1 Diversified Reporting Services, Inc.
2 RPTS CARR
3 HIF293140
4
5
6 ENHANCING PUBLIC HEALTH:
7 LEGISLATION TO PROTECT CHILDREN AND FAMILIES
8 WEDNESDAY, OCTOBER 20, 2021
9 House of Representatives,
10 Subcommittee on Health,
11 Committee on Energy and Commerce,
12 Washington, D.C.
13
14
15
16 The subcommittee met, pursuant to call, at 10:35 a.m. in
17 Room 2123, Rayburn House Office Building, Hon. Anna Eshoo
18 [chairwoman of the subcommittee], presiding.
19 Present: Representatives Eshoo, Butterfield, Matsui,
20 Castor, Sarbanes, Welch, Schrader, Cardenas, Ruiz, Dingell,
21 Kuster, Kelly, Barragan, Blunt Rochester, Craig, Schrier,
22 Trahan, Fletcher, Pallone (ex officio); Guthrie, Upton,
23 Burgess, Griffith, Bilirakis, Long, Bucshon, Mullin, Hudson,
24 Carter, Dunn, Curtis, Joyce, and Rodgers (ex officio).
25
26 Staff Present: Shana Beavin, Professional Staff Member;
27 Waverly Gordon, General Counsel; Tiffany Guarascio, Deputy

28 Staff Director; Perry Hamilton, Clerk; Fabrizio Herrera,
29 Staff Assistant; Stephen Holland, Health Counsel; Zach Kahan,
30 Deputy Director Outreach and Member Service; Mackenzie Kuhl,
31 Press Assistant; Aisling McDonough, Policy Coordinator;
32 Meghan Mullon, Policy Analyst; Juan Negrete, Junior
33 Professional Staff Member; Kaitlyn Peel, Digital Director;
34 Caroline Rinker, Press Assistant; Tim Robinson, Chief
35 Counsel; Chloe Rodriguez, Clerk; Andrew Souvall, Director of
36 Communications, Outreach, and Member Services; Kimberlee
37 Trzeciak, Chief Health Advisor; C.J. Young, Deputy
38 Communications Director; Alec Aramanda, Minority Professional
39 Staff Member, Health; Kate Arey, Minority Content Manager and
40 Digital Assistant; Sarah Burke, Minority Deputy Staff
41 Director; Seth Gold, Minority Professional Staff Member,
42 Health; Grace Graham, Minority Chief Counsel, Health; Nate
43 Hodson, Minority Staff Director; Emily King, Minority Member
44 Services Director; Clare Paoletta, Minority Policy Analyst,
45 Health; Kristin Seum, Minority Counsel, Health; Kristen
46 Shatynski, Minority Professional Staff Member, Health; and
47 Michael Taggart, Minority Policy Director.
48

49 *Ms. Eshoo. Good morning, everyone. The Subcommittee
50 on Health will now come to order.
51 Due to COVID-19, today's hearing is being held remotely,
52 as well as in person.
53 For members and witnesses that are taking part in
54 person, we are following the guidance of the CDC and the
55 Office of the Attending Physician. So please wear a mask
56 when you are not speaking.
57 For members and witnesses taking part remotely,
58 microphones will be set on mute to eliminate background
59 noise, and you will need to unmute your microphone when you
60 wish to speak.
61 Since members are participating from different locations
62 at today's hearing, recognition of members for questions will
63 be in order of subcommittee seniority.
64 Documents for the record should be sent to Meghan Mullon
65 at the email address we have provided your staffs, and all
66 documents will be entered into the record at the conclusion
67 of the hearing.
68 The chair now recognizes herself for five minutes for an
69 opening statement.
70 Today our subcommittee examines 12 bipartisan bills.
71 There is some noise in the background. Can you maybe
72 refrain, or take your conversations out of the hearing room?
73 Today our subcommittee examines 12 bipartisan bills to

74 improve the health care of the American people. Six of the
75 bills focus on children's health and well-being.
76 Pediatric cancer is the number-one disease killer of
77 children in America, but it is chronically underfunded by the
78 public and private sectors. The Gabriella Miller Kids First
79 Research Act 2.0 addresses this gap by redirecting hundreds
80 of millions of dollars in penalties currently paid by
81 pharmaceutical, cosmetic, supplement, and medical device
82 companies into funding for a large-scale genetic and clinical
83 database to help researchers find insights into childhood
84 cancer. We are honored to hear testimony about this bill
85 from Gabriella's mother, Ellyn Miller.
86 Thank you, Mrs. Miller, for joining us today, so close
87 to the eight-year anniversary of Gabriella's death. And
88 thank you for her beautiful portrait that you have at the
89 table with you.
90 Another children's health bill, the Children and Media
91 Research Advancement Act, authorizes the NIH to lead research
92 on the effects of technology and media on infants, children,
93 and adolescents.
94 We can't trust social media companies to do the right
95 thing for our children. This bill provides funding for long-
96 overdue independent research to keep media and tech companies
97 from evading scrutiny about their impact on the development
98 of children in our country.

99 The other four children's health bills seek to prevent
100 and reduce the impact of stillborn -- of stillbirth, newborn
101 hearing loss, lead poisoning, and birth defects or anomalies.
102 We are fortunate to have Stacey Stewart of the March of Dimes
103 as our expert witness for these bills.

104 For over 80 years, the March of Dimes has been a trusted
105 advocate for the health of all moms and children in our
106 country.

107 The next three bills focus on screening and prevention
108 for lung, breast, and prostate cancer.

109 First, Katherine's Law. It provides free coverage of
110 lung cancer screening for individuals over the age of 40,
111 even if they have no history of smoking.

112 Nearly 25 percent of all cancer deaths in the United
113 States are due to lung cancer, and a growing share of lung
114 cancer cases are occurring in never-smokers. If lung cancer
115 in never-smokers were a separate category, it would be in the
116 top 10 cancers in our country for sickness and death. This
117 tragedy hit home for one of our cherished colleagues, former
118 congressman, Rick Nolan, who is with us today. He lost his
119 precious daughter, Katherine, to lung cancer, even though she
120 did not smoke.

121 Thank you, Congressman Rick, for being here today. It
122 is good to see you, and we look forward to hearing your all-
123 important testimony.

124 The PALS Act allows for the early detection of breast
125 cancer through free screenings for women over the age of 40,
126 and the Prostate Cancer Prevention Act funds CDC programs to
127 prevent and detect prostate cancer, the second most common
128 cancer among men in our country.
129 Finally, we are considering two bills to improve cardiac
130 care, and a bill to improve oral health literacy. The CAROL
131 Act is named in honor of Carol Leavell Barr, the wife of
132 Representative Andy Barr, who died last year of sudden
133 cardiac arrest.
134 The bill funds NIH grants to support research into
135 valvular heart disease, as well as increasing public
136 education and awareness of valvular heart disease through the
137 CDC. And the increasing access to quality cardiac
138 rehabilitation care authorizes PAs, nurse practitioners, and
139 clinical nurse specialists to supervise cardiac
140 rehabilitation care, so more Medicare patients can benefit
141 from that care. Patients who receive cardiac rehab typically
142 recover faster from heart attacks or surgery, and improve
143 their quality of life.
144 Through our efforts today, these 12 important bipartisan
145 health bills move closer from being words on a page to
146 actually walking into the lives of our constituents to
147 improve their health and well-being for decades to come.
148

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

150

151 **********COMMITTEE INSERT**********

152

153 *Ms. Eshoo. The chair now is pleased to recognize the
154 gentleman -- and that he is -- Mr. Guthrie, the ranking
155 member of our subcommittee, for five minutes for his opening
156 statement.

157 *Mr. Guthrie. Thank you, Madam Chair, for hosting this
158 important meeting, and welcome to my friend from Minnesota --
159 have you here, and the rest of the panelists that are here
160 with us today.

161 Before us today are several public health bills
162 pertaining to critical prevention and early detection efforts
163 for children and families. But before I get into those
164 bills, I would like to draw attention to the partisan health
165 policies currently being drafted by Democrats behind closed
166 doors here, in Washington.

167 My colleagues on the other side of the aisle are trying
168 to pass a reckless tax-and-spending spree package that would
169 get the government more involved in Americans' lives,
170 including their health care. The Democrats' bill would cost
171 an estimated $4.3 trillion and, according to the
172 Congressional Budget Office letter received yesterday, this
173 bill would lead to 2.8 million Americans losing their
174 employer-based health insurance.

175 Further, this spending bill is a stepping stone for a
176 government-run, one-size-fits-all health care system that can
177 lead to millions more losing their employer or union-

178 sponsored health insurance, along with their doctors.
179 And I have been a long-time supporter of increasing
180 health care access for patients, and allowing patients to
181 keep the doctor of their choice. I believe we need to
182 modernize, personalize, and improve health care, not let the
183 government take it over. That would lead to worst-case,
184 longer waits -- worse care, longer waits, and fewer choices.
185 And further, I must bring up H.R. 3, that is in the
186 spending bill that would stifle innovation for finding new
187 cures, and result in fewer new treatments. I strongly
188 believe in investing in biomedical research to discover
189 innovative solutions to prevent, detect, and treat disease.
190 Innovation improves health care outcomes and saves lives.
191 The drug pricing scheme would do the opposite, and destroy
192 innovation.
193 But fortunately, today we are taking a step in the right
194 direction by examining several important bipartisan public
195 health initiatives. Since 2015 I have been proud to lead,
196 along with my colleague, Representative Doris Matsui, the
197 Early Hearing Detection Intervention Reauthorization Act, or
198 EHDI. This bipartisan bill would provide early diagnosis,
199 intervention, and treatment of children with hearing loss.
200 Nearly 3 out of every 1,000 children in the U.S. are
201 born with a detectable level of hearing loss in one or both
202 ears. Before the EHDI program began 2 decades ago, only 46-

203 and-a-half percent of infants were screened for hearing loss.
204 Thankfully, due to the success of the program, 98 percent of
205 infants are now screened. However, follow-up treatments
206 continue to be a concern, with only 67 percent of infants
207 receiving early intervention treatment. It is essential that
208 infants are screened early for hearing loss, and receive
209 necessary intervention services in a timely manner, so
210 families can get the appropriate care needed.
211 Additionally, I am honored to cosponsor H.R. 1193, the
212 Cardiovascular Advances in Research Opportunities Legacy Act,
213 or CAROL Act. Despite having long been a supporter of
214 legislation that promotes health research, these efforts
215 became much more personal for Representative Andy Barr when
216 he tragically lost his wife, who was 39, Carol, to sudden
217 cardiac arrest in 2020, June of 2020. Inspired by her
218 extraordinary life -- and, those who knew her, she was
219 extraordinary -- he introduced H.R. 1193, the Cardiovascular
220 Advances in Research and Opportunities Legacy, or the CAROL
221 Act.
222 The CAROL Act will address the gaps in understanding
223 about valvular heart disease by authorizing a grant program
224 administered by the National Heart, Lung, and Blood Institute
225 to support research on valvular heart disease, including MVP.
226 The bill has garnered the support of 167 bipartisan Members
227 of Congress, including many on this committee. Companion

228 legislation was introduced in the Senate by Minority Leader
229 Mitch McConnell and Senator Kyrsten Sinema. The legislation
230 would help other families avoid the tragedy that has so
231 profoundly impacted Andy's family and so many others
232 throughout the country.
233 In closing, we do have bipartisan and successful public
234 health programs that should continue. Before Congress
235 authorizes new programs, we need to ensure that current
236 programs are impactful, funds are spent appropriately, and
237 reform or improvements to a program are evaluated. We have
238 learned time and time again that throwing money at a problem
239 is not an effective way to solve issues, or a good use of
240 taxpayer dollars.
241 I yield back.
242 [The prepared statement of Mr. Guthrie follows:]
243
244 **********COMMITTEE INSERT**********
245

246 *Ms. Eshoo. The gentleman yields back. The chair is
247 pleased to recognize the chairman of the full committee, Mr.
248 Pallone, for his five minutes of opening statement.
249 *The Chairman. Thank you, Chairwoman Eshoo.
250 Today the committee continues our important bipartisan
251 work to protect children and families. The COVID-19 pandemic
252 has tested every aspect of family health, and demonstrated
253 how critical physical and social environmental factors are to
254 health outcomes.
255 There are also significant concerns that many children
256 and families have gone without routine care during the
257 pandemic, and this is worrisome, because this care is
258 critical to promoting public health and identifying health
259 conditions early.
260 Unfortunately, it will be some time before we realize
261 the full impact of this lapse in care. Today we are
262 considering legislation that will tackle these challenges in
263 multiple ways.
264 For example, the pandemic created obstacles to
265 preventative care, including cancer screenings, which could
266 have resulted in early forms of cancer going undetected. We
267 will consider three bills that reauthorize or otherwise
268 expand lifesaving screening services for lung, prostate, and
269 breast cancer. And these are important bipartisan pieces of
270 legislation that will help Americans access care and

271 treatment when it is most effective.

272 The pandemic has also undoubtedly delayed care for
273 children, and introduced new challenges in the absence of
274 child care and in-person learning. Some studies suggest that
275 nearly 30 percent of parents postponed or did not seek care
276 for their children, due to concerns about exposure to COVID-
277 19. The impacts have been greater on lower-income families,
278 who have been more likely to delay care, or just simply go
279 without care. And since the pandemic has had a disparate
280 impact on lower-income families, it is important that we act
281 to reverse any harmful effect on the health and well-being of
282 children.

283 And today we are considering multiple bills that seek to
284 expand pediatric research and health care services. We will
285 discuss H.R. 2161, the Children and Media Research
286 Advancement Act, which will reauthorize the National
287 Institutes of Health to expand research into the cognitive,
288 physical, and social, and emotional development effects of
289 media on infants, children, and adolescents. This bill is
290 particularly important right now, as the pandemic has
291 resulted in children spending more time on electronics for
292 learning and social engagement with friends.

293 We will also consider H.R. 5487, the Stillbirth Health
294 Improvement and Education for Autumn Act. This bill would
295 provide resources to state and federal health departments to

296 improve data collection, and increase education about
297 stillbirths, which tragically affect an estimated 24,000
298 families nationwide each year.
299 And these are just a few of the proposals that we will
300 consider. And we have an excellent panel of witnesses ready
301 to discuss the full slate of bills. We hear from medical
302 experts in the fields of cancer, cardiology, and pediatrics.
303 And we will also hear from two parents, who will share the
304 stories of their two daughters, Katherine Bensen and
305 Gabriella Miller, who both lost their lives too soon to
306 cancer.
307 I look forward to hearing from Ellyn Miller, who is also
308 the president and founder of the Smashing Walnuts Foundation,
309 about the Gabriella Miller Kids First Research Act.
310 And I would also like to thank our former colleague,
311 Representative Nolan, for coming to share his daughter,
312 Katherine's story, and to discuss the Katherine's Law for
313 Lung Cancer Early Detection and Survival Act.
314 Finally, I am pleased we are able to work with Ranking
315 Members Rodgers and Guthrie on this hearing, and on this
316 bipartisan slate of bills that will improve the health of
317 children and families all across the nation.
318 And I look forward -- I know we are having these
319 legislative hearings, but we look forward to moving these
320 bills soon. So thank you, and I yield back, Chairwoman.

321 [The prepared statement of The Chairman follows:]

322

323 **********COMMITTEE INSERT**********

324

325 *Ms. Eshoo. The gentleman yields back. The chair now
326 is pleased to recognize Congresswoman Cathy McMorris Rodgers.
327 Is she --
328 *Mr. Guthrie. She is virtual.
329 *Ms. Eshoo. She is virtual? Oh, okay, great.
330 Congresswoman McMorris Rodgers is the ranking member of
331 the full committee, and I am pleased to recognize her for her
332 five minutes for an opening statement.
333 *Mrs. Rodgers. Thank you, Madam Chair, Mr. Chairman,
334 and to all our witnesses. Thank you for being here this
335 morning.
336 Many of the solutions we are considering today renew key
337 public health programs --
338 [Audio malfunction.]
339 *Mrs. Rodgers. -- importance of renewing and updating
340 expired authorizations that continue to be appropriated. So
341 I am pleased that our members are fulfilling the duties we
342 have as an authorizing committee.
343 Mr. Carter's Improving the Health of Child [sic] Act
344 reauthorizes activities at the National Center on Birth
345 Defects and Developmental Disabilities.
346 Mr. Walberg's Lead Poisoning Prevention Act renews
347 critical lead poisoning prevention and screening initiatives.
348 Dr. Dunn's bill reauthorizes prostate cancer activities
349 at the CDC.

350 Other bills reauthorize programs that expire next year,
351 like Mr. Guthrie's Early Hearing Detection and Intervention
352 Reauthorization Act.
353 We will also be considering bills that establish new
354 public health programs, like Representatives Mullin and
355 Herrera Beutler's SHINE for Autumn Act to mitigate the risk
356 of stillbirths, and help more moms and babies, and Mr. Barr's
357 CAROL Act that will improve research and public health
358 outreach related to heart disease.
359 All of these solutions reflect the importance of the
360 committee's authorizing responsibilities over key public
361 health programs.
362 It is important for federal agencies to come before this
363 committee to comment, discuss programs and other related
364 health initiatives that -- and that also should have happened
365 today. In fact, except for a budget hearing with Secretary
366 Becerra on the budget that was not released at the time, no
367 Administration official has come before the Health
368 Subcommittee this Congress.
369 We need to hear from the Administration and public
370 health officials. They have not been before this committee,
371 even after making top-down decisions that impact every person
372 in this country related to COVID-19 data, changing
373 guidelines, schools, vaccine mandates, and booster shots.
374 Unfortunately, it is undermining trust in public health and

375 people's abilities to make the best decisions for themselves.
376 We are also seeing a historic surge in opioid overdose
377 deaths made worse by the economic shutdowns, lost jobs,
378 isolation, fear, and despair. The majority's refusal to
379 bring the Administration before us to address these crises is
380 a complete lack of our oversight and legislative
381 responsibilities. We should be plowing the hard ground,
382 listening, and working together to crush this pandemic and
383 modernize health care.
384 The bills we are considering touch on several important
385 issues, but we also must recognize the central role our
386 public health programs have played over the last year-and-a-
387 half, and the massive influx of funding that they have
388 received as a part of the pandemic response. We should be
389 addressing these public health agencies more holistically.
390 Let's hear from states and the Substance Abuse and
391 Mental Health Services Administration on how to save lives,
392 combat the opioid epidemic, and improve the mental health of
393 children who are in crisis.
394 Let's permanently schedule fentanyl analogues in
395 schedule one. DEA is warning the American public on the
396 increasing dangers of fake prescription pills containing
397 fentanyl.
398 Let's learn from the pandemic on how we safely speed up
399 innovation, like we did to get safe and effective vaccines,

400 and supply those -- apply those lessons to discover new cures
401 and treatments.
402 Let's investigate how this pandemic even started, so it
403 never happens again.
404 This committee has a rich history of bipartisan work by
405 listening and leading on solutions to solve our greatest
406 challenges. Today is a step in that direction, but we have a
407 lot more work to do to address the concerns that are on the
408 hearts and minds of the American people.
409 And this brings me to the tax-and-spending spree that
410 Speaker Pelosi is rewriting right now behind closed doors.
411 It will lead to fewer cures, lost coverage, and force the
412 sick to beg the government for lifesaving care. Just
413 yesterday, CBO provided its analysis that shows the dangers
414 of the majority's -- to socialize medicine that is going to
415 cost more than half-a-trillion dollars: 2.8 million people
416 will lose their employer-sponsored health care. Just like 11
417 years ago, Speaker Pelosi plans to pass a massive bill that
418 radically disrupts people's lives and livelihoods. And if
419 you like your health insurance, you may not be able to keep
420 it.
421 I again urge this committee to get back to the people's
422 work, not the Speaker's agenda, and take a step in the right
423 direction today. I hope we can continue this encouraging
424 trend by addressing the important major public health issues

425 facing our nation today.

426 [The prepared statement of Mrs. Rodgers follows:]

427

428 **********COMMITTEE INSERT**********

429

430 *Mrs. Rodgers. Thank you, I yield back.

431 *Ms. Eshoo. The gentlewoman yields back. I would just
432 like to make a couple of comments. I always welcome
433 constructive criticism, it is always welcome. We learn from
434 each other.

435 But the ranking member is not correct about testimony
436 from Administration officials. We have had the FDA, we have
437 had the NIH. We -- they were both in July. We have had the
438 CDC, Dr. Collins, who testified on long COVID.

439 And there is no bill that is being written behind closed
440 doors. All of the Energy and Commerce Committee were
441 involved in -- what was it, 36, 38, 39 -- hours of markup of
442 the Build Better -- Build Back Better legislation. And the
443 Energy and Commerce Committee, of course, had a significant
444 role in that. So I just want to state that for the record,
445 because those are the facts.

446 I now would like to introduce our witnesses. We are so
447 fortunate to have each one here today.

448 First, our colleague, our former colleague, our --
449 someone that will be a friend for life, Congressman Rick
450 Nolan of Minnesota. He is the father of Katherine, and the
451 namesake of Katherine's Law, which we are considering today.

452 Dr. Donald Lloyd-Jones is the president of the American
453 Heart Association.

454 Welcome to you, too.

455 Ms. Stacey Stewart, the president and the CEO of the
456 March of Dimes. When she came into the hearing room this
457 morning I went over to welcome her, and told her what I
458 recall as a child, maybe seven years old, eight years old, my
459 mother holding my hand and walking through the entire
460 neighborhood, ringing doorbells in the early evening after
461 supper for donations to the March of Dimes. So that is not
462 only etched in my memory, but it is etched in my heart.
463 Dr. Jenny Radesky is the assistant professor of
464 pediatrics at the University of Michigan Medical School, and
465 a constituent of Congresswoman Debbie Dingell. And we will
466 call on Congresswoman Dingell to introduce Dr. Radesky.
467 Dr. Bruce Cassis is the president of the Academy of
468 General Dentistry.
469 Dr. Raymond DuBois is the former president of the
470 American Association for Cancer Research.
471 And Ms. Ellyn Miller is the president and founder of the
472 Smashing Walnuts Foundation, and the mother, most
473 importantly, the mother of Gabriella Miller.
474 So, Congressman Nolan, we will start with you. You have
475 -- you are recognized for five minutes. And welcome again,
476 and thank you for traveling across the country to be with us
477 this morning.
478 [Pause.]
479 *Ms. Eshoo. Is your microphone on, Rick?

480 *Mr. Nolan. There we go.

481 *Ms. Eshoo. There you go.

482 *Voice. Turn it towards you.

483 *Ms. Eshoo. And bring it towards you.

484 *Mr. Nolan. Thank you. It is such a joy --

485 *Ms. Eshoo. And you can take off your mask while you
486 are testifying. And pull the mike up to you. There you go.
487 See, just two years and --

488 *Mr. Nolan. Used to sitting on the other --

489 *Ms. Eshoo. There you go. Two years, and you are out
490 of practice.

491 *Mr. Nolan. -- side of the table.

492 [Laughter.]

493

494 STATEMENT OF THE HON. RICK NOLAN, FORMER U.S. REPRESENTATIVE
495 IN CONGRESS FROM THE STATE OF MINNESOTA; DONALD M. LLOYD-
496 JONES, M.D., SC.M., PRESIDENT, AMERICAN HEART ASSOCIATION;
497 STACEY STEWART, PRESIDENT AND CEO, MARCH OF DIMES; JENNY
498 RADESKY, M.D., ASSISTANT PROFESSOR OF PEDIATRICS, UNIVERSITY
499 OF MICHIGAN MEDICAL SCHOOL; BRUCE L. CASSIS, D.D.S.,
500 M.A.G.D., PRESIDENT, ACADEMY OF GENERAL DENTISTRY; RAYMOND
501 DUBOIS, M.D., PH.D., FORMER PRESIDENT, AMERICAN ASSOCIATION
502 FOR CANCER RESEARCH; AND ELLYN MILLER, PRESIDENT AND FOUNDER,
503 SMASHING WALNUTS FOUNDATION
504
505 STATEMENT OF THE HON. RICK NOLAN
506
507 *Mr. Nolan. It is such a joy to see so many old
508 friends, and thank you for inviting me to be here today.
509 As I was saying, Chairwoman Eshoo, Ranking Member
510 Guthrie, chairman of the full committee, Frank Pallone, and
511 Representative McMorris Rodgers, and thank you all for being
512 here.
513 I am here as -- not as a former member. I am really
514 here as a father, and a public citizen, and a non-lobbyist
515 for anybody, I might add, and to give testimony, and to thank
516 all of you on this committee, your personal staff, your
517 committee staffs for their service, for conducting this
518 hearing, for giving me an opportunity to testify on behalf of

519 H.R. 3749, Katherine's Law, for the early detection and
520 survival of lung cancer victims.
521 It -- a little history. It was in 1971 that President
522 Richard Nixon declared war on cancer. And since that time
523 every president, Democrat and Republican, has entered into
524 that war, and joined with the Congress of the United States
525 and this committee in a very strong, resolute, non-partisan
526 manner to win this war against cancer, which kills so many
527 people. Lung cancer, in particular, which kills more people
528 than virtually all the other cancers combined.
529 Our daughter, Katherine, who was a non-smoker, devoted
530 her terminal cancer diagnosis as what she called her ticking
531 time bomb. It was not a matter -- question of whether, it
532 was just a question of when. And she chose to devote the
533 last years of her life to her four children, her husband, and
534 then doing everything she could to spare people in the future
535 from having to endure what she and so many others had to
536 endure.
537 And it was during that process where Katherine learned
538 and informed her dad that breast cancer, prostate cancer,
539 colorectal cancer benefited from public policies that
540 provided routine, free cancer screening, which enabled early
541 detection. Unfortunately, for lung cancer, the only people
542 -- and by the way, that was starting at age 40 for most of
543 these other cancers. Unfortunately, for lung cancer, the

544 only people who were entitled to that routine screening were
545 55 years of age, and they had to have smoked a package of
546 cigarettes every day for 20 years. Or was it 30 years?
547 Somebody can correct me on that. I forget at the moment.
548 But people who were non-smokers, many of whom are victims of
549 lung cancer, were not entitled to any screening whatsoever.
550 And she learned also -- and informed me and others --
551 that that was in part because of the stigmatization of lung
552 cancer, by virtue of smoking, but also the fact that our
553 lungs don't have any nerves, unlike the other parts of our
554 body. So in the other cancers, in addition to early
555 detection and screening, you might feel a lump, you might
556 feel discomfort, you might feel pain. That doesn't happen
557 with lung cancer. There are no nerves. You don't have any
558 discomfort until it starts pressing against other organs.
559 And without the benefit of early screening, you are not
560 getting the same strong, positive results that the victims of
561 other cancer have. Breast cancer, for example, prostate
562 cancer, colorectal cancer. They, respectively, have survival
563 rates after 5 years of 90 percent, breast -- prostate cancer,
564 98 percent; colorectal, 65 percent. Unfortunately, for lung
565 cancer it is a little over 20 percent after 5 years because
566 of that disparity, very unfair to the victims of cancers,
567 whether they were smokers or non-smokers.
568 And during her journey, that is when we learned this.

569 So she said to me, "Dad, is there any reason why we can't
570 draft a bill to provide that same kind of opportunity for
571 free screening for victims of lung cancer? It kills more
572 people than all the other cancers. Why not do that, give
573 them an opportunity to survive with early detection?''
574 So that is how the bill emerged. And I have told you
575 what the survival rates are. This bill gives each and every
576 one of us here a chance to advance that. And they said it
577 has always been a strong, nonpartisan, bipartisan effort that
578 has resulted in those wonderfully good statistics for so many
579 of the other cancers, but not for the victims of lung cancer.
580 In any event, Katherine said, "Dad, if that bill could
581 be passed, I would gladly, along with -- endure all that I
582 have had endured, along with so many others, gladly,
583 including my fatality at the end, if I knew that it would
584 spare so many other people the pain that we have had to
585 endure.''
586 So the bill was drafted, and Congressman Brendan Boyle
587 agreed to sponsor it, and sponsor it in her name.
588 And let me conclude with just a couple of things here.
589 Several hours before Katherine died -- we, of course, were
590 with her, and she was very weak. And I said to her,
591 "Katherine, one of the great mysteries'' -- most will admit
592 we don't know where we are going when this life of ours is
593 over. But I said, "Wherever that is, I want to be there with

594 you as soon as possible.''

595 And with her weak, but clear voice, she just raised her

596 hand. She looked her dad in the eye and said, "Dad, not

597 until you get my bill passed.''

598 So it is in that spirit that I am here today, and I

599 can't thank -- and each and every one of you.

600 So let me close by saying what that immortal western

601 cowboy hero of ours, John Wayne, who died of lung cancer,

602 might have said. God willing, the creek don't rise, and the

603 Congress enacts this important legislation, Katherine's Law

604 will become the law of the land, and many tens, if not

605 hundreds of thousands of lives will be saved.

606 Thank you.

607 [The prepared statement of Mr. Nolan follows:]

608

609 **********COMMITTEE INSERT**********

610

611 *Ms. Eshoo. Thank you, Congressman Nolan. Katherine's
612 Law will become the law of the land. We are on our way. And
613 your being here to help launch it, and the work that we are
614 doing today is a -- we have a clear path, and we are going to
615 make sure what Katherine said before she left this world
616 becomes reality. How is that? Okay, thank you so much.
617 Dr. Lloyd Jones, you are recognized for five minutes of
618 testimony.
619 *Dr. Lloyd-Jones. Good morning. Thank you. Can you
620 hear me?
621 *Ms. Eshoo. Good morning. Welcome.
622

623 STATEMENT OF DONALD M. LLOYD-JONES

624

625 *Dr. Lloyd-Jones. Thank you. Chairwoman Eshoo, Chair
626 Pallone, Ranking Members Guthrie and McMorris Rodgers, and
627 members of the Health Subcommittee, thank you for the
628 opportunity to testify today on behalf of the American Heart
629 Association and its more than 40 million volunteers and
630 supporters.

631 My name is Dr. Donald Lloyd-Jones and, as president of
632 the American Heart Association, I serve as its chief
633 volunteer officer responsible for the oversight of all
634 medical, scientific, public health, and public policy
635 matters.

636 I am also a cardiologist and a cardiovascular
637 epidemiologist, and chair of the Department of Preventive
638 Medicine, professor of preventive medicine, cardiology and
639 pediatrics at Northwestern University's Feinberg School of
640 Medicine in Chicago.

641 I am pleased to testify today about the ways in which
642 two bipartisan bills under your consideration would improve
643 heart health for all. Specifically, I wish to address the
644 Increasing Access to Quality Cardiac Rehabilitation Care Act
645 of 2021, H.R. 1956, and the Cardiovascular Advances in
646 Research and Opportunities Legacy, or CAROL Act, H.R. 1193.

647 My statement today is a summary of my more extensive

648 remarks in support of these bills that have been submitted
649 for the record.
650 I would like to thank Representatives Lisa Blunt
651 Rochester and Adrian Smith for championing the Increasing
652 Access to Quality Cardiac Rehabilitation Care Act, which
653 would significantly expand patient access to cardiac
654 rehabilitation services.
655 Cardiac rehabilitation, or cardiac rehab, for short, is
656 a medically supervised program for patients who have
657 experienced a serious cardiac event or surgery. It includes
658 monitored exercise training, education about heart healthy
659 lifestyles, and counseling to reduce stress. Participation
660 in cardiac rehab has been shown to significantly reduce the
661 risks of death and cardiovascular events, as well as result
662 in decreased hospital readmissions.
663 As a practicing cardiologist, I am an avid user of
664 cardiac rehab for all of my qualifying patients, and those
665 who have participated routinely tell me that it teaches them
666 about improving their heart health and what symptoms they
667 need to pay attention to in the future. And crucially, that
668 it restores their sense of well-being and their ability to
669 trust their body as they return to normal life and
670 activities.
671 Despite these clear benefits of cardiac rehab, only one-
672 third of all eligible patients, and only a quarter of

673 Medicare, patients will ever receive it. Barriers to
674 participation include things like lack of referral, large
675 disparities in referral patterns based on sex, race
676 ethnicity, socioeconomic position, and geography, and long
677 wait times to enrollment.

678 This Act would improve health equity by facilitating the
679 timely referral of patients, and by enabling greater patient
680 access in rural and underserved communities.

681 It would also remove burdensome requirements for direct
682 physician supervision at cardiac rehab facilities, where
683 highly-trained advanced-practice providers are already able
684 to provide necessary safety oversight.

685 These advances will allow cardiac rehab programs to
686 operate in areas where physicians are scarce, improving
687 patient access to these lifesaving programs.

688 The American Heart Association is also pleased to
689 support the CAROL Act.

690 And first, I would like to express my deepest sympathy
691 to Representative Andy Barr and his family for the tragic
692 loss of his wife, Carol. We are deeply grateful to him for
693 sponsoring this legislation to advance our understanding and
694 awareness of heart valve diseases that kill approximately
695 25,000 Americans each year. With this bill we could help
696 prevent more families from enduring a similar tragedy.

697 The CAROL Act authorizes funding for the National Heart,

698 Lung, and Blood Institute to gather information and fund
699 lifesaving research on heart valve disease. This investment
700 will help address gaps in our understanding, including what
701 causes sudden cardiac death due to mitral valve prolapse, or
702 MVP.
703 MVP is a degenerative heart valve condition that is
704 present in approximately two percent of individuals, many of
705 whom are unaware that they have it, and that led to the
706 untimely death of Carol Barr. MVP uncommonly becomes a
707 serious condition. But when it does, it can cause heart
708 failure, stroke, or abnormal heart rhythms that may become
709 life threatening. Significant MVP poses a three-fold
710 elevated risk of sudden cardiac death, compared to the
711 general population.
712 One of the most troubling aspects of MVP for me, as a
713 clinician, is just how much we still don't know about its
714 causes, factors that lead to progressive problems, when is
715 the best time to intervene, and what increases risk for
716 sudden cardiac death?
717 The CAROL Act would authorize new workshops and research
718 funded by the NIH, increase awareness through projects at the
719 CDC, and invest in efforts to improve data collection about
720 sudden cardiac arrest. Ultimately, it would increase
721 screening, detection, and diagnosis of heart valve disease,
722 and help reduce the incidents of sudden cardiac death.

723 So, in conclusion, the bills under consideration today
724 will advance equity by improving access to care for cardiac
725 rehab, and will expand our understanding of treatment for
726 heart valve diseases, including MVP.
727 Thank you so much for the opportunity to offer my
728 testimony, and I look forward to answering questions.
729 [The prepared statement of Dr. Lloyd-Jones follows:]
730
731 **********COMMITTEE INSERT**********
732

733 *Ms. Eshoo. Thank you, Dr. Lloyd-Jones, for your
734 important and superb testimony. We appreciate you being with
735 us.
736 The chair now recognizes Ms. Stewart for your five
737 minutes of testimony. And welcome, again. It is great to
738 see you.
739 *Ms. Stewart. Great to see you, too.
740

741 STATEMENT OF STACEY STEWART
742
743 *Ms. Stewart. Thank you and good morning, Chairwoman
744 Eshoo, and Ranking Member Guthrie, and members of the Health
745 Subcommittee. Thank you for the opportunity to testify
746 today. I am Stacey Stewart, president and CEO of March of
747 Dimes.
748 The March of Dimes' work is now more important than
749 ever. Our nation is in the midst of a dire maternal and
750 infant health crisis, which the pandemic has worsened. By
751 improving the health of women before, during, and after
752 pregnancy, we can improve outcomes for both mothers and for
753 infants. But we have many public health challenges before
754 us.
755 The U.S. remains the most dangerous developed nation in
756 the world in which to give birth. And it is even more dire
757 for women and babies of color. Pre-term birth is the second
758 leading cause of infant mortality, which has slowly declined
759 over the past few years. Yet still, two babies die every
760 single hour, and two women die from pregnancy complications
761 every single day.
762 This month, as we observe Pregnancy and Infant Loss
763 Awareness Month, we know that one out of every four
764 individuals and families' lives are affected by the death of
765 their children during pregnancy, at birth, and in infancy.

766 We must help these families by remembering their losses, and
767 working to better understand the causes of stillbirth with
768 the goal of lowering the stillbirth rate.
769 We hope new efforts by the Biden Administration and
770 Congress will spur further action to address the maternal and
771 infant health crisis that we face. However, we must continue
772 to focus our attention on the other challenges facing us, and
773 utilize the tools we have to improve the health of children
774 and families.
775 To that end, March of Dimes supports the following
776 legislation that is being considered by the subcommittee
777 today.
778 First, H.R. 5487, Stillbirth Health Improvement and
779 Education for Autumn Act of 2021, or the SHINE for Autumn
780 Act, would invest in research and data collection to better
781 understand stillbirth in the U.S. This will allow us to
782 better track and research stillbirths, find out who is
783 impacted, and the role disparities have in negatively
784 impacting infant and parental health.
785 Second, H.R. 5551, the Improving the Health of Children
786 Act, would reauthorize the National Center for Birth Defects
787 and Developmental Disabilities. The Center's tracking and
788 public health research systems help to identify causes of
789 birth defects and find opportunities to prevent them. It
790 also does critical work at researching developmental

791 disabilities such as autism, addressing blood disorders that
792 affect millions of people each year, and advancing health
793 care for people with disabilities so they can stay well,
794 active, and a part of the community.

795 March of Dimes has partnered with the Center to support
796 research and prevention, promote birth defects prevalence
797 data from states on our Peristats website, and we have led
798 efforts to help reduce health-related stigma through our
799 Beyond Labels initiative.

800 We are also a strong supporter of the Surveillance for
801 Emerging Threats to Mothers and Babies Network -- it is
802 called SET-NET -- which we must scale nationally to have a
803 complete picture, through real-time clinical and survey data,
804 of how COVID-19 impacted care for mothers and babies.

805 Third, H.R. 5552, the Lead Poisoning Prevention Act,
806 would provide critical resources for educational outreach for
807 screenings and referrals, the CDC's Advisory Committee on
808 Childhood Lead Poisoning Preventions, and help lead exposure
809 before children are harmed. Children can be severely
810 affected by lead's impact on brain and body development, with
811 Black children nearly three times more likely than White
812 children to have elevated blood lead levels. High levels of
813 exposure before and during pregnancy can cause fertility
814 problems, hypertension, delayed brain development, premature
815 birth, low birth weight, and miscarriage.

816 H.R. 5561, the Early Hearing Detection and Intervention
817 Reauthorization Act. This Act authorizes the early detection
818 and intervention program for deaf and hard-of-hearing
819 newborns and infants and young children. The program has
820 dramatically increased the number of newborns screened
821 annually, as we heard from Ranking Member Guthrie, from less
822 than 10 percent to currently around 98 percent, which has
823 significantly helped deaf and hard-of-hearing children begin
824 learning speech and language in the first 6 months of life to
825 develop better language skills.

826 Chairwoman Eshoo and Ranking Member Guthrie, I want to
827 say thank you for inviting me to be here. I was so moved by
828 your story, Chairwoman, of your early involvement with March
829 of Dimes. As I know, that has been the case for many of you.
830 Thank you for attention -- for your attention today, for
831 focusing on some of the nation's most critical public health
832 challenges. We must continue to invest in programs in our
833 toolbox, such as prevention, and data collection, and
834 surveillance systems. Thank you so much.

835 [The prepared statement of Ms. Stewart follows:]

836

837 **********COMMITTEE INSERT**********

838

839 *Ms. Eshoo. Thank you, Ms. Stewart, and the entire team
840 at the March of Dimes. It is an organization that is trusted
841 and respected by the American people. Thank you for your
842 leadership.
843 Next we are going to have Dr. Radesky testify, and I am
844 -- we are going to call on our colleague, a distinguished
845 member of our subcommittee, Mrs. Dingell, to introduce Dr.
846 Radesky, who is -- of course, hails from Michigan. And she
847 can tell you the rest.
848 So, Debbie, are you out there?
849 *Mrs. Dingell. Thank you. I am, Madam Chair. Can you
850 hear me?
851 *Ms. Eshoo. Okay, good to see you.
852 *Mrs. Dingell. Good to see you. And it is good to see
853 all of our witnesses, who -- two of whom I have worked with
854 closely for many years, and to see our dear friend, Rick.
855 But I am really proud we have got a Go Blue presence in
856 the House today.
857 Dr. Jenny Radesky is a practicing developmental
858 behavioral pediatrician and assistant professor of pediatrics
859 at the University of Michigan Medical School. Her research
860 focuses on the impact that digital media use and mobile
861 technology has on children's health and behavior, as well as
862 on parent-child interaction. She is a practicing
863 pediatrician who has focused on psycho-social determinants of

864 childhood development, and she is the lead author of the 2016
865 American Academy of Pediatrics policy statement on digital
866 media use in early childhood. Her research has been cited by
867 many people: CBS, the New York Times, and other leading
868 publications.
869 We look forward to her testimony today on the CAMRA Act,
870 and her expertise as a researcher and clinician.
871 Thank you very much, Madam Chair. I yield back, and I
872 have to close again with Go Blue.
873 *Dr. Radesky. Thank you so much, Representative
874 Dingell. Can you hear me okay?
875 So good morning, everyone.
876 *Ms. Eshoo. We can, and welcome.
877

878 STATEMENT OF JENNY RADESKY

879

880 *Dr. Radesky. Thank you. I am so happy to be here. I
881 would like to thank Chairwoman Eshoo, Ranking Member Guthrie,
882 and members of the Committee on Energy and Commerce, the
883 Subcommittee on Health, for the invitation to speak today.
884 I am a developmental behavioral pediatrician at U of M
885 Medical School, where my NICHD-funded research focuses on
886 media, parenting, and child socio-emotional development.
887 So my testimony today is in support of CAMRA, the
888 Children and Media Research Advancement Act, and it
889 represents my expertise as a pediatrician and researcher, not
890 the views of the University of Michigan.
891 So I first want to preface my remarks by emphasizing
892 that caring about children's relationships with digital media
893 is not an emotional issue. It is highly practical. It is
894 good, public health. Digital media are some of the most
895 universal, ubiquitous exposures children experience on a
896 daily basis, and they are often designed by adults untrained
897 in the curious and expansive ways that children experience
898 the world. Consequently, digital design often focuses on
899 monetization or engagement metrics, and may not consider
900 unintended negative consequences on society -- in particular,
901 children.
902 So parents have seen firsthand the way digital design

903 can either support or frustrate their family's needs during
904 the COVID-19 pandemic. For example, whether their child is
905 learning new computer coding skills through a well-designed
906 app, or is distracted from remote learning by YouTube videos,
907 whether their family feels connected through video chat or
908 divided by extreme social media posts.

909 And new digital products are being adopted at an
910 increasingly rapid pace. For example, Pokemon Go reached 50
911 million users in less than 3 weeks, and tech companies are
912 investing millions of dollars in marketing and data analytics
913 to engage child and teen users.

914 Academic research on how these technologies impact our
915 youth cannot keep up. We need the support of the NIH to
916 carry out rigorous, independent research on children and
917 media.

918 In my expert opinion, there are several pressing gaps in
919 scientific knowledge that would benefit from CAMRA's funding.

920 First, we need more nuanced understanding of the day-to-
921 day relationships between media and child well-being.
922 Research studies on children and media have often relied on
923 global ratings of how children use media, such as screen
924 time, which is not detailed enough for the complex outcomes
925 like mental health. We need study designs that follow
926 children in their natural experiences, track their responses
927 to the media they use, and the media messages they consume,

928 so we can uncover sources of resilience and vulnerability.
929 Second, new measurement tools are needed. My research
930 lab has created innovative methods, with the support of
931 NICHD, for studying media use, like harnessing data streams
932 already collected by smartphones to see which apps children
933 are using, and when. My work with Common Sense Media has
934 generated new ways of collecting children's YouTube viewing
935 histories to evaluate what types of content dominates this
936 platform. Tech companies already collect troves of these
937 types of data. However, researchers need more access so that
938 we can truly characterize the positive and negative
939 experiences that children have online.
940 Third, we need to know more about children's
941 differential susceptibility to media. Research usually
942 examines children as homogeneous population, but we know that
943 children have remarkable variability in their strengths,
944 their challenges. Some children are more anxious, some are
945 easygoing, while others are impulsive and reactive, and this
946 likely determines which children will have problematic versus
947 balanced relationships with media. CAMRA specifically calls
948 for this type of research, focusing on individual differences
949 and media use.
950 Fourth, we need to understand more about the interplay
951 between poverty, psychosocial stress, and media use. There
952 are deep, socioeconomic inequities in our country, and this

953 is rarely addressed head on in media research. But as we saw
954 during COVID-19, structural factors play a strong role in how
955 much media children use, and their access to other
956 opportunities.

957 Finally, CAMRA is unique in that it envisions a
958 sustained commitment to this field, which needs to keep up
959 with the rapidly evolving technology around us. For example,
960 we need to understand the impact of virtual reality, or the
961 algorithms that shape children's recommendation feeds, or
962 other understudied areas like online gambling. Sustained
963 CAMRA research dollars would also train a new generation of
964 scientists to use cutting-edge methods, and then translate
965 their findings for parents and policymakers.

966 This is a crucial moment for funding research in
967 children and media. There is a growing consensus that it is
968 time to shift the scientific framework away from only asking
969 what children and parents can do better to also asking what
970 technology companies can change, whether in their designs or
971 their business models, to promote child well-being. This
972 digital ecosystem is relatively young, so there is much that
973 can be done, based in part on solid, independent evidence
974 generated through NIH funding.

975 So I am grateful for your time today, and I appreciate
976 your consideration of the CAMRA bill.

977

978 [The prepared statement of Dr. Radesky follows:]

979

980 **********COMMITTEE INSERT**********

981

982 *Ms. Eshoo. Thank you very much, Dr. Radesky. We
983 appreciate your testimony, and this is an area that really
984 cries out for study. So your testimony is -- and on this
985 legislation, the legislation itself, I think, is really badly
986 needed, and I am glad we are addressing it today.
987 Next we recognize Dr. Cassis to testify for five
988 minutes.
989 We welcome you, and we thank you for being with us, and
990 you are on.
991

992 STATEMENT OF BRUCE L. CASSIS

993

994 *Dr. Cassis. Thank you, Chairwoman Eshoo, Ranking

995 Member Guthrie, Chairman Pallone, and Ranking Member McMorris

996 Rodgers, and members of the subcommittee. Thank you so much

997 for –

998 *Ms. Eshoo. Can you speak up, Doctor?

999 *Dr. Cassis. I certainly can. Thank you so much --

1000 *Ms. Eshoo. Wonderful.

1001 *Dr. Cassis. -- for the opportunity -- is that better?

1002 *Ms. Eshoo. It is much better, thank you.

1003 *Dr. Cassis. Okay. Thank you so much for this

1004 opportunity to speak with you today.

1005 My name is Dr. Bruce Cassis, and I am a general dentist

1006 from Fayetteville, West Virginia. I am also President of the

1007 Academy of General Dentistry, or AGD, which represents over

1008 40,000 general dentists across the country. We exist to

1009 serve the needs of our members through continuing education

1010 and advocacy, which, in turn, better serves the needs and

1011 interests of our patients.

1012 I am pleased to be here today to discuss legislation

1013 that would help improve the health of families and children,

1014 specifically: H.R. 4555, the Oral Health Literacy and

1015 Awareness Act.

1016 Oral health literacy is the degree to which people have

1017 the capacity to obtain, process, and understand basic health
1018 information and services needed to make appropriate oral
1019 health decisions. As a dentist practicing in rural West
1020 Virginia for nearly 42 years, I have seen firsthand more
1021 times than I can count the effects of oral disease,
1022 especially on our most vulnerable population: our children.
1023 Many people are unaware that oral health is linked to
1024 overall health. Diseases related to oral health can cause so
1025 many negative things: pain, loss of school and work time,
1026 nutrition problems, emergency room visits, and even death.
1027 Oral disease does not stop at the mouth and teeth. Diabetes,
1028 low birth weight, even early onset Alzheimer's, and many
1029 more.
1030 Fortunately, most oral-health-related ailments can be
1031 prevented. Good oral health habits are especially important
1032 for expectant mothers, children, and young parents.
1033 Oral disease especially impacts children. Tooth decay
1034 is the most common chronic disease among school-aged youth.
1035 Roughly one in four U.S. adults has at least one untreated
1036 cavity. Most of oral health ailments can be avoided by
1037 increasing oral health literacy among all populations, with
1038 an emphasis on children, to ensure that they develop and
1039 maintain healthy habits into adulthood.
1040 Folks need to complete regular dental visits to stay on
1041 top of their oral health. Unfortunately, the majority of

1042 Americans are not using the oral health care system.
1043 According to the latest data from HHS, 46 percent of the
1044 population had a dental visit in 2018. This is only 1.7
1045 percent higher than the percentage of the population who
1046 visited the dentist in 2003. The lack of progress on this
1047 front is startling, and cannot continue.

1048 Notably, significant disparities continue to exist
1049 within our population when it comes to both oral health care
1050 utilization and status. While 52 percent of non-Hispanic
1051 White people were able to visit a dental provider in 2018,
1052 only around 34 percent of those who are Hispanic and non-
1053 Hispanic Black saw a dentist in the same year. According to
1054 the CDC, nearly twice as many non-Hispanic Black or Mexican
1055 American adults have untreated cavities, compared to other
1056 groups. Adults with less than a high school education are
1057 almost three times as likely to have untreated cavities as
1058 adults with at least some college education.

1059 These disparities highlight the need to focus on oral
1060 health literacy improvement within vulnerable populations.
1061 Fortunately, Representatives Cardenas and Bilirakis have
1062 introduced legislation H.R. 4555 that would do just that.

1063 The Oral Health Literacy and Awareness Act would direct
1064 the HRSA to develop and test evidence-based oral health
1065 literacy strategies. These strategies aim to improve oral
1066 health care education, including education on preventing oral

1067 diseases such as early childhood and other caries,
1068 periodontal disease, and oral cancer. This multi-year
1069 initiative would focus specifically on children, pregnant
1070 women, parents, older adults, and people with disabilities,
1071 and, of course, racial and ethnic minorities.
1072 A strategy HRSA uses would need to communicate with
1073 these populations in a language that resonates with them.
1074 While we are all aware of the pressures and broad messaging
1075 on the importance of oral health, there has never been a
1076 serious effort at the federal level to develop actual
1077 evidence to measure outcomes on oral health literacy
1078 messaging.
1079 I believe HRSA's work through this initiative to measure
1080 outcomes on the effectiveness of targeted oral health
1081 literacy strategies would be indispensable in advising --
1082 *Ms. Eshoo. Dr. Cassis, you need to wrap up.
1083 *Dr. Cassis. Yes, okay.
1084 I want to end today by stressing the importance of
1085 recognizing oral health literacy as an integral part of
1086 national health policy.
1087 And I do greatly appreciate the subcommittee's
1088 recognition that oral health literacy is a priority.
1089 Thank you.
1090
1091

1092 [The prepared statement of Dr. Cassis follows:]

1093

1094 **********COMMITTEE INSERT**********

1095

1096 *Ms. Eshoo. Thank you, Dr. Cassis, for your important
1097 testimony.
1098 Dr. DuBois, we want to thank you for testifying today,
1099 and you now have five minutes to do so.
1100 *Dr. DuBois. Can you hear me okay?
1101 *Ms. Eshoo. Yes.
1102 *Dr. DuBois. Okay, great.
1103

1104 STATEMENT OF RAYMOND DUBOIS

1105

1106 *Dr. DuBois. Well, Chairman Eshoo and Chair Pallone,
1107 Ranking Members Guthrie and Rodgers, and members of the
1108 subcommittee, thank you for inviting me today. I am Ray
1109 DuBois, and I am the past president of the American
1110 Association for Cancer Research. I am editor-in-chief of the
1111 Cancer Prevention Research Journal, and director of the
1112 Hollings Cancer Center here, in Charleston, South Carolina.
1113 I really commend you for this hearing, and holding it to
1114 discuss important prevention for public health, and I am very
1115 pleased you are including cancer screenings as a part of
1116 these discussions, and we have heard some very important
1117 testimony earlier.
1118 The data show that cancer screenings do save lives and
1119 improve outcomes, because cancers, or, in some cases, pre-
1120 cancers, can be identified in an earlier stage, when
1121 physicians can treat it much more effectively. This often
1122 results in less invasive treatment, quicker recovery, and
1123 lower cost.
1124 Cancer organizations such as AACR publish research that
1125 informs the medical community about who, how, and to -- how
1126 to most effectively screen for different types of cancer. We
1127 really want to avoid those false negatives and false
1128 positives, and really have the most sensitive and specific

1129 screening possible.

1130 The U.S. Preventive Services Task Force, or USPSTF,
1131 examines the evidence of lower -- trying to lower cancer
1132 mortality, as well as risk cost and other complications.
1133 They grade guidelines based on an A or B, and the Affordable
1134 Care Act uses those tools, the A or B, so that those
1135 screenings can be covered by insurance without cost to the
1136 patient.

1137 As more research is generated, those guidelines can be
1138 updated. This year they did update the eligibility for lung
1139 cancer and colon cancer screenings. For lung, as you heard
1140 earlier, they did -- they changed the lung cancer deaths by
1141 24 percent after 10 years by expanding screening to smokers
1142 as young as 50 who smoked a pack a day for 20 years. That
1143 doubled the number of individuals who could now be screened
1144 at no cost. Previously, only older Americans could be
1145 screened. These new guidelines are especially beneficial for
1146 women and African Americans, who tend to smoke fewer
1147 cigarettes.

1148 The task force also reduced the age recommendation for
1149 colonoscopies from 50 to 45 because of the increasing
1150 incidence of that disease in the younger population.

1151 I am of the belief that effective screening is extremely
1152 important. However, that does not mean that screening for
1153 all cancers without a scientific basis is in the public

1154 interest. Over-screening can be cost prohibitive, and
1155 sometimes with side effects. The task force has to balance
1156 this evidence with risk and benefits, and be mindful that
1157 those recommendations are based on evolving science.
1158 Colon cancer screenings do not take into account the
1159 growing evidence that the younger, obese Americans are being
1160 diagnosed with colon cancer at a growing rate. For lung
1161 cancer, it is based on smoking history and age, but it does
1162 not take into account whether a person grew up in a home with
1163 smokers, or may have substantial interactions with secondhand
1164 smoke, or increased risk due to occupation and environmental
1165 factors.
1166 The recommendation to start mammograms for women at age
1167 50 will leave many younger women vulnerable to breast cancer
1168 that could spread before it could have been detected. In
1169 some cases I would encourage Congress to consider the
1170 individual, rather than the population as a whole, when
1171 designing these screening criteria. There are many other
1172 factors besides just age, including underserved populations,
1173 occupation, environmental exposures, and lifestyle factors.
1174 The simple age criteria contribute to inequities,
1175 especially in the underserved communities, who are under-
1176 represented in screening trials, and don't usually
1177 participate in those studies, and we want to ensure that all
1178 racial and ethnic groups and socioeconomic classes have the

1179 knowledge to make informed decisions.

1180 In South Carolina the incidence of breast cancer in
1181 Black women is lower than that in White women, but their
1182 death rate is much higher, because many Black women have
1183 longer delays to get screened and treated, possibly due to
1184 their lack of access -- of care to health services.

1185 The mortality rate in prostate cancer for Black men is
1186 much worse than White men. While it could be genetic
1187 influences, it is most likely due to lack of access to
1188 specialty care.

1189 Screening and treatment outcome disparities are areas
1190 that the medical research community must improve on as we go
1191 forward. Many cancers we don't have effective screening
1192 mechanisms for at the current time.

1193 In addition to the advances in health care delivery, the
1194 congressional investment in basic and translational research
1195 is very important. Several academic institutions in the
1196 industry are making progress in cancer blood testing, which
1197 will bring new and innovative ways to screen for these
1198 cancers, once they are validated and studied in large
1199 populations.

1200 Before I conclude, I want to importantly note that we
1201 are still not yet out of the pandemic, and we have lowered
1202 cancer -- screening for all cancers during this time. The
1203 NCI estimates that, due to COVID-19 and delaying cancer

1204 screenings, as many as 10,000 additional Americans could die
1205 of breast or colon cancer in the coming decade alone. As the
1206 scientific community works to improve cancer screening, it is
1207 imperative that we really improve our screening in the --
1208 [Audio malfunction.]
1209 *Dr. DuBois. I want to thank you again for the
1210 opportunity to testify before you today.
1211 [The prepared statement of Dr. DuBois follows:]
1212
1213 **********COMMITTEE INSERT**********
1214

1215 *Ms. Eshoo. Thank you very much, Dr. DuBois, for your
1216 important testimony. There was so much packed into it, with
1217 the statistics, and it is a reminder to all of us how
1218 important witnesses are, the expertise they bring to us and,
1219 obviously, shoring up the reasons why the legislation we are
1220 considering should become law for the people of our country.
1221 So thank you.
1222 Last, and certainly not least, is Ms. Ellyn Miller.
1223 Welcome again to you. Thank you for traveling, and
1224 being with us in person today. You are now recognized for
1225 your testimony.
1226

1227 STATEMENT OF ELLYN MILLER

1228

1229 *Ms. Miller. Thank you. Chairwoman Eshoo, Ranking
1230 Member Guthrie, and distinguished members of this committee,
1231 my name is Ellyn Miller, and I would like to thank you for
1232 the opportunity to testify in support of this childhood
1233 cancer and disease legislation, the Gabriella Miller Kids
1234 First 2.0.

1235 My daughter was only nine years old when she was
1236 diagnosed with a terminal-upon-diagnosis brain cancer called
1237 diffuse intrinsic pontine glioma. This is the same brain
1238 cancer that Neil Armstrong's daughter, Karen, died from in
1239 1962. Sixty years later, and our children that are diagnosed
1240 with this cancer are still receiving the exact same
1241 treatment. But yet, in these 60 years, we have gotten men to
1242 the moon and safely back home. We have a rover on Mars, but
1243 we can't solve something that is a few inches under our skin?

1244 In the 1980s, AIDS was a death sentence. Today it is a
1245 chronic disease. A handful of years ago, Ebola was also a
1246 death sentence. Now it is curable. We, as a country, can
1247 claim these incredible accomplishments because we banded
1248 together to make them a national priority.

1249 In 6 days from now, on October 26, will mark 8 years
1250 since my daughter died. In those 8 years, daily incidences
1251 of childhood cancer diagnoses in the United States has risen

1252 from 36 to 47. And every day, at least seven kids die from
1253 cancer. This means that, in those 8 years since my daughter
1254 died, over 137,000 parents have heard the words "Your child
1255 has cancer.'' And more than 20,000 families have buried
1256 their child.

1257 We must make our children a national priority. And we
1258 have the vehicle to do that with the Kids First 2.0. The
1259 original Kids First was signed into law with strong
1260 bipartisan support in 2014. Many of those members are in
1261 this room right now. And it is because of your support that
1262 over 60 grants have been awarded to institutes across the
1263 country to research childhood cancer and birth defects.

1264 The Kids First program has generated the largest
1265 molecular and clinical data sets, with approximately 50,000
1266 genetic sequences that are publicly available to researchers
1267 across the country. Resources are brought together to
1268 develop new connectivity that allows for real time data
1269 availability. All the while, this program is developing and
1270 implementing a transformative infrastructure that NIH has
1271 embraced, and is using as a template across the institutes.

1272 The Kids First was selected to lead a development of new
1273 technologies that will empower the use of electronic health
1274 records. Its infrastructure is being used for a model for
1275 developing and piloting programs that focus on Down Syndrome,
1276 rare disease, the Childhood Cancer Data Initiative, and more.

1277 It was also chosen to lead the development of the
1278 pediatric COVID clinical trial via the NIH Caring for
1279 Children with COVID Initiative.
1280 The Kids First has opened the door in a transformative
1281 force within NIH and around the world, and it is just the
1282 beginning. I reached out to my congresswoman, Jennifer
1283 Wexton, with the need to continue the work of the Kids First.
1284 She suggested an innovative funding source that Congress has
1285 used in the past: the use of existing, non-designated
1286 penalties against bad actors that knowingly violate the
1287 Foreign Corrupt Practices Act. The Kids First 2.0 proposes
1288 to use this untapped resource from pharmaceuticals, medical
1289 device manufacturers, cosmetics, and natural supplements to
1290 continue the battle against childhood cancer and disease. To
1291 date, 77 bipartisan members agree, 22 of whom are members of
1292 the Energy and Commerce Committee.
1293 Two weeks before Gabriella died, she was interviewed and
1294 asked what message she had for our elected official about
1295 kids like her, and she responded, "Stop talking, and start
1296 doing.'' Our political leaders have certainly done that, and
1297 today I am personally asking the committee to continue doing
1298 by proceeding through markup and moving this critical piece
1299 of legislation to the floor as quickly as possible.
1300 My daughter's name might be on this legislation, but,
1301 truth be told, it could be any number of the hundreds of

1302 thousands of children that are afflicted with cancer and
1303 disease across this country. And I bring with me today
1304 almost 1,000 families that have signed on, because they
1305 wanted their children to be represented here today, and it
1306 could be one of them.

1307 I thank you for your time, and I look forward to your
1308 questions.

1309 [The prepared statement of Ms. Miller follows:]

1310

1311 **********COMMITTEE INSERT**********

1312

1313 *Ms. Eshoo. Thank you so much, Ellyn. Your voice is an
1314 eloquent one, as a mother. And thank you for representing
1315 all the other families that have lost their child. There
1316 can't -- it simply cannot be a greater grief than for a
1317 parent to bury their child. It is not the way it is supposed
1318 to be. But we can do something about it, and that is what we
1319 are here for today. Thank you.

1320 To our former colleague and friend, Rick Nolan, Rick,
1321 you have really taught us all something. I never knew that
1322 that lung cancer patients that never smoked got lung cancer.
1323 And I think that we have -- you have been a great teacher in
1324 that. And is -- can you, just for a moment, tell us when --
1325 I am recognizing myself now for questions that -- when was
1326 your daughter diagnosed, and how?

1327 Did she have any symptoms, or was it -- yes, turn your
1328 mike on.

1329 *Mr. Nolan. Thank you, that is a very good question.
1330 My aunt, Eleanor Nolan -- the first female judge in the State
1331 of Minnesota, by the way -- a real pioneer, was -- a half-a-
1332 century ago was diagnosed with terminal lung cancer, and she
1333 died six months later.

1334 Katherine was diagnosed a little over six -- just about
1335 six years ago. But because of the great progress that has
1336 been made by this committee and people in the past -- by the
1337 way, I like to remind people that, in my grandfather's time,

1338 life expectancy in this country was 47.

1339 *Ms. Eshoo. Right.

1340 *Mr. Nolan. Forty-seven. Today, because of good public

1341 health --

1342 *Ms. Eshoo. We would all be dead and gone, right.

1343 *Mr. Nolan. -- policies, bipartisan policies, it is in

1344 the middle to upper eighties --

1345 *Ms. Eshoo. So how did she find out that she had it?

1346 *Mr. Nolan. Well --

1347 *Ms. Eshoo. Did she not feel well?

1348 *Mr. Nolan. Because, as I mentioned, the lungs don't

1349 have nerves, which is why early detection is so important.

1350 You don't find out --

1351 *Ms. Eshoo. But how did she find out, Rick?

1352 *Mr. Nolan. You don't –

1353 *Ms. Eshoo. I have some other questions –

1354 *Mr. Nolan. You are out of breath. You are out of

1355 breath.

1356 *Ms. Eshoo. I see, okay, all right.

1357 *Mr. Nolan. At which point it is too late. It is

1358 terminal. You didn't get those early indications. You

1359 didn't get the benefit of the early screening.

1360 *Ms. Eshoo. Okay, that is instructive.

1361 *Mr. Nolan. And it is too late.

1362 *Ms. Eshoo. That is instructive.

1363 Ellyn, to you, in the -- the funds that come out of the
1364 penalties that are paid that that you referenced, what
1365 amounts are those, on average, annually, about? What -- how
1366 much are we talking about?
1367 *Ms. Miller. I would love to be able to say a number
1368 with that. The challenge that comes into play is that you
1369 need to have somebody who is violating law. They have to
1370 be --
1371 *Ms. Eshoo. No, I was just curious if you know how much
1372 that is, approximately what goes into that fund.
1373 *Ms. Miller. I would love to be able to answer that. I
1374 could --
1375 *Ms. Eshoo. Maybe we will find out from the --
1376 *Ms. Miller. -- get you information, and share that.
1377 *Ms. Eshoo. -- from the authors.
1378 *Ms. Miller. -- share that with Aisling about those
1379 that are in the past. But moving forward, it is impossible
1380 to say that.
1381 *Ms. Eshoo. I don't know, does the staff on either side
1382 of the aisle know if -- it is hundreds of millions of
1383 dollars?
1384 Well then, that funding is going to be -- those dollars
1385 are going to dance, I think, if it is hundreds of millions of
1386 dollars.
1387 To Dr. Radesky, Facebook research that was shared by the

1388 most recent whistleblower, Frances Haugen, demonstrated that
1389 32 percent of teen girls said that they felt bad about their
1390 bodies, and Instagram made them feel even worse. I think
1391 that this is astonishing. I mean, it just takes my breath
1392 away.

1393 What is the difference, in your view, between internal
1394 company research and the type of research that the CAMRA Act
1395 would enable?

1396 *Dr. Radesky. There are several differences.

1397 First, with academic or independent research, we have to
1398 go through rigorous training in protecting vulnerable
1399 populations, the IOB, and ethical board approval. There is
1400 lots of transparency, and lots of accountability, in terms of
1401 reporting negative side effects or unintended events that
1402 might happen during our research.

1403 And the internal research for Facebook revealed some of
1404 those negative and likely unintended consequences of the
1405 design of Instagram, which is very focused on appearance, and
1406 filters, and other ways of editing images. But they didn't
1407 have the accountability to either stop their research, change
1408 their intervention, their product, or to be accountable to
1409 the users who were involved.

1410 *Ms. Eshoo. Have you ever been asked by a social media
1411 platform to provide any guidance to them?

1412 *Dr. Radesky. I have communicated with several

1413 different teams. Facebook had reached out to me a few years
1414 ago. There has been an invitation to conferences, or more
1415 informal conversations with the child policy and safety teams
1416 at these companies. But I do not have a formal role with any
1417 of them.

1418 *Ms. Eshoo. Thank you very much.

1419 The chair now recognizes Mr. Guthrie, our ranking member
1420 of the subcommittee, for his five minutes of questions.

1421 *Mr. Guthrie. Thanks, Madam Chair, and thanks for all
1422 of you being in this important meeting. And I am just going
1423 to say I am going to step out in a few minutes, not because I
1424 don't find this extremely important. I have a World War II
1425 vet and a couple of other veterans that are going to be
1426 arriving at the World War II memorial, and I am going to see
1427 them, and I will come right back -- I want to greet them --
1428 because this is very important to do.

1429 First, Rick, thanks for sharing your story. It is
1430 important as to how our loved ones live on when we share
1431 their stories and move forward.

1432 And also, Ms. Miller, I had a -- back in the early
1433 1970s, when I was probably 10 or 11, I had a friend of mine
1434 that had leukemia, Tam Hambach -- that is how they live, by
1435 mentioning their names -- and I always think she would be --
1436 could be alive today, if we knew what we were -- if we moved
1437 forward with leukemia.

1438 And then I had a good friend of mine, Abby Cummings.
1439 Her mom, B.J. Cummings, a friend of mine, was 11 in 2006, was
1440 diagnosed with bone cancer, I guess, and passed away a couple
1441 of years later. And it is just like, can we not fix that?
1442 It is the frustrating thing with so much, as you mentioned,
1443 going on.
1444 And I would tell you there is nothing more bipartisan in
1445 Washington. As you see, if you watch the new cable news,
1446 particularly, you think everybody is fighting over
1447 everything. But we are trying to figure out how to do more
1448 for NIH and cancer research, and just trying to find the
1449 right way to do that. And so I appreciate it.
1450 And Ms. Stewart, I enjoyed talking to you the other day.
1451 We are -- Atlanta was the city we would go to when I was a
1452 kid, and we shared some experiences of growing up. My dad
1453 was the only one that -- we never flew, we couldn't afford to
1454 fly, but he took us to the airport to watch planes take off
1455 and land. And I found out your father did, as well. So
1456 maybe we are not that unique.
1457 But I have a question on the early childhood hearing --
1458 I only have a couple of questions, and I have used some of my
1459 time, so I wish I could ask everybody a question, but I have
1460 been a long-term champion of the early childhood detection.
1461 And, as we saw, 98 percent of the kids now have early
1462 detection of everything. If we can catch it early, we can

1463 treat it, hopefully, and develop -- children can develop
1464 further.
1465 But we are having 98 percent get screened, but only 67-
1466 and-a-half percent getting the care that they need for -- as
1467 a result of this screening. And what -- in your opinion, how
1468 can we reduce barriers to access?
1469 *Ms. Stewart. Well, I think that your point is well
1470 taken, in that we have made a lot of progress with early
1471 identification. But the issue is to go further than that, to
1472 not only identify it early, but to make sure the kids have
1473 the right access to the care, the referrals that they need,
1474 the services that they need.
1475 And we know that, for example, when kids are not able to
1476 identify hearing challenges early in life, it affects them,
1477 it affects them over the -- over their lifetime. It affects
1478 their early progress with early education, and it affects
1479 their ability to succeed later in life. I think part of it
1480 is just making sure that that both kids have access to the
1481 right referrals and the right services to follow up with, and
1482 that their families have the right education and awareness to
1483 know how their children can be treated, as well.
1484 You know, parents have a big role to play in this, along
1485 with pediatricians, with early child care providers. We have
1486 to make sure that everyone is aware of hearing challenges,
1487 and making sure that those kids have the right access to

1488 early identification, and then referral and services, as
1489 well. And that may need to continue over a lifetime, not
1490 just early in life.
1491 Of course, we know that the earlier that those problems
1492 can be identified, even within the first month or two of
1493 life, that can make a big difference.
1494 *Mr. Guthrie. Right.
1495 *Ms. Stewart. But we may need to provide services over
1496 a longer period of time, to the extent that children have
1497 continued challenges.
1498 *Mr. Guthrie. Thank you for that, and thank you for the
1499 work the March of Dimes is doing for that. I think a lot of
1500 us know where we were when we got the phone call that my
1501 colleague Andy Barr's wife had passed away. Just tragic.
1502 And people get those phone calls all the -- every day, all
1503 the time. And so the CAROL Act is before us.
1504 So, Dr. Lloyd-Jones, you discovered -- you discussed in
1505 your testimony that some individuals are born with genetic
1506 risks for developing mitral valve prolapse, or MVP. The
1507 CAROL Act improves research that would help medical
1508 professionals detect the existence of this genetic risk, and
1509 diagnose it early on. What are the main barriers hindering
1510 medical professionals from being able to improve detection
1511 methods?
1512 *Dr. Lloyd-Jones. Well, thanks very much for your

1513 question, sir. You know, you are absolutely right. Mitral
1514 valve prolapse is one of the heart conditions that can run in
1515 families. There are other connective tissue diseases and
1516 other considerations that can lead to an increased propensity
1517 for mitral valve prolapse.

1518 But unfortunately, there is really no great way to
1519 diagnose this. Symptoms, as with lung cancer, only occur
1520 very late in the process, so we need people to have access to
1521 health care, so we can listen to their chest with a
1522 stethoscope, which is probably the main way we start to
1523 become suspicious about mitral valve prolapse. But you can't
1524 diagnose this without echocardiography. And so that is
1525 really our main way.

1526 And once again, access to health care, and quality
1527 health care, are major issues for people in order to be able
1528 to be diagnosed and monitored over time, which is a crucial
1529 portion -

1530 *Ms. Eshoo. Doctor, what did you say was needed to
1531 diagnose? I couldn't hear you. And I think it is important
1532 to know this.

1533 *Dr. Lloyd-Jones. Yes, so the firm diagnosis of mitral
1534 valve prolapse requires echocardiography, or ultrasound of
1535 the heart.

1536 *Mr. Guthrie. Echocardiogram.

1537 *Ms. Eshoo. I see.

1538 *Dr. Lloyd-Jones. Yes, in order to actually make the
1539 diagnosis. And it is the main way we monitor patients, as
1540 well, to see if that is progressing over time.
1541 *Mr. Guthrie. Yes, I think Carol actually had been
1542 screened, and was scheduled for one and, because it wasn't
1543 deemed a critical -- as critical at the time, because of
1544 COVID, she couldn't get the service before she passed away
1545 from that, unfortunately.
1546 *Dr. Lloyd-Jones. So sad.
1547 *Mr. Guthrie. So I just want to -- I know my time has
1548 expired, but I have a statement from Congressman Barr on his
1549 bill to introduce to the record, and then also an American
1550 Speech Language Hearing Association statement, I think, that
1551 has been given to the staff. I would like to introduce those
1552 to the record.
1553 *Ms. Eshoo. The gentleman yields back. The chair now
1554 recognizes the chairman of the full committee, Mr. Pallone,
1555 for his five minutes of questions.
1556 Thank you, Mr. Guthrie.
1557 *The Chairman. Thank you, Madam Chair. I want to
1558 emphasize that prioritizing robust funding in these key
1559 children's prevention, research, and screening programs
1560 really is critical in protecting the most vulnerable from
1561 long-term poor health outcomes. But I think the levels at
1562 which we authorize these programs matter, and speak to the

1563 success and confidence and work of these programs and their
1564 policies.
1565 So my questions are all of Ms. Stewart. I know the
1566 March of Dimes is at the front lines of supporting the EHDI
1567 program, and how these investments -- you probably know well
1568 how these investments can help improve health outcomes.
1569 So my first question is, in your view, is the level of
1570 the authorization in the reauthorization of the EHDI program
1571 sufficient to support the program needs, and service as many
1572 families as possible?
1573 And if not, what authorization level do you think is
1574 necessary to ensure sufficient support?
1575 *Ms. Stewart. Thank you. I think, you know, I think
1576 the most important thing is making sure that we can reach as
1577 many kids as possible, and I think what we are asking for in
1578 terms of reauthorization is probably sufficient.
1579 I think the other thing, though, is -- but, you know,
1580 the fact of the matter is we still have a number of kids who
1581 are still being impacted by this issue, and they are
1582 suffering for a long period of time.
1583 I think one of the most important things we can do is to
1584 make sure that the amount of funding over a long period of
1585 time is available. For example, if they are screening early
1586 on, making sure that those resources are available so that
1587 they do have the kind of support that they may need over a

1588 longer period of time.

1589 A lot of families also need more support, as well. So I
1590 think the reauthorization amount is probably sufficient, but
1591 I think we ought to continue to revisit to see what more --
1592 what may be needed, what more may be needed over time.

1593 *The Chairman. All right. And then I have the same
1594 question for the level of support for the National Center for
1595 Birth Defects and Developmental Disabilities.

1596 Do you think the proposed authorization that is included
1597 in that bill, H.R. 5487, is sufficient to support the
1598 program? Same question.

1599 *Ms. Stewart. Well, I think, obviously, the National
1600 Center has done some great work in a number of areas around
1601 birth defects, looking at blood disorders. We have been
1602 working with the Center for a number of years on a number of
1603 these issues.

1604 I think one of the things that, you know, we have to
1605 better understand, for example, during COVID-19 is what is
1606 the effect that it is having on families and children today.

1607 So one of the things that we don't know right now is
1608 what more will we learn over time that we might need to
1609 invest more in later on. For example, what is the long-term
1610 effect of babies that may have been affected by COVID? What
1611 are the long-term effects that children may be affected by
1612 that we still don't understand today?

1613 So I think we need to, again, look at refunding where we
1614 are today, but be prepared that we may need to put more money
1615 into this --
1616 *The Chairman. The --
1617 *Ms. Stewart. -- going forward.
1618 *The Chairman. No, and I agree with you. But, I mean,
1619 as far as the bill, you are okay with it at this point.
1620 *Ms. Stewart. We are.
1621 *The Chairman. You think it is adequate?
1622 *Ms. Stewart. We are, for what is being requested,
1623 yes --
1624 *The Chairman. Because I wanted to ask you one more
1625 question about health inequities.
1626 You know, these health inequities were brought to light
1627 as a result of the pandemic, even more so. And many of those
1628 on the front lines of intervention and screening programs
1629 have been raising these issues for years. But do you see
1630 health inequities as a concern in early intervention and
1631 screening programs such as EHDI?
1632 And should this committee consider more detailed
1633 guidance encouraging the expansion of work in this program to
1634 address disparities in follow-up services among racial or
1635 ethnic minorities, or other medically underserved
1636 populations? My last question.
1637 *Ms. Stewart. So Congressman, in just about every one

1638 of the issues that I have addressed today, starting from the
1639 broadest level of maternal and infant health, all the way
1640 down to issues around lead poisoning, or around other issues
1641 generally around health inequity, this country faces those
1642 challenges across the board.

1643 There -- it is very clear that we have under-invested,
1644 and we have not had the kind of policy environment that
1645 really supports making sure there is an equal playing field
1646 with respect to health equity.

1647 We know that Black women, for example, are three to four
1648 times more likely to die as a result of pregnancy and
1649 childbirth. Black women are 50 percent more likely to give
1650 birth to a baby pre-term. Black women are far more likely to
1651 have a baby born in stillbirth. So the fact that we have all
1652 these statistics really suggests that we are under-investing,
1653 to your point, in eliminating health inequity. But it is
1654 going to have to be a much more comprehensive approach.

1655 There is one big effort that we are supporting right now
1656 around Momnibus, for example, that is intended to address
1657 those issues. But even in the -- some of the issues that we
1658 are dealing with today, it is an issue that we have to
1659 continue to focus on, because the health inequities are
1660 there, and we have historically under-invested in all of
1661 these areas.

1662 *The Chairman. I appreciate that. And let me just say

1663 we are still pushing very hard for the --

1664 *Ms. Stewart. Momnibus?

1665 *The Chairman. -- Momnibus –

1666 *Ms. Stewart. Yes.

1667 *The Chairman. -- in the reconciliation.

1668 *Ms. Stewart. I appreciate that, thank you.

1669 *The Chairman. Thank you.

1670 Thank you, Madam Chair.

1671 *Ms. Eshoo. Certainly. And Mr. Chairman, can you give
1672 the -- our witnesses, especially the parents that are here,
1673 some indication when you think we can bring these bills to
1674 the full committee, and then to the floor?

1675 He is going to kill me for doing this.

1676 *The Chairman. Well, as you know --

1677 *Ms. Eshoo. But I want you to leave --

1678 *The Chairman. As the chairwoman --

1679 *Ms. Eshoo. -- with a lot of hope in your hearts.

1680 *The Chairman. As the chairwoman knows, we wouldn't be
1681 having this legislative hearing today if we weren't trying to
1682 move these bills soon. Believe me. So, I mean, the answer
1683 is yes, that we -- I am not sure I know exactly what she
1684 asked me, but the answer is yes.

1685 *Ms. Eshoo. Yes, you do.

1686 *The Chairman. We want a bill -- we want to move these
1687 bills soon. Thank you.

1688 *Ms. Eshoo. Okay.

1689 *The Chairman. I just have to rush to another meeting.
1690 I apologize.

1691 *Ms. Eshoo. Well, I just wanted to get you before you
1692 left. How's that? Thank you, Mr. Chairman.

1693 Okay, now I am pleased to recognize the gentlewoman who
1694 is the ranking member of the full committee, Congresswoman
1695 Cathy McMorris Rodgers, for your five minutes of questions.

1696 *Mrs. Rodgers. Thank you, Madam Chair. And to all our
1697 witnesses, I just want to thank you for joining us today. We
1698 have heard some really telling, powerful testimony.

1699 Mr. Nolan, on behalf of Katherine's Law, it is good to
1700 see you, and thank you for sharing her story again.

1701 And to Mrs. Miller, I remember when the Gabriella Miller
1702 Act was first passed, and just appreciate everyone for being
1703 here, and advocating for so many others.

1704 And certainly, Carol Barr's death was so untimely, and
1705 hit us all really hard, and I appreciate the work that is
1706 being done to help others that may face similar situations.

1707 I have been very clear about my concerns with Big Tech,
1708 and I am troubled by Big Tech censorship of conservatives,
1709 and anyone that seems to disagree with liberal ideology. I
1710 believe that free speech is fundamental to our great nation.
1711 We need to cherish it, defend it, and not attack it.

1712 I am also very concerned about the harm that Big Tech is

1713 doing to our children. And we have seen it recently again
1714 with Instagram. But you know, they are not alone. The same
1715 applies to TikTok, YouTube, Snapchat, any platform that
1716 profits from, you know, keeping our children online as much
1717 as possible. And that is why the Energy and Commerce
1718 Republicans are committed to leading this fight against Big
1719 Tech.

1720 And, in fact, in July, every Republican on the -- on
1721 this committee rolled out a bill as a part of a larger
1722 package to address censorship, and provide protection for our
1723 kids.

1724 Dr. Radesky, I have been calling on Big Tech to be more
1725 transparent about the impact that their products are having
1726 on children's mental health. And studies have shown that
1727 even passively consuming content is harmful. And yet these
1728 companies continue to design their products to increase this
1729 passive consumption. I just wanted to start by asking you,
1730 what advice do you give to parents as they consider their
1731 children's own use of social media?

1732 *Dr. Radesky. Yes, thanks for that question, and yes, I
1733 work a lot with the American Academy of Pediatrics on
1734 guidelines to help families adapt to this rapidly-changing
1735 tech environment that is often hard to understand.

1736 So the guidance we give is to be as curious and open-
1737 minded as possible. Gather all the information you can, use

1738 resources like common-sense media, be extremely informed.
1739 Because right now, the tech environment still feels like a
1740 Wild West. It feels a little bit like a circus. They are
1741 trying to get lots of attention.

1742 There is a lot of good stuff out there, but in our
1743 research on YouTube we found that the videos with the highest
1744 views, the ones that are getting the most reach through
1745 algorithms, are the ones that are actually the most shallow,
1746 or the most consumerist, or they have some pranking and other
1747 sort of role modeling that we don't necessarily want kids to
1748 be, you know, spending all their time with.

1749 So we encourage parents to watch along, and help their
1750 children recognize when there is bad information, or
1751 stereotypes, or other sorts of messages that they don't agree
1752 with, and to help their kids be savvy, critical consumers.
1753 How to find the right sort of channels to subscribe to, how
1754 to take breaks from social media so you can reflect and see
1755 how it makes you feel.

1756 Our emotional and social reactions to these social media
1757 platforms that are often constructed to really get a lot of
1758 our attention around social relationships, it can happen
1759 without us truly thinking about it. It is supposed to be
1760 frictionless, so that we are not pausing and reflecting on
1761 why we have these relationships. So that is another thing,
1762 is I encourage parents to take breaks --

1763 *Mrs. Rodgers. Thank you --

1764 *Dr. Radesky. -- have experiments, open the
1765 conversation with their children to really help them guide
1766 through.

1767 *Mrs. Rodgers. What -- would you speak to how you
1768 believe COVID-19 pandemic distance learning and social
1769 isolation has also impacted kids' social media use, and the
1770 increase of mental health issues?

1771 *Dr. Radesky. Yes, this is such an important issue.
1772 And even yesterday the AAP, together with other
1773 organizations, released, you know, a state-of-emergency on
1774 child mental health. We have seen a large increase in
1775 emergency room visits for mental health issues in my own
1776 clinical practice. Children have really suffered. School is
1777 very stabilizing for children, and the experience of remote
1778 learning resulted in decreased motivation, decreased sense of
1779 connection, more mood symptoms, sleep disruption, defiant
1780 behavior, or withdrawn behavior. This has been shown in
1781 multiple studies.

1782 And in our own research at Michigan we have found that
1783 parents of elementary school kids said they started social
1784 media accounts for their children younger than they hoped to,
1785 just so they could keep in touch. So this is an extremely
1786 pressing issue, because children now have much more access to
1787 digital platforms that weren't necessarily designed with

1788 young minds in mind.

1789 And so what we have found is that, in some cases,
1790 digital connections such as video chatting has helped child
1791 mental health. Whereas, more online gaming, lots of video
1792 viewing, less sleep isn't as supportive. And this is why
1793 both research and policy on this area right now is equally
1794 pressing.

1795 *Mrs. Rodgers. Well, thank you for sharing your
1796 expert --

1797 *Ms. Eshoo. Who is next?

1798 *Mrs. Rodgers. -- mental health, the suicide crisis,
1799 and the rest.

1800 I yield back, Madam Chair.

1801 *Dr. Radesky. Thank you.

1802 *Ms. Eshoo. And thank you, Cathy. And we are all
1803 saying our prayers that your children are healthy and well
1804 very soon. We miss having you here in person, but want you
1805 to know that we are all thinking about you.

1806 The chair now recognizes the gentleman from North
1807 Carolina, Mr. Butterfield, for his five minutes of questions.

1808 *Mr. Butterfield. Thank you, Madam Chair. Let me first
1809 say good afternoon to all of my colleagues.

1810 And thank you, Madam Chair, for convening this very
1811 important hearing, and thank you to the witnesses. I have
1812 listened to all of your powerful testimonies, and just thank

1813 you for coming forward today and giving us the benefit of
1814 this information. Let me address my comment and my question
1815 to Ms. Stewart.
1816 Ms. Stewart, in your opening remarks, you mentioned how
1817 critical SET-NET, the National Center for Birth Defects and
1818 Developmental Disabilities, is to protect vulnerable mothers
1819 and babies. Can you expand more on this program's
1820 importance, both the reauthorization of the Center, as well
1821 as increased and sustained funding?
1822 *Ms. Stewart. Thank you, Congressman. And I did
1823 mention about SET-NET, and I just want to say a couple more
1824 things about it.
1825 What SET-NET is is really an innovative data collection
1826 system that links maternal exposures during pregnancy to
1827 health outcomes for babies. What we found, especially during
1828 the Zika outbreak, is that SET-NET came in as a very useful
1829 system that allowed us to leverage existing data sources,
1830 enabling CDC and health departments to detect new and
1831 emerging health threats, to understand that health threat.
1832 We also know that in fiscal year 2021 SET-NET has
1833 provided support to 29 state, local, and territorial health
1834 departments to monitor impact on pregnant individuals' and
1835 babies' exposure to Zika, to syphilis, to COVID-19.
1836 So what we know is that, when we have better data
1837 collection, we can monitor these kinds of outbreaks more

1838 successfully, and we can create the right interventions.

1839 The most important thing, though, is that SET-NET, in
1840 fiscal year 2021, was funded at $10 million. The House
1841 proposed increasing funding to -- by another five million,
1842 but we still think that that is woefully inadequate to really
1843 get to the high-quality data collection system that we need.

1844 We have actually recommended SET-NET be funded at $100
1845 million. And what we know is, especially as we are still
1846 dealing with the pandemic, the lack of data to really
1847 understand the impact and what is going on with pregnant
1848 women, with women and with children, is affecting our ability
1849 to serve them and keep them healthy. So we would ask for
1850 that to be certainly reconsidered, and that goes back to the
1851 early question, as well –

1852 *Mr. Butterfield. Yes, let's drill down and -- let's
1853 just drill down, if we can, on data collection. I believe
1854 that data collection is just critically important for making
1855 a positive impact on maternal and child health outcomes.

1856 You may know that, two weeks ago, the Communications and
1857 Technology Subcommittee held a hearing on my bill, which is
1858 referred to as H.R. 1218, the Data Mapping to Save Moms Act
1859 of 2021. The bill would require the FCC to map areas of the
1860 country that have both high rates of negative maternal health
1861 outcomes and gaps in Internet service.

1862 It would also require the GAO to issue a report on the

1863 effectiveness of Internet connectivity in reducing maternal
1864 morbidity rates.
1865 Can you now discuss how broadband and telehealth access
1866 will intersect with maternal and infant health?
1867 *Ms. Stewart. Yes, and we are a proud supporter, the
1868 March of Dimes, of the Data Mapping to Save Lives Act.
1869 We also saw during the pandemic how many pregnant women,
1870 for example, went without prenatal care because they were too
1871 concerned about getting out to their health care provider to
1872 seek care.
1873 We also know, for example, in this country we have --
1874 half of all the counties in this country lack basic access to
1875 obstetric care. And so, if we don't have the ability for
1876 women to seek care through other means, especially through
1877 technology, through digital tools, we are still going to be
1878 leaving too many women without the care that they need,
1879 especially in rural areas.
1880 So this Data Mapping to Save Lives Act is really
1881 important to bridge the gap, to make sure we have technology
1882 available for women who may not be able to seek services
1883 close to where they live.
1884 And we would also want to make sure -- and we support
1885 the provision that the GAO provide a report on the
1886 effectiveness of Internet connectivity in reducing maternal
1887 morbidity rates, as well. So thank you for your leadership

1888 on that.

1889 *Mr. Butterfield. And thank you for including those
1890 comments in the record. That is very important, and we are
1891 going to act accordingly.

1892 Madam Chair, before yielding back, let me just ask that
1893 we consider additional legislative hearings. I encourage the
1894 subcommittee to take up the H.R. -- the bill H.R. 2356, the
1895 Better Wound Care at Home Act, which I jointly introduced
1896 with Congressman Markwayne Mullin. This bipartisan bill will
1897 help patients with chronic wounds stay healthy in their
1898 homes, and avoid future complications, particularly for
1899 patients of color who are at higher risk for infection,
1900 hospitalization, and limb loss.

1901 I thank the chair for listening. I thank you for your
1902 consideration. Thank you for your friendship. And at this
1903 time I yield back the balance of my time.

1904 *Ms. Eshoo. You are such a gentleman, Mr. Butterfield,
1905 and a friend to all of us. Truth be told, I would have a
1906 hearing every single day of the week, I really would. So I
1907 think you need to nudge a little bit at the top of our
1908 committee. I certainly will. There are so many bills
1909 pending.

1910 This subcommittee is really the workhorse of Energy and
1911 Commerce, in terms of subcommittees. We have some 700 bills,
1912 over 700 bills that have been referred to us. But it doesn't

1913 mean that we have taken them up. So I am all for a crowded
1914 calendar. How is that?
1915 *Mr. Butterfield. Let's do it, let's do it.
1916 *Ms. Eshoo. And I would love to take your bill up.
1917 *Mr. Butterfield. Thank you.
1918 *Ms. Eshoo. So let's talk some more about it, talk to
1919 Mr. Pallone, and I would like more hearing dates for the rest
1920 of the fall, so that we can really move, put the pedal to the
1921 metal, and move a lot more legislation. A lot of good bills,
1922 a lot of good ideas, worthy ideas that are going to help
1923 people in our country. So thank you, Mr. Butterfield.
1924 Next it is a pleasure to recognize the gentleman from
1925 Michigan. He is indeed that, a gentleman. And he is the
1926 former chairman of the Energy and Commerce Committee, Mr.
1927 Upton, for your five minutes of questions.
1928 *Mr. Upton. Well, thank you, Madam Chair.
1929 And Ms. Miller, it is nice to see you again. As I
1930 recall, I managed the time on the House floor debate with you
1931 and your daughter and the gallery a number of years ago, and
1932 was glad to shepherd that bill through and get it signed into
1933 law. And I have asked to cosponsor the bill that you
1934 referenced today, H.R. 623.
1935 And Rick, as always, it is a pleasure to see you, even
1936 though you have a mask on. Mine was on a moment ago. But I
1937 am going to help you keep your promise. And I am going to

1938 cosponsor your bill, as well.

1939 Madam Chair, I want to thank you for holding this very
1940 important hearing on a good number of bipartisan, public
1941 health priorities. I want to really thank you also for
1942 looking at the Protecting Access to Lifesaving Screening, the
1943 PALS Act, which is going to help millions of women between
1944 the ages of 40 and 49 keep access to breast cancer screening.

1945 I also want to highlight Representative Walberg and
1946 Tonko's Lead Poisoning Act, which I have cosponsored. We are
1947 certainly having a declared state of emergency in my
1948 district, in Benton Harbor, Michigan, due to the lead in the
1949 water, and this bill is going to help ensure that those
1950 situations don't happen in the future.

1951 And I know that there are several expiring
1952 authorizations from 21st Century Cures that we still need to
1953 look at that were not part of this hearing, going along with
1954 Mr. Butterfield's comments, especially with regards to mental
1955 health. So it is my hope that we can add that to the
1956 workload list for reauthorization soon.

1957 Two questions in my remaining time.

1958 Ms. Stewart, as I mentioned before, we are currently
1959 facing a crisis in my home district, Benton Harbor, related
1960 to lead in the water. And I was able to get $5.6 million in
1961 EPA funding last October for the city to replace lead service
1962 lines, and the state is providing additional resources that

1963 they have referenced in the -- just in the last couple of
1964 weeks.
1965 What are some things that the Federal Government can do
1966 in addition to ensuring continued predictable support that
1967 H.R. 5552 provides for lead poisoning prevention and
1968 screening to ensure that this doesn't happen in communities?
1969 How can agencies at the federal, state, and local levels
1970 work better in order to prevent future crises, Ms. Stewart?
1971 *Ms. Stewart. Thank you, Mr. -- Congressman, and I
1972 acknowledge that we -- you have, in Benton Harbor, been
1973 experiencing and seen it up close and personal, the
1974 devastation that has been created in Benton Harbor. I had a
1975 chance to visit Benton Harbor when I was a student at
1976 University of Michigan. Benton Harbor is a predominantly
1977 Black city, and we know that lead poisoning does impact
1978 disproportionately people of color, especially Black children
1979 and Black families. And what is going on in Benton Harbor is
1980 simply a disaster, and it is a manmade disaster.
1981 And so if we are prepared to deal with manmade disasters
1982 in other areas, we certainly should deal with it in this
1983 area, because lead poisoning has such a devastating effect on
1984 the health of families, on the health of children.
1985 One of the things that the Lead Poisoning Prevention Act
1986 does do is it reconstitutes this advisory committee at the
1987 CDC that, for years, supported CDC's Childhood Lead Poisoning

1988 Prevention Program. It would allow there to be expansion of
1989 resources for grants for support, for relief and recovery,
1990 especially in at-risk communities.

1991 We think that, for a lot of states that are struggling
1992 with some of these issues -- and we think it goes beyond just
1993 Michigan and Benton Harbor -- that states need more support,
1994 and financial support, in dealing with these kinds of crises.
1995 And it is not only in terms of prevention, but it is also in
1996 dealing with the effects of lead poisoning as they exist
1997 today. So there have to be more resources paid to the --
1998 attention to make sure that we can address those children,
1999 especially, that have been impacted by lead poisoning.

2000 But again, to your point, also preventing it, and
2001 putting more resources into the issue in places like Benton
2002 Harbor and more.

2003 *Mr. Upton. Yes, we had some promising news just
2004 yesterday. The governor was there, the lieutenant governor
2005 was there last week, and they have announced that they are
2006 going to replace all of the lines, hopefully, within 18
2007 months. And I know in the -- what we call the BIF, the
2008 bipartisan infrastructure bill that did pass the Senate 69 to
2009 30 back in August, it includes 15 billion for lead lines in
2010 that, as well.

2011 Dr. DuBois, can you speak to how the U.S. Preventive
2012 Services Task Force screening guidelines are tied to

2013 insurance coverage and co-pays?

2014 Isn't it true that any screening decisions, breast
2015 cancer, any other preventive screening decisions that don't
2016 receive that A or B grade, is no longer guaranteed coverage
2017 with a co-pay?

2018 *Dr. DuBois. Can you hear me?

2019 *Mr. Upton. I can.

2020 *Dr. DuBois. Yes, that is correct. The -- if it is not
2021 an A or a B by the task force, then it is not automatically
2022 covered by insurance coverage.

2023 Although many societies and other bodies do recommend
2024 screening starting at age 40, and so there is a lot of that
2025 going on, I think this bill actually helps support funding
2026 for those services.

2027 Most people in the cancer field and other individuals in
2028 this area definitely feel that screening needs to begin at 40
2029 for women for breast cancer.

2030 *Mr. Upton. Thank you.

2031 I yield back. Thank you, Madam Chair.

2032 *Ms. Eshoo. The gentleman yields back. I am pleased to
2033 recognize the gentlewoman from California, Ms. Matsui, for
2034 your five minutes of questions.

2035 *Ms. Matsui. Thank you very much, Madam Chair, for the
2036 recognition.

2037 And I want to thank all the witnesses for joining us

2038 today. Your -- you have been absolutely outstanding, and I
2039 really especially want to say thank you to my former
2040 colleague, Rick Nolan, for sharing your story. It is -- what
2041 a wonderful way to really honor Katherine in the sense that
2042 you are doing her work, as far as trying to ensure that no
2043 one else goes through what she has gone through. So thank
2044 you, Rick.

2045 I want to talk about the Early Hearing Detection and
2046 Intervention, the EHDI program, which has proven key to
2047 improving public health for children and families. Before
2048 the program began 2 decades ago, less than 10 percent of
2049 infants were screened for hearing loss. And today, thanks to
2050 a successful EHDI program, the screening rate is 98 percent.

2051 But I am really concerned that all infants with hearing
2052 loss are not receiving the necessary follow-up treatment they
2053 need in a timely manner. So further, too many of our
2054 children who have been identified as deaf or hard of hearing
2055 are still facing disparities in access to care.

2056 Early childhood is, as we know, a crucial period for
2057 language acquisition, and it is critical that we equip health
2058 care providers and parents with the knowledge and tools they
2059 need to make timely decisions about hearing services and
2060 supports for their children.

2061 Now, with these goals in mind, I recently joined Ranking
2062 Member Guthrie in introducing legislation that will

2063 reauthorize this program, and I am looking forward to our
2064 continued efforts here, and have several questions about the
2065 status of the program.

2066 Ms. Stewart, it is important for the CDC to improve
2067 their hearing loss, surveillance, research, and connection
2068 follow-up services. Could you explain what role CDC plays in
2069 ensuring newborns screened through this program can access
2070 the follow-up services that they need?

2071 *Ms. Stewart. Well --

2072 *Ms. Matsui. Ms. Stewart?

2073 *Ms. Stewart. -- thank you, Congresswoman. As we
2074 talked about, one of the things that is really important in
2075 all of this hearing is understanding the importance of early
2076 detection, of good data collection, and that extends to a lot
2077 of issues, including the issues around early hearing and
2078 detection.

2079 And we are doing a much better job, as we have talked
2080 about. When we look back in 1999, according to NIH, when,
2081 prior to the establishment of this federal universal newborn
2082 infant hearing screening program, we were only screening less
2083 than 10 percent of newborns, we are now screening 98 percent
2084 of newborns.

2085 But what we also know, according to the CDC, and in the
2086 school year -- and this was just -- these are older numbers,
2087 but from the school year of 1999 to 2000, the total cost of

2088 special education programs for children who were deaf or hard
2089 of hearing was about $652 million. That is about $11,000 per
2090 child. But the lifetime educational cost for a child who is
2091 deaf or hard of hearing is estimated at $115,000 per child.
2092 So the costs that go into monitoring kids early in life isn't
2093 just screening them in the first month of life, which is what
2094 the recommendation is, that babies should be screened at one
2095 month, it is also making sure that there is funding and we
2096 are tracking the progress of children over their lifetime
2097 education, for their lifetime educational needs.

2098 And we would hope that the CDC would play a vital role
2099 in making sure that we can track that, as long as -- with
2100 what other lifelong health challenges, or --

2101 *Ms. Matsui. And certainly, Ms. --

2102 *Ms. Stewart. -- other issues that children may
2103 experience.

2104 *Ms. Matsui. Ms. Stewart, would you agree that the
2105 increase in CDC funding in this bill is key to expanding
2106 these activities?

2107 *Ms. Stewart. I would agree with that, for sure.

2108 *Ms. Matsui. Thank you very much.

2109 I was deeply disturbed, as others, about the Facebook
2110 testimony by the whistleblower, Frances Haugen, and about
2111 young users, in particular, who -- leading young users to
2112 anorexia content. I have long been concerned about the

2113 mental health impact of eating disorders on young people,
2114 especially young girls.
2115 In 2015, as the E&C lead of the Anna Westin Act, I was
2116 proud to support passage of this important legislation which
2117 increased education and resources for those suffering with
2118 eating disorders. Now, while we made progress in ensuring
2119 access to treatment, we have to do more to protect our kids
2120 from being exposed to toxic content on social media.
2121 Dr. Radesky, thank you for your testimony. Would you
2122 agree that the connection between mental health, eating
2123 disorders, and algorithms that determine children's
2124 recommendation feeds is an issue area in urgent need of the
2125 funding and research provided by the CAMRA Act?
2126 *Dr. Radesky. Yes, thank you for that question. One
2127 thing I really appreciate about the CAMRA Act is that it
2128 tries to understand individual children's vulnerabilities to
2129 what might make them profiled in a certain way, and therefore
2130 be fed content that is not in their best interest, how they
2131 might be profiled to send them advertising that is -- you
2132 know, also could nudge their behavior, in one way or another,
2133 that is not in their best interest.
2134 *Ms. Matsui. Right.
2135 *Dr. Radesky. One thing about eating disorders, in
2136 particular, is that we do need more research that focus on
2137 specific diagnosis populations. Eating disorders, or autism

2138 spectrum disorder, or learning disabilities, ADHD, all of
2139 this would be much more robustly funded through the CAMRA
2140 Act.

2141 *Ms. Matsui. Okay. Well, thank you very much, Dr.
2142 Radesky.

2143 And I yield back.

2144 *Ms. Eshoo. The gentlewoman yields back. It is a
2145 pleasure to recognize the gentleman from Virginia, my friend,
2146 Mr. Griffith, for your five minutes of questions.

2147 *Mr. Griffith. Thank you very much, Madam Chair. I do
2148 appreciate it.

2149 I want to go a little off subject, because we have the
2150 stillbirth bill, which I think is a good bill. A lot of
2151 these bills are.

2152 But it came to my attention a couple of years ago, as
2153 often happens with us in our profession. I was at a county
2154 fair, and a lady brought a situation to me that I think we
2155 need to work on. It is not our committee, so we can't do
2156 anything about it, but it deals with stillbirth situations.
2157 And many states, including Virginia -- in fact, there was a
2158 somewhat notorious prosecution of a lady who had a
2159 stillbirth, and Virginia law, because she just put the baby
2160 in the trash can, but it was clearly stillbirth, no
2161 misconduct on her part, other than that, and the state
2162 requires that you both fill out the proper forms, but that

2163 you also, once a baby gets to a certain age, we require a
2164 burial, or a proper disposal of the remains, which I think is
2165 appropriate.

2166 But we, as a Congress, have not done anything to give a
2167 tax credit. If the child is born alive and takes one breath,
2168 you get a tax deduction. You have all the same expenses.
2169 And in fact, what was brought to me at the county fair was a
2170 young lady who didn't know her baby had died, and went in on
2171 the due date, only to discover that the baby had had died,
2172 and they had to put her through labor in order to take care
2173 of it. So she went through all the expenses, all the trauma
2174 of having a baby, knowing that the baby was dead, and yet no
2175 help from our Federal Government.

2176 So that is just an aside, and I apologize to our
2177 witnesses, but I think it is important.

2178 I am going to take another side, and go to you,
2179 Congressman Nolan, and I want Dr. Lloyd-Jones to listen, as
2180 well.

2181 I am for the bill, so that is not the issue. But I am
2182 wondering, because I had a constituent who -- his watch told
2183 him, "You are in AFib'', and he went to have it checked out,
2184 they couldn't find it at first. He did a stress test and,
2185 sure enough, they found a heart valve problem. He had it
2186 fixed. It was no problem, as long as he got it fixed, and he
2187 is out there and doing fine today.

2188 I am wondering if, both in regard to lung cancer and you
2189 can't get your breath, is there some kind of -- do we see any
2190 kind of future technology that would make it so that you can
2191 basically do something at home? Your watch isn't going to
2192 tell you you are having a breathing problem, I don't think.
2193 But I am just wondering if you know of any new technologies
2194 coming along.

2195 I am for the screenings. I think that makes sense. But
2196 I am just wondering if there is any other technologies that
2197 you are aware of that might -- that you might be able to do
2198 something at home to get an earlier screening, as well.

2199 *Mr. Nolan. Thank you, Congressman. That is a very
2200 good question.

2201 I think it is reasonable to understand why that early
2202 free screening wasn't initially given to the victims of lung
2203 cancer who were non-smokers, of whom there are many, because
2204 all that was available was a chest X-ray, and that was not
2205 very good, and it caused too many false positives and false
2206 negatives, and -- but over the years since that time, low-
2207 dose CT scans have been developed that are very, very good,
2208 and as good or equal to the screening techniques made
2209 available for other cancers.

2210 So I think it is the advance of technology that makes
2211 this legislation ready --

2212 *Mr. Griffith. And that makes sense. And I will tell

2213 you, because of stuff I had going on as a kid, they spotted a
2214 little teeny spot on my lungs, and popped me into one of
2215 those, and everything is fine, and it is not a problem, it is
2216 just old scarring. But that is what they were looking for.
2217 And -- but you shouldn't have to have a spot caused by
2218 having bronchitis 100 times when you were a kid that gets you
2219 that screening, and I think that your legislation is --
2220 *Mr. Nolan. Well, thank you.
2221 *Mr. Griffith. It is right on. I appreciate --
2222 *Mr. Nolan. And I might tell you, my daughter was very
2223 physically active, and very conscious of her health, and she
2224 had started a new business, and had kind of backed off a
2225 little bit on her daily exercise routines, and figured that
2226 her lack of breath was because she hadn't been exercising
2227 as --
2228 *Mr. Griffith. Right.
2229 *Mr. Nolan. -- as she should have. And so she doubled
2230 down on her exercise, and things didn't get better, they got
2231 worse. So she went to the doctor, and was diagnosed, and by
2232 that time it was too late. It was terminal.
2233 *Mr. Griffith. Yes.
2234 *Mr. Nolan. But I might add to the committee -- and
2235 thank you, because this committee has played such an
2236 important role in the advances in preventing and extending
2237 the lives of cancer victims.

2238 And you know, Katherine, my -- I started to say my aunt
2239 Eleanor Nolan, who was dead in six months after --
2240 *Mr. Griffith. Right.
2241 *Mr. Nolan. Katherine lived another six years.
2242 *Mr. Griffith. Yes.
2243 *Mr. Nolan. And had a great time with her family, and
2244 her husband, and was able to devote much time to advocating
2245 for lung cancer victims, donated her body to the Mayo Clinic,
2246 and was very grateful for the men and women who have promoted
2247 good public policies. And she would be -- I would be remiss
2248 if I didn't thank the committee for the work that has been
2249 done over the years.
2250 *Mr. Griffith. Well, I thank you for that, and the
2251 chairwoman and I were talking about it earlier, in that so
2252 much of what we do here is not partisan, it is just trying to
2253 solve problems, and that is what this committee normally
2254 tries to do.
2255 My time is up. I did -- I may ask a few questions after
2256 the fact of Dr. Lloyd-Jones. I will note, as the head of the
2257 Welsh Caucus, Dr. Jones, that -- or Dr. Lloyd-Jones, that, as
2258 a fellow with the name of Morgan Griffith, it is mighty nice
2259 to have a -- somebody who has got at least some Welsh
2260 ancestry, because you wouldn't have names of Lloyd and Jones
2261 if you didn't have some Welsh ancestry. So I look forward to
2262 your answers to the written questions I will submit later.

2263 [The information follows:]

2264

2265 **********COMMITTEE INSERT**********

2266

2267 *Mr. Griffith. I yield back.

2268 *Ms. Eshoo. Thank you, Congressman. The gentleman
2269 yields back, and he says that with enormous pride, and we are
2270 proud of you, too.

2271 So the chair now recognizes the gentleman from Maryland,
2272 Mr. Sarbanes, for your five minutes of questions.

2273 *Mr. Sarbanes. Thanks very much, Madam Chair. I want
2274 to thank our panel for their testimony. I want to thank, in
2275 particular, our former colleague, Rick Nolan, for being here
2276 and delivering very difficult, but powerful testimony.

2277 All the bills that we are hearing about today are very
2278 critical. I am going to focus on one that has already gotten
2279 a fair amount of attention that I, along with many of our
2280 colleagues, are cosponsors of, which is the CAMRA Act.

2281 We certainly know that the Internet and the digital
2282 revolution have been vital tools. It created vital tools for
2283 innovation, creativity, economic growth, both for individuals
2284 and communities, obviously. But we also know that it has
2285 created a lot of new considerations around safety and health
2286 that we have to address.

2287 I am often discussing the use of media, particularly
2288 social media, in the context of protecting our democracy, and
2289 safeguarding our elections, and things of that nature. But I
2290 am also super concerned about the effects social media is
2291 having on our children's well-being. And we know the topic

2292 is getting a lot of attention, increasingly now, which is
2293 good, but it means we really have to wrestle with what are
2294 the solutions. What do we bring to bear, and make sure
2295 children are protected?

2296 Dr. Radesky, you have already talked at some length
2297 about all of this. I wonder if you could speak for a moment
2298 to whether there is a way -- whether we should have the
2299 ambition, I guess, of trying to kind of flip the presumptions
2300 here that, when these tools are being developed inside of
2301 these large, digital ad companies or, frankly, inside any
2302 organization that is going to deploy them widely, whether
2303 they should, in a sense, have to first demonstrate the
2304 precautions they are taking to protect children before the
2305 tools are more widely deployed. Because, as you know, and I
2306 think you have testified, you know, there is a blind spot
2307 there. These get developed with adults in mind, and how to
2308 sort of cultivate the connection with adults.

2309 But the collateral damage on young people is huge. And
2310 I am sure you have been tracking with your own work, whether
2311 you are beginning to see any culture change inside some of
2312 these organizations, where they frontload their focus on what
2313 this can do when it gets in the hands of children, knowing
2314 that that is going to happen. And then, in a sense, back out
2315 the product line from there, instead of it being an
2316 afterthought.

2317 So if you could speak to that for a couple of minutes, I
2318 would be interested to hear, because I think that could guide
2319 the way we design legislation here on the Hill to try to
2320 protect young people in this digital age with all its
2321 benefits, but, as we know, with some severe drawbacks, as
2322 well.

2323 *Dr. Radesky. Thank you. That is an excellent
2324 question. And I really like the emphasis on children not
2325 being an afterthought.

2326 Children have such different ways of interacting with
2327 digital spaces that it is normal that adult designers
2328 wouldn't recognize all those things. But we have lots of
2329 know-how from really good research on TV and video games
2330 about how children experience those platforms. What we need
2331 is more research to inform our advisement to tech companies
2332 about how a child at different developmental stages, from
2333 infancy to preschool, elementary school, teenage years would
2334 interact with different types of algorithms that elevate
2335 different content that might take off different social
2336 engagement metrics like liking and sharing.

2337 And one thing that I have been impressed with, from a
2338 policy standpoint, is the UK and the EU have done a lot of
2339 movement in the past few years about a child-centered design
2340 code. And here in the U.S., I sit on a steering committee
2341 along with other folks like Center for Humane Technology,

2342 Common Sense Media, Fair Play, where we are trying to find
2343 the same sort of child-centered principles to put children's
2344 needs first before products are released.
2345 In the EU they do -- they are recommending or debating a
2346 child impact assessment before tech is released, so that you
2347 can have child experts and technologists working together to
2348 say, "Can we anticipate how this might be misused? Can we do
2349 some trial runs to see what are the metrics that show
2350 children are really benefiting from this?'' It is giving
2351 them new ideas, not sucking away their time.
2352 *Mr. Sarbanes. Thanks. That is really helpful. That
2353 is exactly the answer I was looking for, and I like this
2354 concept of a child-centered design code, and sort of making
2355 sure, before the broader rollout happens, that that
2356 assessment is being done.
2357 And we can learn from what our peer nations are doing
2358 around the world, absolutely, in this space.
2359 Thank you very much, Madam Chair, I yield back.
2360 *Ms. Eshoo. Thank you, Mr. Sarbanes. The chair is now
2361 pleased to recognize the gentleman from Florida, Mr.
2362 Bilirakis, for your five minutes of questions.
2363 *Mr. Bilirakis. Thank you, Madam Chair, I appreciate it
2364 very much. And I feel blessed to, of course, represent the
2365 12th congressional district in the State of Florida, but also
2366 to sit on this committee and make a real difference, because

2367 this is the best committee in Congress, without question.
2368 Thank you, Madam Chair.
2369 *Ms. Eshoo. Thank you.
2370 *Mr. Bilirakis. Again, I was particularly glad to see
2371 the bill I co-lead with my friend, Representative Cardenas,
2372 the Oral Health Literacy and Awareness Act, including --
2373 included on today's docket. So thank you again for that,
2374 Madam Chair, and the ranking member, as well.
2375 This bipartisan bill would direct HRSA to develop and
2376 test oral health literacy strategies capable of reaching
2377 across vulnerable populations to provide oral disease
2378 prevention education through a five-year oral health literacy
2379 campaign.
2380 Dr. Cassis, can you tell us why HRSA is best equipped to
2381 push out such a campaign, as opposed to an entity like the
2382 CDC?
2383 And can you explain why establishing evidence-based
2384 strategies, as outlined in this bill, are important to ensure
2385 the agency is reaching our communities effectively?
2386 *Dr. Cassis. Certainly, I would be happy to respond to
2387 that. And forgive me, you know I am from West Virginia, and
2388 we don't talk real fast here, unlike some of my distinguished
2389 colleagues on the committee, and witnesses.
2390 But to be quite factual, HRSA is a much smaller
2391 organization than the CDC, and they definitely deal with a

2392 lot of facts, as opposed to how you guys operate, and knowing
2393 is it a good program or not. They can -- with their small
2394 size, we can figure it out real fast, whether it is effective
2395 or not.

2396 And as far as funding for that, you know, it is really a
2397 small amount, but it is this -- the catalyst that may help.

2398 Again, I have -- I have practiced 42 years, and I have
2399 to speak so many different languages of understanding with
2400 all of my patients. So if there is better ways to get people
2401 into the office, then we need to -- that common thread of
2402 what works for everybody.

2403 *Mr. Bilirakis. Thank you, sir. My next question is
2404 for Ms. Miller.

2405 I want to thank you for testifying today, and
2406 highlighting the importance of the Gabriella Miller Kids
2407 First Research Act 2.0.

2408 I appreciate everything, and -- which I am proud to be a
2409 cosponsor, the Republican lead. I am glad to see many other
2410 members joining in support of this, of course, very important
2411 legislation named after your late daughter -- may her memory
2412 be eternal -- and remain hopeful we can continue to move this
2413 forward through the legislative process.

2414 We know that all pediatric cancers are considered rare,
2415 but that is not a rare problem, as you know. And as co-chair
2416 of the Rare Disease Caucus, we need to ensure we are

2417 directing much-needed research funding and attention for
2418 these most vulnerable patients.
2419 Some have expressed concern that using civil fines to
2420 fund the Pediatric Research Initiative could result in
2421 varying levels of money each year. Can you elaborate why you
2422 believe using this particular mechanism can be helpful in
2423 properly funding these critical programs? Because,
2424 obviously, you have a lot of support for the program. If you
2425 could answer that, I think that would be very helpful.
2426 *Ms. Miller. Well, first, let me thank you for being an
2427 original sponsor on this piece of legislation. I appreciate
2428 your leadership on this.
2429 As you stated, the funding for childhood cancer and
2430 childhood diseases desperately needing an infusion, the --
2431 childhood cancer gets approximately four percent of the NCI
2432 budget. And what is so fantastic about this piece of
2433 legislation is the unique funding source does not require our
2434 elected officials to appropriate the other 96 percent -- it
2435 could stay as is -- it supplements what we already have.
2436 And what is also fantastic about it is that it will be a
2437 never-ending source until such time as we have no longer a
2438 need for that. And right now, there is such a desperate
2439 need.
2440 So this source of funding is unique, and innovative, and
2441 will truly move the bar forward. Thank you for asking.

2442 *Mr. Bilirakis. Very good. Sounds great.

2443 I will yield back, Madam Chair. Thank you.

2444 *Ms. Eshoo. I thank the gentleman. The chair now is
2445 happy to recognize the gentleman from Vermont, Mr. Welch, for
2446 his five minutes of questions.

2447 *Mr. Welch. Thank you very much.

2448 *Ms. Eshoo. There you are.

2449 *Mr. Welch. It -- you know, it is always good to see
2450 Mr. Nolan. I mean, most of the time.

2451 [Laughter.]

2452 *Mr. Welch. And it is always good to see Ms. Miller --
2453 such fond memories of us working together with Eric Cantor to
2454 pass the first bill.

2455 But I do want to say sincerely to both of you, it is so
2456 refreshing in this world that is so filled with strife, and
2457 then often times with personal pain and personal loss, to
2458 have before us two people who have turned that loss, that
2459 pain, into progress in benefit for other people. That is
2460 inspiring for all of us.

2461 So Rick, I want to thank you.

2462 And Gabriella [sic], I want to thank you so much on
2463 behalf of your daughter, Gabriella. And I see your husband
2464 is here, too, and I have fond memories of the bill signing.
2465 We went down with Eric Cantor, and President Obama signed it.
2466 And even as that was being signed, you were advocating with

2467 President Obama for the next step. So thank you very much.
2468 Ms. Miller, Marilyn [sic], I want to ask you about the
2469 funding source, because that was the whole issue here, and
2470 how is it that -- just elaborate a little bit about what the
2471 insecurity is of the funding source, and why it is -- that we
2472 need to have this Gabriella Miller 2.0.
2473 Thanks, Marilyn. Go ahead.
2474 *Ms. Miller. Again, as with Congressman Bilirakis, let
2475 me thank you for your support. And you are an original
2476 sponsor of the first piece of legislation. And when I
2477 approached you on this one, you just immediately said, "Count
2478 me in.'' So thank you for that.
2479 The original piece of legislation was a designated
2480 funding amount. We knew that every year that we get it
2481 appropriated, it is $12.6 million. This new funding source,
2482 we don't have that. We need to wait, obviously, for a
2483 penalty to be --
2484 *Mr. Welch. Right.
2485 *Ms. Miller. -- found. But the -- and Madam Chair
2486 asked earlier the amounts of the monies, and I wish that I
2487 could answer that with definite -- you know, a definite
2488 answer, but we don't know how much they could be.
2489 *Mr. Welch. Okay.
2490 *Ms. Miller. It could be, you know, $10 million --
2491 *Ms. Eshoo. My staff tells me that the -- excuse me,

2492 that the total amount of -- in terms of penalties that came
2493 in that go into the general fund in 2019 was 335.8 million.
2494 So I am surprised some member hasn't found that money before
2495 to use for --

2496 *Ms. Miller. It is ours.

2497 *Ms. Eshoo. -- filling the --

2498 *Ms. Miller. It is ours.

2499 *Ms. Eshoo. But it is a --

2500 *Ms. Miller. The kids need it.

2501 *Ms. Eshoo. It is a good sum of money.

2502 *Ms. Miller. Yes.

2503 *Mr. Welch. The bottom line here is it is --

2504 *Ms. Miller. So --

2505 *Mr. Welch. There has got to be some stability in the
2506 funding if we are going to do the research.

2507 *Ms. Miller. So one thing that we truly like about this
2508 piece of legislation is that --

2509 *Mr. Welch. Yes.

2510 *Ms. Miller. -- you know, we don't know that we will
2511 get a penalty every year. So there could be a year that
2512 there is no funding. And what we have done differently in
2513 this year is, once our bill was introduced in the 116th
2514 Congress, I reached out to Dr. Collins, the director of NIH,
2515 and I asked him to help me with language, so that we could
2516 ensure that it is not a use-it-or-lose-it situation, as it

2517 was with the original.

2518 *Mr. Welch. Right.

2519 *Ms. Miller. And his staff helped, and we got that
2520 language put into our current legislation, where it will
2521 allow for it to roll over. So there --

2522 *Mr. Welch. Well, thank you.

2523 *Ms. Miller. -- will never be a year that will go by --

2524 *Mr. Welch. Right.

2525 *Ms. Miller. -- that there won't be any monies that are
2526 allowed for –

2527 *Mr. Welch. Thank you, very –

2528 *Ms. Miller. -- to research.

2529 *Mr. Welch. Thank you very much.

2530 And I wanted to ask Congressman Nolan, if you were back
2531 here, what would you have Congress be doing to assist cancer
2532 patients from diagnosis -- throughout diagnosis and
2533 treatment?

2534 *Mr. Nolan. For lung cancer, I presume.

2535 *Mr. Welch. Yes.

2536 *Mr. Nolan. Yes.

2537 *Mr. Welch. That is right.

2538 *Mr. Nolan. Well, I would like to see it become a
2539 national priority, because it is a national emergency. Every
2540 day 361,000 people die. It is like an Airbus going down
2541 every day, and every passenger being killed.

2542 And I think, you know, there is some very disparate
2543 treatment between lung cancer and many other cancers. Lung
2544 cancer kills more than almost all of them combined. It has
2545 been stigmatized, because of smoking.
2546 *Mr. Welch. Right.
2547 *Mr. Nolan. And while other cancers are given early
2548 detection, as a common procedure, lung cancer victims only
2549 get it if they are 55 years of age and smoked 20, 30 packs of
2550 cigarettes a day for 20 or 30 years.
2551 *Mr. Welch. Right.
2552 *Mr. Nolan. And it has become epidemic among young
2553 women between 20 and 30.
2554 And so, providing early screening --
2555 *Mr. Welch. Right.
2556 *Mr. Nolan. -- as well as additional funding for
2557 research and prevention and those, I think, is the most
2558 important thing, I think, we can do. It will save tens, if
2559 not hundreds of thousands of lives by providing that early
2560 screening and detection for lung cancer.
2561 *Mr. Welch. Thank you very much, and thank you again,
2562 both, for your advocacy.
2563 *Mr. Nolan. Thank you.
2564 *Ms. Eshoo. The gentleman yields back. It is a
2565 pleasure to recognize Dr. Dunn of Florida for his five
2566 minutes of questions.

2567 *Mr. Dunn. Thank you very much, Madam Chair and Ranking
2568 Member Guthrie, for hosting this hearing today to consider
2569 legislation related to public health.

2570 And the public health focus over the last 18 months has
2571 appropriately been on COVID-19, and we have experienced
2572 successes and failures with COVID-19, and should legislate
2573 accordingly.

2574 We also, however, now have to ensure that Americans are
2575 able to get back on track when it comes to maintaining their
2576 health, and staying up to date with routine health care
2577 visits. I am very concerned that the data indicates nearly
2578 10 million screenings for cancer were foregone during the
2579 public health emergency so far, which is why I introduced
2580 H.R. 5558, the Prostate Cancer Prevention Act.

2581 This bill will reauthorize the expired CDC Prostate
2582 Cancer Research Prevention Program, and I want to thank my
2583 colleague, Mr. Bobby Rush, who is chair of the Energy
2584 Subcommittee, for cosponsoring this important bill.

2585 I witnessed firsthand immense progress in the field of
2586 cancer treatment throughout my medical career, and continue
2587 to be amazed at how far we have come.

2588 I am concerned over the impact of COVID-19, what it has
2589 had on the diagnosis, treatment, and outcomes of cancer. An
2590 essential aspect of success in the field of cancer is, of
2591 course, early and accurate detection of disease.

2592 Dr. DuBois, I have a question for you. You spoke during
2593 your testimony about the importance of cancer screening. I
2594 appreciated your comments regarding evaluating the whole
2595 picture of an individual's risk when considering cancer
2596 screening, and I believe that a strong doctor-patient
2597 relationship leads to this type of thoughtful risk
2598 assessment. Doctors should be looking at far more than just
2599 age and race when making determinations about risk, and
2600 physicians should be examining the full spectrum of risk,
2601 including life circumstances and what not when making
2602 screening recommendations.

2603 We should be empowered to make the most appropriate care
2604 recommendations for each of our patients. So Dr. DuBois,
2605 could you elaborate on your concerns regarding the Preventive
2606 Services Task Force reform, and how to ensure that the task
2607 force is not impeding appropriate patient care decisions?

2608 *Dr. DuBois. Well, thank you for the question. I think
2609 the task force has a, you know, sometimes a difficult task.
2610 They really are focused on looking at the whole population –

2611 *Ms. Eshoo. We need you to speak up.

2612 *Dr. DuBois. Okay.

2613 *Ms. Eshoo. We need you to speak -- get closer to your
2614 microphone. Maybe raise your voice a little bit. We don't
2615 want to miss what you are saying.

2616 *Mr. Guthrie. Thank you.

2617 *Ms. Eshoo. Sure.

2618 *Dr. DuBois. Okay, so can you hear me now?

2619 *Ms. Eshoo. Yes, it is better.

2620 *Dr. DuBois. Okay, sorry about that.

2621 You know, the task force looks at the whole population,
2622 and they calculate their risk and benefits of that screening
2623 and who would benefit from it, and who would be harmed by it.
2624 It is really made up of individuals who are mostly public
2625 health experts, or epidemiology experts, and people like
2626 that. And it is -- you know, it is sort of a formula that --
2627 examined.

2628 I think you are right in the sense of there are many
2629 other exposures and issues related to the hereditary issues.
2630 There is environmental exposures, there is secondhand smoke
2631 exposures, and all of those aren't considered in the
2632 calculation. So it is always important for patients to speak
2633 with their primary doctor, let them know if -

2634 *Mr. Dunn. So -- we are -- our time grows short,
2635 Doctor, so I am just going to jump in with another question
2636 to you, and I encourage you, as Chairwoman Eshoo did, to turn
2637 up your microphone a little bit, because we -- you are soft.

2638 So throughout the COVID-19 pandemic, the CDC has
2639 repeatedly released inconsistent guidance surrounding
2640 masking, testing, immunity, you know, just simple knowledge
2641 about the classroom policies, et cetera. Do you think the

2642 inconsistent messaging from public health agencies in
2643 general, but specifically regarding COVID-19, harms our
2644 federal public health efforts regarding cancer screenings and
2645 credibility, moving forward?
2646 *Dr. DuBois. Can you hear me better now?
2647 *Mr. Dunn. A little. Go ahead.
2648 *Dr. DuBois. Sorry about that. I am not sure what has
2649 happened to my --
2650 *Mr. Dunn. The clock is running. Go ahead and answer.
2651 *Dr. DuBois. Well, you know, the CDC, it is a tough
2652 situation. We -- there has been a rapid development of
2653 agents for treating COVID patients and diagnosing them. And
2654 we have learned a lot in a very short time. So it is -- you
2655 know, it has been a very difficult issue for the whole
2656 medical field to deal with.
2657 In terms of, you know, for cancer patients, which is my
2658 main focus, we are trying to get everybody vaccinated. We
2659 are trying to make sure that they are as protected as
2660 possible because of their immune compromised from their
2661 treatment and from their disease.
2662 *Mr. Dunn. Thank you. So I would summarize it -- I
2663 think that credibility in cancer treatment also suffers from
2664 credibility in general public health announcements. And I
2665 suspect that you would agree with that.
2666 With that, Madam Chair, thank you, and I yield back.

2667 *Ms. Eshoo. Thank you, Dr. Dunn. The chair is pleased
2668 to recognize the gentleman from California, a special friend
2669 to me, Mr. Cardenas, for your five minutes of questions.
2670 *Mr. Cardenas. Thank you very much, Madam Chairwoman,
2671 and also Ranking Member Guthrie, for having this very, very
2672 important hearing.
2673 And I want to thank all of my colleagues for the
2674 diligent effort that we have had in this discussion today,
2675 and the work that we have done leading to this day, and the
2676 work that we have yet to do to complete -- to do the work
2677 that is demanded of us. I say that respectfully, "demanded
2678 of us.'' And I want to give a special thank you to somebody
2679 that I love very dearly, my former colleague, Congressman
2680 Rick Nolan.
2681 It is just so wonderful to see you. You are one of the
2682 kindest individuals to ever serve in this House. And I miss
2683 you very much, and we are going to do everything that we can
2684 to keep your promise to your daughter, and to all the people
2685 who deserve the best of us, the best of us.
2686 And we must keep in mind that what we do on this
2687 legislation, these pieces of legislation, not only will honor
2688 those who have passed, but it will, more importantly, honor
2689 those that will live because we have given them the
2690 opportunity to have the respect and the dignity that they
2691 deserve so that if, in fact, cancer comes their way, that

2692 they will survive. Because we are and shall be the greatest
2693 nation in the world, not by our military might, but by the
2694 care that we give to every human being that deserves the best
2695 of us, the best of us.

2696 I would like to start by thanking my colleague,
2697 Representative Bilirakis -- Republican, by the way, and I am
2698 a Democrat, and together we introduced the bill which is H.R.
2699 455, and that bill actually is included. And I want to thank
2700 the chairwoman and the ranking member for doing so. And it
2701 is the Oral Health Literacy Act.

2702 Yes, oral health, something that is very important,
2703 something that has already been explained today that most
2704 Americans don't have access to, or don't afford themselves
2705 the opportunity to get that dental checkup, to be
2706 preventative about saving -- yes, in some cases, actually
2707 saving their life by making sure that they get preventative
2708 care.

2709 This bipartisan bill will allow U.S. Health Resources
2710 and Services Administration, otherwise known as HRSA, to
2711 carry out a public education campaign to increase oral health
2712 literacy and awareness.

2713 Chairwoman Eshoo, I would like to request that we enter
2714 into the record at the end of this committee hearing a letter
2715 of support for this bill, H.R. 455, Oral Health -- by the
2716 oral health professionals and stakeholders.

2717 *Ms. Eshoo. So ordered.

2718 *Mr. Cardenas. Thank you, Madam Chair.

2719 I am grateful again for the inclusion of this bill in
2720 this important hearing, and I hope to see it advance for the
2721 sake of all of us in this great country.

2722 Dr. Cassis, thank you again for being here, and I would
2723 like to ask you a question. Is there -- when it comes to
2724 people in America not having true access to oral health care,
2725 is it only people who, for example, are homeless, or are
2726 there -- does this include people who are working perhaps
2727 one, two, three jobs? Are people who are hardworking
2728 Americans, are they not having access to oral health?

2729 *Dr. Cassis. Thank you for the question, Representative
2730 Cardenas. This -- -- it is across the board. It has nothing
2731 to do with, you know, where you might live. It is definitely
2732 across the board.

2733 We have to do a better job of communicating the
2734 necessary appointments to safeguard their lives. As you
2735 said, there are people that die from dental disease and
2736 complications every day.

2737 *Mr. Cardenas. So, Dr. Cassis, again, could you please
2738 help emphasize that -- we are talking about many of these
2739 individuals are hardworking, full-time workers, people who
2740 are working full time, and they and their family members are
2741 -- don't have true access to oral health care. Is that the

2742 case in America today?

2743 *Dr. Cassis. It is, you are exactly right. There are
2744 -- you know, they have to ration dental care out, just like
2745 they have to ration food at times. And, you know, it is not
2746 a pretty scene, but it is across the board.

2747 *Mr. Cardenas. Yes, thank you. I wanted to emphasize
2748 that because I think in these hearings, when we talk about
2749 helping those who are less fortunate, a lot of people think
2750 that we are not talking about you, hardworking Americans. We
2751 are definitely talking about you, people who are holding down
2752 a full-time job, single moms. We are talking about you.
2753 That is who we are fighting for.

2754 And I see that my time has expired. Thank you very
2755 much, Madam Chairwoman, I yield back.

2756 *Dr. Cassis. Thank you.

2757 *Ms. Eshoo. The gentleman yields back. It is a
2758 pleasure to recognize one of the outstanding doctors that is
2759 a member of our subcommittee.

2760 Dr. Bucshon of Indiana, you are recognized for five
2761 minutes. Good to see you -

2762 *Mr. Bucshon. Thank you, Madam Chairwoman, and I am
2763 sorry for not being here for a good part of the hearing, but
2764 I have read your testimony, and -

2765 *Ms. Eshoo. Oh, Dr. Bucshon, can I just interrupt for a
2766 moment?

2767 *Mr. Bucshon. You can.

2768 *Ms. Eshoo. I -- and I am not going to -- I am not
2769 taking your time away. I have been asked to remind members
2770 and witnesses that are not in the hearing room to turn off
2771 your mikes, mute them, because there is background noise on
2772 the live stream. We are not picking it up here, but
2773 evidently others are. Okay? Thank you very much.

2774 And Dr. Bucshon, you are recognized for five minutes.

2775 *Mr. Bucshon. Thank you, Madam Chairwoman.

2776 Mr. DuBois -- is it DuBois or DuBois? I want to thank
2777 you for focusing in on the importance of preventive health
2778 and routine screenings, especially for cancer. As a doctor
2779 myself, I believe Congress can do better in promoting
2780 preventative health care -- health.

2781 I also agree we need to encourage Americans to screen
2782 early and screen often for preventable diseases, especially
2783 now that so many are behind in their screenings due to the
2784 public health emergency.

2785 A growing concern I have regarding routine screenings is
2786 our ability to maintain timely access to quality cancer care
2787 in all settings. While many facilities are already facing
2788 physician shortages across the country, many are also facing
2789 the reality of having to scale back staff or, even worse,
2790 close due to looming reimbursement cuts that are facing --
2791 they are facing at the start of next year.

2792 Coupling the fee schedule cuts with the proposed update
2793 to the clinical labor component, some providers I talk to are
2794 facing up to 20 percent in cuts. This is especially true for
2795 radiation oncology.

2796 Mr. DuBois, what are the real-world implications of
2797 proposed policies like these, and do you think such drastic
2798 reimbursement cuts would disrupt access to quality cancer
2799 care?

2800 *Dr. DuBois. Can you hear me okay now?

2801 *Mr. Bucshon. Yes.

2802 *Dr. DuBois. Okay, I had to switch my microphone. I am
2803 sorry about that earlier.

2804 Well, those cuts are having impacts, and I know exactly
2805 what you are talking about. My focus on my testimony today
2806 was really on cancer prevention, but those changes in
2807 reimbursements for the radiation oncology and other services,
2808 you know, will have an adverse impact. I don't know the
2809 total extent of that, but clearly, we need to keep an eye on
2810 that, and make sure that, you know, we can continue to
2811 support those individuals who are providing that essential
2812 care.

2813 *Mr. Bucshon. Thank you very much. And earlier this
2814 Congress I joined my friend and colleague, Congressman Rush,
2815 in introducing the PSA screening for HIM Act. This bill
2816 waives deductibles, co-payments, and co-insurance for

2817 prostate cancer screenings for African American men and men
2818 who have a family history of prostate cancer, as both of
2819 these patient populations have a much higher risk of prostate
2820 cancer. By encouraging early and routine screening, doctors
2821 will be able to catch the disease in its early and treatable
2822 stage, saving countless lives.
2823 Congress, I think, has a bad habit of looking at health
2824 care policies in a 10-year budget window, ignoring potential
2825 savings that accrue past the 10-year mark. So frequently
2826 that blocks health care policy, because it costs money in the
2827 short run, but in the long run, I would argue, saves not only
2828 lives, but money.
2829 Although many preventive care policies seem to cost --
2830 again, cost them on the front end, I think it is prudent for
2831 us, for the reasons I have explained, to look at these
2832 policies as they affect the entire lifespan of individuals.
2833 Mr. DuBois, how do screenings for early detection and
2834 preventive health measures lead not only to lives saved, but
2835 also lower costs to the overall health care system?
2836 And how can we do better, as a country, in promoting and
2837 encouraging preventive health?
2838 *Dr. DuBois. Well, thank you for that great question.
2839 You know, I have devoted my entire sort of career to cancer
2840 prevention and early detection, and the data is coming out
2841 now. Some very good studies have been done in colon and

2842 breast and other cancers. Clearly, when we can detect it
2843 early in the precancerous stage, or early, while it still
2844 hasn't metastasized, the outcome is just tremendous. There
2845 is a much more longer term of life. There is, you know, the
2846 -- if it can be removed early by surgery, there is a cure, a
2847 chance for a cure. So early detection definitely pays off.
2848 The health economic studies have been done. And the overall
2849 long-term impact is tremendous.

2850 So I agree with your statement. I think we need to
2851 focus more on disease prevention. It is something that we do
2852 in cardiovascular disease and other diseases, and cancer is
2853 something we just can't ignore.

2854 *Mr. Bucshon. Do you think there are things -- I mean,
2855 obviously, paying for preventative or early detection, things
2856 like -- that we have started to do a number of years ago --
2857 for example, breast cancer screening, and screening --
2858 colonoscopy, for example, I mean, are there things we can
2859 still do better?

2860 Is it primarily just reimbursement, or are there other
2861 things the Federal Government can do more to encourage people
2862 to take advantage of preventive evaluations?

2863 *Dr. DuBois. Well, I mentioned this in my testimony.
2864 There is definitely some underserved rural communities who
2865 don't have good health coverage, and don't have access to
2866 this type of screening, and the outcomes are much worse in

2867 those populations. It is very clear.

2868 One thing that we have been doing here is sending out
2869 screening mobile units to these areas, so that we can include
2870 those populations in that type of early screening.

2871 There is some very exciting research that is supported
2872 by the NCI that has developed a blood test for pan cancer
2873 testing. Cancer cells are released into the bloodstream, and
2874 this test can detect when they are present, and what tissue
2875 they came from. It is too early to deploy this clinically,
2876 but once those tests are validated and sensitive and specific
2877 enough, it could really change the way we do our early
2878 screening for all cancer patients.

2879 *Mr. Bucshon. Thank you, Madam Chairwoman. I yield
2880 back.

2881 *Ms. Eshoo. The gentleman yields back. The chair is
2882 pleased to recognize the gentlewoman from New Hampshire, Ms.
2883 Kuster, to be followed by the gentleman from Missouri, Mr.
2884 Long.

2885 Annie, you are on.

2886 *Ms. Kuster. Thank you so much, Madam Chair. This is a
2887 very important discussion, and I want to thank the witnesses,
2888 especially my very, very dear friend and colleague, Rick
2889 Nolan, for joining us here today.

2890 While this committee has been keenly focused on the
2891 COVID-19 pandemic, we must continue to support and invest in

2892 programs that protect our children and families. We have all
2893 heard the startling statistics of delays in routine health
2894 care during COVID, and there are simply too many Americans,
2895 including, I might add, my own brother, who recently
2896 postponed screenings and surgeries, only to later discover
2897 they may have much more serious health care conditions.
2898 We have also discussed in the Oversight and
2899 Investigation Subcommittee the enormous impact the pandemic
2900 is having on our children, and I recently raised the issue
2901 with -- of adolescent mental health during a visit to
2902 Mountain Valley Treatment Center in my district in
2903 Plainfield, New Hampshire. It was incredible to hear
2904 directly from these teens about the mental health challenges
2905 that they are facing, and I am pleased that today's hearing
2906 includes the CAMRA Act, which would have the National
2907 Institutes of Health research the effects of technology and
2908 media on infants, children, and adolescent health and
2909 development.
2910 We need to better understand the effects of digital
2911 media on our children's well-being, and I am a proud
2912 cosponsor of this legislation, as well as the CAROL Act,
2913 which would expand research on valvular heart disease and
2914 treatment. Many Americans, particularly women, suffer from
2915 valvular heart disease, and they do not know that they are at
2916 serious risk. So we need better public health outreach and

2917 data to address the gaps in understanding, especially for
2918 women, people of color, and those living in rural areas like
2919 my district.

2920 Dr. Jones, could you elaborate on how valvular heart
2921 disease and its related complications, despite requiring
2922 minimal intervention, can become fatal?

2923 *Dr. Lloyd-Jones. Certainly, thank you so much,
2924 Congresswoman.

2925 So we are talking today really about chronic valvular
2926 heart diseases, and they come in two subtypes. There is
2927 either narrowing or scarring of a valve we call stenosis, or
2928 there is leakiness of a valve we call regurgitation. But
2929 really, at the end of the day, both of these lead to a kind
2930 of a final common pathway, where the heart tends to enlarge,
2931 the pump weakens, and that leads to the development of heart
2932 failure symptoms: congestion, development of shortness of
2933 breath, retention, and fluid. And when severe enough, that
2934 leads to rhythm disturbances that can cause sudden cardiac
2935 death.

2936 So because of these processes, it is incredibly
2937 important, just as with cancer, that we catch these processes
2938 early, and that really requires routine screening -- again
2939 with the stethoscope. But also, if there is any suspicion of
2940 a valvular heart problem, that we do echocardiography or
2941 ultrasound to be able to detect both the presence and the

2942 severity of valvular heart disease.

2943 *Ms. Kuster. And what role do health disparities due to
2944 gender, race, or socioeconomic status play in increasing the
2945 risk for fatal heart valvular disease?

2946 *Dr. Lloyd-Jones. Well, there are really no known major
2947 genetic or sociocultural differences that sort of lead to
2948 disparities. So I will come back to the issues of -- really,
2949 of access to health care.

2950 It is really that access problem that means people are
2951 getting diagnosed only when they have symptoms, after the
2952 heart has been damaged too significantly to actually be able
2953 to reverse that damage and avoid some of the complications
2954 and, potentially, deaths that are related to it. So much of
2955 what drives those disparities is the underlying risk factors
2956 for heart disease: high blood pressure, diabetes,
2957 cholesterol problems, and smoking.

2958 So if we can address those things, those upstream
2959 determinants, it will also help with valvular heart disease,
2960 as well. But of course, there are major health disparities
2961 in all of those things, as well.

2962 *Ms. Kuster. And is there a factor related to gender?
2963 I know that women seem to be particularly at risk.

2964 *Dr. Lloyd-Jones. Yes, there are some issues with
2965 gender related to valvular heart disease, and also in some of
2966 the consequences, like sudden cardiac death, where women may

2967 be more susceptible. So, you know, I think that encouraging
2968 women to get this as part of their routine screening, make
2969 sure that someone is paying attention to their heart and
2970 their heart valve, is incredibly important.

2971 We know that only recently fewer women now are dying of
2972 heart disease than men, but still far too many, and over
2973 400,000 women per year dying of heart disease. Much of that,
2974 80 to 90 percent, would be preventable with good, routine
2975 screening and care.

2976 *Ms. Kuster. So I will just close by saying that is why
2977 it is so important for us to provide access to affordable
2978 health care to every American, including those in states like
2979 Florida and Texas, large states with large populations that
2980 did not increase their rolls under the Medicaid expansion.
2981 And that is why we want to include that in the Build Back
2982 Better.

2983 So I thank you, and I yield back.

2984 *Ms. Eshoo. The gentlewoman -- let's see. Oh, the
2985 chair is pleased to recognize the very patient, wonderful
2986 member from Missouri, Mr. Long, for your five minutes of
2987 questions.

2988 *Mr. Long. Thank you, Madam Chair.

2989 And Rick, I would like to start with you. Are you
2990 familiar with Philip Francis Thomas?

2991 *Mr. Nolan. With who?

2992 *Mr. Long. Philip Francis Thomas.

2993 *Mr. Nolan. No, I am not.

2994 *Mr. Long. Philip Francis Thomas was a congressman in
2995 Washington, D.C., and he had a small gap in his service of 34
2996 years, from 1841 to 1875, 34 years. So he is number one.
2997 Who would you think number two is that had a 32-year gap in
2998 their service in Congress?

2999 *Mr. Nolan. Yes, mine was 32 years.

3000 *Mr. Long. Huh?

3001 *Mr. Nolan. Mine -- my gap was –

3002 *Mr. Long. Can you take your mask off, so I can see
3003 what you are saying?

3004 *Mr. Nolan. I guess I am number two, huh?

3005 *Mr. Long. Yes, but -- yes, I just wanted to point that
3006 out to the folks that are seeing this, that you were in
3007 Congress, and then had a little minor 32-year gap, and came
3008 back to Congress the same year that I came in. And it is
3009 very good to see you again.

3010 *Mr. Nolan. Oh, thank you. I enjoyed serving with you.
3011 It was great.

3012 *Mr. Long. And this is a very important hearing that we
3013 are having here today.

3014 And particularly near and dear to my heart, our youngest
3015 daughter was diagnosed with Hodgkin's lymphoma six-and-a-
3016 half, seven years ago, and we thought we were going to lose

3017 her, knew nothing about the disease, and I couldn't talk to
3018 anybody, I couldn't pick up the phone, I couldn't talk to
3019 friend or foe for a couple of weeks when she was first
3020 diagnosed. And I am proud to report that she is six years
3021 past her last chemo treatment, actually got married last
3022 October. And so this is -- and then our older daughter is a
3023 pediatrician, so she deals with a lot of these situations,
3024 especially on the children and things.
3025 And I am also a member of the Black Maternal Mortality
3026 Caucus. We had one of the most heart-wrenching testimonies
3027 ever delivered in this hearing room a couple of years ago by
3028 a fellow that lost his wife during a pre-planned C-section.
3029 And they just -- she was having issues, and they actually
3030 came in and told her that she was not a priority, and he was
3031 begging for her life for a 16, 18-hour period, and she
3032 deceased with her second child, like I said, in a planned C-
3033 section. So I know what the mortality rate is like with
3034 Black women, and it is not acceptable, and I hope to be able
3035 to do something. And I have been on that caucus for a couple
3036 of years now.
3037 Dr. Lloyd-Jones, there is really an untold story about
3038 how COVID took a toll on people, and it is not always
3039 reflected in the numbers. COVID and shutdowns disrupted
3040 normal health care for months, and many people were simply
3041 not able to receive normal treatments. If it was a non-

3042 critical treatment, or if it was a routine procedure, the
3043 hospitals were not allowed to do it. And sadly, that
3044 adversely affected Andy Barr's family, his wife, Carol, who
3045 we have been talking about here today.

3046 She -- I was on the House floor one day, and Andy came
3047 up to me, and he had his cell phone out, and he said, "Read
3048 this, Billy, read this,'' and it -- he had just received the
3049 notes from his wife's doctor. He came home -- 37 years old,
3050 I believe she was 37, 39 -- and was deceased after he came
3051 home from a meeting. And two beautiful young daughters that
3052 Andy is raising now. But he said, "Read this,'' and I read
3053 his cell phone, and it was the notes his doctor had written,
3054 and they said that "echo after virus subsides.''

3055 Well, the virus didn't subside, and Carol subsided
3056 before -- so they couldn't do an echocardiogram because it
3057 was not considered a critical procedure that would have
3058 probably, most likely, have saved her life. And so I am a
3059 proud cosponsor of the CAROL Act, introduced by Andy Barr, my
3060 buddy from Kentucky.

3061 And Dr. Lloyd-Jones, we still don't know a lot about
3062 heart valve disease causes, and the factors that increase
3063 risk for sudden cardiac death. Obviously, that is the reason
3064 why this bill is so important. Can you talk about the
3065 workshop that this bill creates, what its goals are, and how
3066 the findings of the workshop are translated to results at the

3067 National Institute of Health, and the National Heart, Lung,
3068 and Blood Institute?

3069 *Dr. Lloyd-Jones. Thank you, Congressman, and thank you
3070 for sharing that story. I think it is tragic, and really
3071 important that we get our patients back into care as quickly
3072 as possible.

3073 So that NIH uses workshops as very important fact-
3074 finding opportunities. And I have been a member of a number
3075 of these for the NHLBI. But it is really an opportunity to
3076 bring together experts in the field, researchers, even
3077 industry and other public-private partners, to make sure we
3078 understand all aspects of a situation, and that then NHLBI
3079 can use -- or NIH can use -- that information to actually
3080 design calls for research and grant applications, so that we
3081 are really targeting the most important aspects of whatever
3082 the disease of interest is.

3083 In this case, you are absolutely right. We need to know
3084 much more about the causes, the reasons for progression, and
3085 the link to sudden cardiac death related to valvular heart
3086 disease.

3087 *Mr. Long. Okay, thank you. And unfortunately, I am
3088 out of time with all my gift of gab beforehand.

3089 So Madam Chair, I yield back.

3090 *Ms. Eshoo. And we enjoy all of it, Mr. Long. You add
3091 a great deal of interest to our committee. You really do.

3092 The chair is pleased to recognize the gentlewoman from
3093 Illinois, Ms. Kelly, for her five minutes of questions.
3094 *Ms. Kelly. Thank you, Chairwoman Eshoo and Ranking
3095 Member Guthrie, for holding this important hearing. Today we
3096 are focusing on legislation that impacts a wide range of
3097 diseases.
3098 While it is important to increase research funding for
3099 cancer and other diseases to identify new treatments, we also
3100 need to ensure that clinical trials are reflective of racial
3101 disparities and disease. According to the Prostate Cancer
3102 Foundation, Black men are 75 percent more likely to develop
3103 prostate cancer, and more than twice as likely to die of it,
3104 compared to other racial groups. Yet, according to the NIH,
3105 the median percentage of Black participants in prostate
3106 cancer clinical trials funded in fiscal year 2018 was only 8
3107 percent.
3108 Dr. DuBois, how can public research funders, such as the
3109 NIH, hold clinical trial sponsors accountable for increasing
3110 the diversity in clinical trials?
3111 *Dr. DuBois. Thank you for that question. Can you hear
3112 me okay?
3113 *Ms. Kelly. Yes.
3114 *Dr. DuBois. Good. Well, this is a big problem. And
3115 one of the things the NIH has done through the NCI is to
3116 establish these community oncology outreach efforts, where we

3117 have community oncology groups that actually do participate
3118 in clinical trials.
3119 We have five of these sites in South Carolina, and that
3120 -- if we have those trials available in the communities where
3121 most of these people live, there is a much higher likelihood
3122 that they are going to participate. And so we have been able
3123 to increase the percentage of minorities in many of the
3124 trials, and it is really in the outreach effort that we are
3125 doing in those local communities.
3126 I think we really need to -- program, because we are
3127 also missing out on other community groups that -- where
3128 patients just can't get to major urban areas where a lot of
3129 those trials are being held. And the -- so I think more
3130 support for this program would be wonderful, and improve
3131 participation from those groups.
3132 *Ms. Kelly. Thank you. Would there be any benefit to
3133 empowering NIH with greater authority to work with clinical
3134 trial sponsors to establish clear, measurable diversity goals
3135 in the funding application?
3136 *Dr. DuBois. I think that is a great idea. And, you
3137 know, they do look at that in some applications. It is not
3138 as -- probably as stringent as it should be. But I think
3139 that that is something that could be –
3140 [Audio malfunction.]
3141 *Ms. Kelly. Thank you. We do need to increase

3142 accountability to make sure that all clinical trials are --
3143 racial and ethnic disparities and diseases. This is why I am
3144 working on a clinical trial diversity bill with my E&C
3145 colleagues Representative Cardenas, Butterfield, and Clark.
3146 And we look forward to working with the committee to advance
3147 this important issue.

3148 Ms. Stewart, good to see you. In your statement you
3149 mentioned the importance of increasing access to prenatal and
3150 postpartum care. Can you speak to the role that extending
3151 Medicaid postpartum coverage to one year can play in reducing
3152 racial disparities in maternal health outcomes?

3153 *Ms. Stewart. Good to see you, Congresswoman. Yes, we
3154 have been a big advocate of extending Medicaid postpartum at
3155 least 12 months. It is -- we have made some progress towards
3156 that, where it is now an option for some states to do that.
3157 But we feel it shouldn't be an option, it should be
3158 mandatory.

3159 And the reason for that is because, when you look at
3160 maternal deaths, between pregnancy at the time of childbirth
3161 and then after childbirth, about a third of all maternal
3162 deaths happen in that stage one week beyond when the baby is
3163 born out to one year. And that is when women need care just
3164 as much as they do when they are pregnant, just as much as
3165 they do when they are delivering their baby.

3166 We know that a lot of women are suffering with mental

3167 health challenges. They may have extenuating health
3168 challenges that may have developed during pregnancy or at the
3169 time of childbirth, and they need to be seen by a care
3170 provider. And because Medicaid covers 40 percent of all the
3171 births in the country, and because so many women of color are
3172 a part of that coverage, we know that it can go a long way to
3173 helping to eliminate and reduce the disparities that we see
3174 between Black maternal health, Brown maternal health, and
3175 other groups, as well.

3176 *Ms. Kelly. Well, I would like to thank you and commend
3177 the March of Dimes for your work to address maternal
3178 mortality. And you know that I am out here fighting to do
3179 exactly what you said is needed. So thank you so much, and I
3180 yield back.

3181 *Ms. Eshoo. The gentlewoman yields back. It is a
3182 pleasure to recognize the gentleman from Oklahoma, Mr.
3183 Mullin. And then, coming up, followed by Blunt Rochester
3184 from Delaware, followed by Mr. Carter from Georgia. I think
3185 that is the lineup. I know that we have votes scheduled, I
3186 think, at about 1:45. So let's see if we can make it before
3187 the votes are called. Okay?

3188 So Mr. Mullin.

3189 *Mr. Mullin. Thank you, Ms. Chairwoman, I appreciate
3190 it, and thank you for holding this hearing.

3191 Ms. Stewart, with the United States ranked 25th in the

3192 number of stillbirths per capita, why do you think these
3193 rates remain unchanged, despite medical innovations?
3194 And what interventions do you think other countries have
3195 done that we aren't that has lowered their stillbirth rates?
3196 *Ms. Stewart. Thank you, Congressman. I think it is a
3197 very good question.
3198 I mean, yes, we have seen stillborn rates where, today,
3199 24,000 babies by -- die as a result of stillbirth. And that
3200 rate has -- that number has not really improved. In fact,
3201 when you look at other countries, we are ranked 183rd out of
3202 195 countries, in terms of reduction of stillbirth rates over
3203 the last two decades. So we have a lot of work to do.
3204 When you look at other countries, they have implemented
3205 successfully -- for example, in Australia -- some impressive
3206 care bundles that look at issues around early detection of
3207 fetal growth restriction, smoking cessation -- which we
3208 actually do focus on a lot in this country -- decreased fetal
3209 movement, safe sleeping practices for moms, some side
3210 sleeping practices, making sure that babies are avoiding
3211 early C-sections so that they are not born early.
3212 You know, one of the things that we have to do is just
3213 have a more comprehensive approach to maternal care, and I
3214 think a lot of the gaps in our system of care, again, these
3215 maternal care deserts that I talked about, the lack of access
3216 to care, if you don't have insurance, or if you just don't

3217 even live near a care provider are all contributing to the
3218 high rates of stillbirth. And because we have not made
3219 comprehensive improvements in maternal care in this country
3220 is also why we have not seen much improvement in stillbirth.
3221 Even though we have seen increases in NICU care, where we
3222 have seen technology and medical care actually extend life, a
3223 baby's, in the NICU, we have not seen that same kind of
3224 advancement with stillbirth.

3225 *Mr. Mullin. Thank you. How important is adequate
3226 data, then, to fight this, to fight against stillbirths?

3227 *Ms. Stewart. Sorry, I just want to make sure -- how
3228 important is adequate –

3229 *Mr. Mullin. Yes, when you start looking at data, what
3230 is -- what do you feel about --

3231 *Ms. Stewart. Yes.

3232 *Mr. Mullin. I mean, there doesn't seem to be --

3233 *Ms. Stewart. Yes.

3234 *Mr. Mullin. -- that good of information out there when
3235 we start talking about data. And so, when we are looking at
3236 fighting the stillbirth -- I would almost say a pandemic, but
3237 it is not really, but, you know, the serious issues we are
3238 dealing with there, when we are looking at it, how important
3239 is that data?

3240 *Ms. Stewart. So it is really important.

3241 One of the things that we know, when a stillbirth

3242 occurs, is that it may be noted on the death certificate, but
3243 that doesn't explain the full reason, or the --
3244 *Mr. Mullin. Right.
3245 *Ms. Stewart. -- all of the underlying issues that may
3246 have led to the stillbirth.
3247 And in fact, some tests that would determine that
3248 actually are made available sometimes weeks after the death
3249 certificate is actually filed. And so we haven't been
3250 actually collecting all of the best data around stillbirth.
3251 And so what the SHINE for Autumn Act will hopefully do
3252 is to provide more resources so that we can do a much better
3253 job of research and data collection to understand, first, the
3254 underlying causes of stillbirth, which we need to do more of
3255 that around preterm birth, and miscarriage, and all of that,
3256 as well, but also better data collection around stillbirth,
3257 so we can design better interventions.
3258 We saw this same kind of progress made that we made with
3259 maternal mortality when we -- when Congress passed
3260 legislation that would allow for maternal mortality review
3261 committees. Collecting better data allowed us to identify
3262 better underlying causes of maternal death, leading to better
3263 interventions. The same needs to be true for stillbirth, as
3264 well, and that is what we hope the SHINE for Autumn Act will
3265 do.
3266 *Mr. Mullin. Well, thank you. Thank you so much,

3267 because you answered all my other questions while you were
3268 answering that question, and I really appreciate it.
3269 In closing, I just want to second what Mr. Butterfield
3270 said earlier. He made a suggestion that we look at the
3271 Better Wound Care Act at home, and maybe look at doing an
3272 upcoming hearing on this. I, Madam Chair, I would like to
3273 say I would like to second that, because it is an important
3274 policy that is good for patients. And hopefully, I look
3275 forward to advancing this through our -- through the
3276 committee.
3277 With that, I yield back.
3278 *Ms. Eshoo. Thank you, Mr. Mullin. So noted. Thank
3279 you.
3280 The chair now recognizes the gentleman from California,
3281 Dr. Ruiz, for his five minutes of questions.
3282 *Mr. Ruiz. Thank you. Thank you very much. This is a
3283 very important hearing.
3284 The COVID-19 pandemic has illuminated health equity
3285 issues that we have long known to be the norm in the United
3286 States. One disease that continues to disproportionately
3287 impact minorities or -- is cancer, with unacceptably high
3288 death rates and unequal late stage diagnoses.
3289 New multi-cancer early detection tests and development
3290 have the potential to detect many cancers simultaneously,
3291 including cancers without screening tests today, and those

3292 that disproportionately impact underserved populations.

3293 While access barriers to health care services including
3294 prevention have improved over time, there is still much work
3295 to do. Technologies like multi-cancer early detection tests
3296 could reduce late-stage diagnoses by catching cancers earlier
3297 and saving lives. That is why I have joined my colleague,
3298 Congresswoman Sewell, to introduce H.R. 1946, the Medicare
3299 Multi-Cancer Early Detection Screening Coverage Act, which
3300 would provide a possible future pathway for Medicare coverage
3301 of these lifesaving technologies.

3302 While this bill is not under consideration today, I urge
3303 the committee to consider advancing this bill, supported by a
3304 consensus of cancer care stakeholders and over 90 bipartisan
3305 members.

3306 So now onto the legislation at hand. Oral health is
3307 physical health, but too often people neglect their oral
3308 health, whether that is because they don't have access to a
3309 provider, or because they can't afford to see a dentist, or
3310 because they don't realize how critical oral health is. That
3311 is why I really want to highlight the bill introduced by my
3312 colleagues, Mr. Cardenas and Bilirakis, the Oral Health
3313 Literacy and Awareness Act of 2021, which will increase
3314 public education for oral health literacy and awareness.

3315 We know that there are oral health disparities by race
3316 and by income. According to the CDC, for children aged 12 to

3317 19, nearly 70 percent of Mexican-American children have had
3318 cavities in their permanent teeth, compared with 54 percent
3319 of non-Hispanic White children. So for that same age group,
3320 23 percent of children from lower-income families have
3321 untreated cavities in their permanent teeth, twice that of
3322 children from higher-income households.

3323 So, Dr. Cassis, can you speak to some of the disparities
3324 that exist in oral health, and how this bill might help
3325 address those disparities?

3326 *Dr. Cassis. The bill helps in educating. We are so
3327 far behind in how we communicate with minorities and, really,
3328 everybody.

3329 I would like to point out that, pre-pandemic, the --
3330 dentistry was in a good place. You know, we have the best
3331 infection control ever, since the 1980s. And after our
3332 mandatory shutdown, we came back busier than ever, and it
3333 hasn't let up. And what I would like to tell the whole
3334 community is that we see more minorities or underprivileged
3335 patients now than we ever have. So some of that has come out
3336 that, you know, it is safe to go to the dentist. And I would
3337 tell you, absolutely, if you are following the OSHA
3338 guidelines, we are in a great position for that.

3339 However, the bill itself will go so far into getting
3340 more minorities into the dental offices around the country.
3341 It is something I would highly endorse, and would beg the

3342 committee to consider keeping that funding in place.

3343 *Mr. Ruiz. In addition to that we need more dental
3344 offices in minority communities, or in the medically
3345 underserved areas of our country. There is -- so, you know,
3346 it is -- this is one piece of a larger puzzle, a very
3347 important piece.

3348 *Dr. Cassis. Yes.

3349 *Mr. Ruiz. If there is a cost-effective way of
3350 improving health, it is to increase health literacy. In this
3351 case, increasing oral health literacy is vital, and very
3352 important in people to understand not only just the
3353 importance, but the practical way to care for their oral
3354 health, and to really make that association that your oral
3355 health is -- has a direct connection to your cardiac health.
3356 It has a direct connection to your other systems, organ
3357 systems. And so that is why it is so important to really put
3358 that in the forefront, as well.

3359 So with that, I yield back my time, and I thank you for
3360 your work, and bringing attention to this.

3361 And again, I thank my colleagues, Congressmen Cardenas
3362 and Bilirakis, for putting this bill forward.

3363 *Ms. Eshoo. The gentleman yields back. The chair is
3364 pleased to recognize the gentleman from Georgia, Mr. Carter,
3365 for your five minutes of questions.

3366 *Mr. Carter. Thank you, and thank all of you for being

3367 here.

3368 Congressman, good to see you.

3369 I wanted to ask Dr. Radesky and Ms. Stewart -- I will
3370 ask you separately. But first of all, let me say, as you all
3371 know, the National Center on Birth Defects and Developmental
3372 Disabilities, this Center works to detect, to prevent, and
3373 also to research birth defects and intellectual disabilities.
3374 And that is why I feel like it is crucial that we work and
3375 pass my legislation that we are discussing today, the
3376 Improving the Health of Children Act. This would reauthorize
3377 this center for the first time since 2007, and I think it is
3378 extremely important that they would -- that we do that.

3379 Ms. Stewart, I will ask you first, why is it so
3380 important to have early diagnosis for birth defects and
3381 intellectual disabilities?

3382 *Ms. Stewart. Thank you, Congressman. Well, birth
3383 defects are common, and they are also costly, and it is
3384 critical that we provide early detection and early treatment
3385 for babies.

3386 We have been a strong advocate at March of Dimes for
3387 newborn screening for many, many years, and we have been
3388 working in partnership with the National Center on a lot of
3389 these issues around birth defects. There are close to eight
3390 million babies worldwide that suffer from a serious birth
3391 defect, and more than three million of them die before the

3392 age of five.

3393 So -- and there are a range of different birth defects
3394 that babies are sometimes dealing with in newborn babies, and
3395 the screening has to happen very, very, very quickly, in many
3396 cases.

3397 Developmental disabilities, as you mentioned, around
3398 autism. The Center has done an amazing job to really advance
3399 the research around the causes of autism, as an example.

3400 Many families that suffer with blood disorders,
3401 especially, for example, in the African American community
3402 around sickle cell, the Center has done an incredible job of
3403 advancing success there.

3404 And then it is not just babies with disabilities. When
3405 we identify those disabilities early in life, people are then
3406 dealing with those disabilities over a long period of time.
3407 And so the Center has also been there to make sure that
3408 health care and programs are available for people to sustain
3409 them, to keep them active in life, and providing the care
3410 that they need to have an improved quality of life over a
3411 long period of time.

3412 *Mr. Carter. Right. So you would agree the Center does
3413 need to be reauthorized?

3414 *Ms. Stewart. Oh, no question about it.

3415 *Mr. Carter. Okay. Dr. Radesky, let me ask you. The
3416 Center itself, do you feel like parents of newborns and --

3417 with disabilities have easy and readily accessible access to
3418 the resources of the Center?
3419 *Dr. Radesky. You know, I am not sure I am qualified to
3420 answer that question. I can speak to my clinical experience
3421 with families of children with developmental disabilities in
3422 general find it very challenging to access resources
3423 throughout the community, whether provided through private or
3424 public sources. I just think -- I don't know specifically
3425 about the Center in question.
3426 *Mr. Carter. But you are saying your experiences are
3427 that, in general, there is a problem with accessing any of
3428 the centers, or any of the available options for these
3429 parents?
3430 *Dr. Radesky. It varies, depending on the family's
3431 health insurance, and what is authorized in terms of
3432 treatments for things like autism or other developmental
3433 delays.
3434 Another factor is socioeconomic status, or health
3435 literacy, and other material hardships that impact a family's
3436 ability to, say, get transportation for early intervention
3437 for therapies.
3438 And also, just the fact that it is intimidating to
3439 coordinate and navigate all of these different therapies for
3440 your child, that I think some families feel very engaged and
3441 activated for, and other families find it confusing,

3442 overwhelming, and have a hard time engaging.

3443 *Mr. Carter. Well, I appreciate your input on that,
3444 because I consider you to be boots on the ground, if you
3445 will.

3446 And Ms. Stewart, what can we do to improve this? What
3447 do you think the solution is, with the situation like she is
3448 describing?

3449 *Ms. Stewart. Well, I think she is right in that every
3450 state it varies, and every community varies, in terms of the
3451 access of actual resources on the ground. I think what she
3452 is referring to are follow-up with experts, and with
3453 specialists, and others who can help in addressing those
3454 developmental disabilities. So there is a range of care.

3455 What the Center really does is help to provide a lot of
3456 the surveillance, and the data collection, and the
3457 understanding of what kinds of birth defects and other kinds
3458 of health issues can be -- that can be screened at the time
3459 of birth. But there has to be a better way of connecting
3460 that to the health care system and more resources, especially
3461 in low-resource communities, so that it can access the care
3462 that they need, whether that is at home or –

3463 *Mr. Carter. So how do you do that? I mean, do you
3464 educate the caregivers? Do you educate the -- not
3465 caregivers, but the health care professionals, the doctors
3466 and the nurses?

3467 *Ms. Stewart. I think it is not only them, but you have
3468 to educate family members, and you have to educate community
3469 members, school members. A lot of people don't know how to
3470 address these special needs, and without the level of
3471 awareness and the education that is needed -- and, frankly,
3472 the funding that many families need if they don't have access
3473 to high-quality health care, they need additional resources
3474 to access the care that they may be looking for.

3475 *Mr. Carter. Great. My time has expired. Thank you
3476 all for being here today, and I yield back.

3477 *Ms. Eshoo. The gentleman yields back.

3478 Now I need some assist from our staff, because we have a
3479 series of eight votes that are on the floor right now.
3480 Should we take a --

3481 *Voice. So take Ms. Barragan and go into recess.

3482 *Ms. Eshoo. Okay, so the chair is going to recognize
3483 the gentlewoman from California, Ms. Barragan, for her five
3484 minutes of questions. Then we will recess and, I think, have
3485 someone else -- will someone -- oh, we are going to have to
3486 recess because of eight votes on the floor, and there are
3487 still members that are -- that haven't had the --

3488 *Voice. So we will take a two-hour.

3489 *Ms. Eshoo. We are going to take a two-hour break. You
3490 probably -- all the witnesses need a break. I am sorry that
3491 we have to do it this way, but it is a compliment to each one

3492 of you that we have had such wonderful participation of
3493 committee members today, and that is what we want.
3494 So let's hear from or recognize the gentlewoman from
3495 California, Ms. Barragan, for your five minutes of questions,
3496 and then we will recess.
3497 *Ms. Barragan. Thank you, Chairwoman Eshoo, for holding
3498 this important hearing today on legislation that will advance
3499 scientific research, improve our public health system, and
3500 expand access to care for so many families across the nation.
3501 Maternal mental health conditions are a significant
3502 barrier for the health and well-being of women. In my home
3503 state of California, one in five California women suffer from
3504 depression, anxiety, or both while pregnant or after giving
3505 birth. Despite this high prevalence, 75 percent of impacted
3506 mothers never received treatment.
3507 In addition, Black mothers are twice -- two times more
3508 likely, and Latina mothers are one-and-a-half times more
3509 likely than White mothers to develop depression during and
3510 after pregnancy.
3511 Ms. Stewart, how should maternity care, mental health
3512 care, and pediatric health systems work together to ensure
3513 the health and well-being of both the mother and child?
3514 *Ms. Stewart. Thank you, Congresswoman. And the fact
3515 that we pay so much attention to maternal health care from a
3516 physical point of view really doesn't give the most attention

3517 that we need to pay to maternal mental health, which are the
3518 issues that you are dealing -- that you are addressing, and
3519 you are raising, and we are grateful that you are, and your
3520 leadership on these issues.

3521 Maternal mental health challenges are some of the
3522 biggest challenges that many women face during pregnancy and
3523 after pregnancy. We know very, very much the issues of
3524 postpartum depression. A lot of people don't know -- again,
3525 I think I mentioned earlier -- that maternal mental health is
3526 often one of the leading causes of death for women between --
3527 after giving birth to their child.

3528 And we are grateful that there have been some expanded
3529 resources. For example, there is now a maternal mental
3530 health hotline that the March of Dimes advocated for. The
3531 grant was just awarded by HRSA. That is a huge step forward,
3532 but we need to do more.

3533 We have been strong -- given a strong endorsement for
3534 the creation of a federal task force on maternal mental
3535 health through the Triumph for New Moms Act of 2021.

3536 We also are very supportive in the Momnibus of the Moms
3537 Matter Act, which is currently being reviewed by this
3538 committee, and it would also invest critical resources in
3539 maternal mental health, as well.

3540 So one of the things that you mentioned is how stress
3541 and anxiety have an impact on maternal health outcomes and

3542 birth outcomes. That is especially true in communities of
3543 color that are dealing with the issues of stress and anxiety,
3544 often brought on by the racism and discrimination that they
3545 experience in their own lives, especially in the course of
3546 bringing a baby into the world. So the issue of focusing on
3547 maternal mental health is really critical, and we strongly
3548 support all the efforts to improve and create more resources
3549 to address the issue, especially for women of color.
3550 *Ms. Barragan. Well, thank you, Ms. Stewart, for your
3551 important testimony on this subject, for mentioning my bill.
3552 Certainly, given the significant impact of our families, I
3553 hope that the committee will consider my bipartisan Triumph
3554 for New Moms Act and other maternal mental health bills in
3555 the near future.
3556 Ms. Stewart, this next question is also for you. Lead
3557 in older homes remains a persistent problem for families
3558 across South Los Angeles. Roughly 2,000 children are
3559 diagnosed with unsafe levels of lead in their blood each year
3560 in Los Angeles County alone, particularly for communities of
3561 color, where costs are a major barrier to access health care.
3562 Families are often unaware their homes could be a source of
3563 lead until the children are tested.
3564 Ms. Stewart, often times federal outreach and education
3565 programs use language that is overly technical, or does not
3566 resonate with the intended audience. Can you discuss why a

3567 federal advisory committee on childhood lead poisoning should
3568 provide culturally and linguistically appropriate outreach to
3569 communities of color to reduce the risk of childhood lead
3570 poisoning?

3571 *Ms. Stewart. Well, thank you, and I am aware of the
3572 recent issues in communities of color in Los Angeles with
3573 respect to -- especially in the southern part of the city,
3574 with respect to children being -- testing positive for high
3575 blood levels. And it just reinforces the importance of
3576 passing the Lead Poisoning Prevention Act to invest more in
3577 resources and education outreach, referrals, and screenings
3578 for children that are testing positive for lead in their
3579 blood.

3580 It is also really important -- and we have seen this in
3581 the pandemic -- that the way in which we provide information
3582 to communities of color has to be culturally appropriate. It
3583 has to be done in conjunction with those communities, so that
3584 it addresses language barriers, it addresses other barriers,
3585 and it especially addresses the trust barriers that exist in
3586 communities of color, as well.

3587 So we would strongly recommend that all of the education
3588 outreach that happens be done in conjunction with those
3589 communities, so that communities can receive it, understand
3590 how to use that information, and appropriately address the
3591 needs that their children may be having, especially if they

3592 are affected by high blood levels of lead.

3593 *Ms. Barragan. Thank you, Ms. Stewart --

3594 *Ms. Eshoo. The gentlewoman's time has expired, and

3595 your comments about your legislation, so noted.

3596 *Ms. Barragan. Thank you.

3597 *Ms. Eshoo. -- Congresswoman Barragan. I am going to

3598 stay, because Mr. Curtis has been here since the beginning of

3599 the hearing this morning, and I want to call on him for his

3600 five minutes of questions, and then we will take a break.

3601 Mr. Curtis, thank you for your patience, and being here

3602 for the entirety, and you are on.

3603 *Mr. Curtis. Madam Chair, you are too gracious, and I

3604 will go quick, because we don't want you to miss the vote.

3605 *Ms. Eshoo. No, that is -- go ahead. We will make it.

3606 *Mr. Curtis. And to our witnesses, we will all shorten

3607 our answers, if we can do this quickly.

3608 First of all, Madam Chair, thank you. It has been clear

3609 that this is an important hearing. I would just point out I

3610 do have a bill. It is the Fix Nondisclosure in Health

3611 Research Act [sic] that I hope we can include in future

3612 hearings. I would have loved it to be included in this.

3613 In short, it requires the NIH to report to Congress on

3614 funded research grantees that have ties to foreign

3615 governments.

3616 Ms. Stewart, maternal health care is important, and it

3617 is a priority for me, as for so many here, specifically
3618 helping moms who are also suffering from substance use
3619 disorder. And I heard you talk about a number of conditions,
3620 but if maybe we could just touch on that one just a minute, I
3621 authorized legislation that required the Centers for Disease
3622 Control and Prevention to study the causes of opioid
3623 substance use disorder in pregnant and postpartum women, and
3624 that was the POPPY Seed Act [sic].

3625 Have we improved outcomes for those expecting mothers
3626 and postmortem moms dealing with substance abuse disorders?

3627 *Ms. Stewart. Well, I think there is, you know --
3628 obviously, the opioid crisis has had a severe impact on
3629 maternal health outcomes, infant health outcomes. You know,
3630 we have seen a dramatic increase in the number of babies that
3631 are affected by Neonatal Abstinence Syndrome. It is really a
3632 huge issue that we are facing.

3633 We have been a strong supporter of making sure, one,
3634 that we don't penalize women who are suffering from substance
3635 use disorder, that we find them treatment if they are
3636 pregnant or if they are a new mom. And also, making sure
3637 that we identify those babies who are suffering from NAS and
3638 really need additional treatment, as well.

3639 *Mr. Curtis. You think the pandemic has hurt our
3640 efforts? And is there anything specifically you can think of
3641 that you would like Congress to do?

3642 *Ms. Stewart. I think there is no question the pandemic
3643 has created even more of a stress on the system, with respect
3644 to mental health overall, and that has shown up in the ways
3645 in which the opioid crisis, even though we aren't -- we are
3646 not paying attention to it as much as we are the pandemic, it
3647 is still raging in this country, and it is affecting many,
3648 many families. It is affecting pregnant women.
3649 We strongly advocate to do more to make sure that women
3650 are able to get the treatment and the help they need as soon
3651 as they are able to, that they are able to stay in treatment,
3652 because it is going to protect their lives and their babies,
3653 as well.
3654 *Mr. Curtis. Thank you very much. Quickly, Dr. Jones,
3655 I am curious if we should be looking at preventive measures
3656 in addition to the steps you outlined in your testimony to
3657 reduce chronic heart disease in the United States. For
3658 example, I introduced legislation that would make it easier
3659 for small group plans and individual marketplace plans to
3660 invest in social determinants of health services, including
3661 offering, for instance, gym memberships as a benefit.
3662 Could you quickly explain if this would be helpful in
3663 addressing some of these chronic conditions?
3664 *Dr. Lloyd-Jones. Yes, absolutely. As you are
3665 implying, you know, cardiovascular disease remains our
3666 leading cause of death and disability, not only in this

3667 country, but across the globe. And we know what causes 90
3668 percent of heart disease and stroke, and that is the
3669 traditional risk factors of cholesterol, blood pressure,
3670 diabetes, smoking, overweight, and all the things that
3671 actually happen up upstream, those social determinants of
3672 health that are the causes of the causes.

3673 And so it is really critical that we apply all of our
3674 knowledge about improving social conditions, economic things,
3675 education, social and community context, and especially
3676 health care, so that people have access to all of the tools
3677 that we know can prevent cardiovascular diseases and stroke.

3678 So amen to what you said. We need to do a much, much
3679 better job focusing on prevention. And in fact, it touches
3680 on some of these other things. If we improve the
3681 cardiovascular health of our population, we see dramatically
3682 lower rates of cancer, we see much healthier mothers heading
3683 into pregnancy who don't deliver, unfortunately, either
3684 stillbirths or, you know, have adverse pregnancy outcomes, or
3685 have children who start off on less healthy trajectories. So
3686 this is really the key to driving towards a healthier
3687 population. So very much support anything we can do in this
3688 regard.

3689 *Mr. Curtis. Thank you. The chair has slipped out. I
3690 would like to thank her, even though she is not here, for
3691 extending this for a few minutes, and I appreciate

3692 everybody's patience and quick answers. Madam, I yield my
3693 time.

3694 *Ms. Schrier. [Presiding] The gentleman yields. I will
3695 now recognize myself for five minutes.

3696 Thank you to all the witnesses who are here today, are
3697 hanging in there, and I want to thank the chairwoman, who I
3698 am replacing for the moment, for this focus on children and
3699 families.

3700 There is two bills that I would like to speak on today,
3701 and the first is the Gabriella Miller Kids First Research Act
3702 2.0.

3703 And Mr. and Mrs. Miller, I just want to thank you for
3704 being here today. Your experience with Gabriella is, sadly,
3705 one that far too many other heartbroken parents have also
3706 experienced, as you said in your testimony.

3707 And just yesterday I spoke with the mother of a little
3708 girl named Danica, who was diagnosed with a brain tumor at
3709 age 21 months. And she died, sadly, last year, at just five
3710 years old. And her mom, as she told me her tragic story, and
3711 the family's tragic story, I thought about so many children
3712 with cancer who I have taken care of over 20 years as a
3713 pediatrician, and it is because of them and Danica that I so
3714 strongly support this legislation that will increase funding
3715 for pediatric cancer and rare disease research.

3716 The other bill that I would like to talk about today is

3717 the CAMRA Act, and I really want to thank Dr. Radesky for
3718 being here virtually to talk about the importance of this
3719 research into the impacts that screens and screen time and
3720 social media have on our children.

3721 And so, Dr. Radesky, I first want to appreciate your
3722 highlighting that screen time is far too general a term, and
3723 that there is a difference between a FaceTime chat with
3724 grandma and grandpa and violent video games. And so I was
3725 wondering if you could first describe the family media plan
3726 that you created that helps pediatricians work with families
3727 to incorporate screen time in a healthy and balanced way.

3728 *Dr. Radesky. Yes, I am happy to, thank you. So when
3729 our American Academy of Pediatrics guidelines came out in
3730 2016, we wanted to have more practical ideas for families who
3731 were trying to navigate this Wild West of new technologies.
3732 And we thought that having really actionable ideas delivered
3733 through a kind of tailored, digital format through the Family
3734 Media Use Plan on the HealthyChildren.org website would just
3735 help this be delivered a little bit more easily to families.

3736 We also wanted to encourage conversations that really
3737 get to the heart of when is technology a problem, when is it
3738 interrupting our family connections and our meals, when is it
3739 actually fun to do together, and to tell us stories that make
3740 our lives more meaningful? When are we using it for our
3741 human needs?

3742 And so it represented that sort of balanced
3743 conversation, and we have found that, you know, tens --
3744 hundreds of thousands of families have used it, and we are
3745 actually updating it now, because the research is constantly
3746 changing, the platforms that families are constantly
3747 changing, and we want to continue to be a resource for
3748 families, you know, that is relevant, on the ground,
3749 understanding the everyday tensions around this.
3750 *Ms. Schrier. And I know I appreciate that, as a
3751 pediatrician. No devices in the bedroom, not at the kitchen
3752 table, et cetera. And I was wondering if you could give some
3753 quick answers, just a few words on each of these. Generally
3754 speaking, the effect on social media and video games on
3755 attention spans, specifically in school.
3756 *Dr. Radesky. Yes, there have been a couple of
3757 longitudinal studies. These are important, because they look
3758 at how a child started off, and how things change over time.
3759 And a few of the good ones have shown that the more frequent
3760 checking of social media, the more that children's everyday
3761 activities are fractured into different fragments by media
3762 use, that that does impact attention span, and that it is not
3763 only kids who have pre-existing ADHD.
3764 *Ms. Schrier. Thank you. And I will note, just in the
3765 interest of time, the effect of social media and video games
3766 on sleep, staying up too late, social interactions, the

3767 ability to communicate face to face, also between time spent
3768 on screens, and myopia, and obesity, and learning.
3769 And I -- yesterday I was speaking with one of your
3770 colleagues, Dr. Dimitri Christakis at Seattle Children's, and
3771 he noted that schools are spending a lot of money on buying
3772 devices, computers in the classroom, and that it is really
3773 not clear yet whether that is helpful or not.
3774 And so I would just like to round -- to kind of wrap up
3775 by saying that we need to be really strategic about screen
3776 time and media and our children. And the fact of the matter
3777 is that you are researchers, and you still don't have access
3778 to the data that Big Tech does. And that is why the CAMRA
3779 Act is so important, to make sure that the NIH gets this data
3780 to guide us as pediatricians, teachers, parents on our
3781 children's access and use of social media and screen time.
3782 Thank you, and I yield back. I would like to
3783 recognize --
3784 *Voice. So we don't have any members yet, so I would
3785 say that you can adjourn.
3786 *Ms. Schrier. I will adjourn, and call the -- I will
3787 recess this committee.
3788 [Recess.]
3789 *Ms. Schrier. The hearing will resume. Dr. Joyce has
3790 just arrived.
3791 That is all right, we are happy to have you, Dr. Joyce,

3792 and thrilled to resume the hearing. You have five minutes.
3793 *Mr. Joyce. First of all, I want to thank Dr. Schrier,
3794 my colleague and my friend, for bringing us all together
3795 today, because this is an important slate of bipartisan bills
3796 that we are considering.
3797 I would especially like to note that H.R. 1113, the
3798 CAROL Act, named for the late wife of my friend and my
3799 colleague, Andy Barr, and urge that it be marked up by this
3800 committee as soon as we are able to do so.
3801 Since March of last year, the COVID-19 pandemic has
3802 disrupted and upended lives in many ways that none of us
3803 could have ever imagined. Even with the staggering impact of
3804 this virus on public health, as a physician I remain gravely
3805 concerned about the secondary effects that we will ultimately
3806 and continue to see. As businesses and practices have shut
3807 down, routine cancer screenings, health checkups,
3808 immunizations were delayed and even skipped all together.
3809 The delay in diagnosis of possible cancers and other health
3810 disorders will be something that we will be seeing and living
3811 with in the future.
3812 My first question is to Dr. Lloyd-Jones. One of the
3813 other effects that we have seen is the staggering increase in
3814 BMI among school-aged children. Dr. Jones, can you please
3815 speak about what impacts this will have from a general and
3816 from a cardiovascular health standpoint, and provide any

3817 recommendations on how we, as a legislative body, can address
3818 this?

3819 *Dr. Lloyd-Jones. Well, thank you, Congressman. This
3820 is a really critically important issue.

3821 And as you point out, you know, we have looked at data
3822 that showed that 45 percent of Americans delayed routine
3823 health care in the summer of 2020, and it is still running
3824 around 20 percent saying that they are going to delay,
3825 related to the virus and their concerns about coming into
3826 health care facilities. And that plays out in our children,
3827 as well.

3828 As you pointed out, we have seen significant weight
3829 gains in Americans across the board during the pandemic,
3830 because of changes in eating habits, because of forced
3831 sedentariness, as we have been home more. And unfortunately,
3832 that plays out in the COVID-19. We saw that, on average, in
3833 the first year of the pandemic, American adults gained 19
3834 pounds, on average, which is really a striking setback to our
3835 public health.

3836 And that -- we have seen that in children, as well.
3837 When children get obese early in life, it drives not only
3838 immediate metabolic changes, it puts them at risk for type
3839 two diabetes -- usually a disease of adults -- puts them at
3840 risk for higher blood pressures, puts them at risk for worse
3841 cholesterol. And we know that each of those things is time

3842 dependent. The longer you are exposed to those things, the
3843 worse your vascular changes, the damage to your heart and
3844 your arteries, and the earlier the onset of those diseases
3845 will be, in terms of heart attack and stroke.

3846 So it is really a tragedy that we are seeing much
3847 heavier children, and we were already one of the most obese
3848 nations in the world, with regard to our children and our
3849 adults. But we are going to see this play out now over
3850 decades, because it is so hard to lose the weight once it has
3851 been gained, and that will drive earlier and more rapid rises
3852 in blood pressure, blood sugar, cholesterol, and other
3853 metabolic problems that will play out. And we will see,
3854 unfortunately, increases in cardiovascular disease, event
3855 rates, and death.

3856 *Mr. Joyce. Dr. Jones, I think you make an excellent
3857 point in -- we will see this play out over decades.

3858 But immediately, right now, we have seen increases in
3859 overdose deaths, some of the largest in our nation's history.
3860 Losing over 95,000 Americans to overdoses in 2020 is an
3861 unacceptable number. And we need to work fast to reverse
3862 this deadly trend.

3863 In Pennsylvania the availability of illicit drugs,
3864 specifically fentanyl, is a crushing blow to our local
3865 communities. We know these drugs are easy to get, and fast
3866 to kill.

3867 During the COVID-19 pandemic the opioid epidemic has
3868 further spiraled out of control. While Congress recently did
3869 just extend the scheduling of fentanyl analogues until early
3870 next year, we, as a committee, must make this ban permanent,
3871 and I would hope to see our committee activity on this
3872 lifesaving policy very shortly.
3873 Thank you, and I yield back.
3874 *Ms. Schrier. The gentleman yields. I want to thank
3875 you, Dr. Joyce, always my friend and my colleague, for
3876 raising such important points about both of those things, the
3877 opioid epidemic and children's health.
3878 I would like to now recognize my friend, Ms. Blunt
3879 Rochester from Delaware, for five minutes.
3880 You are recognized.
3881 *Ms. Blunt Rochester. Thank you, Madam Chairwoman, for
3882 the recognition, and thank you to the witnesses for being
3883 here today to discuss the critical public health issues of
3884 cancer prevention, children's health, cardiac health, and
3885 oral health. The issues we are discussing today impact
3886 Americans of all backgrounds, but none more than heart
3887 disease.
3888 Heart disease is the leading cause of death in the
3889 United States, and by 2035 nearly half of the U.S.
3890 population will have some form of heart disease. If left
3891 untreated, heart disease can turn fatal because of serious

3892 cardiac events like heart attack, heart failure, and stroke.
3893 In addition to costing the country billions of dollars
3894 annually, serious cardiac events can also disrupt the long-
3895 term quality of life of survivors and families because of the
3896 physical, emotional, and financial trauma that accompany
3897 these events.
3898 Fortunately, we have evidence-based interventions like
3899 cardiac and pulmonary rehabilitation that can help those who
3900 have suffered get their lives back on track. Cardiac
3901 rehabilitation programs help patients recover more quickly by
3902 supporting them through supervised exercise training,
3903 emotional support, and lifestyle education.
3904 However, despite the clear benefits of cardiac
3905 rehabilitation, only one in four Medicaid patients eligible
3906 will ever receive it, simply because many patients are not
3907 being referred by their clinicians. Congress addressed this
3908 referral gap in 2018 by authorizing physician assistants,
3909 nurse practitioners, and clinical nurse specialists --
3910 Advanced Practice Providers, or APPs, for short -- to
3911 supervise cardiac and pulmonary rehabilitative care,
3912 beginning in 2024.
3913 APPs are already delivering this level of care. For
3914 example, some physician assistants order and supervise
3915 cardiac stress tests, pacemakers, and defibrillators, and
3916 some nurse practitioners already perform the care planning

3917 and oversee the care delivery for patients with complex
3918 cardiac conditions.
3919 But the question is, why wait? Let's remove the federal
3920 barrier. This is why I was so pleased to be leading the
3921 Increasing Access to Quality Cardiac Rehabilitation Care Act,
3922 H.R. 1956, with Congressman Smith. This legislation will
3923 build on the previous success in 2018, and eliminate
3924 obstacles that prevent patients from beginning this critical
3925 therapy by allowing APPs to supervise and order these vital
3926 programs.
3927 I want to thank Dr. Lloyd-Jones for his enduring support
3928 of this legislation.
3929 And can you elaborate on how allowing advanced practice
3930 providers to supervise and order cardiac and pulmonary
3931 rehabilitative care could decrease disparities in access for
3932 those in rural and underserved communities?
3933 *Dr. Lloyd-Jones. Certainly. Well, thank you so much,
3934 Congressman Blunt Rochester, and thank you for your
3935 sponsorship of this critically important bill.
3936 You know, APPs are people that we work with every day,
3937 as physicians. They are highly-trained, and they are really
3938 -- you know, some people call them physician extenders, but
3939 they are much more than that, and they are a critical part of
3940 our health care system.
3941 Simply put, there just aren't enough doctors, and

3942 doctors aren't doing enough to order cardiac rehab in the
3943 first place for the 1.1 million heart attack survivors we
3944 have every year. And so we are talking about a lot of people
3945 here.
3946 So it is a lack of referral. We need APPs to be writing
3947 those prescriptions. And it is clear who is eligible for
3948 this intervention.
3949 We also need APPs because, to start and maintain a
3950 cardiac rehab program, you need nurse practitioners. You
3951 need exercise physiologists on site, monitoring the patients.
3952 But what you don't really need is a physician every time.
3953 Yes, you need access to a physician. They need to be, you
3954 know, available to be called if there is a problem. But APPs
3955 know exactly what to do if there is an urgent or emergent
3956 situation. They know how to call 9-1-1. They know how to
3957 administer basic life support, and they know how to give CPR
3958 immediately, and often much more quickly and better than a
3959 physician could do if one waited around for the physician to
3960 arrive.
3961 So I think that is a critically important feature of
3962 this bill, and we are very much in support of it.
3963 *Ms. Blunt Rochester. Thank you so much.
3964 And Dr. DuBois, I am working on legislation to promote
3965 the use of preventive health care services like routine
3966 screenings and examinations, which have been delayed or

3967 foregone because of the pandemic. In your testimony you note
3968 that we are still not back to pre-pandemic levels. Can you
3969 briefly elaborate on what the consequences of that may be for
3970 individuals and for our society?
3971 *Dr. DuBois. Thank you. Well, that is a great
3972 question, and a big concern of mine, because the screenings
3973 did go down dramatically, especially each time we had the
3974 surges. It is really going to delay diagnoses in that, you
3975 know, when that delay happens, it makes the outcome much
3976 worse, because it is harder to treat these cancers when they,
3977 you know, present at a much later stage.
3978 We are trying to encourage everybody we can to get back
3979 in, and get on their screening regimens. And it has improved
3980 considerably since the first surge, but it is still not back
3981 up to normal levels, and we are continuing to do whatever we
3982 can through our societies, through the press, public
3983 education to make that happen. But anything Congress can do
3984 would be well received, because this is still a problem.
3985 *Ms. Blunt Rochester. Thank you so much, Dr. DuBois,
3986 and we are working on it.
3987 Thank you, Madam Chair, and I yield back the balance. I
3988 have no time, but I yield it back.
3989 *Ms. Schrier. The gentlewoman yields. Thank you very
3990 much to my colleague, Ms. Blunt Rochester.
3991 I would like to now recognize for five minutes the

3992 gentlelady from Minnesota, Ms. Craig.

3993 *Ms. Craig. Thank you so much, Madam Chair, and thank
3994 you to this committee for holding this important, important
3995 hearing this afternoon.

3996 Witnesses, just thank you for being here, for sharing
3997 your stories, your expertise. I have to say, though, a
3998 special thank you to Congressman Rick Nolan. It is so good
3999 to see you, and thank you for sharing your story and putting
4000 your pain and your family's experience into progress.

4001 I know Katherine, just like you, was a woman of grit, a
4002 woman of love, of empathy. And just on a personal level, I
4003 will never forget that last moment I saw you and President
4004 Joe Biden embrace just after Beau had passed away, and it
4005 just -- an enormous amount of empathy for what you and your
4006 family have gone through.

4007 You know, in Minnesota, and nationally, lung cancer is
4008 the leading cause of cancer deaths. It is also one of the
4009 most commonly diagnosed types of cancer. Despite that
4010 commonality and lethality, we have made woefully little
4011 progress, compared to other cancer types.

4012 We know that early detection saves lives, yet no-cost
4013 screening for lung cancer is limited, and those over the age
4014 of 55 with a history of smoking. In his testimony, Dr.
4015 DuBois points out that incremental progress is being made by
4016 the USPSTF in recommending screening of lung cancer, which,

4017 of course, could be beneficial for women and African
4018 Americans, who tend to smoke fewer cigarettes than White men,
4019 yet still have a rate -- high risk of developing lung cancer.
4020 Dr. DuBois, what other factors besides smoking history
4021 should be studied in women ages 40 to 49 to increase the
4022 scientific data available for policymakers like ourselves?
4023 *Dr. DuBois. Well, thank you very much for that
4024 question. Some of the things that are related to increased
4025 risk in the younger population are secondhand smoke exposure,
4026 and some of that is not always collected properly or, you
4027 know, put into the record or documented to allow us to know
4028 what degree of risk that is.
4029 There is also things like radon exposure, and other
4030 environmental exposures that increase risk in that younger
4031 population.
4032 And then there is also a segment of those individuals
4033 who have genetic risk factors and a history of lung cancer in
4034 their families that would need to undergo some genetic
4035 testing to sort that out.
4036 So there are other factors, and, you know, that is just
4037 one of the issues with the way the task force works. They
4038 really set things, really, based on age, because they really
4039 look at the population as a collective, instead of these
4040 individual, higher-risk groups.
4041 *Ms. Craig. Thank you so much.

4042 Congressman Nolan, I just want to ask. Katherine
4043 fought. She fought all the way through the very end of her
4044 life. Can you talk just for a minute about that fight, and
4045 why she so strongly believed that she had such purpose at her
4046 end of life, and the mantel that you have now taken up for
4047 her?

4048 *Mr. Nolan. Thank you for that question. I could not
4049 have ever been more proud of her.

4050 She -- I said earlier she said that she would gladly go
4051 through all that she had endured, as so many others have, if
4052 it could result in the passage of this screening to provide
4053 early detection, because it is so critical in saving and
4054 extending lives.

4055 And in her final moments we were with her. And she said
4056 -- I said, "Katherine, the great mystery is -- for many of us
4057 -- is not knowing what is going to happen to us here when our
4058 life is over.'' But I said, "Wherever that is, I want to be
4059 with you there soon.''

4060 Her last words and wishes were, she said, "No, Dad, not
4061 until this bill gets passed.''

4062 So I am so grateful to the committee for considering
4063 this and the other important legislation and, in particular,
4064 for a beautiful young woman's last dying wishes to pass this
4065 bill, because she knew it would save so many lives. And she
4066 said she would undergo everything she has gone, including the

4067 finality of it in losing her life, because she knew it would
4068 save so many thousands -- tens, if not hundreds of thousands
4069 of people, 465,000 people dying every day from lung cancer.
4070 Thank you.
4071 *Ms. Craig. Congressman, this committee looks forward
4072 to taking up this fight with you on her behalf.
4073 Thank you, and I yield back.
4074 *Mr. Nolan. Thank you.
4075 *Ms. Schrier. The gentlewoman yields. Thank you for
4076 those moving comments.
4077 I would like to thank our witnesses today for your
4078 participation in today's hearing, and I will submit the
4079 following statements for the record.
4080 The list here is provided and, with your permission, I
4081 will waive the reading of these. Thank you.
4082 [The information follows:]
4083
4084 **********COMMITTEE INSERT**********
4085

4086 *Ms. Schrier. Members have 10 business days to submit
4087 additional questions for the record.
4088 Witnesses, please respond promptly to any questions that
4089 you receive.
4090 At this time the subcommittee is adjourned. Thank you.
4091 [Whereupon, at 2:12 p.m., the subcommittee was
4092 adjourned.]