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6 EXAMINAING PROPOSALS THAT PROVIDE ACCESS
7 TO CARE FOR PATIENTS AND SUPPORT RESEARCH
8 FOR RARE DISEASES
9 WEDNESDAY, JUNE 14, 2023
10 House of Representatives,
11 Subcommittee on Health,
12 Committee on Energy and Commerce,
13 Washington, D.C.
14
15 The subcommittee met, pursuant to call, at 10:32 a.m.,
16 in Room 2322 Rayburn House Office Building, Hon. Brett
17 Guthrie [chairman of the subcommittee] presiding.
18
19 Present: Representatives Guthrie, Burgess, Latta,
20 Griffith, Bilirakis, Johnson, Bucshon, Hudson, Carter, Dunn,

21 Pence, Crenshaw, Joyce, Harshbarger, Miller-Meeks,

22 Obernolte, Rodgers (ex officio); Eshoo, Sarbanes, Cardenas,

23 Ruiz, Dingell, Kuster, Kelly, Barragan, Craig, Schrier,

24 Trahan, and Pallone (ex officio).

25

26 Also present: Representatives Schakowsky and Tonko.

27

28 Staff present: Kristen Ashford, Fellow; Jolie Brochin,
29 Clerk; Sarah Burke, Deputy Staff Director; Kristin Flukey,
30 Professional Staff Member; Grace Graham, Chief Counsel; Nate
31 Hodson, Staff Director; Tara Hupman, Chief Counsel; Emily
32 King, Member Services Director; Molly Lolli, Counsel; Karli
33 Plucker, Director of Operations (shared staff); Michael
34 Taggart, Policy Director; Lydia Abma, Minority Policy
35 Analyst; Jacquelyn Bolen, Minority Health Counsel; Waverly
36 Gordon, Minority Deputy Staff Director and General Counsel;
37 Tiffany Guarascio, Minority Staff Director; Mackenzie Kuhl,
38 Minority Digital Manager; Una Lee, Minority Chief Health
39 Counsel; and Tristen Tellman, Minority Health Fellow.

40

41 *Mr. Guthrie. The subcommittee will come to order, and
42 I recognize myself for five minutes for an opening
43 statement.
44 Today we are here to discuss legislation about access
45 to care and improve health outcomes for Americans. We will
46 consider bills to help support innovation for therapies and
47 lifesaving cures for rare diseases which affect more than 30
48 million Americans. That is why we are considering H.R.
49 3391, the Gabriella Miller Kids First Research Act 2.0 which
50 would reauthorize the National Institutes of Health
51 Gabriella Miller Kids First Pediatric Research Program.
52 We are also considering H.R. 3226, the PREEMIE
53 Reauthorization led by Ranking Member Eshoo and
54 Representative Miller-Meeks, Kelly, Kiggans, Blunt
55 Rochester, and Burgess. We are also -- have more work to do
56 to protect the long-term health and wellbeing of expecting
57 and new moms. We will consider to build off this work the
58 subcommittee has done over the past several years to address
59 maternal mortality.
60 H.R. 3838, the Preventing Maternal Deaths

61 Reauthorization Act will continue the work done by the CDC
62 and the Health Resources and Service Administration, HRSA,
63 to provide access to resources for women experiencing risky
64 pregnancies and develop best practices to treat at risk
65 moms.
66 We are also considering H.R. 3821, the Firefighter
67 Cancer Registry Reauthorization Act. Our first responders
68 experience adverse health outcomes often resulting from
69 selfless and brave work they do to keep us and our loved
70 ones safe. We are also considering legislation to advance
71 our knowledge of rare diseases and promote access to
72 therapies to treat rare diseases such as Sickle Cell and
73 Parkinson's Disease.
74 As I step forward to address the issues today, we are
75 examining H.R. 384 -- 3884, the Sickle Cell Disease and
76 Other Heritable Blood Disorders Research, Surveillance,
77 Prevention, and Treatment Act, and H.R. 2365, the National
78 Plan to End Parkinson's Act. I would like to thank
79 Representatives Burgess and Bilirakis for their leadership
80 on these bills. And, fortunately, as we are seek -- as we

81 have these breakthroughs, we absolutely need to make sure
82 that people have access to them, and so we have our -- that
83 we had in the hearing last week, the MVP bill that hopefully
84 we can all come together to make sure that the least of us
85 have access to these lifesaving therapies through the
86 Medicaid Program.
87 And last, we are considering H.R. 3887, the Children's
88 Hospital GME Support Reauthorization Act of 2023. This
89 program provides funding the children's hospitals to help
90 train resident physician and dentists. It is critical for
91 us to reauthorize the program before the end of the fiscal
92 year with the necessary policy changes to keep kids safe
93 from experimental procedures.
94 In closing, I am proud of these bipartisan bills before
95 us that will approve access to care and drive innovation.
96 Patients and their families will be better off because of
97 the work we are doing today.
98 [The prepared statement of Mr. Guthrie follows:]
99
100 **********COMMITTEE INSERT**********
101

102 *Mr. Guthrie. And I will yield my remaining time to
103 Dr. Burgess.
104 *Mr. Burgess. And I thank the chair for the
105 recognition.
106 So I am -- it is so important that we are considering
107 the reauthorization of the PREEMIE Act introduced by my good
108 friends, Anna Eshoo and Mary Miller-Meeks, along with
109 several other members. The PREEMIE Act would reauthorize
110 programs that expand research, education, and intervention
111 activities aimed at reducing premature births and treating
112 the complications of prematurity.
113 You know, we are just a few weeks away from the 60th
114 anniversary of the birth of the last child in the White
115 House. Patrick Kennedy was born August 7, 1963.
116 Unfortunately, he did not live too long because of
117 complications of prematurity. And indeed, his father, the
118 President of the United States, tried to enlist help from
119 all sectors in the medical community in order to save his
120 son, but he was unsuccessful.
121 Writing in his great book, William Manchester, in

122 detailing the life and death of President Kennedy, he talked
123 about that trip to Dallas. The day before the trip to
124 Dallas, the President was in San Antonio. In San Antonio,
125 he was shown an experiment that was going on regarding high
126 altitude physiology. There were four men in a container,
127 and they were being simulated 30,000 feet, and they were
128 being given high oxygen.
129 The President pulled the investigator aside, and
130 according to Mr. Manchester's book, he drew Dr. Welch aside.
131 He had one more inquiry. Apart from space research, there
132 must be other medical implications here. Do you think your
133 work might improve oxygen chambers for say premature babies?
134 Clearly, his experience was very much on his mind that day.
135 Very personal to me because 13 years later in August of
136 1976, my daughter was born a few weeks early and suffered
137 from the same complications, idiopathic infantile
138 respiratory distress syndrome, hyaline membrane disease, and
139 because of the work that had occurred over those intervening
140 13 years, the science in neonatology, the specialty of
141 neonatology had come into being and neonatal intensive care

142 units had now occurred. So because of those efforts, my
143 daughter 13 years later, short stay in the hospital, take
144 your medicines, do your treatments, and you live a normal,
145 healthy life.
146 That is the kind of work we are talking about today.
147 That is the type of work we are reauthorizing. I thank my
148 friends for introducing it. This is important work as we go
149 forward.
150
151
152 [The prepared statement of Mr. Burgess follows:]
153
154 **********COMMITTEE INSERT**********
155

156 *Mr. Burgess. I will yield back.
157 *Mr. Guthrie. Thank you. Thank you for your story.
158 The gentleman yields back, and I will yield back the
159 time, and I now recognize the gentlelady from California,
160 Representative Eshoo, for five minutes for an opening
161 statement.
162 *Ms. Eshoo. Thank you, Mr. Chairman, and good morning,
163 colleagues, and thank you to this sterling full table of
164 witnesses that we have with us today.
165 Today we are considering eight proposals that increase
166 access to care and reauthorize critical public health
167 programs and one proposal that does exactly the opposite. I
168 am pleased that my legislation, H.R. 3226, the PREEMIE
169 Reauthorization Act, is included in the hearing. And I
170 thank my co-leads, Representatives Miller-Meeks, Kelly,
171 Burgess, Blunt Rochester, and Kiggans for their work on this
172 important effort.
173 In 2005, I introduced the original PREEMIE Act with
174 former chairman of our full committee, Fred Upton, which was
175 the first and remains the only law to focus solely on the

176 prevention of preterm births. We need a swift
177 reauthorization to ensure the successful programs created by
178 this law can continue. 3226 will also improve future policy
179 by studying the current gaps in our healthcare system that
180 have led to the recent surge in preterm births and how we
181 can address them.
182 Our hearing will also consider critical bipartisan
183 bills such as the Preventing Maternal Deaths Reauthorization
184 Act, the National Plan to End Parkinson's Disease, and the
185 Firefighter Cancer Registry Reauthorization Act. I see
186 Kevin nodding there. But we are also considering a proposal
187 that will damage the Children's Hospital's Graduate Medical
188 Education Program irreparably by making hospitals choose
189 between providing the standard care for children
190 experiencing gender dysphoria or losing funding that keeps
191 them afloat. There should not be a choice here. It should
192 not be one or the other.
193 For nearly 25 years, the CHGME Program has trained half
194 of general pediatricians and a majority of pediatric
195 specialists. In California, CHGME Program funds are used by

196 seven children's hospitals to train over 906 full-time
197 pediatric residents annually. This is an extraordinary
198 record. It is an extraordinary record, something that we
199 are proud of on both sides of the aisle because it has had
200 the full support of members of both sides of the aisle.
201 And that is why it is difficult for me to comprehend
202 why my Republican colleagues are subjecting the children's
203 hospitals to a manufactured culture war that puts politics
204 in between parents, children, and their pediatricians. This
205 just shouldn't be here. It just shouldn't be here.
206 Specifically, the bill prohibits 19 specific procedures and
207 any type of hormone therapy that could be perceived as
208 gender affirming for trans youth.
209 This proposal threatens precious lives. It is not just
210 a bunch of words on a piece of paper. As one pediatric
211 endocrinologist said, "Every time politics and medicine
212 comingle, people die.'' We are already seeing higher rates
213 of maternal and infant death because of abortion
214 restrictions that paralyze providers in an emergency. Now
215 Republicans are attempting to ban 19 more procedures and

216 treatments that should be a private, a private decision
217 between patients, their families, and their doctors. This
218 proposal also worsens the mental health crisis that trans
219 children are facing.
220 This is really sad, and if I had a magic wand, I would
221 just wish this away. But it is something that is before the
222 committee today.
223 I want to close on this with this quote. I was
224 watching the news one night and there was a Nebraska
225 lawmaker, an independent, a woman, a mother, and this is
226 what she said. "I am asking you to love your family more
227 than you hate mine.'' I hope that this issue will somehow
228 not make it here. This doesn't belong here. We file --
229 follow science. We have worked on a bipartisan basis to
230 build and build and build across our health care system. So
231 much of the decision making is private. That is where it
232 belongs.
233 So thank you to our panel of experts that are here
234 today.
235 [The prepared statement of Ms. Eshoo follows:]

236

237 **********COMMITTEE INSERT**********

238

239 *Ms. Eshoo. And I yield back.
240 *Mr. Guthrie. The gentlelady yields back, and the
241 chair now recognizes the chair of the full committee, Chair
242 Rodgers, for five minutes for an opening statement.
243 *The Chair. Today's hearing looks at key programs that
244 aim to improve access to care and support research for rare
245 diseases. This includes solutions to help save the lives of
246 mothers and babies, improve our understanding of blood
247 disorders, coordinate federal efforts related to Parkinson's
248 Disease, and ensure we are appropriately monitoring
249 instances of cancer in firefighters so that we can get these
250 heroes better treatments and care. I look forward to
251 hearing from our witnesses about the effectiveness of these
252 programs.
253 As part of our work to help mothers and babies at every
254 stage of life, we are continuing our work to reauthorize the
255 PREEMIE and Preventing Maternal Deaths Program. Especially
256 for first-time moms, I think about the joy and also the
257 uncertainty, the questions, and all that comes with being
258 pregnant. Across the country there is a need for stable and

259 consistent resources and education around maternal health.
260 That is why I was pleased to see the Preventing
261 Maternal Deaths Reauthorization included a requirement for
262 CDC and HRSA to share best practices to hospitals and other
263 healthcare entities to ensure we are doing everything we can
264 for moms, babies, and families to thrive.
265 I hear often from constituents not knowing where to
266 turn when dealing with postpartum depression in rural areas.
267 HRSA has a national maternal mental health hotline, but
268 getting best practices to doctors on how to best help women
269 will hopefully lead to improvements in maternal mental
270 health.
271 We are also considering the reauthorization of the
272 Children's Hospital Graduate Medical Education Program. In
273 nearly 60 hospitals across the country, this program helps
274 train our next generation of pediatricians. As we discuss
275 other solutions today like the Gabriella Miller Kids First
276 Research Act, I imagine moms and dads who hear the diagnosis
277 no parent wants to hear from a doctor, your child has
278 cancer. And then for the love of their child, the parents

279 pour themselves into making sure that their child will have
280 the best chance to one day achieve their hopes and dreams.
281 From our work on this committee, we know all families
282 have experienced this. That is why we must authorize the
283 Children's Hospital Program. So America's children are
284 cared for by the best doctors in the world. Doctors who we
285 trust to practice with the strongest medicine, data, and
286 science so our kids live full, happy, and healthy lives.
287 We are not shying away from the concerns that children
288 are being rushed to experimental medical interventions that
289 could include puberty blockers, hormone therapies, and
290 surgeries that cause irreversible damage. Dr. Miriam
291 Grossman is here today to share the data and why other
292 countries are stepping back from these interventions for
293 children because of the risk, like permanent infertility,
294 outweigh the benefits. Our children's hospitals and medical
295 institutions should also be urging caution and being honest
296 about where the evidence is lacking.
297 Many times on this committee we have come together to
298 protect the young generation. I have had many conversations

299 with my colleagues about our concern for teenage girls in
300 particular who are facing more stress, anxiety, and pressure
301 than ever before. For them and children in crisis, we have
302 taken historic action on mental healthcare reforms. We are
303 leading right now to stop Big Tech's algorithms from
304 manipulating children and preying on their vulnerabilities.
305 And this work must continue and we need to do everything we
306 can to stand up and protect children.
307 That is our goal today. Let's send a message to the
308 young generation that they are loved as they are. And let's
309 make sure that we are getting the best healthcare possible.
310 They deserve nothing less.
311 To close, I want to thank my colleagues who are leading
312 on solutions we are discussing. Thank you to our witnesses
313 for your time and providing your expertise this morning. We
314 are grateful on this committee and, you know, this committee
315 is about doing the hard work, plowing the hard ground
316 necessary to legislate and to improve the lives of those
317 that we serve.
318 I look forward to the discussion.

319 [The prepared statement of The Chair follows:]

320

321 **********COMMITTEE INSERT**********

322

323 *The Chair. And I yield back.
324 *Mr. Guthrie. The chair yields back. The chair now
325 recognizes the ranking member from New Jersey, the gentleman
326 from New Jersey, Rep Pallone, for five minutes for an
327 opening statement.
328 *Mr. Pallone. Thank you, Mr. Chairman. Today could
329 have been a bipartisan hearing, but once again Republicans
330 are playing political games with the healthcare of
331 Americans, and I am deeply disappointed with the legislation
332 that Republicans are bringing up for consideration today to
333 reauthorize the Children's Hospital Graduate Medical
334 Education Program. This unnecessary and discriminatory bill
335 is going to dominate this hearing, which is unfortunate
336 since there are bipartisan public health policies that we
337 should also be discussing here today.
338 The CHGME Program is a longstanding effort to support
339 the training of pediatricians and ensure that children
340 across the country have proper access to care. And this is
341 a popular program. Since its inception, it has consistently
342 received strong bipartisan support. In fact,

343 reauthorization of CHGME has always been done in a
344 bipartisan manner.
345 Today we should be considering legislation introduced
346 by my colleague, Representative Schrier, that is bipartisan
347 reauthorization of this important program. But instead,
348 Republicans have chosen to notice a partisan bill that
349 includes language to ban medically-necessary care for
350 transgender youth.
351 Now the Republican bill goes against decades of
352 scientific research and evidence that has established clear
353 standards of care. Care that is effective and essential to
354 the health and wellbeing of transgender youth. Care that is
355 supported by the American Academy of Pediatrics, the
356 American Medical Association, and every other leading
357 medical association. Banning evidence-based care is an
358 afront to science and it is dangerous.
359 So let me be clear about what is happening here.
360 Republicans want to prescribe in excruciating detail in
361 federal legislation which medical treatments and care are
362 acceptable to provide to young people. They are trying to

363 overrule doctors, patients, and their parents.

364 We know that transgender youth are already vulnerable
365 to mental health challenges. Nearly one in five transgender
366 and nonbinary youth have attempted suicide and nearly half
367 have seriously considered suicide in the past year. This is
368 staggering, and Republican attempts to deny necessary
369 medical care only puts them at greater risk. We know that
370 providing care decreases suicide risk. We should be
371 supporting and affirming transgender young people for who
372 they are.

373 This Republican ban also restricts options and
374 disregards parental rights. They are telling parents that
375 Republican politicians know better than they do what is best
376 for their child. And this is the height of hypocrisy from a
377 group that supposedly believes in limited government.

378 Not only is this ban an attack on transgender youth and
379 their parents, but it is also an attack on doctors and other
380 healthcare providers. It would prohibit any CHGME funding
381 if a hospital or training program performs this important
382 care. This would cripple the funding mechanism that trains

383 over half of all pediatricians in the United States.
384 Children's hospitals would be forced to make a choice
385 between providing medically-necessary care for their
386 patients or foregoing federal funding dedicated to the
387 training of their residents. By attacking providers and
388 their training, Republicans are trying to dismantle medical
389 education research and care for all children and
390 adolescents.
391 So it is quite simple. Republicans should stay out of
392 the doctor's office. That is what I recommend. Stay out of
393 the doctor's office.
394 [The prepared statement of Mr. Pallone follows:]
395
396 **********COMMITTEE INSERT**********
397

398 *Mr. Pallone. And with that, Mr. Chairman, I yield
399 back
400 *Mr. Guthrie. The gentleman yields back. That
401 concludes opening statements.
402 We will now move to witness's statements, and I will
403 just let you know, as you have -- some of you have testified
404 here before. You have five minutes. There will be a green
405 light in front of you, you will see that. It will turn
406 yellow within a minute, and so that is time to start
407 wrapping up if you haven't move forward -- if you haven't at
408 the time. And then when it turns red, the time is expired.
409 So I will begin by introducing all of our witnesses,
410 and I will call you on one by one to give your opening
411 statement.
412 Our witnesses today are Dr. Elizabeth Cherot?
413 *Dr. Cherot. Cherot.
414 *Mr. Guthrie. Cherot. Dr. Cherot, Senior Vice
415 President and Chief Medical Officer for the March of Dimes.
416 Dr. Alexis Thompson, Chief of the Division of Hematology and
417 Elias Schwartz Endowed Chair in Hematology at the Children's

418 Hospital of Philadelphia, and Professor of Pediatrics at the
419 University of Pennsylvania Perelman School of Medicine. Dr.
420 Meredith McNamara, Assistant Professor at the Yale School of
421 Medicine. Dr. Miriam Grossman, Child, Adolescent, and Adult
422 Psychiatrist. Mr. George Monahan -- Manahan --
423 *Mr. Manahan. Manahan.
424 *Mr. Guthrie. Manahan. Child, adolescent, and adult -
425 - excuse me. Parkinson's advocate and patient. And Mr.
426 Kevin O'Connor, Assistant to the General President for
427 Government Affairs and Political Action for the National
428 Association of Firefighters.
429 Dr. Cherot, you are recognized for five minutes for
430 your opening statement.
431

432 STATEMENT OF DR. ELIZABETH CHEROT, MD, MBA, SENIOR VICE
433 PRESIDENT AND CHIEF MEDICAL HEALTH OFFICER, MARCH OF DIMES;
434 DR. ALEXIS A. THOMPSON, MD, MPH, CHIEF OF DIVISION OF
435 HEMATOLOGY, ELIAS SCHWARTZ MD ENDOWED CHAIR IN HEMATOLOGY,
436 CHILDREN'S HOSPITAL OF PHILADELPHIA, PROFEESOR OF
437 PEDIATRICS, UNIVERSITY OF PENNSYLVANIA PERELMAN SCHOOL OF
438 MEDICINE; DR. MEREDITHE MCNAMARA, MD, MS, FAAP, ASSISTANT
439 PROFESSOR, YALE SCHOOL OF MEDICINE; DR. MIRIAM GROSSMAN, MD,
440 CHILD, ADOLESCENT, AND ADULT PSYCHIATRIST; GEORGE MANAHAN,
441 PARKINSON'S ADVOCATE AND PATIENT; AND KEVIN O'CONNOR,
442 ASSISTANT TO THE GENERAL PRESIDENT FOR GOVERNMENT AFFAIRS
443 AND POLITICAL ACTION, INTERNATIONAL ASSOCIATION OF FIRE
444 FIGHTERS
445
446 STATEMENT OF DR. ELIZABETH CHEROT, MD, MBA
447
448 *Dr. Cherot. Good morning, Chairman Guthrie, Ranking
449 Member Eshoo, members of the Health Subcommittee. My name
450 is Dr. Elizabeth Cherot. I am Senior Vice President and
451 Chief Medical and Health Officer at March of Dimes, the

452 leading organization fighting for the health of all moms and
453 babies. Our work today is more important than ever with the
454 Nation in the midst of a dire maternal and infant health
455 crisis.
456 By improving the health of women before, during, and
457 between pregnancies, we can improve outcomes for them and
458 their infants. But we have many challenges. Recently, the
459 CDC released its 2021 Maternity Mortality Rates Report,
460 which showed an increase of nearly 89 percent in the
461 maternal mortality rate since 2018.
462 At the same time, the number of women who experienced
463 pregnancy-related complications or severe maternal morbidity
464 is increasing at a troubling rate. The state of infant
465 health mirrors that of maternal health. While the most
466 recent preliminary 2022 CDC data on preterm birth shows a
467 one percent decline in preterm birth rates, one in ten
468 babies are still born too sick and too soon. This small
469 decrease, while promising, only highlights the need to
470 redouble our efforts.
471 What is more persistent, racial disparities exist.

472 Black and Native American women are 62 percent more likely
473 to give birth prematurely, and their babies have a mortality
474 rate double that of the white population. Let me share one
475 of the stories from my full testimony that exemplifies the
476 experiences faced by mothers who deliver their babies
477 prematurely.
478 Katie Wilton of Phoenix, Arizona began facing life
479 threatening complications 22 weeks into her pregnancy when
480 she began hemorrhaging. During the next eight weeks, she
481 suffered two more bleeding episodes, and at 29 weeks and two
482 days, Katie found herself in preterm labor. When she
483 arrived at the hospital, she was given treatment to slow her
484 labor and prepare for Colette's early arrival.
485 As Katie soon -- was soon to learn, she was
486 experiencing chronic placental abruption where the placenta
487 prematurely separates from the uterine wall. When Colette
488 was born at exactly 30 weeks gestation, she was diagnosed
489 with severe intrauterine growth restriction. She weighed
490 only three pounds one ounce and measured a mere 14 inches
491 long.

492 During her 63-day stay in a neonatal intensive care
493 unit, Colette was given lifesaving medication. Among them
494 was surfactant therapy, a treatment to advance lung
495 development which was developed by the March of Dimes funded
496 research.
497 This story and hundreds of thousands of others each
498 year just like it highlights the need for one of -- for us
499 to do more. To that end, March of Dimes supports the
500 following legislation being considered by the subcommittee
501 today. H.R. 3226, the PREEMIE Reauthorization Act of 2023,
502 which represents the Federal Government's commitment to
503 preventing preterm birth and its consequences.
504 This legislation specifically reauthorizes CDC's highly
505 successful Pregnancy Risk Assessment Monitoring System, or
506 PRAMS. PRAMS collects site-specific population-based data
507 in 50 jurisdictions tracking maternal attitudes and
508 experiences before, during, and shortly after pregnancy.
509 The act also reauthorizes the Health Resources Services
510 Administration's, HRSA's activities aimed at promoting
511 healthy pregnancies and preventing preterm birth, and it

512 provides a new study by the National Academies of Sciences,
513 Engineering, and Medicine, which will examine the societal
514 costs, the impact of societal factors, and gaps in public
515 health programs related to preterm birth.
516 March of Dimes also supports H.R. 3838, the Preventing
517 Maternal Deaths Reauthorization Act of 2023, which
518 strengthens and expands federal support for the Maternal
519 Mortality Review Committees, MMRCs, established under the
520 authorizing law enacted in 2018. MMRCs play an invaluable
521 role in identifying maternal deaths, analyzing the factors
522 that contributed to maternal deaths, and translating the
523 lessons learned into policy.
524 They have relieved the cardiac -- revealed that
525 cardiac-related issues are the leading cause of deaths for
526 mothers and that the majority of deaths do not occur during
527 childbirth but in days and weeks after. This legislation
528 would continue to disseminate best practices and help MMRCs
529 promote the case review process.
530 Thank you for focusing your attention on these two
531 public health crises. March of Dimes stands ready to work

532 with you to enact this critical legislation.

533 [The prepared statement of Dr. Cherot follows:]

534

535 **********COMMITTEE INSERT**********

536

**This is an unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker**

537 *Mr. Guthrie. Thank you for your testimony. The chair
538 now recognizes Dr. Thompson for five minutes for her opening
539 statement.
540

541 STATEMENT OF DR. ALEXIS A. THOMPSON, MD, MPH
542
543 *Dr. Thompson. Chairman Guthrie, Ranking Member Eshoo,
544 and the distinguished members of the committee, thank you
545 for the opportunity to participate in this hearing to
546 discuss H.R. 3884, the Sickle Cell Disease and Other
547 Heritable Blood Disorders Research, Surveillance,
548 Prevention, and Treatment Act of 2023, and the importance of
549 this reauthorization to federal efforts to improve the lives
550 of the nearly 100,000 Americans living with Sickle Cell
551 Disease.
552 This legislation is critical to support access to care
553 for patients with Sickle Cell and related disorders. With
554 early diagnosis, we have achieved -- which is often achieved
555 through universal newborn screening in this country,
556 effective evidence-based interventions can be introduced
557 that will save lives and reduce suffering.
558 My name is Dr. Alexis Thompson. I am the Chief of the
559 Division of Hematology and the Schwartz Endowed Chair in
560 Hematology at the Children's Hospital of Philadelphia and

561 Professor of Pediatrics at the University of Pennsylvania
562 Perelman School of Medicine. In these roles, I treat
563 children and adults with Sickle Cell Disease, I educate
564 future clinicians for -- about Sickle Cell Disease and
565 comprehensive care, and I lead a research team engaged in
566 innovations in Sickle Cell and other blood disorders such as
567 gene therapy as potential cures.
568 I have also served as President of the American Society
569 of Hematology which is the largest professional society
570 serving both clinicians and scientists who are working to
571 conquer blood disorders.
572 Since the initial authorization of the Sickle Cell
573 Disease Treatment Demonstration Program, HRSA has provided
574 important resources for education and training to care -- to
575 provide -- approve access of quality care for patients
576 living with Sickle Cell Disease and also those with Sickle
577 Cell trait. This program addresses an important
578 recommendation that comes from the National Academy of
579 Sciences, Education -- Engineering, and Medicine Report
580 addressing Sickle Cell Disease and strategic plan and

581 blueprint for action.

582 H.R. 3884 will authorize the Sickle Cell demonstration
583 programs through fiscal year 2028 and will allow the agency
584 to build upon its efforts and the investment that has been
585 made thus far. This program will increase the number of
586 clinicians who are knowledgeable about Sickle Cell disease
587 care, improve quality of care provided for individuals,
588 improve care coordination, and to disseminate best practices
589 for the coordination of services particularly during the
590 critical pediatric to adult transition. This particular
591 program is designed to be a regional approach and currently
592 now covers the entire United States.

593 One example of how this program is effectives is its
594 use of the Project ECHO model which allows providers to have
595 increased confidence in treating Sickle Cell patients by
596 being able to interface with experts in Sickle Cell Disease,
597 many of whom live -- are located some geographic distance
598 from their practices. By establishing a regional Sickle
599 Cell Disease infrastructure, the program partners with
600 states to develop and support comprehensive Sickle Cell care

601 programs that deliver care across the lifespan and
602 implements telemedicine or telehealth technologies in order
603 to do so. It covers the entire country and it utilizes a
604 regional hub and spoke model, and this has been particularly
605 successful in the current funding cycle particularly when
606 individual providers are some distance from academic medical
607 centers.
608 I also urge -- in addition to H.R. 3884, I urge the
609 committee to consider how to improve the program, in
610 particular providing more resources for measurement or
611 metrics. We know that measurement is critical to understand
612 the -- and to quantify increases in certain Sickle Cell
613 complications, which frankly are preventable with
614 comprehensive care, and in addition, will allow us to expand
615 and to identify unaffiliated patients, patients who truly
616 are receiving inadequate, and to the best of our knowledge
617 in some cases, no care.
618 We would also encourage Congress to invest further in
619 the CDC's Sickle Cell Disease Data Collection Program which
620 complements the HRSA effort by utilizing its strengths and

621 surveillance to be able to provide necessary information
622 metrics to help us to understand where Sickle Cell patients
623 live, their current quality of life, and how we can continue
624 to intervene. There are currently only 11 states who are
625 currently participating in this program. It only represents
626 about 35 percent of Sickle Cell patients. We think that
627 there also needs to be continued congressional support for
628 this vital program.
629 We also -- would also encourage the committee to
630 consider supporting H.R. 1672, the Sickle Cell Disease
631 Comprehensive Care Act, which would direct the Centers for
632 Medicare & Medicaid Services to provide funds to create
633 demonstration programs to look at access to comprehensive
634 care and high quality outpatient care for individuals who
635 are enrolled in Medicaid. We believe that these are key
636 federal investments for improving the health of individuals
637 with Sickle Cell.
638 The Sickle Cell community is deeply appreciative of
639 this committee and the Congress for their ongoing commitment
640 to address Sickle Cell through these programs. Again, I

641 urge this committee to act now and to reauthorize H.R. 3884.
642 Thank you for the opportunity to testify before you.
643 [The prepared statement of Dr. Thompson follows:]
644
645 **********COMMITTEE INSERT**********
646

647 *Mr. Guthrie. Thank you for your testimony. The chair
648 now recognizes Dr. McNamara for five minutes for your
649 opening statement.
650

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651 STATEMENT OF DR. MEREDITH MCNAMARA, MD, MS, FAAP

652

653 *Dr. McNamara. Thank you, Health Committee -- excuse
654 me. Thank you, Health Subcommittee Chair Guthrie, Ranking
655 Member Eshoo, and members of the subcommittee. I am a board
656 certified pediatrician and a specialist in adolescent and
657 young adult health. I have spent 12 years in medical
658 training, in direct patient care, and in clinical research.
659 I am honored to serve the diverse needs of young adults age
660 12 to 25. And as an assistant professor at the Yale School
661 of Medicine, I teach medical residents, students, and
662 fellows.

663 I am also the cofounder of the Integrity Project for
664 Child and Adolescent Health which seeks to infuse health
665 policy debate with scientific evidence. My testimony today
666 reflects my academic and clinical work as well as medical
667 consensus and not the views of my employer.

668 The amendment to the Public Service Act before you
669 proposes to defund pediatrics training programs throughout
670 our country if these institutions provide the standard of

671 care to transgender youth. I am honored to speak here today
672 on behalf of esteemed colleagues throughout the Nation who
673 provide this best practice medical care for children and
674 youth, including trans youth, and their families. As a
675 physician with a commitment to patient care, I am honored to
676 be able to do more for them here than I can do in the
677 officer.

678 The past few years mark a rapidly shifting and hostile
679 political climate towards medical care for transgender
680 people with a harsh focus on youth. Care that should be a
681 private matter for families, patients, and providers is now
682 being directed by legislators based on unsupported fears and
683 misinformation.

684 I understand that this care may be confusing to those
685 who are not medical providers with expertise in treating
686 this population or those who do not have a personal
687 connection to a transgender person. That is why it is
688 critical that this body base its decisions on facts and
689 accurate information. Most of us here would not disagree
690 with that.

691 From my position as a medical practitioner and a member
692 of a large community of experts in this care, I see five
693 categories of misinformation. Denial of the medical
694 condition of gender dysphoria, false claims about standard
695 practice, false claims about the evidence that backs care,
696 false claims about the safety of treatments, and an attack
697 on medical authority. And I am here to ensure that you have
698 the facts to address this misinformation.
699 Gender dysphoria, the longstanding and significant
700 distress that many transgender people have from the
701 incongruence between their gender identity and the sex they
702 have at birth, is real. It is a recognized and serious
703 medical condition. Transgender people of all ages exist.
704 Their healthcare is based on established standards of care
705 and clinical practice guidelines, which are themselves based
706 on substantial medical research and evidence as well as
707 decades of clinical practice. Based on these standards,
708 youth and parents receive informed counseling about the
709 risks and the benefits of specific treatments and every
710 major medical organization has endorsed this care.

711 As a pediatrician, I must also address the proposed
712 amendment. Pediatrics residencies and fellowships are the
713 backbone of healthcare for children in this country. During
714 the tripledemic of influenza, COVID-19, and respiratory
715 syncytial virus, also called RSV, it was pediatrics
716 residents and fellows who worked every hour of every day to
717 help children survive life threatening respiratory diseases.
718 They help NICU babies get to kindergarten. They keep
719 outpatient clinics flowing so that kids get routine well
720 care. Residents and fellows form a pipeline of research and
721 innovation that makes this country a global leader in every
722 area of pediatric medical science.
723 This bill would require children's hospitals to deny
724 kids healthcare to maintain funding. As a practical matter,
725 there is no way to banish all transgender youth from
726 children's hospitals nor is there a way for pediatricians to
727 simply refuse to provide these youth with medically-
728 necessary care. All kids suffer when their legislators
729 remove parent's rights and prevent pediatricians from
730 providing the standard of care. And I have to tell you,

731 American pediatricians will not accept being told that they
732 have to leave even a single child behind. There is no room
733 for clinic -- there is no room in our clinics for the
734 government.
735 I had a conversation with a trans teen recently.
736 Gender dysphoria began early in puberty and worsened as
737 puberty progressed. The parents sought and received help.
738 This family asked me to tell members of this committee that
739 gender affirming care gave their kid confidence. This teen
740 stands tall, debates international law in model UN sessions,
741 recently in this city, our capitol, to compete in nationals.
742 This care was lifesaving and life affirming. College
743 options are limited to states that protect trans healthcare,
744 but even still, this teen is excited for the future that
745 lies ahead.
746 That is what every kid in this country deserves.
747 Please don't make it harder for us pediatricians to get them
748 there.
749
750

751 [The prepared statement of Dr. McNamara follows:]

752

753 **********COMMITTEE INSERT**********

754

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755 *Mr. Guthrie. Thank you. Thank you for your
756 testimony. The chair now recognizes Dr. Grossman for five
757 minutes for your opening statement.
758

759 STATEMENT OF DR. MIRIAM GROSSMAN, MD
760
761 *Dr. Grossman. Thank you, Chairman Guthrie and members
762 of the subcommittee. Thank you for the opportunity to
763 address you.
764 My name is Miriam Grossman. I am a board certified
765 child, adolescent, and adult psychiatrist, author, and
766 Senior Fellow at Do No Harm. I have been taking care of
767 patients for 45 years.
768 I am going to use my time to respond to Dr. McNamara.
769 First, I am struck by her use of the phrase "sex assigned at
770 birth.'' Sex is not assigned at birth. Sex is established
771 at conception and it is recognized at birth, if not earlier.
772 Dr. McNamara claims that her views are science-based, but to
773 claim that sex is assigned at birth is without any
774 scientific basis whatsoever. Its language misleads people,
775 especially children, into thinking that male and female are
776 arbitrary designations and can change. That is simply not
777 true.
778 Dr. McNamara claims that social and medical

779 interventions are the only evidence-based treatment and that
780 scientific evidence shows it is lifesaving. Without it, she
781 is warning us kids will commit suicide. Well, a growing
782 number of countries have effectively banned the care to
783 which she is referring. And thank God there has been no
784 wave of suicides or other mental health catastrophes.
785 Three years ago, Finland placed strict limitations on
786 medical interventions for minors. Sweden did the same thing
787 after a 14-year-old girl was found to have osteoporosis and
788 spinal fractures from puberty blockers. An investigation
789 concluded, "The risks of anti-puberty and hormone treatment
790 for those under 18 currently outweigh the possible
791 benefits.''
792 The UK conducted a review and called the evidence very
793 low. They have also placed severe restrictions on the care
794 that Dr. McNamara calls lifesaving. Norway also analyzed
795 the data and has made similar changes in policy.
796 The National Academy of Medicine in France warned,
797 "Great medical caution must be taken in children and
798 adolescents given the vulnerability of this population and

799 the many undesirable, even serious, complications the
800 therapies cause.'' Doctors in New Zealand and Australia
801 have published similar statements.
802 Is Dr. McNamara suggesting that all these countries are
803 rejecting evidence-based treatment and placing their kids at
804 risk of suicide? Regarding that point of view, Finland's
805 gender expert, Dr. Ritta Kaltiala, said, "It's purposeful
806 disinformation, the spreading of which is irresponsible.''
807 All seven countries and Florida, too, of course,
808 concluded that kids don't need their development
809 interrupted. The girls don’t need their periods stopped and
810 their voices lowered, and the boys don't need to grow
811 breasts. What they need is psychotherapy.
812 I have other objections to Dr. McNamara's testimony.
813 She insists that her position, only hers, represents
814 standard medical care. What she doesn't want you to know is
815 that there is no standard. There is a debate. There is a
816 fierce debate, and on the side opposite her stands such
817 prominent figures as Stephen Levine, Kenneth Zuker, Paul
818 McHugh, and James Cantor, among others.

819 These doctors are giants in the field. They have been
820 treating transgender patients, and gathering data, and
821 publishing papers about them, and I mean no disrespect here,
822 but since before Dr. McNamara was born.
823 The point is that those veteran clinicians and others
824 who have wisdom and experience are ignored because they
825 disagree with the current narrative. They are against
826 medical interventions for the same reason those seven
827 countries are. There is no evidence of long-term benefit,
828 but there is evidence of harm.
829 I will end by quoting Jamie Reed, the courageous
830 whistleblower from the Children's Gender Clinic in St.
831 Louis. I believe that that hospital receives the medical
832 education funding that we are discussing today. She said
833 that doctors at that clinic said, "We are building the plane
834 while we are flying it.'' We are building the plane while
835 we are flying it. That is how they described the treatment
836 at their gender clinic. Our precious tax dollars should not
837 support such a perilous experiment. Thank you.
838 [The prepared statement of Dr. Grossman follows:]

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839

840 **********COMMITTEE INSERT**********

841

**This is an unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker**

842 *Mr. Guthrie. Thank you for your testimony. The chair
843 now recognizes Mr. Manahan for five minutes for your opening
844 statement.
845

846 STATEMENT OF GEORGE MANAHAN

847

848 *Mr. Manahan. Good morning, Chairman Guthrie, Ranking
849 Member Eshoo, and members of the Subcommittee on Health. My
850 name is George Manahan, and I am testifying today as a
851 patient and advocate in support of H.R. 2365, or better
852 known as the National Plan to End Parkinson's Act.
853 I am not a policy expert like most of these people up
854 here. I am a small business owner from West Virginia just
855 trying to navigate the world of Parkinson's while providing
856 jobs to 12 full-time employees.
857 Mr. Chairman, can I ask for a show of hands? I am
858 interested to know how many people on the committee know
859 someone personally with Parkinson's Disease. Wow.
860 I ask that question because when I was diagnosed 13
861 years ago at age 49, I didn't know anyone with Parkinson's.
862 It is great to see there is a recognition of the disease by
863 this committee. For those of you who don't know someone
864 with Parkinson's Disease, I humbly say, you do now.
865 Everyone's Parkinson's journey is different. Mine

866 started with tightening of muscles in my right arm and leg
867 followed with tremors. The tremors became so bad that I
868 would hide my shaking arm in a pocket, the couch cushions,
869 or anything that would keep my disease from becoming public,
870 and to relieve the pain that I experienced.
871 I was persuaded to try brain surgery known as deep
872 brain stimulation. The results were incredible. My tremors
873 were mostly gone, as you can see. I remember crying with my
874 wife, Susan, in a doctor's parking lot after my Parkinson's
875 specialist turned on my transmitter and watched my tremors
876 fade away. But DBS is not a cure. It is an effective
877 therapy for someone with movement issues.
878 Over the years my brain has slowed significantly making
879 it difficult for me to manage more than one task at a time.
880 I'm sorry. They call it executive function, but I call it
881 forced retirement. Some nights I act out in my dreams,
882 another byproduct of my Parkinson's, and I feel I will
883 someday injure my wife or myself. My speech has been
884 impacted, and I am having some difficulty swallowing. One
885 of the leading causes of death is choking on food.

886 One of these symptoms by themselves wouldn’t be a
887 problem, but Parkinson's has a way of piling on. When I was
888 diagnosed, I craved to find other people who had this
889 disease like me, but in my hometown there was -- they were
890 nowhere to be found. I found out later that they were home
891 suffering alone.
892 So we started a 5K walk and run that blossomed into
893 support groups, and free exercise classes, and caregiver
894 forums, and more. Soon we had over 200 people or more
895 showing up to raise money, advocate, and learn from each
896 other.
897 A 2022 report on the economic burden on Parkinson's
898 calculates the cost of PD at 52 billion dollars. Half of
899 that money is paid by the Federal Government for Medicare;
900 the other half is paid by patients and families. I don't
901 believe that those figures calculate the tremendous loss of
902 income and jobs that families experience when someone has to
903 stay home to care for their loved ones. I often worry what
904 will be the burden just ahead for my wife.
905 I am here today to speak in support of H.R. 2365, which

906 is an important first step to relieve the economic and
907 emotional burden of Parkinson's Disease. The national plan
908 is bipartisan, no-cost legislation that is being championed
909 by Representative Bilirakis, thank you, and Representative
910 Tonko here in the House, and my senator, Shelly Moore
911 Capito, in the Senate. It is patterned after highly
912 successful legislation that passed 10 years ago for
913 Alzheimer's Disease.
914 What I particularly like about this bill is that
915 patients, caregivers, healthcare providers, people who are
916 on the frontline of the disease will have a seat at the
917 table. The legislation will bring together the public and
918 private sector to develop a national plan. The title of the
919 bill may seem a little ambitious. You might ask, is it
920 possible to end Parkinson's Disease? I believe it is.
921 Through research, all things are possible.
922 We now have a biomarker that can detect Parkinson's
923 Disease with a high degree of accuracy. I imagine we will
924 soon be able to detect Parkinson's Disease long before we
925 see the first symptoms. This will open up research and

926 treatment opportunities that haven't previously been
927 available.
928 Mr. Chairman, Parkinson's patients throughout the
929 country support H.R. 2365. Let's take this first step
930 together to cure the disease. Thank you, sir.
931 [The prepared statement of Mr. Manahan follows:]
932
933 **********COMMITTEE INSERT**********
934

**This is an unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker**

935 *Mr. Guthrie. Thank you. Thank you for your
936 testimony. Mr. O'Connor, you are now recognized for five
937 minutes for opening statement.
938

939 STATEMENT OF KEVIN O'CONNOR

940

941 *Mr. O'Connor. Good morning, full committee Chair
942 Rodgers, Chairman Guthrie, Ranking Member Eshoo,
943 distinguished members of the committee. I am Kevin
944 O'Connor, and it is my honor to be here representing the
945 International Association of Fire Fighters. There are
946 336,000 members who right now are on duty in each of the
947 Nation's 435 congressional districts.

948 My written testimony has been provided. Beyond the
949 IAFF, all major fire service organizations, the volunteers,
950 the chiefs, the Congressional Fire Service Institute, all
951 support the reauthorization of the firefighter cancer
952 registry. The reason is because occupational cancer is the
953 number of one killer of firefighters.

954 Mr. Chairman, close to your district, a 46-year-old
955 battalion chief, Johnnie Jacobs, in Georgetown lost a battle
956 with lung cancer. He was a non-smoker and actually chaired
957 the department's wellness program. Georgetown has since
958 instituted a screening program, but it was too late for

959 Chief Jacobs.

960 Ranking Member Eshoo, 41-year-old Captain Jose Martinez
961 from San Jose just passed from a rare soft tissue cancer.

962 Members of the committee, please talk to your
963 firefighters. You will hear stores and anecdotes like this
964 no matter where you are from.

965 Before I traded in my bunker gear for a suit, I worked
966 on the busiest ladder company in Baltimore County and saw my
967 fair share of fires and hazmats and other incidents. As my
968 career progressed, I delved into the actual statistics on
969 firefighter mortality and the causes of line of duty deaths.
970 I have seen friends die from cancer. As the local
971 president, I consoled families and visited members in
972 Hospice. Then at age 52, I got that dreaded call that I had
973 cancer. Thankfully, I beat it and am cancer free.

974 Firefighting is a filthy and dangerous job in which
975 members are consistently exposed to toxins and other
976 carcinogens. There are persistent inhalation risks even
977 while wearing a breathing apparatus. On a wildfire, the
978 exposure to our members is nonending, lasting through the

979 entire deployment of their tours.

980 Last week, as you may have seen, there was a large
981 truck fire and bridge collapse along I-95 in Philadelphia.
982 Those responders to that incident were exposed for many
983 hours to billowing petroleum-based smoke along with the dust
984 particulates from the collapse. This happens daily.
985 Plastics, adhesives baked in flame retardants and other
986 chemicals make today's smoke composition more accurate and
987 deadly.

988 Firefighters are also exposed to diesel exhaust at the
989 stations where they live 56 hours a week. They sleep
990 directly next to or above a garage. When an engine responds
991 to a call, they pull out leaving a diesel cloud trapped in
992 the engine bay. In many stations, the bay area actually
993 doubles as a rec room or training center.

994 To add a little perspective, in 2020, the last year
995 that statistics are available, 36 million 911 responses were
996 recorded, and that doesn't include fire apparatus routinely
997 leaving the station for inspections, repairs, trainings, et
998 cetera. That is a lot of exposure.

999 We recently uncovered data showing their bunker or
1000 turnout gear is laden with cancer-causing PFAS that absorbs
1001 through a firefighter's skin. Simply put, our own gear is
1002 killing us. That is unacceptable. Every firefighter needs
1003 at least one, and preferably two, sets of PFAS-free gear for
1004 our own health and safety. We get cancer earlier and die on
1005 average at rates 15 percent greater than the general
1006 population, and more than 150 percent above the average for
1007 really lethal cancers like pancreatic, lung, kidney,
1008 testicular, breast, and cervical.
1009 Those are the reasons why the World Health Organization
1010 recently named firefighting as a Group 1 carcinogen. That
1011 is their most deadly level. It is real, it is
1012 scientifically proved, firefighting is a cause of cancer.
1013 The Fire Service does our best to police ourself. We
1014 are supporting early screening processes like GRAIL's
1015 Galleri test that can detect over 50 cancers through a
1016 simple blood draw or the more traditional imaging scans.
1017 Early screening saves lives. And I like to do a commercial
1018 for the Multi-Cancer Early Detection Act. It is very

1019 important that this is passed so these testing methodologies
1020 can be incorporated into Medicare and insurance programs.
1021 They save lives.
1022 Here is the bottom line, the -- without medical data,
1023 researchers and epidemiologists can't uncover trends and
1024 specific profiles to solve this epidemic. We need to track
1025 cancers in the Fire Service and the firefighter cancer
1026 registry is our best and perhaps the only chance to do so.
1027 It took a few years to really get the registry operational.
1028 It finally kicked off in April. Currently there are about
1029 4,000 registrants.
1030 Every single Fire Service organization is working with
1031 CDC to educate and register our members. If the registry is
1032 not authorized, we are back at square one. That can't
1033 happen. Stand with firefighters and pass H.R. 3821.
1034 I will conclude with this. From the time the registry
1035 was enacted until the end of last year, the IAFF had 959
1036 line of duty deaths. 630 of those deaths, or over two-
1037 thirds, were attributable to occupational cancer. No more
1038 needs to be said.

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1039 I thank you for the opportunity and am delighted to
1040 answer any questions.
1041 [The prepared statement of Mr. O'Connor follows:]
1042
1043 **********COMMITTEE INSERT**********
1044

1045 *Mr. Guthrie. Thank you for your testimony.

1046 We are now going to move into member's questions, and
1047 we are going to try to stick to the five minutes, so please
1048 don't ask a question with two seconds left in someone's time
1049 because we want to give people a chance to answer the
1050 question of the important subjects before us today.

1051 So I will recognize myself for five minutes and begin
1052 asking questions.

1053 And to, Dr. Thompson, I want to ask you questions. I
1054 have a good friend whose son is living with Sickle Cell.
1055 What is amazing what happens for members of the committee,
1056 we have people that come -- people -- we had some arguments
1057 on pharma yesterday. Pharma. People think it is four or
1058 five big drug companies. It is actually a lot of innovative
1059 people out there trying to -- small companies. A lot of
1060 them -- and my good friend to my left's district who are
1061 trying to solve big problems.

1062 And I remember Dr. Francis Collins said, we can
1063 actually come into the forefront, we are going to cure
1064 Sickle Cell. And it is not just a chemical pill that people

1065 are going to be able to take. These are procedures,
1066 processes, genetics. They are individual medicine. And
1067 they are expensive.
1068 And so the chair -- the ranking member and I have
1069 worked together on value-based agreements within the
1070 Medicaid programs so the people, the most unfortunate, will
1071 have access to these cures.
1072 Would you talk about value-based agreements and why it
1073 is important to have -- this is where state Medicaid
1074 directors can negotiate with drug companies. Can you
1075 imagine having a state government person negotiate with a
1076 drug company and not get -- I still can't believe we don't
1077 have 435 votes in the House for this. But would you talk
1078 about why those are important to have access?
1079 *Dr. Thompson. Certainly. And thank you for bringing
1080 this to -- attention to the committee.
1081 Yes, I think that thinking about outcome-based payment
1082 arrangements, which are currently allowed in Medicaid, can
1083 and should be extended to some of these new treatment
1084 options. The results from the early results when things,

1085 for instance like gene therapy, are really incredibly
1086 exciting. And in the last three years, we have seen two new
1087 drugs approved -- three new drugs approved for Sickle Cell
1088 Disease, and we believe that there are more in the pipeline
1089 based on current clinical trials.
1090 This is something that I think could be taken on
1091 through the CMMI, the Centers for Medicare & Medicaid
1092 Innovations, looking at improving access. And I do think
1093 that looking at outcomes-based in terms of whether or not
1094 people have fewer Sickle Cell complications, evidence that
1095 their sickling is now gone. Other parameters that
1096 demonstrate durable success with some of these treatments --
1097 *Mr. Guthrie. Yeah, I would like to ask you another
1098 question. If I could move -- just kind of move it just a
1099 little bit. Chair Eshoo and I, working together again, sent
1100 a letter to the Centers for Biological Evaluation and
1101 Research, a receiver at FDA, and it was -- they responded
1102 that the -- about their meetings. The only responses for
1103 Type B meetings almost 80 percent of the time.
1104 These are critical meetings when the FDA, and

1105 regulators, and product sponsors as manufacturers work
1106 through the approval process. FDA responded that 79 percent
1107 of these meetings for complex cell and gene therapy are
1108 without in-person meetings. Would you comment of the
1109 complexity of developing these products and why it is
1110 important that we have -- the challenges of developing these
1111 and not having in-person meetings with FDA?
1112 *Dr. Thompson. I can't with any tremendous detail. I
1113 certainly would point out, though, that it is remarkable how
1114 much we have accomplished in part because of the
1115 requirements during the pandemic, that we have continued to
1116 have conversations as -- I am at an institution where we are
1117 also among those who are developing some of these therapies
1118 and being able to have open communications with them,
1119 whether they are in person or otherwise, today seems to be
1120 reasonably effective, and much of it has been gained by our
1121 hybrid meetings that have come out of the pandemic.
1122 *Mr. Guthrie. Okay, thank you. Thank you for that.
1123 So, Dr. Cherot, I have a cousin who is a neonatologist
1124 and every time we are together -- I am not a healthcare

1125 person by trade, so I have to pick his brain, and what is
1126 amazing is the development over the last decade in
1127 neonatology and how young these babies can live. The age of
1128 viability, if that is what people want to discuss, is
1129 actually pushing back further. It is certainly not at 39 or
1130 40 weeks, it is at -- you know, it is amazing what is moving
1131 forward.
1132 And so would you talk about to what extent the PREEMIE
1133 Program has contributed to these outcomes? And what is
1134 important for this hearing is gaps that you see and what we
1135 need to do better as we reauthorize the PREEMIE Program?
1136 *Dr. Cherot. Thank you for your question. Discovery
1137 research is vital to expanding the quality and volume of
1138 data that we -- that is needed to address the continuing
1139 knowledge gap. There is no silver bullet in treatment.
1140 Preterm birth is complex. 50 percent of it is -- has no
1141 ideology. There is others that we have induced or had c-
1142 sections for babies to be delivered because of maternal
1143 health conditions. And then there -- of course, there is
1144 that leakage of fluid and -- amniotic fluid, and that also

1145 contributes.

1146 The financial costs of preterm birth to society,

1147 including long-term costs and -- to society is one of the

1148 gaps that families in the NICUs, and post-discharge also,

1149 this would hopefully help us. We would also look into

1150 social factors that preterm birth rates need to be

1151 addressed. I would also say that identifying gaps in state

1152 and federal public health programs that have caused

1153 increases in preterm birth as well as practices that have

1154 led positive impacts.

1155 *Mr. Guthrie. Well, thank you. And I have only four

1156 seconds left. To live to what I just said, I am going to

1157 yield back, and I will recognize the ranking member for five

1158 minutes for questions.

1159 *Ms. Eshoo. Thank you, Mr. Chairman. Thank you to all

1160 of the witnesses.

1161 Let me start with Dr. Cherot. Thank you for your

1162 leadership. As I was listening to you, I thought, is it

1163 really 18 years ago that we wrote this legislation. I am

1164 very proud of it and everyone that was a part of it. Of

1165 course, we have reauthorized more than once.

1166 Briefly, because I have more than one question to ask
1167 of witnesses. What do you think has been effective over the
1168 last 15 years, and what do you think some of the causes of
1169 the recent surge are, and how does this reauthorization
1170 address those concerns?

1171 *Dr. Cherot. So there are several factors that
1172 contributed to the high rate of preterm birth. Inadequate
1173 prenatal care, and preexisting maternal health conditions,
1174 like diabetes, hypertension, obesity, all contribute. I
1175 would say that addressing this in the future is that we are
1176 looking at exciting, promising research. March of Dimes
1177 contributes to that research, and we have prematurity
1178 research centers.

1179 We -- actually, if you think about it, we had
1180 enhancements in diagnostic test we never had before such as
1181 preeclampsia, which is the number one morbidity for black
1182 women in this country. And those are type of the solutions
1183 that we are trying to research, that this PREEMIE Act will
1184 help further.

1185 *Ms. Eshoo. Wonderful. Okay. To, Dr. McNamara, you
1186 just sat through testimony that I believe is chock full of
1187 dangerous misinformation and pseudoscientific "facts,''
1188 warped to fit, I think, a really outdated narrative of the
1189 trans experience in our healthcare system. We could spend a
1190 long time talking about that, but I want to give you the
1191 opportunity for a minute to respond.
1192 I have spoken to pediatric endocrinologists in my
1193 district who treat hormone disorders in children every day.
1194 Every day. And as we all go about doing whatever we are
1195 doing, this is taking place. This is taking place in our
1196 country. And it includes, which I was not aware of, early
1197 cases of -- cases of early puberty in children as young as
1198 two years old. I had never heard of that.
1199 This causes, obviously, a lot of serious issues. One
1200 of the treatments is providing GnRH analogue therapy, a
1201 banned medical intervention under the legislation that is
1202 being considered here today. And I -- again, to have, you
1203 know, two-year-olds, six-year-olds, youngsters subjected to
1204 this is -- well, I think you can hear it in my voice. I am

1205 deeply unsettled about this.

1206 Do you want a like 30-second response --

1207 *Dr. McNamara. Thank you, Congresswoman.

1208 *Ms. Eshoo. -- since I ate up some of your time?

1209 *Dr. McNamara. Yes. So all five themes of the
1210 misinformation that I have identified in my work are on
1211 display. I am a coauthor of extensive rebuttals with
1212 science to all of them, it is entered into my testimony, and
1213 those documents have been used to successfully challenge
1214 bans on care for trans youth in Texas, Florida, and Alabama.

1215 The other testimony espouses two levels of harm:
1216 abolishing evidence-based care and creating a vacuum. The
1217 force withdrawal of care is akin to experimentation.
1218 Dangerous, discredited conversion practices that attempt to
1219 convince a young person that they are not gay or not trans,
1220 we have moved on from that. Most states have banned that
1221 care in this country.

1222 It is toxic for an adult to tell an adolescent that
1223 there is something wrong with them. I am sure there are
1224 many parents in the room, and you would never want your kid

1225 to go through that. Suicidality is a debilitating way to
1226 endure adolescents. A suicide attempt is a traumatic
1227 interruption in a young person's life.
1228 Let's be clear. Pediatricians know that lifesaving
1229 means life sustaining. When trans youth receive the
1230 standard of care, they thrive. They develop talents, they
1231 discover their strengths, and they get to be who they
1232 deserve to be.
1233 *Ms. Eshoo. Thank you.
1234 Kevin, I wanted to know why CDC took almost five years
1235 to implement the legislation and now we are reauthorizing
1236 it, but I think you are going to have to maybe answer that
1237 question for someone else, but at least I get it on the
1238 record.
1239 *Mr. Guthrie. Okay.
1240 *Ms. Eshoo. Thanks for being here.
1241 *Mr. Guthrie. Yeah, we will have the chance where we
1242 can do it --
1243 *Ms. Eshoo. I yield back, Mr. Chairman.
1244 *Mr. Guthrie. -- moving forward. Thank you for

1245 yielding back. The chair now recognizes the chair of the
1246 full committee for five minutes for questions.
1247 *The Chair. Just to clarify, the bill does not ban
1248 treatment for precocious puberty, which the ranking member
1249 just alluded to.
1250 So a recent report found that the number of clinics in
1251 the United States focused on providing puberty blockers,
1252 hormone therapies, and surgeries for gender affirming care
1253 has grown from just a few to more than a hundred as of
1254 February 2023. Dr. Grossman, in your written testimony you
1255 mentioned how certain European countries have decided to
1256 take a more cautious approach and significantly limit the
1257 use of puberty blockers and hormone therapies to treat
1258 gender-related conditions in minors. Is the United States
1259 an outlier?
1260 *Dr. Grossman. Well, it certainly -- yes, more and
1261 more becoming so. I just want to take one moment because
1262 this is really bothering me. Representative Eshoo, I am
1263 sorry if I am mispronouncing your name.
1264 *The Chair. That is right.

1265 *Dr. Grossman. Representative, you are very confused
1266 about something. When we -- when --
1267 *Mr. Guthrie. I am sorry, just -- [indiscernible]
1268 suspend.
1269 *Dr. Grossman. Yes. Representative, you -- I would
1270 like to clarify something for you.
1271 *The Chair. You can clarify it to me. Clarify it to
1272 me.
1273 *Dr. Grossman. Yes. Precocious puberty is a medical
1274 condition. It is a condition in which the child had --
1275 *Mr. Guthrie. What's that -- I am sorry, would you --
1276 could you suspend the clock for a second?
1277 *Ms. Eshoo. She spoke to me directly, Mr. Chairman.
1278 *Voice. And she can't characterize how you --
1279 *Ms. Eshoo. You can't characterize me.
1280 *Mr. Guthrie. Yeah. Okay, you can't characterize the
1281 way that she is -- her question or what she has asked, so if
1282 you would just respond to --
1283 *Dr. Grossman. Okay, I am --
1284 *Mr. Guthrie. -- the chair who is asking the question.

1285 *The Chair. Yes.

1286 *Dr. Grossman. Okay.

1287 *Mr. Guthrie. Thank you.

1288 *Dr. Grossman. The point is that precocious puberty,
1289 which we have treated with blockers for decades and is
1290 approved by the FDA for that use, that is a medical
1291 disorder, that is a disorder in which the child has abnormal
1292 hormone levels circulating that causes their bodies to
1293 premature enter -- prematurely enter puberty. We do not
1294 want that to happen.

1295 We are talking about an experimental use of these
1296 agents in children that are completely healthy. They have
1297 no medical disorder. So we are artificially blocking a
1298 biological process, a natural process called puberty.
1299 Puberty is not a disorder. We need to go through puberty in
1300 order to reach adulthood. Every system of the body, the
1301 brain included, needs to go through puberty to reach
1302 adulthood.

1303 And what we are doing in gender affirming care is
1304 stopping that natural organic process and blocking it and

1305 then shortly thereafter, in most cases, over 90 percent of
1306 cases, administering the hormones of the opposite sex so
1307 that the child will go through a synthetic puberty, not the
1308 organic puberty --
1309 *The Chair. Thank you.
1310 *Dr. Grossman. -- but a synthetic puberty. Okay, I am
1311 sorry.
1312 *The Chair. Thank you.
1313 *Dr. Grossman. You asked me about the European
1314 countries.
1315 *The Chair. I asked you if the United States was an
1316 outlier.
1317 *Dr. Grossman. Absolutely.
1318 *The Chair. Okay, thank you.
1319 *Dr. Grossman. The United States and Canada are out --
1320 *The Chair. And would you speak to what the data tells
1321 us about the long-term impacts of these medical
1322 interventions?
1323 *Dr. Grossman. So that is the thing. You see, this,
1324 until recently, was an extremely rare condition. It was so

1325 rare that when I went to medical school decades ago, I never
1326 expected to see one case in my life. That is how rare it
1327 was. And now that is all I do.
1328 So you see, in the past 10 years or so, specifically
1329 since maybe 2015, there has been an explosion of cases, an
1330 absolute tsunami of cases, and the question is why is that.
1331 And those cases are very different than previous cases.
1332 This is a new population. The old -- the prior gender
1333 dysphoric cases that we studied were mostly --
1334 *The Chair. Thank you.
1335 *Dr. Grossman. -- boys.
1336 *The Chair. Okay. Yes, thank you. I wanted to get to
1337 girls, too, because I am -- I had mentioned my concern about
1338 the mental health crisis for young girls. And over your
1339 career, would you speak to how patients experiencing gender
1340 dysphoria changed in the number and characteristics, and
1341 also speak to the long-term impacts for these medical
1342 interventions?
1343 *Dr. Grossman. Okay. So what I was -- wanted to say
1344 is that when we speak about long-term, we don't have the

1345 data yet because these are just -- this is a new population
1346 called ROGD, rapid-onset gender dysphoria. And we are just
1347 studying them now. It is a new demographic. Mostly girls
1348 but lots of boys as well. My practice is 50 percent boys.
1349 These are kids who have a lot of previous mental health
1350 conditions --

1351 *The Chair. Okay, thank you, Dr. Grossman. Thank you.
1352 I am going to have to cut it off there because I heard my
1353 colleagues say that this should be a private decision
1354 between parents, teachers, and doctor -- or parents,
1355 children, and doctors, that we should protect parent rights,
1356 and that Republicans are putting politics between children,
1357 parents, and the doctor.

1358 The truth is parents are being removed from their
1359 children's doctor's offices and kids are being taken from
1360 their parents and their homes. It is making it us versus
1361 them. That is my fundamental concern.

1362 I yield back.

1363 *Mr. Guthrie. Thank you. The chair yields back. The
1364 chair now recognizes the ranking member of the full

1365 committee, Mr. Pallone, for five minutes for questions.

1366 *Mr. Pallone. Thank you, Mr. Chairman.

1367 I have to say I am deeply disappointed in the partisan
1368 Children's Hospital GME legislation being considered today.
1369 It prescribes in very minute detail the types of care that
1370 must be prohibited in order to receive funding and tells our
1371 healthcare providers, major medical associations, and
1372 patients that Republican members of Congress know better
1373 than them about what should be considered standards of care
1374 within our medical system. And that should scare us all,
1375 particularly when this program is designed to train the next
1376 generation of pediatricians and pediatric subspecialists.

1377 So my questions are of Dr. McNamara. I know that
1378 transgender people and those who advocate for the rights of
1379 transgender people are currently facing fear, intimidation,
1380 threats of violence. But I believe that we must speak out
1381 on their behalf and support them, and I want to say thank
1382 you to you today for doing so.

1383 Now turning to my questions. If this bill were to
1384 become law, what would the impact be on pediatric care?

1385 *Dr. McNamara. So I am very privileged to sit next to
1386 two people who have shared details about the types of
1387 medical care that benefit patients who I have cared for in
1388 my career, people with Sickle Cell Disease, premature
1389 babies. Many people here might not know what goes into that
1390 type of care, but I do. And it is not my specialty anymore.
1391 I have subspeciality training in adolescent medicine.
1392 But the experiences that I had in a NICU in the middle
1393 of the night resuscitating preterm infants, counseling their
1394 parents, working with my colleagues, offering advanced
1395 treatments for Sickle Cell to children with crippling pain
1396 have forever shaped my training. I am an excellent clinical
1397 researcher because of my training as well. And I think that
1398 I am not the only person. You know, I spoke to so many of
1399 my colleagues about this testimony. Everyone expressed
1400 disbelief and regret that it would escalate this far.
1401 Everybody wants children to be healthy and safe, but
1402 their care and what they require to be healthy and safe is
1403 expert. We know what we are doing. We know how to do it
1404 really well. And all that we ask is that we be allowed to

1405 do it without any sort of legal interference.

1406 *Mr. Pallone. I appreciate that. I mean, what I am
1407 seeing here, and in so many different forums, is Republicans
1408 -- Republican Congress people trying to or determined to
1409 substitute their opinion for experts, experts in medical
1410 fields, experts in agencies, and it is truly scary.

1411 The legislation is not only an attack on transgender
1412 youth and their families but it is an attack on providers
1413 and the training they receive. Can you speak to how this
1414 would impact the training that pediatric residents receive?
1415 Briefly, because I have one more question.

1416 *Dr. McNamara. Yes, of course. We are already seeing
1417 that less people are looking to go into pediatrics because
1418 it has been politicized and interfered with. There is a
1419 great deal of moral injury that accompanies being told what
1420 you can and can't do and needing to legally withhold care
1421 from people who need it whose lives depend on it. So I
1422 would expect not only would it cut off at the knees the vast
1423 majority of training for pediatrics residents and fellows in
1424 this country, but it would deter the future of

1425 pediatricians.

1426 *Mr. Pallone. So what -- you are seeming to suggest
1427 that this would have an impact on the pediatric workforce.
1428 Do you want to comment on that?

1429 *Dr. McNamara. It would have a devastating impact on
1430 the pediatric workforce. People would bring sick kids into
1431 children's hospitals and there wouldn't be anyone there to
1432 take care of them.

1433 *Mr. Pallone. Well, thank you.

1434 You know, Mr. Chairman, I can't understand why the
1435 majority has chosen to hijack this critical program to have
1436 an ideological battle. I just don't understand it. This
1437 committee has a long history of working together to solve
1438 important healthcare challenges and training our healthcare
1439 workforce being one of the most important. It is just
1440 disappointing that instead of considering Representative
1441 Schrier's bill to reauthorize this program on a bipartisan
1442 basis as we have done in the past that the Republican
1443 majority has instead decided to jeopardize the
1444 reauthorization of the CHGME through this harmful and

1445 inhumane policy, and I just don't understand it.

1446 I urge my colleagues to strongly oppose this build --

1447 this bill. And I yield back, Mr. Chairman.

1448 *Mr. Guthrie. Thank you. The ranking member yields

1449 back. The chair now recognizes Dr. Burgess for five minutes

1450 for questions.

1451 *Mr. Burgess. Thank you, Mr. Chairman.

1452 Dr. Thompson, I have worked with Representative Davis

1453 for a number of years on this issue that you have brought to

1454 us today and the reauthorization of the Sickle Cell Disease

1455 bill. 2018 was the first reauthorization that has happened

1456 since 2004 when it was tacked onto a tax bill, believe it or

1457 not. So can you speak to why it is important that we

1458 reauthorize the bill?

1459 *Dr. Thompson. I am happy to. And thank you so much

1460 for your long-term support.

1461 One of the important things that happened in this most

1462 recent cycle was the ability to expand this program so that

1463 it now covers all 50 states. But all of the efforts prior

1464 to that were focused on certain areas, and the fact -- prior

1465 to this most recent cycle, there was a substantial region,
1466 and that is the U.S. Southeast. That was not included in
1467 competitive -- as a competitive region, clearly an area
1468 where there was a high concentration of Sickle Cell
1469 patients.
1470 This current structure allows us not only to ensure
1471 that with this regional hub and spoke approach that we are -
1472 - we have access in all 50 states, but they are actually now
1473 diffusing the expertise that occurs primarily at academic
1474 medical centers and ensuring that patients actually have
1475 access to physicians who are more knowledgeable, even if
1476 they are in primary care practices, even if they are in
1477 community practices, and that was a fundamental change --
1478 *Mr. Burgess. Sure.
1479 *Dr. Thompson. -- for the comprehensive care that is
1480 dispersed, I believe, in a more equitable way.
1481 *Mr. Burgess. And something you said during your
1482 testimony, there have been various FDA approved therapies
1483 that have happened in the past couple of years, is that not
1484 correct?

1485 *Dr. Thompson. That is absolutely correct, yes.
1486 *Mr. Burgess. And we sat in this same hearing in 2016,
1487 the Sickle Cell Disease advocate was at the table where you
1488 are. I can't say that I was paying complete attention, but
1489 she made the statement, it has been 40 years since there was
1490 an FDA approved treatment for Sickle Cell. It really -- I
1491 mean, it jarred me because 40 years took me back, I was an
1492 intern at Parkland Hospital taking care of Sickle Cell
1493 patients in the emergency room. So in that 40-year
1494 timespan, we hadn't helped.
1495 I know the things that Representative Guthrie is
1496 talking about in his value-based care that he offered in a
1497 different bill that we heard in a markup, and it is
1498 expensive, and we have to pay attention to that. But is
1499 there any way to estimate what was the cost of doing nothing
1500 for 40 years?
1501 *Voice. Oh, I forgot to do this.
1502 *Dr. Thompson. I think that is a very difficult
1503 equation. You are absolutely right. But having said that,
1504 even in that 40 years when we just had one drug, that drug

1505 was hydroxyurea, a repurposed chemotherapeutic agent. And I
1506 dare say that since it was originally approved in the late
1507 1990s, we really have seen repeated clinical trials, many of
1508 which were federally funded, that continue to demonstrate
1509 its effectiveness, and it is not expensive.
1510 Having said that, it is currently one of the many drugs
1511 that we currently are experiencing in shortages in this
1512 country.
1513 *Mr. Burgess. I see.
1514 *Dr. Thompson. And so certainly we have multiple
1515 problems. We have a limited number of drugs, and then even
1516 some drugs that clearly will work, we currently are
1517 experiencing a shortage. We also still have providers who
1518 are unaware that there are any treatments available for
1519 Sickle Cell Disease, and so we think that there are
1520 opportunities to utilize things --
1521 *Mr. Burgess. True.
1522 *Dr. Thompson. -- like the HRSA program to disseminate
1523 that kind of education and training.
1524 *Mr. Burgess. That is absolutely critical.

1525 Dr. Cherot, let me just ask you a couple of questions
1526 on both the PREEMIE Act and the Preventing Mental (sic)
1527 Deaths Act. On the Preventing Maternal Deaths
1528 reauthorization, you kind of answered this question for
1529 Representative Eshoo, but can you just speak to the fact
1530 that it is important to reauthorize to build on the work
1531 that has happened before?
1532 *Dr. Cherot. Absolutely, yeah. First and foremost,
1533 thank you, and thank you for your story of your daughter.
1534 The PREEMIE Act helps shrink our knowledge gap, I should
1535 say, and closes that gap around the data that we need to
1536 continue to fill in to be able to do that research. We need
1537 the -- CDC's PRAMS Program is one such highly effective tool
1538 that has allowed us to better understand trends, risks, and
1539 other factors impacting pregnant and lactating people, and
1540 that alone is in this.
1541 *Mr. Burgess. So -- and this will help providers,
1542 right, taking care of those very premature infants?
1543 *Dr. Cherot. Absolutely. We talked about neonatal
1544 intensive care unit that at -- who are at the bedside who

1545 need better data. I think about the 30 years I have been
1546 delivering babies. The surfactant was a huge impact helping
1547 lung expansion, getting more research and solutions to help
1548 preemies is where -- the aim of this.
1549 *Mr. Burgess. Very good. Thank you, Mr. Chairman, I
1550 will yield back.
1551 *Mr. Guthrie. The gentleman yields back. The chair
1552 recognizes Mr. Sarbanes for five minutes for questions.
1553 *Mr. Sarbanes. Thanks very much, Mr. Chairman. As
1554 this hearing makes clear, Congress must authorize this year
1555 several healthcare programs to continue critical data
1556 collection, research, treatment efforts that promote better
1557 access to care and cures for millions of Americans. One of
1558 those, as we have heard, is the National Firefighter Cancer
1559 Registry which seeks to improve data collection to better
1560 target efforts to address cancer prevalence among
1561 firefighters. It is a vitally important effort because
1562 these selfless first responders are often exposed to PFAS,
1563 as we heard, and other toxins daily as they protect our
1564 community.

1565 Mr. O'Connor, first, thanks for your lifetime of
1566 service, thanks for your service to the citizens of
1567 Baltimore County, which I am very familiar with. Given the
1568 high-risk exposures that firefighters face, explain again
1569 the important of the registry, and then in particular, the
1570 actions the Fire Service and local governments are taking to
1571 ensure that their firefighters are getting the requisite
1572 screenings, if you would?
1573 *Mr. O'Connor. Thank you, Congressman. The Fire
1574 Service traditionally has not been awash in good data. In
1575 fact, quite frankly, the data that we have is terrible.
1576 That is partially responsible for the fact that it is a
1577 local function of government, so there has never been a
1578 repository for anything really in the Fire Service. And as
1579 medical science and research has proven the occupational
1580 risk of cancer, we have never been able to get a handle on
1581 the overall number of firefighters who have cancer, where
1582 they are located, what specific exposures are the cause, the
1583 frequencies of the cancers, many of which are very, very
1584 anomalous, they are not the normal prostate, they are very

1585 strange cancers.

1586 What proves that more than anything else is the
1587 aftermath of 911. We lost 343 firefighters that day during
1588 the collapse, but since then there has been over 1100 who
1589 have died from various respiratory and cancer illnesses, and
1590 they are just very strange illnesses. So we are trying to
1591 get a handle on that.

1592 So the registry, when it was originally conceived, it
1593 is voluntary, but to try to actually get a full accounting
1594 of all the firefighters, career and volunteer, we encourage
1595 people to register, whether or not they have been afflicted
1596 with cancer, so that we develop a baseline for future
1597 studies.

1598 In our view, the best mechanism to try to deal with
1599 this is through early screening. And regrettably, there is
1600 no mechanism to do that. In our State of Maryland, the
1601 Professional Firefighters of Maryland, the local that you
1602 represent in Anne Arundel County, Howard County, Annapolis,
1603 the airport, their members self-pay essentially to have
1604 screenings, cancer screenings. The jurisdictions don't

1605 provide it.

1606 That is a real problem because we know that if we get
1607 firefighters early, they are detecting Stage 1 pancreatic
1608 cancers, for example. That is treatable. When it gets
1609 beyond that, it is a death sentence.

1610 So our two challenges are, one, making sure that we
1611 have adequate data and making sure that our members have
1612 access to that type of testing. What would be ideal, quite
1613 honestly, if HHS followed the World Health Organization and
1614 essentially recognized firefighting as a high-risk
1615 profession so that insurance coverages would take care of
1616 these testings and our people wouldn't have to self-pay.

1617 *Mr. Sarbanes. Thank you very much, I appreciate it.

1618 Let me switch gears quickly. One of the benefits of
1619 this graduate medical education program that we have been
1620 taking about with Children's Hospital is that it contends
1621 with two significant and intersecting challenges. One being
1622 the children's mental health crisis and the other being
1623 healthcare workforce shortages at every level of care. And
1624 this program holds a unique opportunity to help us address

1625 both simultaneously.
1626 Dr. McNamara, as a pediatrician, medical professor, can
1627 you speak to the importance of a strong GME program for
1628 children's hospitals on our ability to strengthen an expand
1629 the pipeline of both mental and physical heath providers we
1630 need both now and into the future?
1631 *Dr. McNamara. Thank you very much. Sorry about that.
1632 We are very good at we do in supporting young people in
1633 navigating this new mental health crisis. We cannot do with
1634 less resources. It is simply not tenable.
1635 We do need more, but we are training ourselves in how
1636 to provide excellent mental healthcare by consulting with
1637 other experts. The guidelines are improving in order to
1638 kind of address the crisis that you have alluded to. If we
1639 are less supported, there will be nothing that we can do,
1640 and I just have to make that abundantly clear. We cannot
1641 make do with less.
1642 *Mr. Sarbanes. I appreciate that very much, and it is
1643 unfortunate that there is this effort to undermine the
1644 program when it can protect the health and wellness of every

1645 single child and adolescent. That concern, that focus is
1646 too important for partisan politics, so I urge the committee
1647 to take that responsibility seriously. Let's pass a clean
1648 reauthorization bill. And I yield back.
1649 *Mr. Bucshon. [Presiding] The gentleman yields back.
1650 I now recognize Mr. Latta for his five minutes.
1651 *Mr. Latta. Thank you, Mr. Chairman, and thanks to our
1652 witnesses for being here today.
1653 And, Mr. O'Connor, if I could start my questions with
1654 you. First, thanks for your service out there. You know,
1655 when I -- in fact, last night about 9:00, right across from
1656 this building there was a ladder truck, another fire -- a
1657 pumper truck, and an ambulance right here on campus. And so
1658 we all know that our firefighters and our first responders
1659 are there 24/7 for us, and so we thank you for it.
1660 One of the things I would like to maybe check -- talk
1661 to you a little bit about because I know you were talking
1662 about the registry and the baseline and the screening, you
1663 talked a little bit earlier because, again, when I look at
1664 my district, the vast majority is volunteer. And so, you

1665 know, when you are talking about volunteers, first of all, I
1666 go to so many fish frys, pancake days, barbecues to try to
1667 help support. But there is no way we can keep up with it
1668 for them because, again, in talking with our chiefs out
1669 there and other fireman and firefighters, you are looking at
1670 probably 11 to $13,000 to equip a person just, you know, a
1671 fireman -- a firefighter out there right now, and so it is
1672 pretty expensive.

1673 But, you know, when you are talking about with the
1674 registry and the baseline and the screening, can -- how do
1675 we work with our volunteers out there, because first of all,
1676 with 70 percent of the country at volunteers, and we are --
1677 we have seen volunteers -- unfortunately, we are losing
1678 folks that they just aren't volunteering like they used to.
1679 What -- how do we help there?

1680 *Mr. O'Connor. Well, first, thank you for recognizing
1681 the difference between a ladder truck and a pumper. A lot
1682 of people don't make that distinction.

1683 I don't presume to speak for the National Volunteer
1684 Fire Council, but I will say this, under the leadership of

1685 our new General President, Ed Kelly, for the very first time
1686 in history, our organization sat down with the leadership of
1687 the NVFC and we are trying to forge a path together to help
1688 volunteers with retention and recruitment and making sure
1689 that for a lot of our members, the mandatory overtimes and
1690 the staffing shortages are abated.
1691 So I share your overall concern with the Volunteer Fire
1692 Service. They provide an invaluable service to the
1693 community which they serve, and the dedication of providers
1694 is really unmatched.
1695 With respect to the actual cancer registry and how we
1696 address that, it is more of a challenge. What we are trying
1697 to do on the career side, in departments large and small --
1698 and there is a misconception, too, with the IAFF. Most of
1699 our locals are under 30 members. Yes, we represent New
1700 York and the big locals, but throughout Ohio we have 285
1701 affiliates in a lot of small towns, so we face the same
1702 challenges. But, of course, on a volunteer basis, they are
1703 not employees.
1704 So we are trying to figure out a way to create

1705 incentives that the people register because their risks are
1706 no less than the risks that our people face. So in terms of
1707 your larger question, you know, it really needs to be an
1708 overall effort.

1709 I also want to credit the U.S. Fire Administrator, Dr.
1710 Lori Moore. We have a summit -- the first summit in like 50
1711 years of all the fire service organizations up at
1712 Emmittsburg, and we came out with one theme, and it is one
1713 voice fire service. And I can assure you the partnership
1714 between the organizations and the providers at the local
1715 level is very strong.

1716 *Mr. Latta. Oh, thank you.

1717 Mr. Manahan, if I could switch real quick to talk to --
1718 about your very -- your testimony is so powerful. You know,
1719 I -- hopefully we will have a cure in the future but, you
1720 know, some of the statistics out there, you know, in your
1721 testimony that 1.2 million people in the United States
1722 struggle with Parkinson's today, and it is expected to
1723 double by 2040.

1724 *Mr. Manahan. Yes, sir.

1725 *Mr. Latta. Could you -- and I know I only have about
1726 a minute left, but could you maybe go into that? Why are we
1727 going to see a doubling of the numbers in Parkinson's and
1728 what we can do?
1729 *Mr. Manahan. Well, I think there are several factors.
1730 Let me give all the statistics first real quick and then I
1731 will address your question. There is over a million people
1732 with Parkinson's. 50 percent -- I am sorry, 90,000 new
1733 people get diagnosed every year, and that is 50 percent
1734 higher than they first originally thought. Well, we are
1735 getting a lot of firefighters who are also getting
1736 Parkinson's Disease.
1737 It is the fastest growing neurological disease in the
1738 country. The number of people with Parkinson's, as you had
1739 mentioned, is supposed to double by 2040. Chemicals are
1740 playing a role in that. I -- you know, I think chemicals in
1741 firefighting obviously. But there is a lot of chemicals
1742 that people have been exposed to early on in their years and
1743 as they grow older they get Parkinson's Disease, and they
1744 make themselves more susceptible to Parkinson's Disease.

1745 But I -- you know, I think without a congressional
1746 mandate, we may be waiting for a cure for many years down
1747 the road. I think we have the time right now to do
1748 something really, really great for people with Parkinson's.
1749 *Mr. Latta. Thank you.
1750 Mr. Chairman, my time is expired, and I yield back.
1751 *Mr. Bucshon. The gentleman yields back. I now
1752 recognize Mr. Cardenas from California for his five minutes.
1753 *Mr. Cardenas. Thank you, Chair Guthrie. I appreciate
1754 this opportunity for us to have this hearing. Really
1755 pleased to see some of the bipartisan bills that we have
1756 been working on that we will be discussing here in this
1757 committee. But at the same time, I am deeply disappointed
1758 in the partisan Children's Hospital GME proposal put forth
1759 by my Republican colleagues.
1760 There is bipartisanship; however, clean reauthorization
1761 that easily could have been noticed by my Republican
1762 colleagues just had to take -- they just had to take another
1763 punch at young people, trans kids. These children, human
1764 beings just like you and me, who have done no wrong, no harm

1765 to anybody else, but just want to live their lives in truth.
1766 It is unfortunate that this bill is here before us.
1767 Welcome, everybody, to Pride Month.
1768 This Republican majority has gone out of its way not
1769 only to demonize access to care for trans children but to
1770 cut off access to Children's Hospital GME resources for any
1771 provider of those services. Why? Why is it so critical
1772 that you control the medical decisions of other people's
1773 kids and of those kid's doctors? I am once again shocked by
1774 the party of limited government stunning overreach into
1775 these private medical decisions.
1776 Now let's look at the numbers. In 2022, nearly one in
1777 five transgender kids attempted suicide. Of trans children
1778 who received gender affirming care, there were 60 percent
1779 lower odds of depression and 73 percent lower odds of self-
1780 harm or suicide thoughts. That is, in fact, lifesavings.
1781 There has been real honest bipartisan agreement in this
1782 committee on the need to improve youth mental health, yet
1783 now, we are further attacking these kids' access to care,
1784 degrading their mental health in the process, and pouring

1785 gas on the fire.

1786 You want to protect kids? All kids? Well, gender
1787 affirming care seems to have lifesaving, positive impacts on
1788 the mental health of trans youth. So this isn't about
1789 protecting American kids at all. And that is what is worse.
1790 You are pulling this political stunt when we know that one
1791 of the greatest threats to our healthcare ecosystem is
1792 workforce shortages. It is shameful that Republicans are
1793 holding pediatric care resources hostage to score political
1794 points at the expense of already vulnerable trans children,
1795 young human beings.

1796 The price of admission to practice pediatric medicine
1797 cannot and should not be discriminated against, especially
1798 when it comes to children.

1799 Dr. McNamara, in your experience, when patients have
1800 access to gender affirming care and can exist in gender
1801 affirming environments, in what ways does this improve
1802 adolescent outcomes?

1803 *Dr. McNamara. Thank you, Congressman Cardenas, for
1804 this question. We have spent a lot of time talking about

1805 how vulnerable transgender youth are, but I would like to
1806 take a moment to talk about how privileged I am to be able
1807 to care for them and how privileged I am to be part of a
1808 larger medical community that does.

1809 When transgender youth have unrestricted access to an
1810 affirming social environment and to medical treatments that
1811 they qualify for, and that they desire, and that their
1812 parents consent to, they thrive. Now what does it mean for
1813 an adolescent to thrive? It means that they are not their
1814 gender identity solely. It means that they develop their
1815 talents, they get really good at the piano, they learn how
1816 to ice skate, they get scholarships to college, they become
1817 productive members of our community who will make us
1818 stronger for years to come.

1819 In my clinical experience, I have seen this happen in a
1820 myriad of ways, and it is often that triangle of patient,
1821 parent, provider support that makes it happen. There is no
1822 room in there for anything else.

1823 *Mr. Cardenas. Thank you. We have limited time for
1824 our questioning, but I just wanted to say thank you so much

1825 for putting your heart and soul into every single one of
1826 your patients and treating every single one like a deserved
1827 human being. You say that you are privileged to have them
1828 and care for them. They are privileged to have you truly,
1829 truly care for them, to see them, to love them, and to give
1830 your heart and soul to your work and to them and their
1831 lives. Thank you very much.
1832 My time has been expired. I yield back.
1833 *Mr. Bucshon. The gentleman yields back. Mr. Griffith
1834 is now recognized for five minutes for his line of
1835 questioning.
1836 *Mr. Griffith. Thank you very much, Mr. Chairman.
1837 Mr. O'Connor, can you elaborate on some of the work
1838 being done to help lower PFAS toxins in firefighter gear
1839 that would make it more resistant to both the PFAS and maybe
1840 help firefighters as well?
1841 *Mr. O'Connor. We are -- technology is trying to catch
1842 up to this issue, and I am certain that Representative
1843 Dingell will probably bring it up. I know that she and
1844 Chairman Graves from the Transportation Committee are

1845 working on a bill that will soon be introduced on that
1846 issue.
1847 The first thing that really needs to be done is more
1848 testing. It is very, very abundantly clear that this exists
1849 in a vapor barrier. The history behind it is most
1850 firefighting gear, apparatus training, et cetera is
1851 established by standards promulgated by the National Fire
1852 Protection Association. They have a standard, without
1853 getting into all the details, that essentially a composite
1854 turnout -- a piece of turnout clothing has three layers: an
1855 outer layer, an inner layer that is a moisture barrier, and
1856 a layer beyond that.
1857 The moisture barrier is the area in which the PFAS is.
1858 And quite honestly, the way the standards were promulgated,
1859 only gear that had PFAS in it would be able to meet the
1860 standard. It is an ultraviolet light standard, which
1861 intuitively makes no sense because it is the middle layer of
1862 a garment. Its opportunity to see ultraviolet light is
1863 basically nonexistent. And this has created the problem.
1864 So there is various enterprises looking, studying it.

1865 The University of Notre Dame was the first one that really
1866 brought it up. I can't think of the researcher's name, but
1867 I will get you the information on some of the definitive
1868 evidence with respect to it.
1869 But there are people looking at it now, and I know
1870 there is going to be a field test that is going to begin in
1871 Metro -- West Metro, Colorado. Chief Don Lombardo is
1872 partnered with his local affiliate there, and they are
1873 putting a first set of supposedly non-PFAS gear into the
1874 field. It is a major issue. I am not the safety and health
1875 issue expert in our organization, but it is our number one
1876 issue in the Fire Service addressing the status of our gear.
1877 *Mr. Griffith. So here is one of the things I love
1878 about these hearings, and I know sometimes people think why
1879 am I here, people are moving in and out, and we have two
1880 hearings going on right now, and some people have other
1881 committees, but it raises questions in your mind.
1882 So I toured a number of years ago a facility in
1883 Pembroke, Virginia, that is Giles County, a few miles
1884 outside of the area where Blacksburg is, i.e., Virginia

1885 Tech. They have a product or they have a company out there
1886 called NanoSonic. They actually make fire gloves. So I
1887 called them -- had my team call them while I was in here
1888 listening to the testimony.
1889 They don't use PFAS. And it is basically a fabric with
1890 a glass, and I am going to get it all wrong, but it was
1891 really interesting. It is glass inside that creates your
1892 barrier to temperatures. I mean, I have had my hand in one
1893 of their gloves over an acetylene torch. Nothing.
1894 Now you can only use it once because once it is heated,
1895 the glass transforms and will no longer provide the
1896 protection. But it provides that protection while the
1897 firefighter is wearing it and there is no PFAS. So add that
1898 to your list. NanoSonic out of Giles County, Virginia.
1899 *Mr. O'Connor. If I can just comment.
1900 *Mr. Griffith. Yes.
1901 *Mr. O'Connor. I will make sure that our safety and
1902 health people reach out to them. But as a W&L guy, I know a
1903 lot of good things come from the Shenandoah Valley.
1904 *Mr. Griffith. There you go.

1905 *Mr. O'Connor. So thank you very much.

1906 *Mr. Griffith. There you go. Yeah, and I was W&L Law,
1907 just so you know. Yeah, that's good.

1908 *Voice. Go Generals.

1909 *Mr. Griffith. Let's talk about the cancer registry
1910 itself. So you want folks to sign up for it. Is that
1911 before they have a cancer, you want everybody to sign up for
1912 it, and how does it work, and then how does it identify what
1913 the cancers are, and can it eliminate -- or can it maybe
1914 focus in on some of the substances that are causing these
1915 cancers?

1916 *Mr. O'Connor. What I alluded to in my oral testimony
1917 --

1918 *Mr. Griffith. Yeah.

1919 *Mr. O'Connor. -- is it really just started in April.
1920 And part of the reason -- to answer, I know she's no longer
1921 in the room, but the Ranking Member's question --

1922 *Mr. Griffith. Yeah.

1923 *Mr. O'Connor. -- is it was a combination from what we
1924 have been told -- we are obviously sorely disappointed that

1925 it has taken this long, but a combination of COVID and some
1926 cyber issues related to protecting people's personal health
1927 information.
1928 *Mr. Griffith. Right. Yeah.
1929 *Mr. O'Connor. So that is what the delay was. And,
1930 again, right now we only have 4,000 people. We want
1931 everybody to sign up because the key is a baseline.
1932 *Mr. Griffith. Yeah.
1933 *Mr. O'Connor. When people are hired into the Fire
1934 Service, there is fitness requirements. So generally people
1935 coming in are a heck of a lot healthier than the general
1936 population. That is the one of the reasons that local
1937 governments always want firefighters included in their
1938 medical plans because we bring down the risk.
1939 *Mr. Griffith. Right.
1940 *Mr. O'Connor. As the exposures occur over the years,
1941 that is when the cancers develop. So what we need is for
1942 the kid that comes into the fire academy or to volunteer,
1943 test him immediately --
1944 *Mr. Griffith. You want to follow him all the way

1945 through.

1946 *Mr. O'Connor. -- and follow him through to --

1947 *Mr. Griffith. I am running out of time. I want to

1948 ask one more question. It is not because I am against it, I

1949 am just curious because I am going to have to defend it with

1950 some of my friends. The number in the bill is almost double

1951 what it was previously. Can you tell me quickly why the

1952 reason for that is?

1953 *Mr. O'Connor. The technology, trying to trace some of

1954 it.

1955 *Mr. Griffith. Okay.

1956 *Mr. O'Connor. And, again, I think it is -- in the

1957 scheme of things, it is a very modest --

1958 *Mr. Griffith. It is 5.5 million overall.

1959 *Mr. O'Connor. Right, right.

1960 *Mr. Griffith. That is after it has been doubled.

1961 *Mr. O'Connor. Yes, sir.

1962 *Mr. Griffith. All right, I yield back.

1963 *Mr. Bucshon. The gentleman yields back. I now

1964 recognize Mrs. Dingell from Michigan for her line of

1965 questioning.

1966 *Mrs. Dingell. Thank you, Mr. Chairman.

1967 I want to thank all of the witnesses for being here
1968 today because you each have a very personal story, and it is
1969 -- we understand it, and it is hard, and quite frankly, I
1970 have been on the board, I have worked with almost all of
1971 your organizations, and members have personal stories here.
1972 So I want to just thank you for that and sharing that with
1973 us.

1974 My late husband used to say that our children are 25
1975 percent of our population and a hundred percent of our
1976 future. And I know that it is really important that we make
1977 sure that we have got all the tools and resources to make
1978 sure that all of our children live, and grow, and thrive,
1979 and that should be one of our top priorities. So I do have
1980 to make a point before I get to my other questions, that I
1981 am concerned about the dangerous impact of the current bill
1982 we are considering on reauthorizing the Children's Hospital
1983 Graduate Medical Education Program because I think we are
1984 putting politics into deeply personal healthcare decisions.

1985 The CHGME Program extends far beyond transgender youth.
1986 It provides vital federal support for children's hospitals
1987 across the Nation. The program trains 56 percent of all
1988 general pediatric residents. Its importance in training the
1989 workforce that keeps our children healthy and safe cannot be
1990 overstated.
1991 But this bill would not only prohibit funding for
1992 gender affirming care, but it withholds funds from any
1993 hospital providing it. Just in my state, the Children's
1994 Hospital in Detroit and the University of Michigan treat
1995 anybody who comes through its doors. These are mental
1996 health issues, and we really need to understand what we are
1997 doing here, and I think it is unacceptable.
1998 But I want to turn my attention to the bill that
1999 deserves our full support. It is bipartisan. The Gabriella
2000 Miller Kids First Research Act 2.0, which we authorize an
2001 increased funding for pediatric care research.
2002 I was glad to introduce this lifesaving bill alongside
2003 Representative Wexton, Cole, and Bilirakis. For those who
2004 don't know, DIPG is a devastating pediatric brain tumor. It

2005 is almost always fatal, and the average overall survival for
2006 children diagnosed is less than one year. The bill is named
2007 after Gabrielle Miller, a childhood cancer advocate who lost
2008 her battle with DIPG when she was 10 years old.
2009 But I have had the sadness, unfortunately, of working
2010 closely with children and families struggling with the
2011 horrors of DIPG, like the Carr family. Jason -- or Jason is
2012 the father. Chad Carr. I lived with him from the time that
2013 he was diagnosed until he died at age 5. And Jack Demeter,
2014 a young boy who lost his battle with DIPG at the age of 3.
2015 Watching someone live with cancer at any age is hard, but it
2016 is gut wrenching when you are watching a child.
2017 So, Dr. Thompson, I know you are here to discuss Sickle
2018 Cell Disease, but within your capacity as Chief of the
2019 Division of Hematology at Children's Hospital of
2020 Philadelphia, you are also a professor of pediatrics, could
2021 you talk about or do you agree that more robust funding for
2022 pediatric cancer will help find new treatments and cures for
2023 young patients, and can you also, because I am not going to
2024 have a lot of time and I got to get one firefighter question

2025 in, talk about why childhood cancer differs from adults?

2026 *Dr. Thompson. I will do my best. But certainly there

2027 are many childhood cancers that are completely unique. They

2028 are not ones that occur at an early stage in children. Some

2029 of them actually occur only in children. We have made some

2030 remarkable advances in pediatric care, such that 80 percent

2031 of children, because of research, are surviving. DIPGs --

2032 children with DIPGs, unfortunately, are not in that group.

2033 We are lucky if they survive one year.

2034 These are the opportunities for research, and many of

2035 our children's hospitals are also some of our most important

2036 sites for pediatric research. Pediatric research only makes

2037 up about 10 percent of the NIH's budget, but what we do with

2038 that is remarkable, and so certainly we look for it to be

2039 funded by nonprofits, by private-public partnerships, as

2040 well as other governmental agencies.

2041 But we can't underscore the number of advances that we

2042 have made in pediatric care that have largely come from

2043 evidence bases, and those are from research.

2044 *Mrs. Dingell. Thank you. Okay, 20 seconds left.

2045 Mr. O'Connor, we -- I have highlighted, and I want to
2046 thank my colleague, who really asked the questions that I
2047 was going to ask, and I hope -- Mr. Graves has been busy, so
2048 we are hoping to get our bill, and we hope you will join us.
2049 But is there anything that -- you have highlighted the
2050 importance of it and the danger. Is there anything you want
2051 to add in three seconds?
2052 *Mr. O'Connor. [Laughter.] Just that it needs to get
2053 done. Our lives are at stake. And we thank everybody for
2054 their leadership and support of it.
2055 *Mrs. Dingell. Thank you for all our firefighters do.
2056 I yield back, Mr. Chair.
2057 *Mr. Bucshon. The gentlelady yields back. I now
2058 recognize Mr. Bilirakis for his five minutes.
2059 *Mr. Bilirakis. Thank you. And thank you, Mr.
2060 Chairman, I appreciate it very much. I wanted to
2061 specifically thank Chair Rodgers for including two of my
2062 bills, the Gabriella Miller Kids bill with Representative
2063 Dingell and a couple others, but also the National Plan to
2064 End Parkinson's Act. Thank you very much for including them

2065 in today's hearing.

2066 The Gabriella Miller Kids First Research Act 2.0, H.R.
2067 3391, is legislation I co-lead, again, with Representative
2068 Wexton as well and, of course, Representative Tonko. And it
2069 would authorize the important pediatric research initiative
2070 at the National Institutes of Health, NIH. Sadly, cancer is
2071 the single leading cause of death of children in the United
2072 States of any disease, approaching 10,000 diagnosed annually
2073 under the age of 15. We still have a long way to go to
2074 improve survival for our most vulnerable patients, our
2075 children, who are diagnosed with brain tumors, prevalent
2076 cancers, and other pediatric rare conditions. We must
2077 continue to allow this program to conduct the critical
2078 research needed to improve outcomes and accelerate
2079 treatments and cures.

2080 My other bill is H.R. 2365, the National Plan to End
2081 Parkinson's Act that I lead with Representative Tonko, and
2082 it would unite the Federal Government through an advisory
2083 council, public and private stakeholders, in a national
2084 effort and strategy to support research, development,

2085 recommendations with the goal of treating and curing
2086 Parkinson's Disease.
2087 So I have a question for Mr. Manahan, and I tell you
2088 what, you did an outstanding job, sir. Thanks for sharing
2089 your story.
2090 *Mr. Manahan. Thank you.
2091 *Mr. Bilirakis. We really appreciate it very much. It
2092 makes a big difference when you hear the personal stories.
2093 Thank you again for sharing your story. Your advocacy is
2094 extremely impactful and I greatly appreciate you sharing it.
2095 You have highlighted the burden that this disease has
2096 on the patient and the families physically, emotionally, and
2097 financially. I personally understand this. My uncle died
2098 from Parkinson's, late 50s, and my brother just passed way
2099 over -- just over a month ago, and Parkinson's. He was
2100 diagnosed in his mid-40s. My father has Parkinson's, early
2101 stages, and my mother-in-law, late -- mid to late stages.
2102 So I understand the disease even though I am not a
2103 physician.
2104 So, again, this -- the lack of treatment options leave

2105 patients, families, and the American taxpayers in a terrible
2106 predicament with little place to turn, as you said. Could
2107 you please elaborate on why this legislation is so vitally
2108 important right now? Time is of the essence.
2109 *Mr. Manahan. Yes, sir. I am excited about the
2110 National Plan because for the first time it is going to give
2111 the Federal Government and stakeholders a chance to sit down
2112 and talk face to face. There is going to be a seat at the
2113 table where it hasn't been before for patients, caregivers,
2114 Parkinson's specialists and doctors. And I think without a
2115 mandate, without a mandate, it is not going to happen.
2116 And we need this plan because I fear that if we don't
2117 do something this year or next year, the problem is going to
2118 be that we will not come up with a cure for Parkinson's in
2119 years, which I hope, versus decades.
2120 *Mr. Bilirakis. Thank you. And I want to also commend
2121 Michael J. Fox, obviously.
2122 *Mr. Manahan. Yes.
2123 *Mr. Bilirakis. What he has done. His foundation,
2124 what he has done to define treatments and potential cures

2125 for this disease, and I know they are behind this
2126 legislation as well. So he has been extraordinary, there is
2127 no question.
2128 I have talked extensively about the need to ensure we
2129 are coordinating federal efforts, that is the key,
2130 coordination, rather than a duplicative and siloed approach
2131 to healthcare. And initiatives like Operation Warp Speed
2132 proved that with the right public-private partnership we can
2133 accomplish a significant amount.
2134 So again, Mr. Manahan, what will the creation of an
2135 advisory council mean for coordinated and comprehensive
2136 public and private research?
2137 *Mr. Manahan. Well, I look at the biomarker which we -
2138 - I had mentioned earlier today, as the hope for the future.
2139 But this legislation is the hope for people that have the
2140 disease right now. It is going to bring together the
2141 Michael J. Fox Foundation, and the private foundations, and
2142 the Federal Government. In fact, you know, I talked to
2143 someone who served on the advisory board for Alzheimer's,
2144 and one of the things she said to me was that this national

2145 plan really worked out well because the federal agencies got
2146 a lot of opportunity to find out what they are doing.
2147 So it is just not the federal agencies and the private
2148 foundations talking, it is actually the federal agencies
2149 talking amongst themselves.
2150 *Mr. Bilirakis. Yeah. And this piece of legislation
2151 is modeled after that piece of legislation.
2152 *Mr. Manahan. Yes, sir.
2153 *Mr. Bilirakis. To cure Parkinson's.
2154 *Mr. Manahan. Sure is.
2155 *Mr. Bilirakis. I mean, Alzheimer's in this case.
2156 Thank you very much, and I really appreciate it. I have a
2157 couple more questions, but I am not going to go too far
2158 over.
2159 So I appreciate it, and I yield back, Mr. Chairman.
2160 *Mr. Bucshon. The gentleman yields back. I now
2161 recognize Ms. Kuster -- Mr. Ruiz showed up. I didn't see
2162 him down there. Dr. Ruiz --
2163 *Mr. Ruiz. Thank you, Doc.
2164 *Mr. Bucshon. -- is recommended -- is recognized --

2165 *Mr. Ruiz. I'm just clearing my throat. Allergies.

2166 *Mr. Bucshon. I'm recommending him, too.

2167 *Mr. Ruiz. [Laughter.]

2168 *Mr. Bucshon. But he is recognized for five minutes.

2169 *Mr. Ruiz. Before I begin, I want to give a very
2170 special recognition and shout to students from my district
2171 from the Migrant Farmworker Education Program that are here
2172 visiting Washington, D.C. They are -- some of them are
2173 walking in right now. They are very, very, very special to
2174 me because my mother was a migrant farmworker who toiled the
2175 fields day in and day out with calloused hands, and tired
2176 backs, and minimal rest day after day after day. And they
2177 are attending the same schools that I attended, and I am
2178 true and blue from the farmworker community. And so if you
2179 don't mind, let's give them an applause for being here.

2180 [Applause.]

2181 *Mr. Ruiz. Thank you. Thank you very much.

2182 I want to touch on two different topics here today.
2183 Frist, I would like to address the policy that would pull
2184 funding from children's teaching hospitals that provide age-

2185 appropriate gender affirming care for transgender and
2186 nonbinary youth. I echo my colleagues who have already
2187 spoken out to protect the relationship between patients and
2188 their doctors and this harmful and misleading rhetoric and
2189 policy that purports to protect kids is actually doing the
2190 opposite, it is a bully policy that bullies one of -- some
2191 of our most vulnerable kids.
2192 Research shows that gender affirming care improves the
2193 short and long-term mental health and wellbeing of trans and
2194 nonbinary youth. The science is there, the studies are
2195 there. And every major medical association supports it.
2196 Decisions to get age-appropriate gender affirming care is
2197 one that should be made by parents and their kids in
2198 consultation with their doctor, not by the Federal
2199 Government.
2200 And in addition to placing transgender and nonbinary
2201 youth's mental health at risk, these policies are also
2202 risking the future of our pediatric workforce. We already
2203 have a pediatric shortage. Children's hospitals train half
2204 of our country's pediatricians, and this proposed policy

2205 only forces those hospitals to choose between doing what is
2206 best for their patients or training the next generation of
2207 pediatricians.
2208 Dr. McNamara, as a doctor, and I am very concerned how
2209 this policy will harm the mental health of our transgender
2210 and nonbinary youth as well as the future pediatric
2211 workforce of our country. Can you address the consequences
2212 these policies will have both on our transgender and
2213 nonbinary youth and on our pediatric workforce?
2214 *Dr. McNamara. It all goes hand in hand, sir. Thank
2215 you for your question because it highlights the fact that
2216 pediatric healthcare is a tightly-knit fabric and you cannot
2217 pull out one thread, the whole tapestry would unravel. The
2218 healthcare of one child is -- you know, we don't think about
2219 it like that, I guess. We don't parse out groups of youth
2220 and say, you know, well, it is okay to care for you, and it
2221 is not okay to care for some of them.
2222 *Mr. Ruiz. Correct.
2223 *Dr. McNamara. So we simply would never accept this
2224 policy. As far as mental health goes, I mean, even just the

2225 rhetoric that we have heard today is very damaging and
2226 harmful to trans youth. I think that one of the reasons why
2227 rates of suicidal ideation over the past couple of years and
2228 other mental health harms in trans youth has been going up
2229 is because of how they have been demonized.
2230 *Mr. Ruiz. Yeah, and the rhetoric leads to depression,
2231 leads to anxiety, leads to suicidal ideation. It also
2232 encourages others to use the same rhetoric, their peers,
2233 that leads to bullying. Transgenders are already number one
2234 on the hate violence crime list.
2235 So I would like to pivot to another topic, cancer
2236 detection. Mr. O'Connor, thank you for your remarks today
2237 and for General President Ed Kelly's and the International
2238 Association of Fire Fighters' longstanding leadership in
2239 promoting the health and safety of our Nation's
2240 firefighters. Thanks to your work with Congress to
2241 establish the Firefighter Cancer Registry, we now know that
2242 cancer is the leading cause of death for firefighters
2243 exceeding heart attacks, smoke inhalation, burn injuries,
2244 vehicular accidents, and other fatal injuries. In fact,

2245 firefighters face a cancer risk that is 14 percent higher
2246 than other Americans, and it is truly an epidemic.
2247 So the IAFF's leadership goes beyond researching the
2248 data. You are leading the Nation in ideas. Look, I led the
2249 -- help lead the effort on the burn pits and the associated
2250 ingestion of the toxic smoke, so I know that a lot of the
2251 things that burn have carcinogens.
2252 Will you -- Mr. O'Connor, will you share with the
2253 committee how the ability to find more cancers earlier would
2254 benefit your retirees, their families, and so many others at
2255 risk, seniors across the country?
2256 *Mr. O'Connor. Real quickly before I answer that
2257 directly, I --
2258 *Mr. Ruiz. You only have 15 second.
2259 *Mr. O'Connor. I know, I know. I want to add that
2260 wildfire is a constant smoke is exposing to everybody
2261 including citizens.
2262 *Mr. Ruiz. I agree.
2263 *Mr. O'Connor. Screening is the key. Screening is the
2264 key. If we get our people in early and we are able to track

2265 it, we will be able to solve the -- we will be able to cure
2266 the cancers and catch them at early stages. But screening
2267 is crucial.
2268 *Mr. Ruiz. Great. Well, I truly support this bill,
2269 and I also have another bill called the Nancy Gardner Sewell
2270 Medicare Multi-Cancer Early Detection Screening Coverage
2271 Act, which will be able to more efficiently detect cancers
2272 early, and I encourage the committee to also look into that
2273 one.
2274 *Mr. O'Connor. I know we expired. I mentioned that in
2275 my oral testimony.
2276 *Mr. Ruiz. Thank you. Bye.
2277 *Mr. Bucshon. The gentleman yields back. I now
2278 recognize Mr. Johnson from Ohio, five minutes.
2279 *Mr. Johnson. Well, thank you, Mr. Chairman. I want
2280 to thank Chairman Guthrie for having this hearing today, and
2281 thank you to our panelists for joining us here today.
2282 We are considering a number of bills and important
2283 reauthorizations here today, including the Children's
2284 Hospital's Graduate Medical Education Payment Program which

2285 funds freestanding children's hospitals. This money helps
2286 their graduate medical education programs train resident
2287 physicians and dentists.
2288 We all understand the toll that the pandemic took on
2289 the most vulnerable in our society, particularly our
2290 children, from not being able to go to school, something we
2291 will not know the true side effects of for years to come, to
2292 masks, and anxiety. COVID-19 weighed heavy on America's
2293 boys and girls.
2294 It is critical that we support our Nation's children's
2295 hospitals. Nothing is more important to me than ensuring
2296 the mental and physical health of our young people. That is
2297 why I am proud to support Representative Crenshaw's
2298 legislation reauthorizing the graduate medical education
2299 payment program.
2300 Yes, I am deeply troubled by reports that a growing
2301 consortium of American medical professionals are pushing
2302 highly controversial treatments like gender affirming
2303 surgeries, hormone therapy, and puberty blockers on children
2304 and teenagers when we do not know the true impact of their

2305 long-term mental and physical health.
2306 So question number one. Dr. Grossman, in your position
2307 as a child, adolescent, and adult psychiatrist, what types
2308 of treatment methods for kids diagnosed with gender
2309 dysphoria are backed by scientific data? If you need me to
2310 repeat that, I will.
2311 *Dr. Grossman. No, no, no, I heard you. Thank you
2312 very much, Congressman, for the question. We have known for
2313 decades that if these kids are left alone or just given
2314 psychotherapy and family support, that the vast majority
2315 will become comfortable with their sex, with being a boy or
2316 a girl. We have known that for a very long time.
2317 Recently, we have started applying so-called gender
2318 affirming care to a new cohort, a new group of kids that we
2319 have never seen before, and those are kids who suddenly out
2320 of the blue develop the gender dysphoria as part of what
2321 more and more people are realizing is a social contagion.
2322 *Mr. Johnson. So you are saying that if they received
2323 the kind of support at home and mental health counseling,
2324 traditional mental health counseling, that they grow through

2325 this phase and they become comfortable with who they are?

2326 *Dr. Grossman. I am not -- yeah, I am not saying every
2327 single person.

2328 *Mr. Johnson. Sure, sure.

2329 *Dr. Grossman. But in the past, the research that has
2330 been done on those kids would say so.

2331 *Mr. Johnson. Well, that is interesting because, you
2332 know, as my colleagues across the aisle frequently like to
2333 say, we need to follow the science here. In Dr. Grossman's
2334 opening remark, she noted that the United States is moving
2335 in the opposite direction from our European counterparts in
2336 terms of how those nations view gender dysphoria treatment.
2337 Simply look at our friends in Great Britain. Just recently
2338 the National Health Services in London announced that
2339 publicly funded services will no longer routinely offer
2340 puberty blocking drugs to children.

2341 This on the back of a 2023 global public opinion survey
2342 of 30 countries asking whether or not transgender teens
2343 should be allowed to receive gender affirming care. This
2344 survey showed the United States as having even less public

2345 support for these treatments than virtually every single
2346 European country polled, including the UK.
2347 The fact of the matter is the United States is moving
2348 in the wrong direction. It is moving in a very extreme
2349 direction and is becoming a global outlier on this issue. I
2350 personally believe it is irresponsible and essentially child
2351 abuse to allow minors to make these types of life changing
2352 medical decisions. But on the facts, we simply do not know
2353 enough to say for certain that we should be allowing these
2354 treatments at all.
2355 I find it disturbing that some children's hospitals are
2356 pushing puberty blockers or hormone therapies on children
2357 incapable of understanding the life-long -- long-term
2358 effects of these treatments. Children's hospitals are meant
2359 to be the gold standard of pediatric care in our
2360 communities, and their support for such programs will lead
2361 parents and families to trust what they are saying despite
2362 the data telling a different story.
2363 I do have other questions that I will submit for the
2364 record, Mr. Chairman. I realize my time is expired. This

2365 is a real important and emotional issue for many of us,
2366 especially those of us who are grounded in our faith and as
2367 parents. We see this as an aberration and --
2368 *Mr. Bucshon. The gentleman's time is expired.
2369 *Mr. Johnson. -- I yield back.
2370 *Mr. Bucshon. I now recognize Ms. Kuster for her five
2371 minutes.
2372 *Ms. Kuster. Thank you, Chairman Guthrie. I am glad
2373 this committee is dedicating time to reauthorizing several
2374 important health programs, all on a bipartisan basis. The
2375 list is impressive. Supporting premature infants, expanding
2376 the dental workforce, committing federal resources to end
2377 Parkinson's, protecting our firefighters, to name a few.
2378 Today's hearing should be an opportunity to celebrate
2379 the important role that Congress plays in dedicating
2380 resources to people with rare diseases and providing support
2381 to our country's health workforce. However, I am extremely
2382 disappointed as a parent that today's hearing includes a
2383 partisan attempt to villainize children and bring politics
2384 into our healthcare system.

2385 I recently had a lovely breakfast with our chair. We
2386 share a concern about the wellbeing of our youth. But I
2387 want to quote her comments at the beginning of this hearing.
2388 She said she wants to send a message to our children that
2389 they are loved as they are. Trying to scare our Nation's
2390 pediatric hospitals into denying gender affirming care to
2391 patients to fit a political agenda is not just cruel, it is
2392 nonsensical, and it puts the health of millions of children
2393 at risk.
2394 As Dr. Ruiz has recounted and our experts today have
2395 affirmed, this type of rhetoric from members of Congress in
2396 hearings like this leads to suicidal ideation and bullying
2397 and is harmful to our children. Let's make one thing clear
2398 right now. The government has no role in policing what care
2399 doctors and nurses should provide to their patients.
2400 Medical decisions are between a patient, their family, their
2401 parents, their guardian, and their physicians. Trying to
2402 insert the Federal Government into these incredibly private,
2403 incredibly sensitive decisions is simply unacceptable.
2404 In my home State of New Hampshire, our state motto is

2405 to Live Free or Die. We value privacy. We value the
2406 privacy of our medical decisions and we do not need the
2407 United States Congress to interfere in that privacy. This
2408 legislation flies in the face of our state motto.
2409 So, Dr. McNamara, in your testimony you state that
2410 healthcare providers must consult with parents and legal
2411 guardians about care that is provided to children. Could
2412 you explain to this committee and to my colleagues the
2413 importance of informed consent when providing all kinds of
2414 medical care to our youth?
2415 *Dr. McNamara. Absolutely. Thank you for your
2416 question, Congresswoman, and the thank you for your
2417 comments, it makes my patients feel safer.
2418 So parents play a central role in all medical decision
2419 making for minors in the vast majority of cases, and
2420 regarding medical treatments for gender dysphoria, it is no
2421 exception. Parents know their kids best. They know what
2422 they need. We as pediatricians rely on their knowledge of
2423 their young person in order to help support them best.
2424 In the case of medical treatments for gender dysphoria,

2425 the standard of care and the way that care is practiced in
2426 this country is with a multidisciplinary team with an --
2427 excuse me, an iterative over several visits, several months,
2428 mental health assessment, and long conversations that don't
2429 really have an end point. That may be a little bit
2430 different from other aspects of pediatric care, but it is
2431 something that my colleagues are -- and I are very skilled
2432 at doing. We know how to do it. And this care
2433 overwhelmingly benefits transgender youth.
2434 *Ms. Kuster. I just have to -- as an aside, I was an
2435 adoption attorney for 25 years, and I primarily represented
2436 birth parents who made the decision to place their children
2437 for adoption. And I can remember working with two
2438 teenagers. I remember when we went before the judge,
2439 looking over and realizing that the young man had never
2440 shaved, he still had the peach fuzz on the side of his face.
2441 And trust me, there was no room for the Federal Government
2442 in making those personal, private decisions about our
2443 health, our wellbeing, and the wellbeing of our families.
2444 I just want to say that the claims that we hear about

2445 gender affirming care in this room and in the media are
2446 dangers, and I want to join my chair in sending a message to
2447 our children that they are loved as they are. Thank you so
2448 much.
2449 I yield back.
2450 *Mr. Bucshon. The gentlelady yields back. I now
2451 recognize myself for five minutes for my line of
2452 questioning.
2453 I am a physician, and I understand the issues related
2454 to gender dysphoria, and I do recognize it is real.
2455 However, I can never support permanent surgical procedures
2456 on children, regardless of other -- the other need for
2457 treatment for their dysphoria. Again, I would remind
2458 everyone, these are irreversible. Permanent surgical
2459 procedures, in my view, should not be part of a treatment
2460 plan for transgender children.
2461 In the House Energy and Commerce Committee, look, we
2462 are a legislative workforce. You look at the House floor, a
2463 lot of our bills come from here. And we manage to do much
2464 of our work on a bipartisan basis, and we are doing I think

2465 mostly that today. And I am proud of that. We are
2466 continuing to be a workhorse for Congress as we have a
2467 number of important public health priorities we are
2468 discussing here today.
2469 So I am going to ask a couple of questions. Doctor --
2470 is it Dr. Cherot? Dr. Cherot, in Indiana we have the third
2471 highest maternal mortality rate in the Nation with 44 deaths
2472 per 100,000 live births as of 2022. According to the March
2473 of Dimes own data, Indiana has an infant mortality rate of
2474 6.6 which is higher than the U.S. rate of 5.4. These are
2475 statistics we are not proud of, but our Governor, and our
2476 state government, as well as the medical community are
2477 trying to find ways to improve this and we are focusing on
2478 that.
2479 Can you talk about how H.R. 3226 and H.R. 3838 will
2480 benefit mothers and babies in states like Indiana and how we
2481 can -- how this will help us advance?
2482 *Dr. Cherot. Absolutely. Thank you for the question.
2483 The -- within states we have our MMRCs and our really
2484 important -- to look at the details of the deaths that do

2485 happen. And what happened is that we identify those
2486 contributing factors using that to then translate those into
2487 action. And those MMRCs are important across every state to
2488 collect that data.
2489 I would say that the federal collection activities
2490 underpin the work of the March of Dimes, and that those
2491 agencies and partners address the maternal and infant health
2492 crisis. We want to increase that data to get to solutions
2493 that are vital to be able to impact.
2494 *Mr. Bucshon. Well, thank you. I just want to say we
2495 have had a hearing in the past -- a number of hearings in
2496 the past on this, and we had data out of Parkland Hospital
2497 in Dallas, Texas, a famous hospital, and their data is
2498 outstanding on this issue --
2499 *Dr. Cherot. Yes.
2500 *Mr. Bucshon. -- on maternal mortality. And they have
2501 defined protocols on how they manage --
2502 *Dr. Cherot. Yes.
2503 *Mr. Bucshon. -- the patients. And their patient
2504 population are primarily the underserved, uninsured, and

2505 also ethnically diverse population, so it can -- this can be
2506 done, correct?
2507 *Dr. Cherot. Yes, absolutely. We have seen states
2508 that have changed their outcomes using different PRQCs to
2509 get to really standardized protocols, realizing that there
2510 are lots of impacts that we can have both on maternal death
2511 rates as well as preterm birth.
2512 *Mr. Bucshon. Yeah, and it is shocking that this does
2513 cross socioeconomic class also. We -- you may or may not
2514 know, we just had a famous athlete who was --
2515 *Dr. Cherot. I do.
2516 *Mr. Bucshon. -- who we found out what resulted in her
2517 death, tragically, at home, and why that happened I don't
2518 think we know.
2519 Dr. Thompson, can you talk about what innovation means
2520 to patients with Sickle Cell Disease? That is kind of open
2521 ended. I want you to basically comment on what you want to
2522 say about where we are in innovation and what we can do.
2523 *Dr. Thompson. Thank you. And innovation actually is
2524 a spectrum. Innovation in -- I think in its best possible

2525 terms really is looking at discovery science that moves to
2526 the bedside. And so if I were to look at the best case
2527 scenario today, today is a possibility of gene therapy for a
2528 variety of blood disorders and immunodeficiencies.
2529 For some people, innovations is what I otherwise call
2530 standard of care, because today there still are individuals
2531 in this country whose current providers, whose current
2532 communities lack resources for them to actually understand
2533 what is available to them. So we know that there are now a
2534 number of disease modifying therapies that have been FDA
2535 approved across a wide range of ages. If innovation means
2536 that those individuals now have access to those, then
2537 certainly that should also be a form of innovation that I
2538 hope we would also embrace.
2539 *Mr. Bucshon. Yeah. I will finish with this. I did
2540 my medical school at the University of Illinois in Chicago,
2541 and at Cook County Hospital we had a lot of people come in
2542 with -- in Sickle crisis, and this is just a -- you know, if
2543 we -- particularly genetic therapy is exciting because it is
2544 just a tragic disease. Also people in renal failure and

2545 organ -- other organ failure because of it. So I am excited
2546 about the future, particularly of gene therapy in diseases
2547 like Sickle Cell.
2548 With that, I yield back.
2549 And I recognize now Ms. Craig for her five minutes.
2550 *Ms. Craig. Thank you so much, Mr. Chairman. I am
2551 incredibly disappointed to see my Republican colleagues
2552 today taking what has always been a bipartisan effort to
2553 reauthorize a program that we have always supported and
2554 twisting it into a partisan process that undermines parent's
2555 rights and ignores evidence-based care guidelines for the
2556 treatment of trans youth.
2557 We should be here today to support a clean
2558 reauthorization of the Children's Hospital Graduate Medical
2559 Education Program. But oh no, you are putting the program
2560 in jeopardy in support of your continued culture war
2561 crusade. Look, I have a newsflash for my colleagues. It is
2562 none of your business what evidence-based care a parent in
2563 consultation with their healthcare provider decides for
2564 their child. In fact, after listening to you today, I am

2565 absolutely certain that most of you have no idea what the
2566 range of gender affirming care actually is. So let me start
2567 with that.
2568 Dr. McNamara, can you define for us what age
2569 appropriate gender affirming care actually is for my
2570 colleagues? Just a little bit.
2571 *Dr. McNamara. This is absolutely crucial. Thank you
2572 so much for the question. Gender dysphoria is real. It
2573 represents a discordance and distress that emerges from the
2574 difference between -- I minced my words. It is the
2575 difference -- I minced my words again. I am so sorry.
2576 It is distress that emerges from the difference between
2577 sex assigned at birth and gender identity. Without
2578 treatment, this care -- with this condition is dangerous and
2579 debilitating. Gender affirming care starts with
2580 affirmation. It starts with very simple things like is it
2581 okay to get a haircut, is it okay to wear certain clothes,
2582 or to change your name into something that feels more
2583 authentic.
2584 And from there, we see that youth begin to blossom.

2585 Some youth qualify for and desire medical aspects of gender
2586 affirming care, and it is a highly individualized process.
2587 It depends on who the young person is, their parents, and
2588 the conversations that evolve from there. There is no end
2589 point and there is no prescripted plan of care. It depends
2590 on the person who is before us.

2591 *Ms. Craig. And, Dr. McNamara, that care has been
2592 supported by 20 major medical associations, including the
2593 American Academy of Pediatrics, the American Psychological
2594 Association, and the American Medical Association. Am I
2595 correct?

2596 *Dr. McNamara. Absolutely.

2597 *Ms. Craig. Can you just for a moment rebut the claim
2598 that has been made here today that the United States is
2599 somehow an outlier in the care that gender affirming care
2600 represents?

2601 *Dr. McNamara. So I urge this body to make any
2602 decisions based on sound information and science. No other
2603 country in the world who is a peer of the United States has
2604 gone as far as to ban and criminalize the provision of

2605 medical treatments for gender dysphoria. What you have
2606 heard today is a cherry-picked collection of unverified
2607 information that portrays outlier views in some countries in
2608 this world.
2609 There are many countries in this world that nobody has
2610 brought up today that I could list off like Ireland,
2611 Australia, Spain, Portugal, Canada, Mexico, among others.
2612 But this is the greatest country in the world, right, and
2613 our medical science and innovation here is amazing. I am so
2614 privileged to be able to practice this care.
2615 *Ms. Craig. Dr. McNamara, thank you so much. You have
2616 already spoken to how dangerous it can be if that care is
2617 denied or if medical professionals are not appropriately
2618 trained in order treat this and provide this care.
2619 I get that some of my colleagues think this topic is a
2620 political winner. I would extend an innovation to every
2621 single one of you, many of whom I respect, to attend a panel
2622 of parents of trans youth to hear their stories. What you
2623 are attempting today undermines the rights and
2624 responsibilities of the parents of trans kids and is opposed

2625 by all the major medical organizations in our Nation.
2626 We agree, Madam Chair, I have so much respect for you,
2627 that the goal is to love our children for who they are.
2628 Some of our children are transgender. Do we have enough
2629 space in our hearts to love and accept them, too, for who
2630 they are? Some of your kids and grandkids will be trans.
2631 Do you really want any politician sitting in this room
2632 involved in their healthcare decisions?
2633 And with that, I yield back.
2634 *Mr. Bucshon. The gentlelady yields back. I will now
2635 recognize Mrs. Harshbarger for five minutes. I surprised
2636 her.
2637 *Mrs. Harshbarger. Yeah, you surprised me. Thank you,
2638 Mr. Chair. I thank all the witnesses for being here.
2639 And, Mr. Manahan, I am proud to be an original
2640 cosponsor of the National Plan to End Parkinson's Act
2641 introduced by Reps Bilirakis and Tonko. The bill aims to
2642 unite the Federal Government in a mission to cure and
2643 prevent Parkinson's and alleviate financial and health
2644 burdens on American families and reduce government spending

2645 over time. And the biomarker which detects the protein that
2646 is associated with damaged neurons that is used -- now you
2647 can detect Parkinson's earlier is amazing to me.
2648 My father has suffered from Parkinson's. He will be 90
2649 next month. And it is an ongoing battle, and I understand
2650 everything you are talking -- the younger you are, the more
2651 problems you have as you age.
2652 The National Institutes of Health is a federal agency
2653 with the largest budget for supporting Parkinson's Disease
2654 research. I think 259 million in 2022.
2655 *Mr. Manahan. Mm-hmm.
2656 *Mrs. Harshbarger. My question is, do you have a sense
2657 of what the NIH thinks of this legislation?
2658 *Mr. Manahan. Well, Dr. Richard Hodes, who is the
2659 director of NIA, testified in the Senate and answered a
2660 question from my senator, Senator Shelly Moore Capito, about
2661 whether or not they thought that the national plan would be
2662 a -- something that they would support. And his quote is he
2663 found it to be extraordinarily valuable. I have not had any
2664 other conversations with NIH or NIA, but apparently the NIA,

2665 Richard Hodes, has -- supports it.

2666 *Mrs. Harshbarger. Okay.

2667 *Mr. Manahan. Thank you.

2668 *Mrs. Harshbarger. Thank you.

2669 Dr. Cherot, I know the March of Dimes is a strong
2670 advocate for the PREEMIE Reauthorization Act and to
2671 reauthorize the important federal research education
2672 intervention programs to improve pregnancy outcomes and
2673 infant health, of course, to reduce the premature, preterm
2674 births and infant mortality, and I am pleased we are taking
2675 that legislation up.

2676 I wanted to ask you about another issue, though, that
2677 has come across my desk. It is about the aluminum content
2678 in parental nutritional products. It has been recognized
2679 for decades as a toxic contaminant, especially dangerous for
2680 preterm babies due to their immature kidney function where
2681 they can't, you know, expel that, and it causes bone
2682 toxicity, brain toxicity, developmental delays, and
2683 premature babies are especially susceptible to aluminum
2684 toxicity because of their digestive systems that are not

2685 fully functioning.

2686 Previously, the FDA took the position that preterm

2687 infants not receive more than four to five micrograms per

2688 kilogram of body weight of that aluminum product. Now the

2689 FDA is poised to raise that aluminum to almost 17 times the

2690 previous approved standards.

2691 Does the March of Dimes agree that we should

2692 continuously strive to reduce those aluminum levels in

2693 prenatal (sic) products and that the FDA should not approve

2694 or permit to remain on the products with high aluminum

2695 levels when lower aluminum products are available?

2696 *Dr. Cherot. So, first, I appreciate the question, but

2697 I am not a nutritionist nor am I neonatologist. So I am an

2698 obstetrician/gynecologist.

2699 *Mrs. Harshbarger. Okay.

2700 *Dr. Cherot. But I would say the March of Dimes is

2701 absolutely advocating for research in nutrition.

2702 *Mrs. Harshbarger. Mm-hmm.

2703 *Dr. Cherot. Breastfeeding as well as nutritional

2704 supplements to look for the best things for premature birth

2705 for those babies. But I would have to get back to you on
2706 that answer.
2707 *Mrs. Harshbarger. Yeah. Yeah, I wish you would do
2708 some research on that because there is --
2709 *Dr. Cherot. I'll note that. Yeah, absolutely.
2710 *Mrs. Harshbarger. Yeah, there is a lot of toxic side
2711 effects associated with that aluminum product. So for them
2712 to change course on this is to me unacceptable. So thank
2713 you for that.
2714 And with that, Mr. Chairman, I yield back.
2715 *Mr. Bucshon. The gentlelady yields back. I now
2716 recognize Ms. Kelly for her line of questioning.
2717 *Ms. Kelly. Thank you so much, Mr. Chair. I am so
2718 happy to see so many bipartisan bills to improve the state
2719 of health -- of the healthcare system for all Americans.
2720 First I would like to recognize the bipartisan action for
2721 Dental Health Act of 2023 that I gladly led with my
2722 colleague, Rep Mike Simpson. Oral health affects our
2723 ability to eat, speak, smile, and show emotions. Oral
2724 health also affects a person's self-esteem, school

2725 performance and attendance at work or school.
2726 Regular, preventive dental care is essential for oral
2727 good health so one can find problems earlier when they are
2728 easier to treat. Unfortunately, many don't get the care
2729 they need. More people are unable to afford dental care
2730 than other types of healthcare. Children, low-income
2731 Americans, minorities, and the elderly are especially at
2732 risk for having limited dental care and poor health
2733 outcomes.
2734 I would also like to submit for the record a letter
2735 from the American Dental Association in support of this
2736 legislation which provides a crucial workforce grant program
2737 focused on providing access to care for those most in need.
2738 Additionally, I am elated to see so many bipartisan
2739 bills being brought forward to address the maternal health
2740 crisis. I would like to take this moment to pay respects to
2741 Tori Bowie, a 32-year-old black woman who was an Olympic-
2742 winning track star. Unfortunately, she passed away on May
2743 2nd. A preliminary autopsy has determined that her cause of
2744 death is attributed to possible complications of pregnancy.

2745 And I am so tired of learning about these stories,
2746 especially when data shows that 84 percent of maternal
2747 deaths are preventable. This is unacceptable. I will
2748 continue to work on legislation to address this issue.
2749 I would like to thank my colleague, Rep Burgess, for
2750 including a piece of my MOMMAs bill in the Preventing
2751 Maternal Death Act, and I would lock arms with anyone who
2752 wants to make this country the safest place to give birth.
2753 Dr. Cherot, would you please elaborate on how maternal
2754 mortality review committees determine if a pregnancy-related
2755 death is preventable, and do any state MMRCs in particular
2756 stand out as a success story so we can continue to promote
2757 best practices?
2758 *Dr. Cherot. So first, thank you. Yes, MMRCs are
2759 crucial at getting at the data, and they need -- their
2760 state, federal -- really getting to all of the data from the
2761 stakeholders and getting to our PQRCs. Our maternal
2762 mortality rates are better in some states than others. Our
2763 -- and just as the March of Dimes puts out data on maternity
2764 care deserts and preterm birth, we also look at this data

2765 exclusively.

2766 Specifically for your state, I am dragging data through
2767 and hoping that my crowd is pulling up yours. But there are
2768 some that are much, much better because they take the data
2769 and then really put into action some of the stuff that comes
2770 out of the American College of OB/GYB and AIMs, really
2771 looking at how do we standardized protocols and procedures
2772 were some of the most crucial, like hemorrhage, like
2773 cardiovascular. And we have made huge efforts in those and
2774 there is more to come that needs to be done. And clearly
2775 black and brown women are suffering in this country, and our
2776 Olympian died in the month of May.

2777 *Ms. Kelly. Mm-hmm.

2778 *Dr. Cherot. And she died -- what they think, we don't
2779 know, but what has been put out in the press is on
2780 eclampsia, which is seizing. I have dealt with this many a
2781 time, and it is preventable.

2782 *Ms. Kelly. Right.

2783 *Dr. Cherot. And she was supposedly found in labor and
2784 preterm labor.

2785 *Ms. Kelly. Mm-hmm.

2786 *Dr. Cherot. So not only do these women suffer, their
2787 babies are dying, too, and are more likely to. So thank you
2788 for bringing that to the attention.

2789 *Ms. Kelly. Well, thank you for your work.

2790 And I just wanted to tell Mr. Manahan, my grandmother
2791 had Parkinson's. And I wanted to thank Mr. O'Connor for
2792 your service. I used to work for local government, so I
2793 know how important you are.

2794 Lastly, I would just like to state that it is
2795 unacceptable that clinics and clinicians that provider
2796 gender-affirming care to our youth have seen a rise in
2797 harassment and death threats. I have heard from those who
2798 are on the front line and want to speak up but are remaining
2799 publicly silent for the safety of themselves and those
2800 around them. This is unacceptable in our society. I am
2801 proud to speak up and speak out on their behalf.

2802 Defunding postgraduate pediatric training programs if
2803 they give proper care to transgender youth is reckless and
2804 dangerous. The Federal Government should not be involved in

2805 the healthcare decisions between a parent and their child.

2806 And with that, I yield back. Thank you.

2807 *Mr. Bucshon. The gentlelady yields back. I now
2808 recognize Mr. Carter for five minutes.

2809 *Mr. Carter. Thank you, Mr. Chairman, and thank all of
2810 you for being here. This is extremely important. And as a
2811 healthcare professional, healthcare outcomes have been my
2812 focus since I have been a member of Congress and long before
2813 that, even when I was a member of the Georgia State
2814 Legislature.

2815 I am from Georgia, and we have one of the highest
2816 maternal mortality rates in the country. And for the life
2817 of me, I cannot figure that out. It baffles me. I do not
2818 understand why Georgia has such a high maternal mortality
2819 rate. And it is something that I have worked on for
2820 probably the last -- when I was in the Georgia State
2821 Legislature and when I have been here, so probably 20 years,
2822 and I think I am just as confused now as I was when I
2823 started, and it is really disappointing.

2824 The CDC just recently released data that showed that

2825 the number of pregnancy-related deaths in the United States
2826 continued on an upward trend in 2021 with over 1200 deaths
2827 that year. 1200. In America, in the United States. And,
2828 again, I am just baffled by this. But I am proud that I am
2829 co-leading along with Dr. Burgess legislation to Preventing
2830 Maternal Deaths Reauthorization Act, and hopefully we can
2831 get that passed, and I think we will, and it is very
2832 important.
2833 Now I know you were just talking about maternal
2834 mortality review committees, and they are very important.
2835 In fact, when I was in the Georgia State Legislature, we
2836 passed Senate Bill 273 which created the MMRCs, putting it
2837 into the Georgia Department of Public Health, and it was one
2838 of the things that we have done to address this embarrassing
2839 situation that we have in our state.
2840 Dr. Cherot, I wanted to ask you, again, we have talked
2841 about the role of MMRCs and -- but why are they so
2842 important?
2843 *Dr. Cherot. Well, they are vital in understanding the
2844 causes and implementing changes to prevent future tragedies.

2845 Most of the information on maternal deaths cited today are
2846 based on data from MMRCs, and we need more of it.
2847 *Mr. Carter. Okay. Well, let me ask you, are you
2848 familiar with Georgia and how --
2849 *Dr. Cherot. Yep.
2850 *Mr. Carter. -- they are using it?
2851 *Dr. Cherot. So --
2852 *Mr. Carter. Because that was legislation I worked on
2853 when I was in the legislature there.
2854 *Dr. Cherot. Yeah. Because the Preventing Maternal
2855 Deaths Act grant funding to be sustained so, yes. In
2856 Georgia, they recently published a series of recommendations
2857 for providing these case management services for women
2858 during pregnancy and up to one year postpartum, implementing
2859 a blood pressure check at 72 hours, not three weeks, not two
2860 weeks, but 72 hours after discharge when a patient has pre-
2861 eclampsia.
2862 *Mr. Carter. Good.
2863 *Dr. Cherot. They educate patients, right? They also
2864 provide reproductive life planning and counseling, and they

2865 improve communication coordination for patient care --
2866 *Mr. Carter. Good, good. Well, thank you.
2867 And I want to shift gears real quick and talk about
2868 Sickle Cell Disease because, again, here we are in Georgia
2869 and we have got some of the highest rates in -- and, you
2870 know, I am proud of my state, and I love my state, it is my
2871 home, it is where I have lived all of my life, where I
2872 intend to live the rest of my life, but I just cannot figure
2873 out why we are leading in some of these things. And Sickle
2874 Cell is -- and as a pharmacist, I know and I have seen and
2875 witnessed just how awful a disease it is and how painful it
2876 is. But we are home -- Georgia is home to one of the
2877 largest Sickle Cell Disease populations in the country.
2878 Dr. Thompson, how does -- and let me preface this by
2879 saying that Dr. Burgess again and I have legislation that we
2880 are co-sponsoring, H.R. 3884, the Sickle Cell Disease and
2881 Other Heritable Blood Disorders Reauthorization Act. So how
2882 does the reauthorization of critical cell disease programs
2883 ensure that patients have the support and resources that
2884 they need?

2885 *Dr. Thompson. Well, the principal benefit of this act
2886 really is to the extent that we actually can disseminate the
2887 education and training, moving it from our academic medical
2888 centers to where the patients are. And so really having --
2889 utilizing the hub and spoke model for actually getting more
2890 information, more knowledgeable providers and taking care of
2891 Sickle Cell Disease.
2892 I should also note, especially from your State of
2893 Georgia, that the benefits of actually combining the work
2894 that HRSA does with the data collection from the CDC has
2895 also been quite helpful. That the Centers for Disease
2896 Control started out with two states, Georgia and California,
2897 and that that data from those two states has helped to
2898 inform --
2899 *Mr. Carter. Good.
2900 *Dr. Thompson. -- better ways to actually identify
2901 patients and to treat them.
2902 *Mr. Carter. Great, great. I am sorry, I don't have
2903 long, but do you want it? I will yield to the lady from
2904 Washington.

2905 *The Chair. Thank you. I appreciate the gentleman
2906 yielding.
2907 I just wanted to address the CDC bills. We are
2908 considering these specific individual reauthorizations today
2909 because they are set to expire, but we also plan on looking
2910 at broader CDC authorization and reform this Congress. We
2911 must do our job as authorizers to ensure these programs are
2912 operating as intended with proper accountability and
2913 oversight.
2914 CDC has a history of often relying on Section 301 or
2915 317 of the Public Health Service Act, which provides very
2916 broad research and grant authorities to continue these
2917 programs, even if Congress does not specifically reauthorize
2918 them. These authorities were initially crafted in the 1940s
2919 and 1960s and then built upon further since then. As a part
2920 of looking at CDC reform, I think perhaps a good initial
2921 step would be to examine the use of these broad authorities
2922 and ensure that there is transparency as to when, how, and
2923 to what extent they are given as well as if these
2924 authorities are even still necessary at all given work on

2925 smaller programs like the ones that we are considering
2926 today.
2927 I appreciate the gentleman yielding.
2928 *Mr. Carter. And I will yield back. Thank you, Mr.
2929 Chairman.
2930 *Mr. Bucshon. The gentleman yields back. I now
2931 recognize Dr. Schrier for five minutes.
2932 *Ms. Schrier. Thank you, Dr. Bucshon, and thank you to
2933 all of our witnesses here today.
2934 I want to just talk about two things today. First is
2935 Children's Hospital Graduate Medical Education funding, and
2936 the other is direct primary care. I am going to start, just
2937 like so many of my colleagues, just up in arms that this
2938 funding would be held hostage for political gains.
2939 I am a pediatrician. My residency training was funded
2940 by CHGME. That was at Children's -- Lucile Packard
2941 Children's Hospital at Stanford. And I understand how
2942 important that training is and that pediatricians need to be
2943 trained in a whole gamut of care and need to be prepared for
2944 whomever comes in their office.

2945 Children's Hospital GME funding has been reauthorized
2946 on a regular basis five times in a bipartisan way since
2947 1999, has increased the number of pediatricians available to
2948 all of us and our kids. Right now, thanks to COVID and a
2949 number of other factors, we are facing a shortage of
2950 pediatricians and other physicians. This is coming at a
2951 time of increased need. We hear a lot of discussion in this
2952 committee and elsewhere about children's mental health and
2953 increased needs.
2954 And it is just unimaginable to me. I mean, frankly,
2955 until today's hearing, I could never have thought that this
2956 funding would be held up for some sort of political agenda,
2957 and putting kids who are already bullied and vulnerable
2958 right at the center of it.
2959 This program needs to be reauthorized in a timely
2960 fashion. Children's hospitals depend on it. I just -- the
2961 Children's Hospital Association has requested a clean
2962 authorization. I would like to submit a letter into the
2963 record on this specifically from the Children's Hospital
2964 Administration.

**This is an unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker**

2965 *Mr. Guthrie. No objection.

2966 [The information follows:]

2967

2968 **********COMMITTEE INSERT**********

2969

2970 *Ms. Schrier. Because healthcare, whether we are
2971 talking about women's healthcare, or children's healthcare,
2972 or other training of physicians, this is not something that
2973 should be dictated by politicians. I don't have any
2974 questions about that particular topic.
2975 The other topic is about direct primary care, and I am
2976 excited to see that the Medicaid Primary Care Improvement
2977 Act is on the docket today, clarifying that Medicaid can
2978 utilize the direct primary care model. This is designed
2979 around healthcare not fee for service billing, and the way
2980 it works is patients, or Medicaid, or insurance companies
2981 pay an affordable monthly fee that allows doctors the time
2982 they need to just really work on their patient's health.
2983 Doctors have a certain number of patients in their
2984 panel who they are responsible for providing the best
2985 possible care for. A smaller patient population often means
2986 that more time can be spent on preventative care, diet,
2987 counseling, preventative measures. And it often turns into
2988 a better relationship between doctor and patient, fewer
2989 visits to the emergency room, and better outcomes.

2990 One doctor in my state, Dr. Garrison Bliss, is a
2991 pioneer in this effort. He has done it in many different
2992 contexts, including Medicaid. Was one of the first in
2993 Washington State. And he notes that most of his patients
2994 are over 60 years old and none of them died from COVID. And
2995 he credits that relationship and close contact and avoidance
2996 of ER visits. This model of care just deserves to have more
2997 pilots around the country, hopefully with similar results.
2998 And I was just going to ask, Dr. McNamara, first, thank
2999 you for speaking to beautifully about the care of
3000 transgender kids, and if you want to add anything or correct
3001 the record on that, you are welcome to do that in the
3002 remaining minute, but I also wanted to ask you whether this
3003 direct primary care model, how that would affect your
3004 practice and the relationship you have with your patients.
3005 *Dr. McNamara. Thank you, Congresswoman, and it is a
3006 pleasure to speak to a fellow pediatrician.
3007 Primary care is the foundation of health and wellness
3008 in this country. It is a privilege to take part in our
3009 primary care system and to see children flourish into

3010 adolescents who become my favorite patients.

3011 As far as correcting the record, it is difficult to do
3012 so in a way that does justice to the amount of
3013 misinformation that we have all heard today. I urge this
3014 body to deliberate over the extensive documents that have
3015 been submitted to the record that debunk this disinformation
3016 and misinformation and to base their decisions on science.

3017 *Ms. Schrier. And I will just add in my 10 seconds
3018 that I appreciate your noting how much engagement with the
3019 patient and the family happens with counselors,
3020 psychologists, psychiatrists, physicians, endocrinologists
3021 to make sure that you have got this right and the care that
3022 these children and young adults really deserve. I wanted to
3023 call attention to that thoroughness and the care that you
3024 provide. Thank you.

3025 I yield back.

3026 *Mr. Guthrie. Thank you, the Congresswoman yields
3027 back. The chair now recognizes Mr. Crenshaw from Texas for
3028 five minutes.

3029 *Mr. Crenshaw. Thank you, Mr. Chairman. I first want

3030 to thank my friend, Representative Schrier, for her great
3031 bipartisan work on the direct primary care bill that we have
3032 been working on. It is -- look, there is a lot of things we
3033 can agree on and this is certainly one of them, and this is
3034 a small step in the right direction. I am really excited
3035 that we are going to get this through.
3036 But now there are some things we disagree on here, and
3037 that is what we have been talking about a lot in this
3038 hearing. So let's shift focus to the giant elephant in the
3039 room, and this is the reauthorization for the Children's
3040 Hospitals GME funding. And, yes, it is true, this is my
3041 bill, and what it does is it withholds funding from these
3042 hospitals if they engage in what they call gender
3043 affirmation therapy, these physical changes to a child's
3044 physiology, permanently disfiguring them through either
3045 puberty blockers or even surgical modifications.
3046 Now, look, I understand that the other side of the
3047 argument here believes they are on the side of compassion
3048 and maybe that is a sincerely held belief. It is just as
3049 true that I believe we are on the side of compassion. I

3050 think it is indeed compassionate to stop kids from being
3051 permanently, physically altered based on little to no
3052 evidence that it will improve their underlying mental
3053 condition.
3054 Now why is this controversial? That is actually beyond
3055 me. Not too long ago I think we all agreed that performing
3056 double mastectomies on a 12-year-old girl was wrong. Now it
3057 has become a political movement where radical activists have
3058 bullied mainstream medical associations and members of
3059 Congress into repeating this propaganda.
3060 Now it should be noted that in the public, this subject
3061 is actually not very controversial. In fact, a recent poll
3062 just last month by the Washington Post showed that 68
3063 percent of Americans opposed using puberty blockers on
3064 children. That is just a question about puberty blockers.
3065 Imagine if the question had been about castration or
3066 surgical interventions?
3067 So you have got to convince me that 70 percent of
3068 Americans are just a bunch of fools that refuse to accept
3069 the so-called science. Or maybe -- look, I have another

3070 theory. Maybe they have a very baseline understanding of
3071 ethics and common sense which tells us that maybe, just
3072 maybe, it is a bad idea to submit children to permanent
3073 life-altering medical interventions based solely on a
3074 temporary ideation about their gender.
3075 Gender affirmation is not science and there is no
3076 evidence-based standard of care. To say that is a lie, or
3077 is at best redefining the term evidence-based. What this is
3078 is a social contagion. It is based in pseudoscience and
3079 radical ideologies, and it is sweeping across our country
3080 and encouraging children to make irreversible changes to
3081 their gender. What is worse, it is coming from adults and
3082 institutions who know better, to include our children's
3083 hospitals and institutions that are supposed to be tethered
3084 to sound science and their Hippocratic Oath of do no harm.
3085 Now maybe I am an optimist, but I do believe that
3086 science and evidence will win out in the end, and in the
3087 future we will look back at these gender affirming therapies
3088 as we now look at lobotomies and electric shock therapies.
3089 I have some reason to be hopeful. Notably, Great Britain's

3090 National Health Service restricted these clinical
3091 interventions from minors just last week. Reviews published
3092 in the British Journal of Medicine, the Journal of the
3093 Endocrine Society, even in the American Academy of
3094 Pediatrics, all cite the lack of evidence.
3095 We want to submit for the record this review published
3096 in the Journal of Endocrine Society that found that there
3097 is, "Low quality evidence for the idea that hormonal
3098 treatment improves quality of life, depression, and anxiety
3099 among adolescents.'' Now here is the important part. This
3100 was a systematic review, which by definition is not cherry-
3101 picked data, but it is an all-encompassing review of all the
3102 data. It has thoroughly debunked the notion that any of
3103 these treatments are "evidence-based'' let alone recognized
3104 as "standard care.'' My colleagues are using these terms
3105 not as accurate representations of the data but as
3106 propaganda.
3107 Now this funding program is reauthorized every five
3108 years. It provides taxpayer funds to train resident
3109 physicians at children's hospitals across the country. It

3110 is true, it has been a bipartisan funding mechanism for
3111 years. Let's keep in mind something, though, this is
3112 taxpayer money, and when 70 percent of taxpayers oppose
3113 these barbaric treatments on minors, then taxpayer money
3114 should not fund it.
3115 That is why I am stipulating that as part of this
3116 reauthorization we will not provide any funding through this
3117 program to children's hospitals that push gender transition
3118 on minors through puberty blockers, hormone therapies, and
3119 surgeries. Now let's be clear, because there is another lie
3120 that's been told. It does not prevent any mental health
3121 therapies at all. Despite these lies being told, it does
3122 not prevent those kind of therapies at all.
3123 This is the issue of our time. This is the hill we are
3124 going to die on. It is too important. It is too important
3125 to protect our kids from this.
3126 In my very limited time -- I have too limited -- too
3127 much limited time, so I will wait for my colleagues to yield
3128 to me to ask questions, and I yield back. Thank you, Madam
3129 Chair -- or Mr. Chairman.

3130 *Mr. Guthrie. The gentleman yields back and the chair
3131 recognizes -- do you have anyone --
3132 *Voice. Mr. Joyce.
3133 *Mr. Guthrie. Dr. Joyce, you are recognized for five
3134 minutes.
3135 *Mr. Joyce. Thank you for yielding, Mr. Chairman, to
3136 our witnesses for appearing here today.
3137 I think there is some subjects that we can agree on.
3138 Innovation. Innovation in healthcare is critical for
3139 producing better outcomes and improving the quality of care
3140 that patients receive. That is why I, like many others on
3141 this panel, are very concerned over the impact that the
3142 Inflation Reduction Act is having and will continue to have
3143 on future development of new treatments and new cures.
3144 It has been 40 years since the Orphan Drug Act was
3145 signed into law. And I am quite worried that the new
3146 misguided law will undermine one of the greatest incentives
3147 that we have seen, which has led to the development of over
3148 600 novel therapies and cures, cures for diseases. However,
3149 there is still much work to be done.

3150 There are over 10,000 rare diseases, 95 percent of
3151 which lack an FDA approved treatment. As enacted, the IRA
3152 disincentivizes post-approval research and development and
3153 seeks additional indications for promising treatments. This
3154 will acutely impact pediatric patients, who by their nature
3155 make up a much smaller subset of the total population.
3156 Dr. Thompson, thank you for being here from CHOP in
3157 Philadelphia. Is a decline in the research and development
3158 investment in pediatric research a concern, and what impact
3159 will that have long-term on the patients that you treat each
3160 and every day?
3161 *Dr. Thompson. Thank you, Dr. Joyce. I think that
3162 there are some phenomenal opportunities to continue to make
3163 progress not only in pediatric health but also in the health
3164 of Americans overall when we have the opportunity to
3165 intervene, to diagnosis children and to treat them, largely
3166 coming from innovation. The ability to incentivize
3167 manufacturers to continue to stay in the space for rare
3168 diseases has been extraordinarily helpful.
3169 There have been challenges with continue -- with the

3170 continuum to determining what will actually be paid for in
3171 terms of insurers, and I do think that that continues to be
3172 something that we need to be very mindful of because it is
3173 not entirely clear that the incentives that are there to
3174 manufacture the drugs are being paralleled with incentives
3175 to actually cover them in the clinical space.
3176 *Mr. Joyce. Dr. Thompson, programs like Sickle Cell
3177 Disease and Other Heritable Blood Disorders Research,
3178 Surveillance, Prevention, and Treatment Act help prevent
3179 much needed -- help bring much needed hope to the rare
3180 disease patient communities and help spur the research and
3181 development that will add new and improved treatments for
3182 these rare diseases. How can the lessons that we have
3183 learned from this program be used to support research and
3184 treatment for other rare diseases?
3185 *Dr. Thompson. I think that the rare disease community
3186 is energized and is quite unified in trying to continue to
3187 learn from each other on how we can best go about that.
3188 Some of them are private-public partnerships. There are
3189 certainly area number of nonprofits that have been very

3190 active, especially family foundations, in bringing some of
3191 these things to our attention. Encouraging science and
3192 following the science and looking at ways to bring
3193 innovation from the bench to the bedside is I believe one of
3194 the things that many of our academic medical centers do
3195 quite well.

3196 I think without taking full advantage of the
3197 innovations, the breakthroughs that are occurring in Sickle
3198 Cell Disease, if we don't take advantage of those in this
3199 patient population, it really does send a message to those
3200 who are suffering from other more rare diseases. And so I
3201 think we -- I think embracing this in Sickle Cell should be
3202 a very positive message to all.

3203 *Mr. Joyce. Thank you for that insight. Dr. Thompson,
3204 in the past few years alone there have been a number of new
3205 innovations in the cell and gene therapy space to cure, cure
3206 hematologic diseases. Dr. Thompson, can you speak to how
3207 impactful curative therapies for diseases could be for the
3208 patients that you treat and the impact that they have on
3209 their life to be cured of these diseases?

3210 *Dr. Thompson. It has been absolutely extraordinary
3211 and very -- and I have had the privilege of being part of
3212 the gene therapy efforts over the last 10 to 15 years in the
3213 hemoglobinopathy space. It has done two things. It --
3214 certainly for the individual patients who have been
3215 successful, it has been transformational. These are
3216 individuals who can now complete their educations, raise
3217 their families, maintain full employment, and can really
3218 live their best lives. And so for the individuals, without
3219 question.

3220 For me, it has also been a very hopeful one because
3221 many of these diseases are now diagnosed by newborn
3222 screening. And while I think in the past, many of these
3223 families were devastated when they thought that they were
3224 bringing home a perfectly healthy infant, yet to be told two
3225 weeks later that their child screened positive for
3226 something. Gene therapy that is being used right now in
3227 adults gives them tremendous hope that their children can
3228 not only live long lifespans, they can hopefully lead
3229 lifespans with far less disability than they would have in

3230 the past.

3231 *Mr. Joyce. I think we can all conclude that
3232 innovation must be maintained and must be maintained as one
3233 of the cornerstones of American medical treatment. Thank
3234 you again, Dr. Thompson.

3235 And, Mr. Chairman, I yield.

3236 *Mr. Guthrie. Thank you. The gentleman yields back.
3237 The chair now recognizes the gentlewoman from Massachusetts,
3238 Mrs. Trahan, for five minutes.

3239 *Mrs. Trahan. I thank the chair. I am grateful to all
3240 the witnesses who came today prepared to talk about the
3241 bipartisan public health bills that are being covered in the
3242 hearing.

3243 We desperately need to advance proposals to address
3244 firefighter cancer rates, end Parkinson's, tackle the
3245 maternal health crisis, and so much more. Like so many of
3246 my colleagues, I am disappointed that the legislation
3247 focused on critical funding for our children's hospitals,
3248 and that is the one that is being politicized, which is why
3249 so many of the moms on this committee are speaking up.

3250 There are 59 children's hospitals who receive funding
3251 for graduate medical education from CHGME. Just one percent
3252 of all hospitals in the country. But together, they train
3253 more than half of our pediatricians and pediatric
3254 specialists across the country. Boston Children's Hospital
3255 in my home state is home to one of those training programs.
3256 In fact, the training program at Boston Children's receives
3257 no funding through Medicare, meaning it relies solely on
3258 CHGME funds to support their work with interns, residents,
3259 and fellows.
3260 The team at Boston Children's works around the clock to
3261 serve the children who travel from all over the country for
3262 specialized care. They deserve to feel supported by those
3263 of us in positions of power, not like that they are pawns in
3264 a political game. Pediatric providers are training,
3265 learning, and making contributions to advance and promote
3266 high-quality and effective care and treatment that every
3267 single one of us would want for our own child, if it was
3268 ever needed.
3269 Dr. McNamara, what are some of the challenges that

3270 pediatric care workforce is facing, and can you give us
3271 examples of the specialized care that would be disrupted if
3272 a partisan battle over reauthorization of CHGME continues?
3273 *Dr. McNamara. So children need us more than ever.
3274 They have more complex health needs and mental health needs
3275 than they ever have. Part of that is because we are very
3276 good at providing advanced care that we have been developing
3277 over the years and part of it is because of the current
3278 post-pandemic climate.
3279 The examples of care that would be affected would be
3280 care for congenital heart disease, intensive care for sick
3281 kids, sick neonates, routine well care, dentistry. I could
3282 go on.
3283 *Mrs. Trahan. I appreciate that. Boston Children's
3284 Hospital is home to the first pediatric and adolescent
3285 transgender health program in the United States. However,
3286 misinformation has repeatedly spread online suggesting the
3287 hospital performed gender affirming genital surgeries on
3288 young children, when in reality, surgeries are only
3289 performed on consenting adults. But that hasn't stopped

3290 healthcare workers at Boston Children's from being subjected
3291 to threats and attacks.
3292 Threats and attacks, by the way, that are a direct
3293 result of a coordinated campaign designed to, and I am
3294 quoting a conservative political action conference speaker
3295 here, "eradicate transgenderism.'' And by inviting a
3296 witness to elevate that dangerous rhetoric in the United
3297 States Congress, the majority is allowing a target to be
3298 painted on the backs of some of our Nation's most vulnerable
3299 children and the healthcare professionals they rely on.
3300 Dr. McNamara, can you speak to the dangers of increased
3301 threats and attacks on our Nation's pediatric healthcare
3302 professionals, and do you think this intimidation undermines
3303 their ability to recruit specialists or continue providing a
3304 high level of care?
3305 *Dr. McNamara. I absolutely do. I think if I was a
3306 medical student looking at the current political climate, it
3307 would feel overwhelming.
3308 *Mrs. Trahan. I appreciate your candor, Doctor. Time
3309 and time again I have heard my colleagues across the aisle

3310 discuss the urgent need to address the youth mental health
3311 crisis. But we can't do that if we ignore the fact that
3312 trans youth are suffering higher rates of mental illness,
3313 higher rates of suicide ideation, and higher rates of self-
3314 harm, a problem with a large body of medical literature
3315 demonstrating that with support at home, in school, and in
3316 communities, coupled with access to gender affirming care,
3317 trans youth do as well on mental health measures as their
3318 cis gender peers.
3319 We should be working to increase access to healthcare
3320 for all of our children, not to restrict the ability of
3321 children to define and express themselves. A ban on gender
3322 affirming care is dangerous, it is misguided, and it is
3323 cruel, and it is a shame the Republicans are using what
3324 should be a bipartisan piece of legislation to contribute to
3325 the dangerous attack on our most vulnerable children. They
3326 deserve better.
3327 I yield back.
3328 *Mr. Guthrie. The gentlelady yields back. The chair
3329 now recognizes Dr. Dunn for five minutes for questions.

3330 *Mr. Dunn. Thank you, Mr. Chairman. I appreciate the
3331 hard work this committee is putting in to ensure that
3332 critical public health programs do not lapse this year. I
3333 am pleased with the level of bipartisan collaboration shown
3334 to ensure that the programs that are aimed at improving
3335 childhood and maternal health serve our most vulnerable
3336 constituents. We are also supporting research to fight rare
3337 diseases.
3338 I do want to take a moment to echo the comments of my
3339 colleague, Dr. Burgess, regarding the Children's Hospital
3340 GME Program. I appreciate the bill put forth by my
3341 colleague, Mr. Crenshaw, to protect children from harmful
3342 gender approving care and hormone therapy, and I understand
3343 that many children may feel immense peer pressure and
3344 psychological distress for many different reasons. These
3345 children need loving, caring parental involvement, they need
3346 emotional support, and they need highly specialized medical
3347 experts with their best interest at heart. It is a
3348 monumental decision to undertake gender transition surgery
3349 on a potentially fertile person. The radical race to

3350 embrace gender transition is undoubtedly harming some of our
3351 children.
3352 When considering pediatric GME, it is critical that we
3353 strike the right balance between banning appropriate
3354 treatments and procedures and properly equipping physicians
3355 with the skills and the knowledge they need to perform
3356 complex surgeries and inform the choices that patients and
3357 parents make. There actually are unique cases in which a
3358 baby is born with genetic disorders that cause truly
3359 ambiguous genitalia. This is a mix of male and female
3360 reproductive organs.
3361 As a urologist, I am very familiar with such cases.
3362 Medical surgical interventions may be needed to mitigate
3363 harmful side effects and even to save lives. In these
3364 cases, it is important that pediatric urologists have the
3365 specialized knowledge and the proper skillsets to make the
3366 best decisions with the patients, with the consent of their
3367 parents.
3368 I actually do not have any questions, Mr. Chair. I am
3369 willing to yield time to anybody on the panel. Mr.

3370 Crenshaw, I recognize you.

3371 *Mr. Crenshaw. Thank you to my colleague, and I do
3372 have a few questions.

3373 You know, I want to say a few things first. We keep
3374 hearing this is a politicized issue, this is a manufactured
3375 culture war. I got to say, we aren't the ones who did that.
3376 We aren't the ones that came up with this radical new
3377 movement that is performing permanent physiological changes
3378 to children with no evidence of any benefits. We didn't
3379 start that, we are just trying to stop it because it is
3380 crazy.

3381 It is a contentious issue, which almost 70 percent of
3382 Americans oppose, so we are just saying here that taxpayer
3383 money shouldn't be used for it. That is all. This should
3384 not be that controversial of an issue.

3385 My questions are for Dr. McNamara. I just want to ask
3386 you, honestly, you are not concerned about the unknown
3387 effects of puberty blockers, hormones, and surgical
3388 interventions in kids, the long-term effects, you are not
3389 concerned about that?

3390 *Dr. McNamara. Everything I have said here today comes
3391 from a place of deep honesty and conviction for the care
3392 that I provide in the community that I am a part of.
3393 *Mr. Crenshaw. You have said that we have cherry-
3394 picked data. How do you mean by -- what -- how do you mean
3395 that?
3396 *Dr. McNamara. So it is very unscientific and flawed
3397 to pick a single study or a single statistic and to discuss
3398 it in isolation.
3399 *Mr. Crenshaw. Totally agree.
3400 *Dr. McNamara. Medical experts are able to talk about
3401 all of the evidence as a whole.
3402 *Mr. Crenshaw. Totally agree. So it is good to look
3403 at systematic reviews, right, that is the gold standard of
3404 evidence when you are trying to understand whether something
3405 works or whether or it doesn't. So the British Journal of
3406 Medicine looked at 61 systematic reviews with the conclusion
3407 that, "There is great uncertainty about the effects of
3408 puberty blockers, cross-sex hormones, and surgeries in young
3409 people.'' The Journal of Endocrine Society came up with the

3410 same conclusion. Even the American Academy of Pediatrics.
3411 They all cite the lack of evidence.
3412 And so here is the thing, if you are doing a therapy,
3413 and it is, you know, temporary, whatever, fine, maybe let's
3414 try it, let's see if it works. But when you are talking
3415 about permanent physiological changes, do you not agree,
3416 just from an ethical standpoint, that you might want
3417 extremely strong evidence of the benefits? And there is no
3418 systematic review that states that there is strong evidence
3419 of benefits.
3420 *Dr. McNamara. Sir, are you aware of how the quality
3421 evidence grading system works and how it is applied?
3422 *Mr. Crenshaw. Yeah. Yeah, we read through it. That
3423 is why I am citing these journals. So which journal says
3424 something different? I am -- we should have that debate.
3425 Tell me a journal that has done systematic reviews that
3426 cites different evidence, that cites strong evidence for
3427 benefits of these therapies.
3428 *Dr. McNamara. The standards of care were developed
3429 based on extensive --

3430 *Mr. Crenshaw. You are not telling me any journal, you
3431 are not telling me any study. Don't say standards of care -
3432 -
3433 *Dr. McNamara. But that is not what -- yeah. So --
3434 *Mr. Crenshaw. Tell me one.
3435 *Dr. McNamara. The standards of care.
3436 *Mr. Crenshaw. The standards of care. That is --
3437 *Dr. McNamara. Yes, standards of care.
3438 *Mr. Crenshaw. -- not a journal, that is not a study.
3439 That is not an organization, that is not an institution.
3440 You are just saying words. Name one study.
3441 I am out of time. I yield back.
3442 *Mr. Guthrie. And the gentleman's time is expired.
3443 Mr. Dunn yields back. The chair now recognizes Dr. Miller-
3444 Meeks for five minutes for questions.
3445 *Mrs. Miller-Meeks. Thank you, Mr. Chair, and I thank
3446 our witnesses for being here and testifying before the
3447 committee today.
3448 I am proud to see my bill, H.R. 3226, PREEMIE
3449 Reauthorization Act, included in today's hearing. And I

3450 thank Ranking Member Eshoo as well as Representative Kelly,
3451 Blunt Rochester, Burgess, and Kiggans for their hard work on
3452 the legislation. As a mother and a physician, I understand
3453 the harmful health implications of preterm birth and
3454 recognize the importance of public health programs like
3455 PREEMIE which seek to address the root causes. Also because
3456 I was a director of the Department of Public Health.
3457 In 2021, Iowa mothers gave birth to almost 3700 preterm
3458 babies which represented 10 percent of all births in the
3459 state that year. Not only do preterm births pose great
3460 health risks to the mother and her baby, but they are close
3461 -- very costly to the healthcare system, as was alluded.
3462 Over 28 percent of infant deaths are preterm related, and
3463 the average cost associated with preterm births in Iowa is
3464 $50,000 -- $58,000.
3465 Dr. Cherot, in your written testimony, you state that
3466 almost two-thirds of pregnancy-related deaths are
3467 preventable and that preterm birth rates worsened in 38
3468 states between 2018 and 2019. Can you please explain how
3469 reauthorizing PREEMIE will help reduce those rates and how

3470 funding will be used?

3471 *Dr. Cherot. So first, the financial impact of preterm
3472 birth on the U.S. economy and families. Medicaid pays for
3473 40 percent of all deliveries and an estimated 40 percent of
3474 medical costs associated with preterm birth has a
3475 significant impact on both federal and state budgets. Our -
3476 - what we are trying to advocate for here is more research
3477 to go into more solutions that will solve for the preterm
3478 problem in this country that you just alluded to or
3479 highlighted and have dealt with in the neonatal intensive
3480 cares across this country. And the point of this is to be
3481 able to collect that data to translate those into real
3482 actions.

3483 *Mrs. Miller-Meeks. Thank you.

3484 I would also like to speak in support Congressman
3485 Crenshaw's legislation to reauthorize Children's Hospital
3486 GME. The Republicans wish to reauthorize this, it is the
3487 parties on the other side of the aisle that wish not to.

3488 I know firsthand that a physician's training is a
3489 lengthy and expensive process, which is why renewing CHGME

3490 to ensure that there is sufficient supply of pediatricians
3491 to meet demand is so important. The timely reauthorization
3492 of this program through 2028 will continue a legacy of over
3493 20 years of supporting our healthcare providers. However, I
3494 am also supportive of a ban on funding for hospitals that
3495 furnish puberty blockers, hormone therapies, and surgeries
3496 for the purpose of altering biological genitalia to minors.
3497 So, Dr. McNamara, is an XY chromosome assigned at
3498 birth?
3499 *Dr. McNamara. I am sorry, I don't understand the
3500 nature of your question.
3501 *Mrs. Miller-Meeks. Simple question. Is an XY
3502 chromosome at birth?
3503 *Dr. McNamara. We often don't do routine chromosome
3504 testing on infants.
3505 *Mrs. Miller-Meeks. So an XY chromosome would not be
3506 assigned at birth nor would an XX chromosome, although you
3507 say that sex is assigned at birth. There is a lack of
3508 scientific evidence regarding the effectiveness of these
3509 medical interventions, especially among minors, which is why

3510 countries in Europe, such as Denmark, Britain, Sweden have
3511 described treatments as experimental and are urging doctors
3512 to proceed with caution and why they have changed their
3513 guidance.
3514 The purpose of healthcare is to treat and heal, and it
3515 is not of interest -- at the expense of physical and mental
3516 wellbeing of patients.
3517 What evidence, Dr. Grossman, do we have that the
3518 thriving Dr. McNamara talks about is because of hormones, or
3519 surgery, and psychotherapy, family support, regression to
3520 the mean, placebo effect, or some other confounding
3521 variable? After all, there have been no randomized
3522 controlled trials. Have there been randomized controlled
3523 controls, Dr. McNamara?
3524 *Dr. Grossman. There have not. Randomized controlled
3525 trials are what are the gold standard. That is what we are
3526 always looking for in medicine. We do not have those kind
3527 of studies.
3528 As you said, there are variables, confounding variables
3529 that can interfere if a child is going through these gender

3530 affirming cares, so-called. The child may also be getting
3531 psychotherapy. The family may be getting support. How do
3532 we know that the improvement on the other side is due to the
3533 hormones or the surgeries or the psychological support.
3534 *Mrs. Miller-Meeks. Yeah. Thank you. And I think to
3535 say that the Federal Government is not already involved in
3536 healthcare is either naïve or disingenuous. We saw that
3537 throughout the pandemic that federal and state governments
3538 were both involved in the doctor-patient relationship.
3539 As a veteran, I defended the right -- the
3540 constitutional rights of Americans. As a doctor, I swore to
3541 do no harm because I care about the physical and mental
3542 health of your children as much as I do my own children.
3543 *Mr. Guthrie. Thanks --
3544 *Mrs. Miller-Meeks. I support restricting federal
3545 funding for experimental care --
3546 *Voice. Time.
3547 *Mrs. Miller-Meeks. -- that is permanent and
3548 irreversible in minors.
3549 *Mr. Guthrie. The gentlelady's time is expired.

3550 *Mrs. Miller-Meeks. Thank you, I yield my time.
3551 *Mr. Guthrie. The chair now recognizes Mr. Pence for
3552 five minutes.
3553 *Mr. Pence. Thank you, Chairman Guthrie and Ranking
3554 Member Eshoo.
3555 I would like to speak in support of the Action for
3556 Dental Healthcare (sic) Act of 2023. Across my district,
3557 dental professionals continually communicate to me the
3558 impacts they are feeling from workforce shortages.
3559 Healthcare facilities, including dental practices, are
3560 struggling to maintain existing staff and rising salaries,
3561 let alone find enough qualified individuals to fill open
3562 positions. Universities are also straining to maintain the
3563 necessary pipeline of our next generation's health
3564 professionals.
3565 As we look to reauthorize dental workforce programs
3566 through the Action for Dental Health Act, it is important we
3567 ensure HHS is prepared to support the growing demand for
3568 dental professionals across the country and my Hoosier
3569 State.

3570 I would like now to yield time -- the rest of my time
3571 to my colleague, Congressman Crenshaw, a champion for our
3572 young children.

3573 *Mr. Crenshaw. I thank the gentleman.

3574 And, look, I just want to make a few more points. And
3575 I want to run everyone through this thought experiment. So,
3576 you know, my daughter is going to grow up with a father with
3577 one eye, and at some point she might say, you know, I want
3578 one eye, right, I identify as somebody with one eyeball.
3579 Which by the way, is far less important than your gender,
3580 just physiologically speaking.

3581 And so if I take her to the doctor and I say can you
3582 just enucleate that eye for us because she identifies as a
3583 one eye -- she wants to be just like her dad, what would the
3584 doctors say? They would say you are crazy and I am going to
3585 have you arrested. That is what -- well, that is what they
3586 should say. And this is for a physiological intervention
3587 that is far less important than your actual gender and your
3588 reproductive organs. We have to stop this madness. This
3589 has gone too far.

3590 You know, I asked before about what evidence is there
3591 that there is benefit for these so-called standards of care.
3592 I mean, anyone can say that they have a standard of care,
3593 but it has to be based on some kind of evidence and
3594 research. And when you have done systematic reviews, which
3595 is, again, is the gold standard for how you come to a
3596 conclusion within the scientific community, systematic
3597 reviews of 61 other systematic reviews, and you find little
3598 to no evidence that there is benefits for this, maybe you
3599 just press pause.
3600 Maybe you just press pause. Because if we are doing
3601 permanent physiological interventions to children that have
3602 -- permanently disfiguring them for some hope of a benefit
3603 that is not conclusive, then maybe we should press pause.
3604 Like that is all we are saying. Press pause.
3605 And actually that is -- and actually it is even less
3606 than that. All we are saying is let's not put taxpayer
3607 money toward it, right. This is no different than how this
3608 Congress deals with the Hyde Amendment. This is a
3609 controversial issue. Abortion is a controversial issue, and

3610 so we say, look, we disagree on this so let's make sure we
3611 don’t put taxpayer funding toward it. That is all this bill
3612 is.
3613 Let's not put taxpayer funding towards something that
3614 is so obviously unproven and contentious. Actually, I don't
3615 even think it is -- it is really not that contentious. 70
3616 percent of Americans oppose it, so it is actually the
3617 American people are pretty much on the side of not doing
3618 this, or at least pressing the pause button.
3619 Dr. Grossman, you are a child psychiatrist. Can you
3620 expand upon the profound lack of clinical reviews and the
3621 long-term impacts of these treatments: puberty blockers,
3622 hormones, and surgeries?
3623 *Dr. Grossman. Well, yes, as I said, we don't have the
3624 kind of studies that we would like. And I think it is very
3625 important for people to understand that when we talk about
3626 standards of care and we talk about guidelines and all the
3627 various associations that have come out for gender affirming
3628 care and about politics and partisanshipness, those
3629 organizations themselves are rife with politics. They are

3630 permeated with politics. The American --

3631 *Mr. Crenshaw. Can you expand that? Just tell us how
3632 those activists have pressured dissenting voices in this
3633 field.

3634 *Dr. Grossman. Well, yes, I just interviewed a number
3635 of doctors for my book, pediatricians, endocrinologists, who
3636 reported back to me on the fact that when they tried to
3637 speak up and have panel discussions or presentations that
3638 challenged gender affirming care at the American Academy of
3639 Pediatrics or at the Endocrine Society, they are simply not
3640 given that opportunity. Even people, you know, who have
3641 written -- writing articles, the articles are turned by a
3642 lot of journals. People have to understand that politics
3643 has -- medicine, unfortunately, is permeated with politics
3644 at this point.

3645 Now, ideally, we wouldn't be stepping in. Who wants
3646 the government stepping in between doctors, and parents, and
3647 children? Of course we ideally don't want that. But when
3648 there is something that is so wrong that is going on, then I
3649 think we have to.

3650 *Voice. Time.

3651 *Mr. Crenshaw. Thank you.

3652 And I yield back to Mr. Pence.

3653 *Voice. Time. Time.

3654 *Mr. Guthrie. Yeah, Mr. Pence yields back. The chair
3655 now recognizes -- seeing that all members of the
3656 subcommittee have been recognized, the chair now recognizes
3657 Ms. Schakowsky for five minutes for questions.

3658 *Ms. Schakowsky. Thank you for allowing me to waive on
3659 to this -- to the subcommittee.

3660 I just want to briefly begin by talking about
3661 children's hospital -- the medical education programs for
3662 children's hospitals. I -- in Chicago, I have Lurie
3663 Children's Hospital which is such a fabulous institute and
3664 the largest medical provider in Illinois, but is very
3665 concerned because of the disparity between what is given to
3666 other hospitals and the children's teaching hospitals. And
3667 I just wanted to mention that because we do rely so much on
3668 that.

3669 But I really now feel obligated and it is a privilege

3670 to now talk about -- as the only parent I think in this
3671 room, or grandparent, of a trans young man, someone whose
3672 life has been enormously improved because of his ability.
3673 Born as a girl but finding his true self now as a young man
3674 who is living the life that he -- that belongs to him. He
3675 is now graduated from college, he is teaching school, he is
3676 living with his girlfriend, and fortunately in a place where
3677 he has the opportunities to get the care that he needs and
3678 has throughout the period that he needed it.
3679 And so, Dr. McNamara, I want to thank you first of all
3680 for your voice, and I wondered if you could just enumerate
3681 some of the other falsehoods that we are hearing and that I
3682 have experienced now in my family's lifetime.
3683 *Dr. McNamara. Thank you. So first of all, regarding
3684 standards of care, that is not just a causal term. The
3685 standards of care that outline how gender affirming care
3686 should proceed for people of all ages, including
3687 adolescents, have been published in reputable journals. The
3688 Journal of the Endocrine Society has published their
3689 extensively vetted guidelines, which they have issued

3690 several times after re-examining the evidence.

3691 The World Professional Association for Transgender
3692 Health issued the 8th Edition of the Standards of Care,
3693 which is based on peer review of hundreds of global experts
3694 who basically perform systematic reviews in partnership with
3695 Johns Hopkins. The AAP has also issued statements that
3696 issue kind of practice guidelines that are taken very
3697 seriously in our community.

3698 Now I want to address the low quality evidence argument
3699 that comes up a lot and it is critical that we all
3700 understand here today that that is a technical term and that
3701 when it is used for public consumption, it can be quite
3702 confusing. There are ways to grade evidence using a very
3703 specific rubric where the number of study participants, the
3704 length of follow-up, et cetera is assessed. In medicine, we
3705 recognize that all clinical care is different, all clinical
3706 research is different, and the practicalities of conducting
3707 studies are different.

3708 Low quality evidence means that there is a basis of
3709 evidence, and it often informs strong recommendations for

3710 care.

3711 *Ms. Schakowsky. Thank you for that. And I also want
3712 to see if you could actually help us understand the kind of
3713 work that is done with families. It -- you would think that
3714 these children are snatched away and taken someplace and
3715 done -- but isn't there a whole process that patients and
3716 their families go through, and if you could tell us about
3717 that?

3718 *Dr. McNamara. Yes, ma'am. Well, oftentimes the care
3719 begins with long conversations that take place over months
3720 and months where families hear about all of their options.
3721 Parents hear about the risks and the benefits, they hear
3722 about various options, they ask lots of questions, and the
3723 young person gets mental health support.

3724 *Ms. Schakowsky. And let me -- and, finally, let me
3725 just say, if you could speak to the importance of having
3726 both behavioral healthcare and also the medical needs of
3727 these kids, how both are so important. It is implied that
3728 it is only, you know, the --

3729 *Dr. McNamara. Gender dysphoria is real and it needs

3730 to be diagnosed by a specialist. That is the standard of
3731 care in this country. Medical care does not proceed unless
3732 a mental health specialist has diagnosed this condition.
3733 *Ms. Schakowsky. Thank you.
3734 *Mr. Guthrie. Thank you.
3735 *Ms. Schakowsky. I yield back.
3736 *Mr. Guthrie. The gentlelady's time has expired and
3737 yields back. The gentleman from New York is recognized for
3738 five minutes.
3739 *Mr. Tonko. Thank you, Mr. Chair. I thank you and our
3740 Ranking Member Eshoo for the opportunity to waive on. I
3741 thank you for including the National Plan to End Parkinson's
3742 Act as a part of this hearing. In Congress, I have made
3743 helping those with neurological disorders one of my top
3744 priorities. I have long led efforts related to the other
3745 top neurological disorder facing Americans which is
3746 Alzheimer's. I am proud to expand my championship to facing
3747 Parkinson's as well.
3748 Currently, more than one million people in the U.S.
3749 live with Parkinson's Disease and there are no treatments to

3750 cure, prevent, or significantly slow down its progression.
3751 Parkinson's is the second most common neurological disease
3752 and is fortunately -- unfortunately growing and growing
3753 fast. Nearly 60,000 Americans are diagnosed every year and
3754 the disease is estimated to cost the U.S. 52 billion dollars
3755 annually. With the number of Americans diagnosed with
3756 Parkinson's Disease expected to increase as the population
3757 ages, the cost to the U.S. economy is also expected to
3758 balloon to nearly 80 billion dollars every year by 2037.
3759 I thank my good friend and colleague, Gus Bilirakis,
3760 for working on the National Plan to End Parkinson's Act with
3761 me. It is an honor to work with him on this, and I know how
3762 much it means to him personally, and I thank him for the
3763 relentless work as we work together to push this forward.
3764 Our bipartisan no-cost legislation will for the first
3765 time unite the Federal Government in a mission to cure and
3766 prevent Parkinson's, alleviate financial and health burdens
3767 on American families, and reduce government spending over
3768 time. This pioneering legislation is greatly needed.
3769 I also thank Mr. George Manahan for joining us here

3770 today --

3771 *Mr. Manahan. Sure.

3772 *Mr. Tonko. -- and bravely sharing your journey with

3773 Parkinson's. By speaking here today, you do give a face to

3774 Parkinson's. As Mr. Manahan noted, we all know someone with

3775 this devastating disease. I first learned about Parkinson's

3776 from a friend who suffered with it, and recently my good

3777 friend and colleague, Congresswoman Jennifer Wexton, was

3778 diagnosed with Parkinson's. I thank the Congresswoman for

3779 showing another face of Parkinson's and bravely sharing

3780 publicly her journey.

3781 With that in mind, I would like to share a brief

3782 message from Congresswoman Wexton, and I quote, "As many of

3783 you know, earlier this year on World Parkinson's Disease

3784 Day, I shared that I myself have been diagnosed with

3785 Parkinson's Disease, or PD. Over the past several months, I

3786 have been touched by the hundreds of messages of

3787 appreciation and hope that I have received from people who

3788 suffer from PD, but even more often from their loved ones

3789 and caregivers.

3790 A diagnosis of Parkinson's Disease affects not only
3791 those of us who suffer from the disease itself but all of
3792 the many people in our lives who love us and want us to be
3793 well again. Parkinson's is the fastest growing brain
3794 disease worldwide and is estimated to affect at least 14
3795 million people by 2040. PD is a progressive
3796 neurodegenerative disease, and although there are things we
3797 can do to slow its progression, at this time there is no
3798 cure.
3799 Eventually, many of us who have Parkinson's will be
3800 unable to walk, talk, or even feed ourselves. We will
3801 require extensive and expensive institutional or in-home
3802 care, the cost of which will likely be borne primarily by
3803 U.S. taxpayers. Research has shown that although
3804 heritability is a factor, PD is largely caused by
3805 environmental toxins and it can therefore be prevented if
3806 adequate precautions are taken.
3807 In addition, great strides are being made to identify
3808 genetic markers of Parkinson's, which we believe will lead
3809 to identifying variations of PD that will allow researchers

3810 to develop targeted treatments that will help alleviate
3811 symptoms and improve quality of life for those with the
3812 disease and slow or even halt its progression. By bringing
3813 together key stakeholders to build the national plan to
3814 prevent and cure Parkinson's, this bill is taking a critical
3815 and historic step for the millions of Americans with
3816 Parkinson's and their families just like mine. I urge you
3817 to advance this critical bipartisan legislation.''
3818 And I end there with Jennifer's quote. I could not
3819 agree more. I understand that receiving a Parkinson's
3820 diagnosis is truly devastating for individuals and their
3821 loved ones. It is incumbent upon Congress to ensure
3822 Americans know they will be supported during this
3823 frightening and life-altering time. Our legislation does
3824 just that. My hope is that this bill, when signed into law,
3825 will do for Parkinson's what national plan did for
3826 Alzheimer's and bring together coordination, care, and
3827 research all to help those with Parkinson's as well as their
3828 loved ones.
3829 So to, Mr. Manahan, I again thank you and ask, what

3830 would this legislation mean for those living with
3831 Parkinson's, and what about their families and their
3832 friends?
3833 *Mr. Manahan. It would give us hope. And really we
3834 haven't had hope until just recently. We have found a
3835 biomarker which can detect Parkinson's Disease at a very
3836 early stage. So, you know, for those people who are left
3837 who have Parkinson's, this would give us hope that we can
3838 find a solution working together hand in hand.
3839 *Mr. Tonko. And I would think the investment and
3840 coordination factors of the legislation would provide for
3841 more effective treatments?
3842 *Mr. Manahan. Yes.
3843 *Mr. Guthrie. Thank you.
3844 *Mr. Tonko. With that, I yield back.
3845 *Mr. Guthrie. Thank you. The gentleman --
3846 *Voice. [Indiscernible.]
3847 *Mr. Guthrie. Thank you. Absolutely. The gentleman
3848 yields back. The chair now recognizes Ms. Barragan from
3849 California for five minutes.

3850 *Ms. Barragan. Thank you, Mr. Chairman. I want to
3851 echo some of my colleague's comments about the importance of
3852 the Children's Graduate Medical Education Program and how
3853 critical it is. I was recently in my congressional district
3854 where I had an opportunity to meet with the Long Beach
3855 Memorial Care to hear about the importance that it has and
3856 why we need to continue to support it and fund it.
3857 I am highly disappointed in my colleagues across the
3858 aisle who are basically holding this bill hostage and this
3859 funding hostage by, you know, putting in provisions that are
3860 just unacceptable, and so it is really unfortunate, and I
3861 just wanted to echo that concern that we continue to work to
3862 get this funded and taking out some of these harmful
3863 provisions.
3864 I want to kind of follow-up on my colleague,
3865 Representative Tonko. Mr. Manahan, I found your testimony
3866 to be very powerful, particularly on your optimism that we
3867 can develop a national plan to end Parkinson's Disease. I
3868 agree we need to use every available resource to fight
3869 Parkinson's Disease. It is costing patients their lives and

3870 significantly increasing our healthcare costs with an
3871 estimated 52 billion dollars in direct and incorrect costs
3872 to society. And now that we have an accurate biomarker that
3873 can detect Parkinson's Disease before the first symptoms
3874 appear, innovation is urgently needed to find a cure.
3875 Now as my colleague said, we all know somebody who has
3876 Parkinson's. My father had Parkinson's for most of my
3877 youth. My father died when I was 23 years old, and for most
3878 of my memory, he was shaking, and I would have to sit next
3879 to him and hold his hand or try to hold his arms because I
3880 wanted the shaking to stop. I didn't know any better, I was
3881 a kid, and he and I, we watched baseball games together.
3882 And so it has been a personal issue for me and
3883 something I know we need to continue to champion. That is
3884 why I am a strong supporter of H.R. 2365, the National Plan
3885 to End Parkinson's Act, which will create an advisory
3886 council to prevent and cure Parkinson's.
3887 In your testimony you speak about the lack of services
3888 available for people with Parkinson's. How can the Federal
3889 Government support efforts to build out a stronger public

3890 health and caregiving infrastructure to support patients and
3891 families living with Parkinson's Disease?
3892 *Mr. Manahan. Well, it is interesting you mention that
3893 because, you know, unlike Alzheimer's, we don't have
3894 Parkinson's services on a state by state basis. So when I
3895 was diagnosed, I didn't know anybody with Parkinson's and
3896 there was no support groups, so we started those in West
3897 Virginia. We started a 5K that raised money for the Michael
3898 J. Fox Foundation, we raised $500,000. We have support
3899 groups, free exercise classes. So we did it ourselves. But
3900 there has to be a way that state by state there has to be
3901 some continuity of care and continuity of support.
3902 *Ms. Barragan. Right. Well, thank you for your
3903 advocacy, for starting the support group. When I was -- I
3904 remember when Michael J. Fox came out with his diagnosis, I
3905 thought, you know, oh, this is going to be some hope, there
3906 is going to be a foundation that is going to invest in this.
3907 But certainly they can't do it alone, and so it is critical
3908 that Congress also help out. And so I want to thank my
3909 colleagues who are working on that issue.

3910 I want to turn to maternal health. Dr. Cherot, would
3911 you please explain how maternal mortality review committees
3912 align and/or collaborate with perinatal quality
3913 collaboratives to identify opportunities to prevent
3914 pregnancy-related deaths?
3915 *Dr. Cherot. Sure, happy to. And I would say the
3916 California PRQ (sic) is a big success story, especially
3917 around preterm birth, and March of Dimes has been
3918 collaborating with them for some time.
3919 Fundamentally, the PQCs do the work. And so what they
3920 do are state or multistate, what they tend to do is to --
3921 are their networks that improve quality and outcomes. So
3922 they have multiple stakeholders, whether it is clinicians,
3923 hospitals, communities that work together and fundamentally
3924 take what the MM -- the recommendations from the committees
3925 that -- I can't -- now I am so tired by the end of the day.
3926 MMRCs, they take that and fundamentally drive the best
3927 outcomes, right. So they take the data, turn around and
3928 say, this is what we would recommend, and do the hard work.
3929 *Ms. Barragan. Great, thank you so much.

3930 With that, I yield back.

3931 *Mr. Guthrie. Thank you. Thank you so much. And so
3932 many of us have families come tell their stories to us, and
3933 it is so powerful to hear stories, and thanks for sharing
3934 because it -- we have -- Congress is made up of America and
3935 so we have the same stories, and so this is important to do.

3936 Well, thanks. That has concluded all of our members
3937 and people who have waived on that would like to ask
3938 questions. Thanks for your testimony and your willingness
3939 to sit here so long and answer so many questions. And it is
3940 important and it informs our work, and we really appreciate
3941 the opportunity for all of you to be here today.

3942 To do a little committee business, we have a list of --
3943 and actually, Representative Wexton's statement was read
3944 from, but she had submitted that for record, too, so it is
3945 part of it as well.

3946 But I ask unanimous consent to insert in the record the
3947 documents included on the staff hearing documents list that
3948 have been reviewed by both sides.

3949 Seeing no objection, that will be an order.

3950 [The information follows:]

3951

3952 **********COMMITTEE INSERT**********

3953

3954 *Mr. Guthrie. Again, and thanks so much. And there
3955 will be other questions. I know you all sat here for a long
3956 time. There could be other --
3957 *Ms. Eshoo. Chairman.
3958 *Mr. Guthrie. -- questions that members could submit.
3959 *Ms. Eshoo. May I just add something?
3960 *Mr. Guthrie. Yeah. Yes.
3961 *Ms. Eshoo. Yeah. I would just like to -- Mr.
3962 Manahan, you are the only one that I didn't get to speak to.
3963 Thank you. Thank you to each one of you. Whether I agree
3964 or disagree, this is an important place, it is the People's
3965 House.
3966 And, Mr. Manahan, I want to add to your envelope of
3967 hope because the Congress did in the last session toward the
3968 end of the session pass legislation creating a new very
3969 small limber agency that is designed to take on the death
3970 sentences of diseases, and Parkinson's is one of them. So I
3971 want you to know that, you know, there are a lot of members
3972 that poured their hearts and souls into that, understanding,
3973 you know, that if it is pancreatic cancer, it is a death

3974 sentence, if it is Parkinson's, if it is, you know, the
3975 cancers.
3976 So I just want to -- I wanted to share that with you.
3977 *Mr. Manahan. Thank you, Congresswoman.
3978 *Ms. Eshoo. So thank you for being here. You are very
3979 courageous.
3980 *Mr. Manahan. Thank you.
3981 *Ms. Eshoo. You are very courageous.
3982 And, Kevin, I am going to write the question to you. I
3983 can't believe that we did legislation, it became law, and
3984 the CDC didn't do a damn thing with it for almost five
3985 years, and now we are reauthorizing it. Go figure.
3986 *Mr. Guthrie. We're going to --
3987 *Ms. Eshoo. Ladies, thank you.
3988 *Mr. Guthrie. -- have oversight of that, I can
3989 guarantee you that.
3990 *Ms. Eshoo. Yes. Yeah, good.
3991 *Mr. Guthrie. Thank you so much.
3992 *Ms. Eshoo. Okay.
3993 *Mr. Guthrie. So I appreciate it. But I -- there will

3994 be written questions. I will remind all the members that
3995 they have 10 business days to submit questions for the
3996 record, and I ask the witnesses to respond promptly.
3997 Members should submit their questions by the close of
3998 business on June 28th.
3999 Again, thank you for your patience. We appreciate you
4000 being here. And the subcommittee is adjourned.
4001 [Whereupon, at 2:00 p.m., the subcommittee was
4002 adjourned.]