can you please tell us  
3296 briefly what the VA payment system for ambulance services  
3297 was before the VA issued the rule and basically what is the  
3298 payment framework now that the Department is changing? And  
3299 the reason I ask is I have a huge VA center in my district  
3300 and they service probably \_ well, close to 150,000 veterans,  
3301 so \_

3302 \*Mr. Strozyk. Great. Thank you, Congresswoman, I  
3303 appreciate the question. Today the payment system is the  
3304 same, it has not changed. There was a plan to implement the

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3305 payment rule which would change the reimbursement for ground  
3306 ambulance services from the usual regulated customary rate  
3307 in a community to the Medicare rate, and you can imagine the  
3308 financial impact to systems around the country.

3309 The VA did \_ has delayed the rule until February 16,  
3310 2025, a one-year delay on that. The challenge is is that  
3311 the VA has not specified nor defined how they are going to  
3312 come back to that and look at the impact of this change  
3313 between now and then. Congressman Bost \_

3314 \*Mrs. Harshbarger. Yeah.

3315 \*Mr. Strozyk. \_ and others have bills that would  
3316 require the VA to do a study on the impact of this both in  
3317 terms of ground EMS services and air EMS services. We are  
3318 asking that those bills be passed so that while we  
3319 appreciate the one-year delay, it doesn't take the problem  
3320 away.

3321 \*Mrs. Harshbarger. No. I deal with this all the time.  
3322 They push it down the road in my profession. You are asking  
3323 for transparency maybe? Yeah, yeah.

3324 \*Mr. Strozyk. We are asking for a clearer study and  
3325 review so that the impact is clearly understood.



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3326           \*Mrs. Harshbarger. Gotcha. I understand completely.

3327           Dr. Annunziata, in your testimony you reference support  
3328 for the Screens for Cancer Act which would reauthorize the  
3329 National Breast and Cervical Cancer Early Detection Program  
3330 through 2028, and it will give greater flexibility to  
3331 grantees to implement innovative evidence-based early  
3332 detection screening interventions. You know, I have noticed  
3333 and read reports that there has been numerous reports on the  
3334 concerning increasing cancer rates in young people and  
3335 especially in cervical cancer diagnoses in women between the  
3336 ages of 30 and 44. Breast cancer as well in younger women.  
3337 To me that is deeply troubling.

3338           My question is, you spoke of greater flexibility, so  
3339 how can we improve detection screenings and health outcomes  
3340 with this bill?

3341           \*Mr. Guthrie. I just want to say we have a scoreboard  
3342 clock problem. The score on the field is \_ you got time \_

3343           \*Mrs. Harshbarger. Yes, go ahead.

3344           \*Mr. Guthrie. \_ but just after you answer this  
3345 question, I would like to answer a question, but \_

3346           \*Mrs. Harshbarger. Yeah, that is my last question.

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3347           \*Mr. Guthrie. Thank you.

3348           \*Dr. Annunziata. Thank you for the question. So \_ and  
3349 I think the short answer is that there are still women in  
3350 the United States who are underinsured and are uninsured who  
3351 don't have access to these potentially lifesaving screening  
3352 services. These women \_ women have lower breast and  
3353 cervical cancer screening rates, people without access to  
3354 the screening obviously have lower screening rates which  
3355 means they are at greater risk of being diagnosed with later  
3356 and more advanced stages of the disease.

3357           So the American Cancer Society Cancer Action Network  
3358 does advocate for this program because it is actually a gold  
3359 standard for providing breast and cervical cancer screening,  
3360 diagnostic tests, and treatment referral services to women  
3361 with limited income and under and uninsured.

3362           \*Mrs. Harshbarger. But even if you have some younger  
3363 women with insurance, I mean, I had a pharmacist who worked  
3364 with me was 35 when she was diagnosed with intraductal  
3365 carcinoma, and it is \_ you know, it is the ages in a lot of  
3366 cases, they are not covering those preventative measures  
3367 like 3D imaging or whatever on breast to detect early breast

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3368 cancer, so we need to work on that.

3369 \*Dr. Annunziata. Absolutely, we do need to work on  
3370 that and that is why more research is needed. We have clear  
3371 data for people over 50, over 45 to have their screening.  
3372 We need more data as to who is at risk in the younger  
3373 population.

3374 \*Mrs. Harshbarger. We absolutely do. Thank you.  
3375 With that, I yield back, Mr. Chairman.

3376 \*Mr. Guthrie. The gentlelady yields back. I apologize  
3377 for the clock. And the chair recognizes the gentlelady from  
3378 California, Ms. Barragan, for five minutes for questions.

3379 \*Ms. Barragan. Thank you, Mr. Chairman, and I think  
3380 this hearing is a great hearing and the topic, and I want to  
3381 just commend all our witnesses for the work that you do. It  
3382 is a \_ it is great to have so many areas of health  
3383 represented here and discussing how we can help caregivers  
3384 and patients.

3385 I am no stranger to being a caregiver, as I am one for  
3386 my mother who has Alzheimer's, and I often talk to my  
3387 colleagues sometimes about me flying back for a day  
3388 sometimes just because I have a caregiver issue at home and

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3389 the response I sometimes get is how are you doing this and  
3390 being a member of Congress. And we are just like everybody  
3391 else and have these challenges, too, so it is so important  
3392 that we look to see how we can support not just our patients  
3393 but our caregivers and their families as well.

3394 I know during COVID there was a long waitlist for  
3395 federal \_ the Federal Government to help fund more in-home  
3396 care under the WPCS Program, something that I didn't even  
3397 know about. And so one of the things that I want to make  
3398 sure we are doing is figuring out how can we make sure that  
3399 patients and their caregivers know about the resources out  
3400 there on something we have a lot of work to do.

3401 Dr. Pike, my questions are going to be directed at you.  
3402 I want to thank you for your work in the Alzheimer's  
3403 Association, for all you have done to advocate for our  
3404 community. I am encouraged by the progress made on  
3405 groundbreaking innovation in diagnostic treatments and  
3406 treatments for Alzheimer's. There are 53 million unpaid  
3407 family caregivers in the U.S. and they are more likely to be  
3408 people of color and women. The importance of short-term  
3409 relief or respite care for caregivers cannot be understated.

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3410 As I mentioned, when I travel to D.C., it is often making  
3411 sure that I have a caregiver or a backup plan.

3412 Now the Lifespan Respite Care Program provides grants  
3413 to make quality respite accessible to family caregivers, but  
3414 in addition to federal funding for the Lifespan Respite Care  
3415 Program, how else can Congress support unpaid family  
3416 caregivers?

3417 \*Dr. Pike. Thank you, Congresswoman, for your strong  
3418 and consistent leadership on this topic on behalf of our  
3419 constituents, and I know it hits home personally for you.

3420 \*Ms. Barragan. Thanks.

3421 \*Dr. Pike. I think one of the things that as we make  
3422 decisions about the reauthorizations that we have in front  
3423 of you, the BOLD Reauthorization that does have caregiving  
3424 responsibility and deliverables within it, the Lifespan  
3425 Respite Plan and the grants that come along with it, we need  
3426 to think about who those programs truly serve and how we get  
3427 that to the community level.

3428 We often need to think about and consider the barriers  
3429 to the information about the respite program, the awareness  
3430 that needs to be delivered around it, and the awareness that

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3431 caregiving creates a need around the healthcare system as  
3432 well. So there are many ways that Congress can continue to  
3433 consider the needs around respite. Awareness and building  
3434 awareness for those caregivers, the stigma that it holds,  
3435 and building the tools, the grants and capability at the  
3436 community level is incredibly important.

3437       \*Ms. Barragan. Well, thank you. One of the other  
3438 issues that has come up not just in \_ for me and others I  
3439 have talked to, is the need to find culturally-competent  
3440 caregivers for different communities. How can the NAPA Act  
3441 or other legislative proposals increase the availability of  
3442 quality, culturally-competent caregivers to support people  
3443 with Alzheimer's or other illnesses?

3444       \*Dr. Pike. I think of caregivers not only as the  
3445 family caregivers but also our paid caregiving workforce as  
3446 well, and I think there is ways that we can build education  
3447 and resources at the community level that build capability  
3448 within both of those caregiving populations. The paid  
3449 caregiving population is unique in that we learned a lot  
3450 during COVID on how to build capability and how to extend  
3451 education beyond the typical walls of education and

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3452 training.

3453           In particular, telementoring is another way to think  
3454 about building the caregiving infrastructure with our paid  
3455 caregivers, whether they are primary care or advanced  
3456 practitioners long term. A great example of a telementoring  
3457 program that builds that capability is Project ECHO, and the  
3458 work that we have seen within the primary care, the advanced  
3459 practitioner space, but also within the dementia care  
3460 community long term in building knowledge, awareness of the  
3461 tools in the community, but also the education to create  
3462 more specialist level care within our primary care and  
3463 advanced practitioners around the country.

3464           \*Ms. Barragan. Great. Thank you. I yield back.

3465           \*Mrs. Miller-Meeks. [Presiding.] The chair now  
3466 recognizes Representative Pence for five minutes.

3467           \*Mr. Pence. Thank you, Madam Chair, and thank you to  
3468 the witnesses for being here today.

3469           We are considering several bills today that would  
3470 improve the health and wellbeing of patients and support  
3471 caregivers, including legislation focused on Alzheimer's  
3472 Disease. The BOLD Infrastructure for Alzheimer's Act

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3473 championed by my good friend, Mr. Guthrie, would ensure HHS  
3474 continues to have the resources and infrastructure needed to  
3475 support the prevention, treatment, and care for patients  
3476 with Alzheimer's.

3477         Alzheimer's Disease is a brain and cognitive disorder  
3478 that robs people of the capacity to live their lives to  
3479 their fullest. Symptoms are typically gradual, evolving to  
3480 a point where they interfere with an individual's ability to  
3481 complete basic tasks and enjoy relationships with loved ones  
3482 and members of the community. The NIH currently ranks  
3483 Alzheimer's as the seventh leading cause of death in the  
3484 United States amongst older adults. In Indiana, there are  
3485 110,000 people age 65 and older suffering from Alzheimer's  
3486 and 2200 Hoosiers have tragically lost their lives to this  
3487 terrible disease in 2021, according to the CDC.

3488         Innovators in the Hoosier State, such as Eli Lilly and  
3489 Roche Diagnostics are leading the charge to develop reliable  
3490 testing and therapeutics. It is important we continue to  
3491 support and invest in the programs and strategies necessary  
3492 to ensure continued innovation in the fight against  
3493 Alzheimer's.



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3494           Dr. Pike, this question is going to be for you. Now  
3495 that we have FDA approved Alzheimer's therapeutics, I have  
3496 urged the Biden administration to provide access to these  
3497 critical drugs. While Medicare has traditionally covered  
3498 all FDA approved drugs, CMS has now set up a registry portal  
3499 that could create logistical challenges for patients and  
3500 caregivers as well as providers in rural areas.

3501           Can you explain what current regulatory policies serve  
3502 as a barrier for patients to efficiently access these  
3503 treatments such as the national coverage determination  
3504 reconsideration, and how can we streamline and approve this  
3505 access?

3506           \*Dr. Pike. Thank you, Congressman Pence, for the  
3507 question. I think this is an incredibly important time  
3508 period to talk about the advances that we are seeing in  
3509 Alzheimer's research, what is coming out of the pipeline,  
3510 and ensuring that access gets to the patient level. As you  
3511 mentioned, we are in a unique situation in that for the  
3512 first time we have FDA approved treatments, however CMS has  
3513 limited access to those through a coverage with evidence  
3514 development policy on those treatments.

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3515           As this committee may be aware, the Alzheimer's  
3516 Association actively requested CMS to change their position  
3517 on this coverage with evidence development on this national  
3518 coverage determination, and right now the requirement for  
3519 patients is that they access treatments through a registry.  
3520 We want to see that there are as few barriers to accessing  
3521 treatment as possible. We have seen as part of these  
3522 treatments being available in community that any barrier  
3523 potentially limits access, including whether it is knowledge  
3524 about reimbursement or accessing a specialist in a  
3525 community.

3526           So I agree with you that there needs to be immediate  
3527 access to any FDA approved treatment.

3528           \*Mr. Pence. Got any ideas how we could make that  
3529 immediate?

3530           \*Dr. Pike. I think there is a couple of things that we  
3531 have learned, certainly. The healthcare infrastructure is  
3532 not \_ we learned in the last about 12 to 18 months that the  
3533 healthcare infrastructure needs support in order to make  
3534 sure that access is immediate. But the other side of that  
3535 is looking at the evidence and being able to say that

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3536 coverage should not be limited by utilizing a registry.

3537           \*Mr. Pence. Yeah, sure. And, you know, in rural areas  
3538 where it is a little hard to get to the folks and educate  
3539 them makes it a little bit more important since I am in a  
3540 rural area.

3541           And with that, Madam Chair, I yield back.

3542           \*Mrs. Miller-Meeks. Thank you. The chair now  
3543 recognizes herself for five minutes.

3544           And I am going to thank all the witnesses for being  
3545 here and for the \_ the real chair for having this hearing  
3546 today.

3547           Ms. Whitten, I co-led H.R. 2923, the Living Donor  
3548 Protection Act which would prohibit life, disability, and  
3549 long-term care insurance companies from denying or limiting  
3550 coverage and from charging higher premiums for living organ  
3551 donors. The Family Medical Leave Act of 1993 does  
3552 specifically include living organ donation as a serious  
3553 health condition for private and civil service employees and  
3554 direct HHS to update their materials on live organ donation  
3555 to reflect these new protections and encourage more  
3556 individuals to consider donating an organ. Can you or any

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3557 of the other witnesses speak to the importance of  
3558 encouraging organ donation and why it is a cost-effective  
3559 solution in the long term?

3560 \*Ms. Whitten. Just to be clear, I am not an organ  
3561 transplant donor expert, but I do run the Global Down  
3562 Syndrome Foundation and we have found discrimination on both  
3563 ends, we \_ in terms of donating an organ and then receiving  
3564 the organ, and clearly both \_ you know, our \_ prohibiting  
3565 lifesaving organ transplants. So I think from our  
3566 perspective, we totally are appreciative of the bill, we  
3567 need to call out discrimination in terms of accepting organ  
3568 transplants and then receiving those organ transplants. And  
3569 it is kind of a no brainer to us that, you know, this is  
3570 lifesaving and it needs to be encouraged across the board.

3571 \*Mrs. Miller-Meeks. To follow-up on that, I also  
3572 cosponsored the Charlotte Woodward Organ Transplant  
3573 Discrimination Prevention Act which prohibits entities from  
3574 determining that an individual is ineligible to receive a  
3575 transplant or related services based solely on the fact that  
3576 the individual has a disability. Currently 40 states across  
3577 the country have non-discrimination laws in place which

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3578 would prohibit transplant stakeholders from discriminating  
3579 against individuals with disabilities. Why do we need a  
3580 federal law?

3581       \*Ms. Whitten. Wow. And I wanted to call out  
3582 Charlotte, who is here today, a Happy Valentine's Day, and  
3583 she had a heart transplant and, you know, we have to fight  
3584 for these kinds of things. 40 states have it, 10 states  
3585 don't. The consistency of how the law is implemented needs  
3586 to be addressed on a federal level. Also in terms of  
3587 litigation, if these things are happening where they are  
3588 discriminating, that has to be done at a federal level as  
3589 well.

3590       \*Mrs. Miller-Meeks. Thank you.

3591       Mr. Feist, as a physician, this topic is very important  
3592 to me. According to the Heroes Foundation, more than 400  
3593 physicians die each year by suicide and rates of physician  
3594 suicide differ by specialties. Notably, Dr. Lorna Breen  
3595 Healthcare Provider Protection Act included Section 764,  
3596 programs to promote mental health among health professional  
3597 workforce to the Public Health Service Act. Under this  
3598 section, HHS awards three-year grants and contracts to

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3599 healthcare entities to establish or enhance evidence-based  
3600 or evidence-informed programs dedicated to improving mental  
3601 health and resilience in the profession.

3602           What evidence-based interventions have been employed to  
3603 date and have you seen improved outcomes?

3604           \*Mr. Feist. Yes, we have seen improved outcomes. I am  
3605 \_ I just want to be clear. The organizations that are  
3606 convening those are IHI and GW, and they have given me some  
3607 notes for today, so we have not been right at the center of  
3608 that, but we certainly have reports.

3609           From an organizational change perspective, what we have  
3610 seen is that leadership is getting training and support that  
3611 they didn't have before, and that cascades down to the  
3612 workforce environment which drives burnout. We have seen  
3613 engaging healthcare workers in advancing solutions, and I  
3614 would say that because often the workers are less included  
3615 in just finding out what the solutions are to do things that  
3616 drive burnout, like reducing administrative challenges,  
3617 addressing work/life challenges, as well as improving team-  
3618 based care models.

3619           So those are some of just \_ some of the examples that

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3620 have occurred, but what I want to point out is that there  
3621 are over 6,000 hospitals in this country, and 44 so far have  
3622 received our program, so we have a very long way to go to  
3623 scale these programs and to really make that impact on the  
3624 workforce that we need.

3625 \*Mrs. Miller-Meeks. And, Mr. Strozyk, I am both a  
3626 veteran, and a doctor, and a former director of the Iowa  
3627 Department of Public Health, and EMS fell under our purview.  
3628 You have discussed \_ and I am also on the Veterans  
3629 Committee, so this is an important question, follow-up from  
3630 Mrs. Harshbarger.

3631 You have discussed several significant challenges  
3632 facing ambulance agencies, including staffing shortages and  
3633 insufficient reimbursement. We have also heard a lot about  
3634 drug shortages on this committee, particularly in generic  
3635 sterile injectables in pediatric cancer. However, we know  
3636 that injectable drugs are very important in EMS. And can  
3637 you share your thoughts on the impact of drug shortages on  
3638 emergency medical services?

3639 \*Mr. Strozyk. Yes, I can, thank you, Congressman \_  
3640 Congresswoman. It is hard to imagine that we would have a

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3641 difficulty finding things like injectable epinephrine to  
3642 deal with anaphylaxis, that we would \_ just sterile  
3643 solutions for clearing lines. We have run across other  
3644 cardiac medications we can't get. And in turn, you may  
3645 recall, that when the hurricane hit Puerto Rico we were  
3646 unable to get quantities of sterile saline solution in bag  
3647 form, it was made by one plant.

3648           So this continues and it seems incredible that it does  
3649 today, that we have this rolling shortage of medications, up  
3650 to and including pain relief medications and certain  
3651 narcotics. So it continues. The National Association of  
3652 Emergency Medical Physicians, NAEMSP, is \_ this is a  
3653 critical agenda item for them and we look to support any  
3654 work that can be done to go forward.

3655           \*Mrs. Miller-Meeks. Thank you. I have gone over. I  
3656 yield back.

3657           The chair now recognizes Representative Crenshaw for  
3658 five minutes.

3659           \*Mr. Crenshaw. Thank you, Madam Chair, and of course I  
3660 want to say to our \_ to the Chairwoman who is retiring,  
3661 thank you \_ I don't see her here, but I want to say thank



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3662 you for her service and she will be sorely missed.

3663 Pleased to be focusing today on traumatic brain injury.  
3664 I have a lot of personal friends who have suffered from  
3665 TBIs. They have served our country in the Armed Forces,  
3666 they have served our country in law enforcement, and they  
3667 live with these injuries for years. Five million Americans  
3668 live with a TBI. In the military, the estimate is that 30  
3669 percent of our service members experience some type of brain  
3670 injury, and similar in law enforcement.

3671 We think that a third of veterans have PTSD, a fifth of  
3672 police officers have PTSD, and they are definitely linked to  
3673 TBI and the symptoms that they face every day. That is a  
3674 lifetime of issues, and so I think we should be supporting  
3675 and funding more research for those who are injured, and I  
3676 echo Mr. Strozyk's remarks about reauthorizing programs to  
3677 support that research. And we also have to do our best to  
3678 make sure that that information just doesn't stay in an  
3679 agency in Washington, D.C. but that best practices filter  
3680 down to all practitioners.

3681 Mr. Strozyk, you are a first responder. What do you  
3682 see as the biggest gaps in identifying TBIs early on?

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3683           \*Mr. Strozyk. Well, Congressman, thank you. If we  
3684 speak in terms of EMS providers or we speak in terms of  
3685 public safety law enforcement or fire service, it may be  
3686 identification and acknowledgement that something has  
3687 happened. So be it an accident where there has been an  
3688 airbag deployment, there has been a fall, there has been  
3689 something that would trigger a reason to do an evaluation  
3690 needs to be established. The military has done a marvelous  
3691 job, and unfortunately has had to, recognizing and  
3692 identifying traumatic brain injury.

3693           I refer back to a comment I made earlier in our  
3694 presentation that motorsports and youth sports have become  
3695 extremely focused on identifying initial signs of TBI and  
3696 doing secondary and tertiary follow-up on this. I would  
3697 think, and I would hope, and I would look forward to  
3698 physician groups, NAEMSP, United States Fire Administration,  
3699 other groups that are involved in this, and also  
3700 neurological groups, that we establish standards that says  
3701 if A, B, C, or D has occurred, then that person must receive  
3702 a screening, an initial screening and a backup screening.

3703           \*Mr. Crenshaw. Yeah. And, you know, I don't need to

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3704 tell anybody this, but the reason it is difficult, too, is  
3705 because if you don't have a baseline to operate off of \_ so  
3706 in the military I know that we started doing baselines a  
3707 long time ago. I don't know if that is the case in law  
3708 enforcement.

3709 Dr. Pike, another one of the worst diseases we see in  
3710 the TBI space is CTEs. People with CTEs are also two to  
3711 four times more likely to get dementia. Can you share your  
3712 opinion on the barriers to diagnosing these difficult  
3713 diseases in the brain?

3714 \*Dr. Pike. Thank you. The relationship between TBI  
3715 and CTE is a growing area of research certainly, and like  
3716 Alzheimer's, CTE is characterized by tangles of an abnormal  
3717 form of the protein tau in the brain. And evidence, as you  
3718 just mentioned, indicates that even a mild TBI increases the  
3719 risk of developing certain forms of dementia. In fact,  
3720 recent results have shown a 70 percent increase of dementia  
3721 risk from any form of TBI.

3722 But the fact is more research is needed. We need to  
3723 understand CTE diagnosis and prevention and another way of  
3724 early identification within that space. We also need to

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3725 think about the investments within the workforce and  
3726 training within the workforce for the earliest signs and  
3727 symptoms of TBI and the connection to CTE, and that is  
3728 exactly why we are requesting to reauthorize NAPA and the  
3729 Alzheimer's Accountability Act.

3730 \*Mr. Crenshaw. Okay, I appreciate it.

3731 I want to end with a conversation about breast cancer.  
3732 It is deeply personal to me, I lost my mom to breast cancer,  
3733 and early detection can be life or death. Dr. Annunziata,  
3734 what role do you see for diagnostic innovation in solving  
3735 this problem?

3736 \*Dr. Annunziata. Yes, we certainly need more  
3737 innovation in the diagnostic sense. The American Cancer  
3738 Society recommends traditional screening for women at risk  
3739 of breast cancer and those are based on data that we have  
3740 collected over the years. But we did \_ American Cancer  
3741 Society does also support that any tests recommended by a  
3742 doctor or a study recommended for women with, for example,  
3743 for \_ with dense breasts should be covered at cost sharing.  
3744 And we are pleased that the FDA finalized a rule last year  
3745 specifically requiring all mammogram reports to be sent to

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3746 patients and doctors to include information on dense  
3747 breasts.

3748       \*Mr. Crenshaw. Thank you. And I am out of time, I  
3749 yield back.

3750       \*Mrs. Miller-Meeks. Thank you. The chair now  
3751 recognizes Representative Tonko for five minutes.

3752       \*Mr. Tonko. Thank you, Madam Chair. And again, I am  
3753 so honored to stand with the Alzheimer's community and  
3754 champion many of their efforts.

3755       Given the enormous impact of Alzheimer's on my  
3756 community, this summer I proudly hosted a public discussion  
3757 that we called the Faces of Alzheimer's Disease in the  
3758 capitol region where we did a spotlight of the local  
3759 experiences of patients, their families, and caregivers. I  
3760 heard from Beth Smith-Bovin who, as the leader of the  
3761 Alzheimer's Association of Northeastern New York, introduced  
3762 us to Eugenia who was there to give a face to Alzheimer's,  
3763 as well as her husband Dick, who serves as her caretaker.  
3764 And we were welcomed also by Sherry and Jenny who also both  
3765 care for spouses living with Alzheimer's. We heard from the  
3766 neurologist, Dr. David Hart, and from Nancy Cummings, the

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3767 center director of Alzheimer's Center at Albany Med, as well  
3768 as many others.

3769 To everyone who participated, I thank them for  
3770 providing a face and a voice to Alzheimer's. To the capitol  
3771 region community living with Alzheimer's, I see your pain  
3772 and struggles, but I also see your strength and your  
3773 resilience. I fully recognize that we must do more and  
3774 provide much needed hope.

3775 In that vein, I am thrilled to see the increased  
3776 investment in Alzheimer's and dementia research funding at  
3777 the National Institutes of Health, and I am glad to see how  
3778 the Alzheimer's laws we are considering for reauthorization  
3779 today have helped lead us here.

3780 But with over 410,000 individuals in my home state  
3781 alone facing this devastating disease, it is clear that not  
3782 only funding but a strong national strategy for prevention,  
3783 detection, and treatment is necessary on a federal level to  
3784 help districts such as mine respond to this growing threat  
3785 to the health of our country. During my first term I was  
3786 proud to support the National Alzheimer's Project Act. A  
3787 decade later NAPA allowed us to establish a federal plan to

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3788 address Alzheimer's and dementia that was successful at  
3789 bringing coordination and attention to the disease.

3790         However, those essential federal programs are soon set  
3791 to expire. I am proud to help lead the bipartisan National  
3792 Alzheimer's Project Act Reauthorization Act. I also  
3793 strongly support incorporating provisions that more robustly  
3794 support and include populations that experience Alzheimer's  
3795 Disease and related dementia at a rate that is markedly  
3796 higher than the general population, such as individuals with  
3797 down syndrome. I am also proud to co-lead the Alzheimer's  
3798 Accountability and Investment Act which ensure scientists  
3799 speak directly to Congress on resources that they need to  
3800 effectively treat the disease.

3801         So, Dr. Pike, can you speak to the importance of the  
3802 national plan to address Alzheimer's Disease and the  
3803 Alzheimer's bypass budget? How do these blueprints together  
3804 play a role in equipping researchers with the funding that  
3805 they need to effectively prevent, continue to treat, and one  
3806 day cure Alzheimer's?

3807         \*Dr. Pike. Thank you. Congressman Tonko, your  
3808 leadership and even the storytelling that you do within your

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3809 own community is amazing for the work that we have seen and  
3810 the progress that we have been able to make. NAPA and the  
3811 Alzheimer's Accountability Act have led to significant  
3812 progress within the Alzheimer's community, and certainly  
3813 robust and steady investment. Scientists have been able to  
3814 work faster to advance basic disease knowledge, explore ways  
3815 to reduce risk, uncover new biomarkers for early diagnosis,  
3816 and develop national treatments.

3817       Due to the creation of NAPA, that national plan, and  
3818 the work of the bypass budget since 2014, research funding  
3819 for Alzheimer's and dementia at NIH has increased more than  
3820 seven-fold over the past decade. And the work of both of  
3821 these bills has been crucial over that decade to continue  
3822 this important work among and to coordinate all of the  
3823 agencies within the Federal Government, so thank you.

3824       \*Mr. Tonko. Thank you. I am also honored to lead the  
3825 efforts once again on the BOLD Infrastructure for  
3826 Alzheimer's Reauthorization Act along with my good friend,  
3827 Congressman Guthrie. This effort, as we know, will allow us  
3828 to continue to strengthen our Alzheimer's and dementia  
3829 public health infrastructure across our Nation.



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3830           So, Dr. Pike, again you discussed in your testimony how  
3831 the CDC awards through BOLD have made real world impacts in  
3832 many states. Can you share some more examples of this type  
3833 of innovation, particularly perhaps examples from my home  
3834 state of New York?

3835           \*Dr. Pike. Yes. New York has been a leader within the  
3836 public health space for quite some time, both at the state  
3837 level and within the application of CDC funds. Since 2018,  
3838 CDC has established three Alzheimer's public health centers  
3839 of excellence, and one of which, the Center on Early  
3840 Detection, is based at New York University. Most recently  
3841 in September of 2023, CDC funded 43 public health  
3842 departments across the country, including New York State and  
3843 New York City.

3844           New York State Department of Health proposed an  
3845 initiative to expand dementia related services statewide,  
3846 resulting in the New York Alzheimer's Disease Caregiver  
3847 Support Initiative. Within this initiative's first year,  
3848 community support services for people with dementia and  
3849 their caregivers reached approximately 13,000 individuals  
3850 and families. Through the public health initiatives such as

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3851 these, and certainly the Center of Excellence at New York,  
3852 we know that New York continues to lead the way in the fight  
3853 against Alzheimer's and other dementia.

3854 \*Mr. Tonko. Thank you so much, and it is obvious that  
3855 we need to continue to invest through the Federal Government  
3856 in research on behalf of Alzheimer's, so I thank you.

3857 And with that, Madam Chair, I yield back.

3858 \*Mrs. Miller-Meeks. Thank you. The chair now  
3859 recognizes Representative Cammack for five minutes.

3860 \*Mrs. Cammack. Thank you, Madam Chairwoman, and thank  
3861 you to all my colleagues that are here. I know that I am  
3862 here at the tail end, but thank you to all our witnesses for  
3863 appearing before us today to talk about these very important  
3864 issues.

3865 I am thrilled to see my bill, the Charlotte Woodward  
3866 Organ Transplant Discrimination Prevention Act included in  
3867 today's hearing. Now as many people know that this bill, it  
3868 was named for Charlotte Woodward, who is with us here today  
3869 somewhere. There she is. Hi, Charlotte. An adult woman,  
3870 an amazing woman with down syndrome who is with us and is  
3871 with us today because of a lifesaving heart transplant over

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3872 12 years ago.

3873           Now sadly not all individuals with disabilities have  
3874 that same opportunity. This issue is one that has become  
3875 personal for me as one of my constituents, Bobbi and Josh  
3876 Sarmiento. They are loving and devoted parents in Ocala,  
3877 Florida. They lost their son, Baby Zion, who was born with  
3878 down syndrome and in need of a heart transplant at just six  
3879 months old. Zion's family were told that his life did not  
3880 have the same value as mine or yours and was subsequently  
3881 denied a heart transplant because of his disability. This  
3882 is unacceptable. Ooh, that gets you.

3883           Charlotte's bill would seek to prevent this type of  
3884 discrimination from happening and creates an avenue for  
3885 timely relief at the Office of Civil Rights at the  
3886 Department of Health and Human Services for those who have  
3887 been discriminated against. I want to thank my colleagues  
3888 across the aisle, particularly Congresswoman Debbie Dingell  
3889 for leading this important priority alongside me.

3890           And, of course, at this time I would like to submit a  
3891 letter of support for this bill led by the National Down  
3892 Syndrome Society and signed by over a dozen disability

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3893 advocacy and organ transplant stakeholder groups.

3894 \*Mrs. Miller-Meeks. Without objection.

3895 [The information follows:]

3896

3897 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

3898

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3899            \*Mrs. Cammack. Thank you. And with that, I am going  
3900 to jump right into a few questions.

3901            Ms. Whitten, where are you? There you are. You  
3902 mentioned in your response to Representative Dingell that it  
3903 is clear that you \_ that legislation is needed in states  
3904 that do not have a nondiscrimination law in place for  
3905 individuals with disabilities. For patients who are  
3906 discriminated against, could you please briefly explain what  
3907 relief a bill like ours would provide?

3908            \*Ms. Whitten. Yes, thank you so much. And also just  
3909 from a background, my daughter who is 20 who has down  
3910 syndrome, when reading about the history of say Baby Doe  
3911 where, you know, a lifesaving procedure was feeding a baby  
3912 with down syndrome in a hospital and legislation had to be  
3913 passed so that you couldn't starve a baby to death. I mean,  
3914 that was just in the 1970s and then Willowbrook was only  
3915 shut down in the 1990s. So, yeah, we have got this whole  
3916 human rights things going on, and so your work,  
3917 Congresswoman, is just so meaningful for our families and  
3918 for me.

3919            Yes, it is important to be able to actually litigate,

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3920 right, if you are being discriminated against, going to the  
3921 Office of Civil Rights and presenting your case. So that  
3922 wasn't possible before, certainly in the 10 states that  
3923 didn't have any laws, and then the consistency of which to  
3924 do that now at a federal level is just profoundly impactful.

3925 \*Mrs. Cammack. Now and one of the concerns that we  
3926 have heard repeatedly on the bill is regarding what effect  
3927 the provisions would have on the current practices of  
3928 physicians.

3929 \*Ms. Whitten. Yeah.

3930 \*Mrs. Cammack. So how would this bill impact or  
3931 preserve I should say \_

3932 \*Ms. Whitten. Yes, I was going to say \_ yeah.

3933 \*Mrs. Cammack. \_ preserve a physician's role in the  
3934 transplant process?

3935 \*Ms. Whitten. Yeah, it is important.

3936 You know, we are not getting in the physician's  
3937 business and telling them how \_

3938 \*Mrs. Cammack. Yes.

3939 \*Ms. Whitten. \_ to make decisions, but we have found  
3940 again and again that there are people, physicians who have

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3941 based solely on the diagnosis of down syndrome or a  
3942 disability said, no, this person is not qualified to be a  
3943 recipient, and so this addresses that. It doesn't take away  
3944 the ability to look at the whole medical profile and make a  
3945 decision \_

3946 \*Mrs. Cammack. Yeah.

3947 \*Ms. Whitten. \_ you know, based on how that transplant  
3948 will, you know, be received over time, but that is what we  
3949 are doing, we are getting the worst discrimination out there  
3950 and we are still preserving the rights of the medical  
3951 professional.

3952 \*Mrs. Cammack. Thank you for making sure that that is  
3953 on the record, that we still preserve that autonomy. But as  
3954 a follow-up on top of that, 2019 National Council on  
3955 Disability Report highlighted that many transplant  
3956 stakeholders believe individuals with down syndrome cannot  
3957 adhere to post-operative care.

3958 \*Ms. Whitten. Yeah.

3959 \*Mrs. Cammack. Therefore, they are risky candidates  
3960 for transplants.

3961 \*Ms. Whitten. Mm-hmm.

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3962           \*Mrs. Cammack. Is that an accurate assumption?

3963           \*Ms. Whitten. No. You know, I think that with people  
3964 with down syndrome, many of them have a support system that  
3965 has to be taken into account, and if you just said, oh, this  
3966 person, can they do self-care, you know, I mean, like I  
3967 don't know that I could do the self-care, that a lot of  
3968 people could do the self \_ we all have a support system. So  
3969 this law or this legislation will address the fact that  
3970 there has to be a support system looked at not just that  
3971 individual.

3972           \*Mrs. Cammack. Thank you so much and thank you to all  
3973 of the wonderful advocates in attendance today. I believe  
3974 Charlotte Woodward will be a member of Congress one day, so  
3975 shout out.

3976           And thank you, Madam Chairwoman, I yield.

3977           \*Ms. Whitten. Yeah, thank you.

3978           \*Mrs. Miller-Meeks. Thank you very much. The chair  
3979 now recognizes Representative Castor for five minutes.

3980           \*Ms. Castor. Thank you, Madam Chair. You are about at  
3981 the end now, so thank you. Thank you to all the experts who  
3982 have stuck with us today, and thank you to all the patient



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3983 advocates, and caregivers, and families, and the medical  
3984 professionals who support them. It takes a lot to get  
3985 legislation to committee and then get it actually heard in  
3986 committee and get it moving along, so congratulations to  
3987 you. We have a little more to do, though.

3988         And I want to thank the committee for including two of  
3989 my bipartisan bills, especially the bipartisan and bicameral  
3990 SHINE for Autumn Act. This bill is not new to the  
3991 committee, we passed it before, but the necessity for  
3992 passing it into law remains urgent. The bill is named after  
3993 Autumn Joy who was born still on July 8, 2011, and her  
3994 mother, Debbie, has turned Autumn's tragic death into a  
3995 mission to increase stillbirth awareness and education and  
3996 ultimately decrease the number of families who experience  
3997 such a heartbreaking loss.

3998         Stillbirth is a public health crisis in the United  
3999 States with over 21,000 stillbirths every year. That is  
4000 almost 60 babies every day. This exceeds the number of  
4001 deaths for children age zero to 14 from guns, accidents,  
4002 preterm birth, SIDS, drownings, fire, and flu combined. And  
4003 like too many other maternal and child health issues, there

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4004 are persistent and longstanding disparities with black women  
4005 more than twice as likely to experience stillbirth as white  
4006 women.

4007           At least one out of ever four stillbirths are estimated  
4008 to be preventable, but there is still so much that we do not  
4009 know. That is why we need real change that will lead to  
4010 measurable improvements in the outcomes for families. The  
4011 SHINE for Autumn Act would improve surveillance and data  
4012 collection relating to stillbirth nationwide and invest in  
4013 research to examine the causes and risk factors.

4014 Additionally, it would seek to increase education and  
4015 awareness.

4016           American parents deserve better data and science to  
4017 help improve pregnancy outcomes, and I am proud to lead this  
4018 legislation with my colleagues, Reps. Young Kim, Robin  
4019 Kelly, and Dave Joyce, to keep the memory of Autumn Joy  
4020 alive. Together our committee can address the serious  
4021 maternal and infant health crisis that is tearing families  
4022 apart and causing significant pain and trauma.

4023           At this time, Madam Chair, I would like to ask  
4024 unanimous consent to enter into the record testimony from

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4025 Debbie who has really spearheaded this effort and I know she  
4026 is watching and listening today. And thank you from the 300  
4027 plus endorsing organizations of SHINE for its inclusion in  
4028 the hearing.

4029 \*Mrs. Miller-Meeks. No objection.

4030 [The information follows:]

4031

4032 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

4033

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4034           \*Mrs. Cammack. We need a clearer picture on why babies  
4035 are dying if we want to make progress towards reducing  
4036 stillbirth rates and improving outcomes. With timely and  
4037 accurate data we can begin to understand the underlying  
4038 causes of stillbirth and guide policy actions and much  
4039 needed strategies for prevention.

4040           I would also like to highlight another bill of mine on  
4041 the agenda, H.R. 6960, the Emergency Medical Services for  
4042 Children Reauthorization, which I led with Rep. Carter \_  
4043 Reps. Carter, Schrier, and Joyce. Our bill would  
4044 reauthorize the vital EMSC initiative for another five years  
4045 at the current funding levels. I have the privilege of co-  
4046 chairing the Children's Healthcare Caucus in the Congress,  
4047 and I have learned over the years from a lot of folks like  
4048 you that children have specific healthcare needs, including  
4049 in an emergency when there is little time to spare.

4050           For the past 40 years, EMSC funding has spurred  
4051 innovation and advanced research to address the unique needs  
4052 of children in emergency medical systems, saving countless  
4053 lives and improving health outcomes. EMSC benefits children  
4054 every day in every state in every territory, and here is an

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4055 example. Back home in Florida, EMSC served 4.3 million  
4056 children and their families.

4057       You all may remember that monster Hurricane Ian when it  
4058 was bearing down on Southwest Florida in 2022. They  
4059 evacuated 81 critically ill neonatal and pediatric patients  
4060 from local hospitals, and they \_ we knew that the transport  
4061 vehicles were properly equipped at that time thanks to  
4062 Florida EMSC safe transport work groups' earlier  
4063 distribution of hundreds of pediatric restraint devices.  
4064 Using this kind of resource, it allows \_ it allowed the  
4065 disaster response committee to develop a pediatric mass  
4066 casualty triage tool that has been distributed.

4067       So I am grateful to everyone that has worked on this.  
4068 Thank you very much. And I would also like to ask unanimous  
4069 consent to submit for the record a letter of support from  
4070 the endorsing organizations for H.R. 6960. And thank you  
4071 all very much.

4072       \*Mrs. Miller-Meeks. No objection.

4073       [The information follows:]

4074

4075 \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

4076

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4077            \*Mrs. Miller-Meeks. The lady's time is expired. Does  
4078 she yield back? Thank you.

4079            I ask unanimous consent to insert in the record the  
4080 documents included in the staff hearing's document list.

4081            Without objection, that will be the order.

4082            [The information follows:]

4083

4084            \*\*\*\*\*COMMITTEE INSERT\*\*\*\*\*

4085

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4086            \*Mrs. Miller-Meeks. I remind members that they have 10  
4087 business days to submit questions for the record and I ask  
4088 the witnesses to respond to their questions promptly.  
4089 Members should submit their questions by the close of  
4090 business on February 28th.

4091            Without objection, the subcommittee is adjourned.

4092            [Whereupon, at 1:31 p.m., the subcommittee was  
4093 adjourned.]