

House Committee on Energy and Commerce
Legislation to Improve Americans' Health Care Coverage and Outcomes
January 8, 2020
10:00 am, 2322 Rayburn House Office Building

Purpose

The purpose of this hearing was to discuss and consider seven pieces of legislation: [H.R. 1379](#), the "Ensuring Lasting Smiles Act", [H.R. 2271](#), the "Scarlett's Sunshine on Sudden Unexpected Death Act", [H.R. 2468](#), the "School-Based Allergies and Asthma Management Program Act", [H.R. 2477](#), the "Beneficiary Enrollment Notification and Eligibility Simplification Act of 2019" or the "BENES Act of 2019", [H.R. 3935](#), the "Protecting Patients Transportation to Care Act", [H.R. 4801](#), the "Healthy Start Reauthorization Act of 2019", [H.R. 5534](#), the "Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act"

Members Present

Chairman Eshoo, Ranking Member Burgess, Representatives Pallone, Upton, Matsui, Griffith, Kuster, Bucshon, Cardenas, Guthrie, Barragan, Brooks, Kelly, Carter, Ruiz, Long, Blunt- Rochester, Gianforte, Kennedy, Doyle, Bilirakis, Schrader, Mullin,

Witnesses

Panel I

Lee Beers, M.D., President-Elect, American Academy of Pediatrics

Kenneth Mendez., President and Chief Executive Officer, Asthma and Allergy Foundation of America

Stephanie Zarecky., Mother of Scarlett Pauley, Ambassador Program and Public Relations, Manager, SUDC Foundation

Panel II

Matthew Cooper, M.D., Director, Kidney and Pancreas Transplantation, Medical Director, QAPI, Medstar Georgetown Transplant Institute, Professor of Surgery., Georgetown University School of Medicine

Kevin Koser., Patient Advocate, *On behalf of* the National Foundation for Ectodermal Dysplasias

Fred Riccardi., President, Medicare Rights Center

Opening Statements

Chairman Eshoo said today, this committee continues its dedication to working in a bipartisan manner. Many of the bills being considered today have bipartisan support and all of them would save lives. The greatest tragedy any family can experience is the death of a child. H.R. 4801 would help to improve birth outcomes in at risk communities. Furthermore, additional bills attempt to address the infant death crisis in other ways. No family should have to suffer the death of a child without knowing why, but far too often that is the case. This committee will also consider legislation that seek to improve coverage options by closing coverage gaps and expanding access to medically necessary medical services.

Ranking Member Burgess said the bills being considered today are designed to improve access to medical coverage and services. Specifically, kidney transplants are a vital investment in an individual's future health. However, in order for the investment to be realized, the patient must take immunosuppressant drugs. Unfortunately, Medicare does not cover these drugs for the duration of the treatment and often leave patients vulnerable and without coverage. H.R. 5534 will ensure that patients can carry out their kidney transplant care to completion and reduce the odds of future complications. The remaining bills come to the subcommittee as part of a bipartisan effort to improve the lives of Americans and keep the nation healthier.

Congressman Pallone said that today this committee will examine bipartisan bills to expand coverage options and improve health outcomes for countless Americans. There are several bills that will enhance existing programs and act to fill gaps in care. Other bills seek to create programs designed to address growing needs such as asthma in school aged children. It is vital to work in a bipartisan manner to implement these common sense proposals.

Congressman Walden said that H.R. 2271 works to further explain unexpected infant death and improve data collection surrounding this tragedy. No one should have to lose a child without an explanation. H.R. 2468 is designed to improve the care of school aged children with asthma and better equip school systems to address the condition. It is remarkably encouraging that many of these bills come to the subcommittee with bipartisan support. In order to implement any of these bills in to law, they will need to have bipartisan support. Of course there will be disagreements among this committee at times, but it is important to continue to try to work together and focus on areas of agreement.

Testimony

Panel I

Ms. Zarecky said that her daughter, Scarlett, passed away when she was just 16 months old. 3 years ago, Scarlett caught a slight fever and was put in bed. The next time she was checked on, she had passed away. Despite all of the research, there has never been a cause attributed to Scarlett's death. Scarlett was diagnosed with Sudden Infant Death Syndrome (SID). There is no known cause for SID and countless infants and families suffer from it every year. Research into the causes of SID is necessary and standardizing data collection surrounding the event is crucial. It is possible to stop these tragedies but it requires a significantly improved effort by Congress and the medical community.

Dr. Beers said that H.R. 2271 will help save the lives of countless infants. Persistent ethnic and socioeconomic disparities exist among sudden infant death cases. It is crucial to work to close these disparities and seek to understand the causes of these deaths. In order to do this, the medical community must use evidence based practices and improve data collection. H.R. 4801 will help to ensure that women in low socioeconomic communities have access to post-partum care and support. Although, infant mortality is dropping in the United States, the rates are still far too high. This is also true for maternal mortality. Programs like healthy start are vital to the life time health of infants and mothers.

Mr. Mendez said that H.R. 2468 is an important step in securing the health of American children living with asthma and food allergies. Childhood asthma is one of the number one reasons for lost school days. This translates to lost educational time and lost economic benefits due to caregivers taking off work. Schools can help by being prepared for asthma related events and empowering staff members to act. This is also true for food related allergies. Nearly 1 out of 13 school aged children has a food related allergy. It is vital that schools are prepared to deal with a significant health event related to food borne allergies. Schools should have emergency protocols for asthma related events and allergic reactions.

Panel II

Dr. Cooper said that organ transplants are a medical success story. Transplants not only increase the length of life, but also the quality of life. Unfortunately, everyone who needs a kidney transplant does not get one, and there is a dramatic shortage of organs in the United States. Furthermore, Medicare does not adequately cover all of the services necessary for a successful transplant. This results in individuals losing their transplant and being placed back on a waiting list. From a medical and financial stand point, this system makes no sense.

Mr. Koser said that H.R. 1379 would help patients who are diagnosed with a congenital anomaly. This bill will ensure that all health plans will provide coverage for Americans born with congenital anomalies and then require access to medically necessary treatments to restore function to body parts. This bill is common sense. However, insurance systems systematically do not cover these procedures despite medical diagnosis. Insurance systems exploit loopholes and harm patients.

Mr. Riccardi said that H.R. 2477 would help consumers make informed coverage choices. Although most individuals are automatically enrolled in Medicare part A, many others have to enroll by themselves. It is also true that individuals have to self-enroll into part B. Enrolling into Medicare part B can be intimidating and the consequences huge. If enrolled improperly, individuals may be stuck with a plan that does not work for them and results in a coverage gap. The rules of enrollment are too confusing. HR 2477 implements common sense solutions to notify individuals about eligibility and align future enrollment strategies.

Questions and Answers

Panel I

Chairman Eshoo asked what the most important thing Congress can do to address SID is.

Ms. Zarecky said there needs to be more research, and in order for that to happen there needs to be more standardized data collection. **Chairman Eshoo** asked if there is research being conducted right now. **Ms. Zarecky** said yes, but it is limited. **Chairman Eshoo** asked if it is true that the American medical system is focused more on fetal safety than maternal safety. **Dr. Beers** said that is a hard question to answer. However, there needs to be a greater focus on maternal health and cultural competency. **Chairman Eshoo** asked how H.R. 4801 would improve maternal mortality. **Dr. Beers** said it would help most by addressing social determinants of health.

Ranking Member Burgess asked what recommendations are given to parents regarding how infants should sleep. **Dr. Beers** said infants should sleep alone in a crib, on their back, with no foreign objects.

Rep. Pallone asked how support services can be helpful to families who have experienced SID. **Ms. Zarecky** said that there is no greater gift than being able to connect with a family that truly understands your experience. Support Services have made it possible to move on and live a normal life. **Rep. Pallone** asked what forms of support services should be available to families. **Dr. Beers** said timely access to mental health services is crucial, especially grief counseling. The types of services will vary by family based on individual need.

Rep. Congressman Upton asked if new moms are made aware of safe sleep recommendations. **Dr. Beers** said yes, that information is pretty standard in a hospital. However, when you are a new mom you may not remember or absorb everything in the moment.

Rep. Matsui asked what best practices for managing food allergies in schools are. **Mr. Mendez** said having train personnel in the school is crucial. Furthermore, there should be an explicit anaphylaxis program along with written instructions and accurate records. **Rep. Matsui** asked where the greatest gaps exist. **Mr. Mendez** said awareness needs to be increased. There are countless stories of food allergy bullying. There should also be more diversity in clinical trials. **Rep. Matsui** asked if there are disparities among schools. **Mr. Mendez** said that schools with high health disparities in general tend to have high disparities among food allergies.

Rep. Griffith asked if training school employees to be address asthma events would be burdensome. **Mr. Mendez** said it would not be burdensome. There are free pieces of educational materials and incentives to do so. **Rep. Griffith** asked if the language in the bill would require drastic environmental changes around the school. **Mr. Mendez** said no, it is more about internal conditions such as an air filtration system.

Rep. Kuster asked what more can be done to train parents and child care workers to prevent SID. **Ms. Zarecky** said that Scarlett's death was not related to unsafe sleep. Her death is still unexplained. **Dr. Beers** said that education needs to be provided to large and small child care centers alike. Furthermore, local jurisdictions should require this type of training. **Rep. Kuster** asked if there is an increased risk at the stage when babies begin to roll over. **Dr. Beers** said that is possible, but there needs to be more data to say for sure.

Rep. Bucshon asked how H.R. 2468 would use a proven model to improve health outcomes. **Mr. Mendez** said that by providing training for school officials upfront, the number of asthma attacks and asthma related absences falls greatly. **Rep. Bucshon** asked if there are parts of the country that are more vulnerable than others. **Mr. Mendez** said yes. The Northeast and Midwest seem to be the worst.

Rep. Cardenas asked what social determinants of health effect health outcomes for mothers and newborns. **Dr. Beers** said food and housing insecurity are both risk factors. Transportation is another large barrier to care for many individuals. **Rep. Cardenas** asked if these social determinants of health are more prevalent in rural or urban communities. **Dr. Beers** said they are prevalent across the board. **Rep. Cardenas** asked if this a minority issue or a wide spread American issue. **Dr. Beers** said it is a wide spread issue. There are significant gaps in care in minority communities, but it affects everyone.

Rep. Guthrie asked why infant mortality has dropped. **Dr. Beers** said there has been tremendous progress related to access to care. Furthermore, programs like 'Healthy Start' have helped to decrease the impact of social determinants of health. **Rep. Guthrie** asked what states are doing to address food allergies. **Mr. Mendez** said that it varies by states. But many states are mandating that medication must be available in schools.

Rep. Barragan asked how HR 2468 will reduce racial disparities surrounding asthma. **Mr. Mendez** said that this bill incentivizes schools to create action plans for asthma attacks. This will help every school that does not already have one. **Rep. Barragan** asked how else Congress can address asthma. **Mr. Mendez** said roll backs of legislation have contributed to dirty air. It would be useful to focus on environmental regulations.

Rep. Brooks asked how Ms. Zarecky got connected to services after her daughter's death. **Ms. Zarecky** said that she was only connected to resources through her own effort. There was no formal or official process of providing connection to support services. **Rep. Brooks** asked how to institute more protocols to support families and medical professionals. **Dr. Beers** said there need to be clear and consistent resources that are presented to families at the time of incident. Furthermore, there needs to be a central registry for data collection.

Rep. Kelly asked why updates to the health start program are necessary. **Dr. Beers** said there is more knowledge and evidence since the program as created. It should be updated to reflect that evidence.

Rep. Carter asked how important accurate data collection is. **Dr. Beers** said the data is the most important part. Currently, researchers are asking some of the right questions but not all of the right questions. There needs to be more data surrounding access to services and individual health care experiences. **Rep. Carter** asked what challenges currently exist. **Dr. Beers** said that it is hard to get data on social conditions. **Rep. Carter** asked if states have uniform death certificates. **Dr. Beers** said no, they vary by state.

Rep. Ruiz asked how important the children's treatment asthma grant program is. **Mr. Mendez** said the program is vitally important and should be rolled out to more states.

Rep. Long asked how the 'healthy start' program has been able to reduce barriers in accessing care. **Dr. Beers** said that the program is patient and family centered. Furthermore, the program is very engaged in the whole community and all of the resources

available. **Rep. Long** asked how the 'healthy start' program supports provider training. **Dr. Beers** said the program helps connect providers with training materials that are relevant to the specific community they serve.

Rep. Blunt-Rochester asked what parts of H.R. 2271 make the bill strong. **Ms. Zarecky** said the addition of the family support legislation is crucial. **Rep. Blunt Rochester** asked how the Asthma and Allergy Foundation of America came up with their list of recommendations for schools. **Mr. Mendez** said the foundation worked with families and medical providers to develop evidence based strategies.

Rep. Gianforte asked what the process was like for SID to be ruled the cause of death for Scarlett. **Ms. Zarecky** said that a little less than 48 hours after death, the autopsy ruled the cause of death as undetermined. 5 months later, a second autopsy came back which still said undetermined, but ruled it SID. **Rep. Gianforte** asked what the Indian Health Service can do to prevent SID. **Dr. Beers** said they need to address social determinants of health. That includes conducting intake assessments and meeting families where they are. **Rep. Gianforte** asked if maternal mortality and infant mortality are linked. **Dr. Beers** said they are related in the fact that they often have similar root causes.

Rep. Kennedy asked if it would be beneficial to simplify Medicaid enrollment and screening. **Dr. Beers** said yes. Anything that can reduce the barriers to care is beneficial.

Rep. Doyle asked what the difference is between SID and sleep related deaths. **Dr. Beers** said that SID is mysterious, there is no good data surrounding it and no known cause. Sleep related deaths are deaths that originally seem mysterious until an investigation reveals it was the cause of sleep practices.

Panel II

Chairman Eshoo asked why the Medicare program continues to be inefficient after 50 years of the same problem. **Dr. Cooper** said it is most likely because Part A, B, C and D do not communicate with each other very often. Thus it took several years to even recognize a problem. **Chairman Eshoo** asked if our country allocates organs well. **Dr. Cooper** said there is currently an effort to change the allocation system. **Chairman Eshoo** asked why CMS does not notify soon to be eligible enrollees. **Mr. Riccardi** there needs to be a statutory change to mandate this notification.

Ranking Member Burgess asked why Medicare has gaps in coverage for kidney transplant treatments. **Dr. Cooper** said when the law was being written, the author did not think about the unintended consequences. Specifically, the authors did not consider a cost benefit analysis. **Ranking Member Burgess** asked if private insurance typically covers immunosuppressant drugs. **Dr. Cooper** said yes.

Rep. Matsui asked how Mr. Koser became involved in advocacy. **Mr. Koser** said his son was diagnosed with ectodermal dysplasia. Mr. Koser said that this experience showed him how predatory health plans can be. **Rep. Matsui** asked how federal regulations can help

ensure access to coverage. **Mr. Koser** said that current laws are written in open ended ways that allow health plans to interpret and choose what they cover. Federal regulations can help to provide the necessary oversight to close loopholes.

Rep. Bilirakis asked what percentage of seniors have an adequate understanding of Medicare and their coverage options. **Mr. Riccardi** said that millions of beneficiaries are under informed or misinformed. Only 60% of people are automatically enrolled. **Rep. Bilirakis** asked what the best way to notify individuals about their eligibility status is. **Mr. Riccardi** said that research shows that when social security sends a letter, individuals open it and read it. The notifications would be accompanied with these letters.

Rep. Schrader asked it would be a good idea to allow individuals on COBRA insurance to be able to move on to Medicare one month after their COBRA insurance expired. **Mr. Riccardi** said yes.

Rep. Cardenas asked what types of services do individuals use non-emergency medical transport for. **Mr. Riccardi** said beneficiaries use these services to attend medical visits. This includes checkups, pharmacy visits, preventative care and therapeutic care. **Rep. Cardenas** asked if dual eligible beneficiaries utilize a lot of Medicaid services throughout the year. **Mr. Riccardi** said yes. This population tends to have comorbid conditions.

Rep. Mullin asked what the easiest way to reduce cost in the Medicare program is. **Dr. Cooper** said identifying chronic kidney disease early is crucial. Transplants also save money over time. **Rep. Mullin** asked if transplants are more cost effective than dialysis. **Dr. Cooper** said the return on investment is very quick. Transplants are more cost effective.

Rep. Ruiz asked if enrollment laws have been amended since they have been enacted. **Mr. Riccardi** said the enrollment rules have not changed in over 50 years.