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RPTR MERTENS

EDTR HUMKE

LEGISLATION TO IMPROVE AMERICANS' HEALTH CARE COVERAGE AND OUTCOMES
WEDNESDAY, JANUARY 8, 2020
House of Representatives,
Subcommittee on Health,
Committee on Energy and Commerce,
Washington, D.C.

The subcommittee met, pursuant to call, at 10:03 a.m., in Room 2322, Rayburn House Office Building, Hon. Anna G. Eshoo [chairman of the subcommittee] presiding.

Present: Representatives Eshoo, Engel, Matsui, Sarbanes, Welch, Kennedy, Cardenas, Schrader, Ruiz, Dingell, Kuster, Kelly, Barragan, Blunt Rochester, Pallone (ex officio), Burgess, Upton, Shimkus, Guthrie, Griffith, Bilirakis, Long, Bucshon, Brooks, Mullin, Hudson, Carter, Gianforte, and Walden (ex officio).

Also Present: Representatives Doyle, and Soto.

Staff Present: Austin Flack, Staff Assistant; Waverly Gordon, Deputy Chief Counsel; Stephen Holland, Health Counsel; Saha Khaterzai, Professional Staff Member;

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Zachary Keita, Intern; Aisling McDonough, Policy Coordinator; Meghan Mullon, Staff Assistant; Samantha Satchell, Professional Staff Member; Kimberlee Trzeciak, Chief Health Advisor; Rick Van Buren, Health Counsel; Madison Wendell, Intern; C.J. Young, Press Secretary; Nolan Ahern, Minority Professional Staff, Health; S.K. Brown, Minority Press Assistant; William Clutterbuck, Minority Staff Assistant; Tyler Greenberg, Minority Staff Assistant; James Paluskiewizc, Minority Chief Counsel, Health; Brannon Rains, Minority Legislative Clerk; and Kristen Shatynski, Minority Professional Staff Member, Health.

Ms. Eshoo. Good morning, everyone.

The Subcommittee on Health will now come to order. I just want to note that we will be recessing the hearing for an all Member classified briefing today on Iran and Iraq at 1:00, so if needed, we will return and continue the hearing once the briefing is complete.

The chair now recognizes herself for 5 minutes for an opening statement. I want to welcome our witnesses and thank them for being here, and the chair wishes all of the members, everyone that is in the room, those that are here to observe, a blessed new year to each one of you and to your families.

Last year, our subcommittee was remarkably productive. We held 19 hearings and passed 31 bills, all of which had some bipartisan support, and today we will continue that progress by examining seven bipartisan bills to improve Americans' healthcare and coverage.

Our first panel will deal with three bills, important bills, that aim to prevent the single greatest tragedy a family can experience, the death of a child. Among developed nations, the United States has one of the highest infant mortality rates. For every 1,000 live births in our country, nearly six babies will not live to see their first birthday.

The Healthy Start Reauthorization Act of 2019 introduced by Representatives Tim Ryan and Anthony Gonzalez invests $135 million annually to improve birth outcomes in high risk communities by providing services to women and families before, during, and after pregnancy. The Healthy Start program has been proven to reduce rates of low birth weights, pre-term births, and prenatal opioid exposure.

We will also consider the Scarlett's Sunshine on Sudden Unexpected Death Act introduced by Representatives Gwen Moore and Tom Cole. We are honored today to have with us Scarlett's mother, Stephanie Zarecky. A warm welcome to you, Ms. Zarecky.

This is what I would consider an imaginably difficult day for you because it is the third anniversary of Scarlett's unexplained death, so we are very grateful to you, and know that you are surrounded by a full room of people that care deeply about this and that you are here to inform us, and we will pay close attention to what you instruct us relative to action.

No family should suffer the death of a child without knowing why. Yet, over 400 children and 3,600 infants die each year from unexplained causes. We will honor these children today by considering the Scarlett's Sunshine Act which provides funding to improve data collection and death scene investigations related to unexpected deaths and promotes safe sleep practices.

The third bill is the school-based Allergies and Asthma Management Program Act introduced by Representatives Steny Hoyer and David Roe. Children should be able to go to school feeling secure that their school can handle an asthma attack or an allergic reaction. This is not the case today. The legislation preferentially awards children's asthma treatment grants to States whose public schools have plans for managing asthma -- I like the sound. That is all right. Let them fuss. It sounds good -- for managing asthma and allergy triggers in emergencies.

With our second panel, we are going to consider four bills that close damaging gaps in health insurance coverage. The first is the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patient Act, mouthful, that is a mouthful, introduced by Representatives Ron Kind and our own Dr. Burgess.

While Medicare covers a lifetime of dialysis, kidney transplant recipients currently lose their Medicare coverage 36 months after transplant. It doesn't make sense. Without Medicare coverage for needed immunosuppressive drugs, transplant patients risk losing their new kidney. The legislation closes that gap by continuing coverage for kidney transplant recipients, which a non-partisan HHS analysis found would save 375 kidney transplants each year.

The Ensuring Lasting Smiles Act, introduced by Representatives Collin Peterson and Denver Riggleman requires health plans to cover medically necessary dental services related to a patient's congenital anomaly. About 4 percent of children in the United States are born with congenital anomalies such as cleft palate, and health plans systematically delay claims for dental-related procedures to treat them. This practice leaves families in debt from high out-of-pocket costs despite their paying for their health insurance that really should cover medically necessary procedures.

And the final two bills reform core pieces of the Medicare and Medicaid programs. And I am not going to go into them, but the Protecting Patients Transportation Care Act is introduced by Buddy Carter -- two members of this subcommittee, Buddy Carter and Tony Cardenas. And we will have an excellent conversation about that because Medicaid's coverage of transportation to health services is a lifeline for patients, especially those that live in rural or underserved areas.

And the final bill, introduced by Representatives Raul Ruiz and Jackie Walorski, updates the Part B enrollment process for the first time in 50 years.

So today's hearing, I would say, is bursting with commonsense legislation that will improve the health and the care for every American from the youngest to the oldest, and I am proud to help advance these bills and continue our record of bipartisan productivity in the new year.

The chair now recognizes the ranking member of our subcommittee for 5 minutes for his opening statement, Dr. Michael Burgess.

[The prepared statement of Ms. Eshoo follows:]

******** COMMITTEE INSERT ********

Mr. Burgess. And I thank the chair, and we are considering seven bills this morning. We might call them the magnificent seven since they are the first bills to be considered in our health subcommittee this year. And these are bills designed to provide access to medical services or medicines for different American patients.

I am appreciative of the inclusion of H.R. 5534, the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2019. This is something where I have worked for nearly 10 years to try to effect. Congress enacted legislation in 1972 to allow certain individuals with end stage renal disease to be covered under Medicare. It was the first time that individuals under the age of 65 became eligible to enroll in Medicare because of a medical condition.

Medicare beneficiaries with end stage renal disease are about 1 percent of the total Medicare enrollment, but they are 7 percent of Medicare spending. These patients are incredibly ill. They often have numerous other costly chronic conditions.

A kidney transplant is an investment that the government makes into the patient's future. Medicare pays for the patient's kidney transplant if they have this end stage renal disease benefit, and that transplant should be a solid investment in the future health of that patient. Unfortunately, that investment is lost, and the patient's health will take a turn for the worst if they cannot get their immunosuppressive drugs and then ultimately reject the kidney transplant. We should protect that investment.

Currently, Medicare covers only immunosuppressive drugs for 36 months. However, these patients require these immunosuppressives for the rest of their lives. H.R. 5534 directly addresses that problem by extending Medicare coverage of immunosuppressive drugs past 36 months for patients who do not obtain health coverage elsewhere. This is a policy that has the support from patients and transplant surgeons, and it is something the kidney community has been behind for years.

In July. I attended the launch of President Trump's Advancing American Kidney Health Initiative which aims to improve care and foster innovation to benefit kidney patients across the country. This policy, H.R. 5534, aligns with the goals of the administration. In fact, both the Center for Medicare and Medicaid Services Office of the Actuary and the Office of the Assistant Secretary for Planning and Evaluation at Health and Human Services have published reports on the benefits of extending Medicare coverage for immunosuppressive drugs which includes financial savings for the Medicare program.

There is momentum. We can make a difference in the lives of kidney patients, and H.R. 5534 is a critical component of that effort as it will improve patient adherence to an immunosuppressive regimen and help ensure that patients can maintain their transplant and avoid future kidney-related complications.

Other bills are part of this hearing, and they include efforts to improve access to different types of care. For example, Representative Carter's bill, H.R. 3935, would continue the requirement that State Medicaid programs provide coverage of nonemergency transportation to medically necessary services.

Other bills such as H.R. 2477, the BENES Act, are well intentioned, and we want our health system working better for individuals, but we also know from the Congressional Budget Office that this particular bill comes with a significant cost. People may avoid late enrollment penalties, but we want to make sure that in trying to ease enrollment, we do not harm the integrity of the enrollment processes.

H.R. 2271, the Scarlett's Sunshine on Sudden Unexpected Death Act, aims to improve the investigation of sudden unexpected deaths amongst infants and children. This bill has a goal similar to that of the Preventing Maternal Deaths Act which was signed into law in the last Congress, and that would help States equip themselves to identify and address the causes of these tragedies.

H.R. 4801 will reauthorize the Healthy Start Program at the Health Resources and Services Administration, and it is also imperative in improving health outcomes for American mothers and children.

On the topic of children's health, 2468, the School-Based Allergies and Asthma Management Program Act, would equip schools to better handle asthma and allergies among students. Ten percent of children have asthma. Our schools must be better prepared to handle that growing population.

So Madam Chair, I am glad we are looking at these bills today, and we had an agreement to consider them all before the subcommittee, and I hope other bills that we requested to be part of this hearing are soon under consideration.

I want to thank all of our witnesses for being here today and sharing their information with us, and I will yield back.

[The prepared statement of Mr. Burgess follows:]

******** COMMITTEE INSERT ********

Ms. Eshoo. The gentleman yields back. I have the fullest intention to break our first year record, so I look forward to more and more bills being heard, taken up, acted upon.

It is a pleasure to recognize the chairman of the full committee, Mr. Pallone, for his opening statement for 5 minutes.

The Chairman. Thank you, Madam Chair.

Today, the Health Subcommittee continues its bipartisan work to improve health outcomes and healthcare coverage. Our first panel will examine three bills to improve health outcomes for babies and children.

The first bill, H.R. 2271, the Scarlett's Sunshine on Sudden Unexpected Death Act, will improve investigations, data collection, surveillance, and research into sudden unexpected infant death and sudden unexpected death in childhood. It also includes critical support for families who face these unimaginable tragedies. As the author of the Sudden Unexpected Death Data Enhancement and Awareness Act, which was signed into law by President Obama in 2014, I have long supported this cause, and I am glad we are taking further steps today.

The subcommittee will also examine H.R. 4801, the Healthy Start Reauthorization Act, which will enhance programs that support perinatal health, reduce infant mortality, and improve long-term health outcomes. Despite serving communities that have much higher rates of infant mortality, Healthy Start grantees have shown their ability to bring their community's overall infant mortality rate below the national average, demonstrating the program's success and the need to expand and strengthen it.

In rounding out the first panel, the subcommittee will review H.R. 2468, the

School-Based Allergies and Asthma Management Program Act, a bill that will provide incentives for schools to help prevent and treat asthma and allergy-related emergencies.

Now, our second panel will examine four bills that improve health insurance coverage. H.R. 2477, the BENES Act, will provide individuals approaching Medicare eligibility with critical information about the Medicare enrollment process. This commonsense notice will empower people to make better choices about their healthcare coverage and avoid costly lifetime late enrollment penalties, and it will also eliminate harmful gaps in Medicare coverage.

We will also discuss H.R. 5534, the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act. This bill removes the 36-month limit on Medicare coverage of immunosuppressive drugs after a kidney transplant surgery. Those who are fortunate enough to receive the kidney transplant rely on this medication for the rest of their lives, so it is important that Medicare offers the coverage necessary to protect the incredible gift of life that a transplant brings.

We also discuss H.R. 1379, the Ensuring Lasting Smiles Act, which requires all individual and group market health plans to cover medically necessary treatment resulting from congenital abnormalities. About 3 percent of American children are born with congenital abnormalities or birth defects that affect the way they look, develop, or function and often for the rest of their lives.

So these children require serious medical treatment that is often not covered by health plans either because it is deemed cosmetic or because the treatment involves dental services. However, this treatment is critically important and medically necessary, particularly for children with serious dental anomalies.

Our witness today, Kevin Koser, will tell us about his family's longstanding struggles to get his son Kannon's medical treatment covered, and H.R. 1379 would ensure that children like Kannon get the treatment they need.

And finally, we will consider H.R. 3935, the Protecting Patients Transportation to Care Act, which will ensure that some of the most vulnerable Americans will continue to be able to access the care they need through Medicaid regardless of where they live.

These bills make important strides to improving health outcomes and health coverage. I agree with Chairwoman Eshoo who said that these are -- this is a group of very commonsense, rational proposals, and I look forward to the witnesses' testimony. Thank you, Madam Chair, and I yield back.

[The prepared statement of The Chairman follows:]

******** COMMITTEE INSERT ********

Ms. Eshoo. The gentleman yields back.

It is a pleasure to recognize the ranking member of the full committee, our friend from Oregon, Mr. Walden, for his 5 minutes.

Mr. Walden. Thank you, Madam Chair, and welcome to everyone in the new year and a good group of bills before us today in our first hearing of the new year.

As you know, at today's hearing, we will have the opportunity to review initiatives intended to advance public health and wellness in children as well as other proposals affecting the Medicare and Medicaid programs.

H.R. 2271, the Scarlett's Sunshine on Sudden Death Unexpected -- Sudden Unexpected Death Act, works to improve current efforts to further understand both sudden unexplained infant death and sudden unexplained death in childhood.

I would like to thank Stephanie Zarecky for being here today, the mother of Scarlett for whom the bill is named, for being here to share Scarlett's story. It is really important.

Circumstances surrounding these unfortunate tragedies are oftentimes not fully understood which makes determining the causes of sudden deaths of infants and children very challenging. H.R. 2271, as you know, would improve the comprehensiveness and standardization of child infant death investigations.

As someone who has lost a child, I can't imagine the added heartache of a child's death being without any explanation. My hope is this legislation will find answers to those questions, and more importantly, prevent deaths in the future.

In addition to H.R. 2271, we will review H.R. 4801, the Healthy Start Reauthorization Act, which reauthorizes grants to State and local organizations to provide services and support that reduce infant mortality and improve pregnancy outcomes.

We will also review H.R. 2468. That is the School-Based Allergy and Asthma Management Program Act. This bill authorizes the Department of Health and Human Services in making asthma-related grants to give preferences to a State with comprehensive school-based allergy and asthma management programs and include on-site personnel trained in the administration of allergy and asthma rescue medications.

We will also review H.R. 1379, the Ensuring Lasting Smiles Act, which will ensure that children with congenital anomalies have their medically necessary treatment covered by private insurance. Last year, I met with Dr. Keith Krueger, a surgeon in central Oregon, about this issue and heard the frustrations of his patients and their parents who had to fight too hard just to get the treatment covered.

So I think my colleagues on both sides of the aisle would agree that the language in this bill could be improved to avoid any unintended consequences, but I do believe we should fix this issue and give patients the peace of mind that their care will be covered.

We will also review H.R. 3935. That is the Protecting Patients Transportation to Care Act which codifies in statute the nonemergency medical transportation benefits for the States which has the odd distinction of being a mandatory benefit that is not in the statute but instead established through regulation.

So I am glad we are having a hearing on this bill as it is critical we hear from States and communities served by this benefit as to how it is working and what value it brings to the Medicaid program.

Next, there is H.R. 2477, the BENES Act, which seeks to better align enrollment under Medicare Part B. The bill also seeks to provide more outreach to those eligible for

Medicare Part B to sign up as soon as an individual is eligible and attempts to mitigate enrollment penalties for those who do not sign up in time.

The version of the bill we are considering today and what has been reported out of Ways and Means are both improvements over previously introduced versions, and I look forward to negotiating the language if the majority chooses to proceed with the markup, Madam Chair.

Finally, we will review H.R. 5534, which Dr. Burgess has championed for years. It is a great example of how Medicare rules can be nonsensical -- not what he has championed but what he wants to fix. Individuals who have received a kidney transplant require immunosuppressive drugs for the rest of their life in order to minimize the risk of their immune system rejecting the kidney.

Unfortunately, Medicare currently only provides payment for immunosuppressive drugs for 3 years, while providing coverage for a lifetime of dialysis treatments. So Medicare will currently pay for dialysis, pay for a transplant, pay for the drugs for 3 years, and then stop paying so patients are more likely to lose their transplanted kidney, and then guess what, Medicare goes back to paying for dialysis, will pay for a new transplant and 3 more years of drug coverage.

Extending immunosuppressive drug coverage for the lifetime of kidney patients is a cost effective way for the Federal Government to improve clinical outcomes for those with end-stage renal disease. Despite decades of legislative efforts and supporting clinical data, extending coverage for immunosuppressive drugs has not been passed into law. Though I am pleased we are reviewing this bill today, hopefully, we can change that in this year.

So together these are really important pieces of legislation, Madam Chair, and I look forward to hearing from our witnesses and working with you going into the new year.

And also just as a note, I have to go down to the other subcommittee. We have two subcommittees meeting simultaneously. So some of us you will see come and go.

And so thanks for having this important hearing today, and I yield back the balance of my time.

[The prepared statement of Mr. Walden follows:]

******** COMMITTEE INSERT ********

Ms. Eshoo. Thank you. The gentleman yields back.

The chair reminds members that pursuant to committee rules, all members' written, openings statements shall be made part of the record.

Now I would like to introduce our witnesses for our first panel. First, our collective thanks to each one of you. Ms. Stephanie Zarecky, she is the mother of Scarlett Pauley, and the public relations manager of the SUDC Foundation. Welcome to you. Thank you very much.

Dr. Lee Beers is president-elect of the American Academy of Pediatrics. Welcome to you. It is lovely to see you.

And Mr. Kenneth Mendez, it is great to see you, President and CEO of the Asthma and Allergy Foundation of America.

So we are all grateful for your testimony today. We look forward to hearing it. I think you are all familiar with the lights. Maybe Ms. Zarecky isn't, but green is go, yellow means red is coming up, and then we stop, okay.

So let me call on Ms. Zarecky first. You are recognized. You have 5 minutes, and we look forward to hearing your testimony.

And again, we are really indebted to you for traveling to us. And as I said in my opening statement, this is a -- this is a tough day, but just think of how you are optimizing your time and instructing us so that others hopefully will not have to bear the sorrow that you have. So you are recognized for 5 minutes.

**STATEMENTS OF STEPHANIE ZARECKY, MOTHER OF SCARLETT PAULEY, AMBASSADOR PROGRAM AND PUBLIC RELATIONS MANAGER, SUDC FOUNDATION; LEE BEERS, M.D.,**

**PRESIDENT-ELECT, AMERICAN ACADEMY OF PEDIATRICS; AND KENNETH MENDEZ, PRESIDENT AND CHIEF EXECUTIVE OFFICER, ASTHMA AND ALLERGY FOUNDATION OF AMERICA**

### STATEMENT OF STEPHANIE ZARECKY

Ms. Zarecky. Thank you.

Ms. Eshoo. Turn the microphone on. I should have said that.

Ms. Zarecky. I am sorry.

Ms. Eshoo. That is all right. No penalties.

Ms. Zarecky. Okay. I thank the committee for inviting me today. I also thank Representatives Moore, Herrera Beutler, and Cole for introducing Scarlett's Sunshine Unexpected Death Act in the House of Representatives and Senators Casey and Isakson for their leadership in the Senate. I know this issue is one that the chairman and Ms. Moore in particular have cared about and worked on for many years.

As grateful as I am, I hope you will understand why I wish I weren't here. This legislation is named after my daughter Scarlett Lillian Pauley, and I am here because she cannot be. Today is the third anniversary of the worst day of my life, the day when the girl you see with big blue eyes and an angelic face left this earth when she was just 16 months old. Scarlett lit up the world from the moment she entered it. She loved to read. Her favorite book was Barnyard Dance by Sandra Boynton. Her face would light up when I would read it to her as she sat on my lap and my husband Ryan would do a dance that matched each line.

Scarlett also loved music. Her favorite song was "You Are My Sunshine" which is the inspiration for the legislation's name.

Scarlett loved to smile. She was known for her serious face which led many to think she didn't like them, but we always knew it was just because she was studying them. Once she learned how much she loved to smile and to make others smile, Scarlett was never happy until she could get everyone around her smiling.

Scarlett loved life and made the most of her short one. January 7, 2017, Scarlett came down with a mild cold and had a slightly elevated temperature. Three years and approximately 16 hours ago, Scarlett enjoyed her bath and a final performance of Barnyard Dance. I nursed her to sleep, gave her warm cheeks some final kisses and put her in her crib. Three years and 11 hours ago, I checked on her, as parents often do, before heading to bed. I opened the door to her room, expecting to hear the sweet noises of her sleeping peacefully.

If you have children, I am sure you remember holding your breath waiting for your child to take their next one. If it took a bit too long, your heart would sink into your stomach until you heard that next sweet inhale and your heart bounced back to your chest. Three years and approximately 11 hours ago, that next breath never came for Scarlett.

The next hour is a blur of EMTs, police officers, ambulances, sitting on the bathroom floor praying to God for a miracle, a police car ride to the hospital, and being escorted into a room of doctors and nurses, one of whom I recall wiped away tears as we entered.

Three years and 10 hours ago, a doctor told us there was nothing more they could do and my Scarlett, the very reason for every beat of my heart and every breath I took, was gone.

To this day, we do not know what took Scarlett from us. We agonized for 5 months and 6 days waiting for the results of her autopsy. Even participating in research being conducted at New York University on deaths like Scarlett's did not give us answers as to why she is not here. Scarlett's death is considered sudden unexplained death in childhood, or SUDC. SUDC is a category of death in children between the ages of 1 and 18 that remains unexplained after a thorough investigation, including an autopsy.

At this time, we do not know what causes SUDC, how to predict it, or how to prevent it. Since losing Scarlett, we have been blessed with our second daughter, Eliana. She is the one making the noise in the back. Because we don't know what happened to Scarlett, we live every day in fear we will lose Eliana as well. We also don't know that it won't happen to your children or grandchildren.

According to the Centers for Disease Control and Prevention, SUDC occurs in about 400 children in the U.S. each year, but because of the lack of a specific way to record sudden and unexplained deaths in children that have been thoroughly investigated, it is impossible to know how widespread the problem is. And there are more than 3,600 infants lost annually to sudden unexpected infant death, or SUID, which is the sudden death of an infant under 1 year of age that when first discovered did not have an obvious cause.

Research into the potential causes of SUDC and SUID is desperately needed. Facilitating and standardizing data collection and analysis, as this legislation seeks to do, is an essential step in one day preventing these tragedies. Losing a child is the single greatest pain we could ever imagine, and to be without answers as to why magnifies it exponentially. We read parenting books, followed all recommended safe sleep guidelines, and made sure Scarlett received good medical care. Yet we still lost our healthy, thriving, precious baby girl. It is an unimaginable tragedy no parent should have to live with, and there are thousands of us who do it every day.

We have done far too little for far too long to try to stop these tragedies. We have to change that in memory of all the children who are deeply loved and dearly missed, and for the future of all children.

Scarlett's Sunshine on Unexpected Death Act will help us take steps to solve this medical mystery and prevent future deaths, and I thank the committee for their support of it.

[The prepared statement of Ms. Zarecky follows:]

******** INSERT 1-1 *******

Ms. Eshoo. We thank you. I want to recognize our colleague, Congressman Mike Doyle, that is here. Ms. Zarecky is represented by Congressman Doyle, and the reason that he hasn't spoken up yet is because he is not a member of our subcommittee.

We have these funny rules around here, but he will be recognized, but it is after members of the committee are -- we finish recognizing them, but we welcome Congressman Doyle to the subcommittee and for your testimony.

I now would like to recognize Dr. Lee Beers. Again, the President-Elect of the American Academy of Pediatrics. Welcome to you, and you have 5 minutes for your testimony.

## STATEMENT OF LEE BEERS, M.D.

Dr. Beers. Wonderful. Good morning, Chairwoman Eshoo, Ranking Member Burgess, and members of the subcommittee. My name is Dr. Lee Beers, and I am a pediatrician and president-elect of the American Academy of Pediatrics.

First, thank you, Ms. Zarecky, for your powerful testimony.

I am here today officially representing the AAP, a non-profit professional medical organization of over 67,000 pediatricians, pediatric medical subspecialists, and pediatric surgical specialists.

Thank you for holding this hearing today on a number of bills to improve health outcomes. Today I will speak to two of them, the Scarlett's Sunshine on Sudden Unexpected Death Act and the Healthy Start Reauthorization Act. The AAP strongly supports both pieces of legislation. The together, these bills will help reduce infant mortality, prevent sudden unexpected infant and child death, and promote healthy child development.

I will first discuss opportunities to address sleep-related infant deaths and other unexplained child deaths through the AAP endorsed Scarlett's Sunshine on Sudden Unexpected Death Act.

In the 1990s AAP recommended that babies sleep on their back and partnered with government agencies on a successful Back to Sleep campaign. These efforts initially led to a substantial declined in sudden unexplained infant deaths. However, we have seen little progress in over a decade, and persistent racial and ethnic disparities remain.

To make additional progress, we need better information on the circumstances surrounding sleep-related death and other unexplained child death and to better promote what we already know about keeping children safe.

Scarlett's Sunshine would help improve and standardize death scene investigations and autopsies and would provide training on best practices. In addition, the bill would expand the vital work of child death review teams. It would help promote evidence based, safe infant sleep including providing safe sleep products like cribs and play yards to low-income families.

Finally, the bill would authorize funding for parent support services like grief and bereavement counseling. I vividly remember the first time I consoled a grieving father in the emergency department after losing his infant son to a sleep-related death. The lack of answers or services for this family left me feeling helpless and angry.

Scarlett's Sunshine would help us better understand and prevent these and similar tragedies while better supporting affected families. I urge the committee to advance this legislation as written.

I also thank the committee for advancing the Safe Sleep For Babies Act which would ban dangerous inclined sleepers and crib bumpers. The full House passed that bill last year, and we urge the Senate to pass it without delay.

The AAP also strongly supports the Healthy Start Reauthorization Act of 2019. In the United States, the infant mortality rate fell by 14 percent between 2007 and 2017. Healthy Start has played a critical role in this success by working to ensure that women living in communities with higher than average infant mortality rates have access to early prenatal, post partum, and infant care.

However, despite a declining infant mortality rate nationally, significant inequities persist in infant birth outcomes. In fact, infants born to non-Hispanic black, Native American, Alaskan Native, and Pacific Islander mothers all experience higher than average rates of mortality.

Maternal mortality is also a serious ongoing crisis in the United States. According to the CDC, the national rate of maternal mortality has more than doubled since 1987. Alarmingly, black women, Native Americans, and Alaska Natives are two to three times more likely to experience pregnancy-related deaths regardless of socioeconomic status.

These staggering statistics on maternal health and infant mortality illustrate the importance of reauthorizing Healthy Start. As a pediatrician right here in Washington, D.C., I have seen firsthand the need for and the positive impact of programs like Healthy Start.

Mothers, infants, and families greatly benefit from the connection to resources that may not otherwise be available to them, including healthcare services like prenatal care, enabling services like case management, and public health services such as immunizations.

The Healthy Start Program has positively impacted families and communities throughout the United States and here in D.C. For instance, in 2015, Healthy Start reduced infant mortality rates among program participants compared to the national rate. Despite its success, this program has not been renewed since 2013.

The Healthy Start Reauthorization Act of 2019 would not only reauthorize this essential program for 5 years, it also makes key updates, including explicit consideration of social determinants of health. We know that negative social influences can impact physical health, social, emotional development, and educational achievement throughout the life span.

Healthy Start is a much-needed program that works in reducing preterm birth, infant mortality, and maternal mortality. We urge its swift reauthorization.

Thank you for the opportunity to be here today, and I look forward to answering any questions you may have.

[The prepared statement of Dr. Beers follows:]

******** INSERT 1-2 ********

Ms. Eshoo. Thank you, Dr. Beers. I think you would be pleased to know that the subcommittee has addressed the issue of maternal mortality rates in our country, and that legislation now awaits the full committee.

It is a pleasure to -- the floor. I am sorry. Big difference between the two. But we are on our way on that one. It is just a horrible statistic, shameful statistic in our country.

It is a pleasure to recognize Mr. Mendez for 5 minutes for your testimony. Welcome again and thank you.

## STATEMENT OF KENNETH MENDEZ

Mr. Mendez. Thank you, Chairwoman Eshoo, Ranking Member Burgess, and members of the committee. I am Kenneth Mendez, President and CEO of the Asthma and Allergy Foundation of America, or AAFA. AAFA is the leading patient organization for Americans with asthma and allergies and the oldest asthma and allergy patient group in the world.

Thank you for inviting me to offer testimony in support of 2468, the School-Based Allergies and Asthma Management Program Act.

This bipartisan bill is an important step in promoting health and even preventing death for the millions of American children living with asthma and with food allergies. First I would like to give you some perspective on American children living with asthma and food allergies, and then I would like to tell you how this bill helps.

One in 13 American children have asthma. One in 13 have food allergies. This means that every school in the U.S. is likely to have children with these conditions. Imagine breathing through a straw filled with cotton and the fear you would feel knowing you weren't getting enough air to breathe. That is what it is like to have asthma.

About 3,600 people die every year from asthma in the U.S. For example, just last month, we heard about a 13-year-old Broadway star, Laurel Griggs, dying of an asthma attack. No one needs to die from asthma.

Here is some more statistics. Asthma is the most common chronic disease among children and major cause of childhood disability. Asthma is more common among children from low-income families and among Black and Hispanic children. Childhood asthma is one of the top reasons for missed school days, close to 13.8 million missed school days and substantial economic costs through lost work days for caregivers.

Now imagine having a life-threatening food allergy where accidental exposure to a known food allergen can trigger an allergic reaction that could kill you if you don't have life-saving epinephrine administered in the first few minutes of the reaction. That is what it is like to live with food allergies.

Food allergy deaths are relatively rare but are tragic and often preventable. Food allergy prevalence among children, along with related emergency department visits have increased sharply over the past 2 decades. Food allergy prevalence among children increased by 50 percent with peanut allergies more than tripling.

Schools can help by preparing to address emergency situations, promoting awareness among teachers and staff, and providing a safe and healthy school environment that minimizes asthma and allergy triggers.

AAFA issues a State honor roll looking at asthma and allergy policies related to schools. We have seen a great deal of progress over the years in many areas with 15 States on our 2019 honor roll compared to 8 in 2013.

However, there is still too many gaps. For example, only 27 States require schools to have emergency protocols for asthma and only 36 require emergency protocols for anaphylaxis. Only 24 States require schools to maintain allergy and asthma incidents reports. Only 12 require indoor air quality management plans, and only 8 accept acceptable minimum standards for nurse-to-school ratios.

H.R. 2468 would help address these gaps by creating a grant-making preference in CDC's existing asthma grants program for those States that require all public secondary and elementary schools to have certain key measures in place as part of a comprehensive school-based allergy and asthma management program.

The bill has support from the number of major stakeholder organizations including AAFA, the two major allergy, asthma, and immunology doctor organizations, the National Association of School Nurses, and other non-profit patient organizations in the asthma and allergy community.

This bill is important because both food and asthma and food allergies present serious threats to health and children's learning, as well as posing enormous economic burdens on families and on the healthcare system.

This bill will help children be safe, healthy, and ready to learn. AAFA is grateful for the subcommittee's consideration of the bill, and we stand ready to help the committee in any way.

[The prepared statement of Mr. Mendez follows:]

******** INSERT 1-3 ********

Ms. Eshoo. Thank you very much for your testimony to each of the witnesses, and now we will move to -- that we have concluded the witnesses' testimony, I will recognize myself for 5 minutes of questions.

I will start with Ms. Zarecky. Again, thank you for being here today. What do you think is the single most important thing Congress can do to address sudden unexplained deaths of infants and children?

Ms. Zarecky. For me personally, research is very badly needed. Sudden unexplained death in childhood which is what happened to Scarlett, research is absolutely critical, and we can't do good research unless we have good data which is what the legislation seeks to accomplish. It is a terrible medical tragedy, and we -- families need more answers, and research is just so badly needed into why it happens.

Ms. Eshoo. Is there any -- I am familiar with what the bill does, but is there any research being conducted today, and if so, where, by whom?

Ms. Zarecky. Sure. Yeah. So we participated in research being done out of New York University. It is the Sudden Unexplained Death and Childhood Registry and Research Collaborative. And my understanding is there is also research being done at Seattle Children's and Boston as well, Boston Children's Hospital. Although I am less familiar with that, but there is limited amount of research being conducted already.

Ms. Eshoo. And in the aftermath of Scarlett's death, can you describe to us what was available or what was not available to you given that probably one of the darkest chapters -- darkest chapter of your life?

Ms. Zarecky. Yes. I mean, the Sudden Unexplained Death in Childhood Foundation has been a lifeline to our family. They have provided not only emotional support, they have allowed us to be connected with other families who have experienced this tragedy.

When something like this happens to you, you think you are the only one that it has ever happened to. So being able to be connected with other families has been critical, but also being able to have support in terms of having someone who can make a phone call to the medical examiner's office. I can't tell you how impossible even dialing that phone number is at times.

And even just to ask, you know, after a little while, when is my daughter's autopsy going to be done, having that support not only from an emotional standpoint but also just, you know, logistical things that you never really think of until, you know, you have lost a child, has been -- has been really critical.

Ms. Eshoo. And the legislation covers what you just pointed out?

Ms. Zarecky. It mostly covers data collection and so that we can support research and figure out what happened to these children.

Ms. Eshoo. Okay. Dr. Beers -- thank you -- the United States, you said, is the most dangerous place in the developed world to deliver a baby. I can't believe that that is a statistic next to the two words "United States," but that is our challenge, and we need to meet the challenge.

Each year, 700 American women die and 50,000 women are severely injured due to complications related to child birth. For African American women in the United States, it is even more dangerous because they are three times more likely to die from childbirth than white women.

In ProPublica's reporting, it found that, quote, the American medical system is focused more on fetal and infant safety and survival than on the mother's health and well being. Do you agree with that finding?

Dr. Beers. I don't know that it is focused more on that, but I would say that we need a much greater and more intense focus on maternal health and on access to high quality accessible and culturally sensitive --

Ms. Eshoo. We really shouldn't be pitting one against the other.

Dr. Beers. Correct.

Ms. Eshoo. It is not a race to the bottom.

Dr. Beers. And healthy mothers and healthy families engender healthy babies.

Ms. Eshoo. Now, do you have recommendations on how the Healthy Start Program -- and you gave it very good scores which I like hearing -- how it could improve maternal health while also helping infants?

Dr. Beers. Yeah. Absolutely. I think a couple of the areas where Healthy Start really helps improve maternal health. I think, one, the services are really targeted to areas where there are higher rates of infant mortality which are often coexistent with higher rates of maternal mortality as well.

The services Healthy Start provides are very individualized and targeted to the individual mother and really do help address some of the social determinants. When we look at maternal mortality rates and infant mortality rates, a significant contributor to those are social influences and social determinants.

Ms. Eshoo. Well, do you think the program is doing enough to address racial disparities in maternal and infant health, and if not, what more should be done?

Dr. Beers. I think there is always more we can do. When we look at the data and the evidence, we see these tremendous disparities. We see the tremendous disparities in race and ethnicity regardless of socioeconomic status. And if we see those numbers, we know we are not doing enough. And so we need to continue to provide culturally appropriate services. We need to continue to engage communities and families in developing solutions and in addition to addressing bias that exists naturally in healthcare.

Ms. Eshoo. Thank you. Well, I am out of time, so Mr. Mendez, I will submit my questions to you in writing. And I know you will respond in a very timely way.

The chair now recognizes Dr. Burgess, the ranking member of the subcommittee, for his 5 minutes to ask questions.

Mr. Burgess. And again I thank the chair, thank our witnesses for being here today. I apologize because some of us have been in and out, but there is another hearing going on downstairs. I don't know why the committee leadership chooses to schedule important hearings on top of each other, but I guess it happened when we were in charge too so I won't to be too critical.

Ms. Eshoo. We can handle it, that is why.

Mr. Burgess. Dr. Beers, in your written testimony, you talked about that you get a lot of questions related to the sleep, that they are at the top of any new parent's list when they come to see me, and the guidance I give parents is critical to promoting safe practices.

So here you are in the Subcommittee on Health on the Committee on Energy and Commerce with the vast audience on C-SPAN that turns in and -- tunes in and hangs on every word that we say. So this is your opportunity to give that advice very broadly and recognize it doesn't suffice for advice which you will get from your own doctor, but in general, what are those recommendations that you are giving?

Dr. Beers. Right, right. So thank you for that opportunity. I appreciate that. There is several very important things for safe sleep. Infants should sleep in their own sleep space -- without blankets, pillows, crib bumpers, other things -- on their backs. And I think those are very important things in spaces without exposure to cigarette smoke as well, so --

And I recognize as a pediatrician and as a parent that sometimes that is difficult because sometimes you have babies who don't sleep well, sometimes you have babies who are fussy. You are pretty much always exhausted, and so I recognize that that is difficult, but it is just critically important.

Mr. Burgess. So that is -- is that advice for a newborn, or is that continue -- for some time continue in the base -- the baby's life?

Dr. Beers. Well, I think that is a great question. So the evidence and the research that we know shows that infants are at risk for sleep-related death up to a year of age, and so that is relevant up to a year of age. I do think it is important to note, though, that, and particularly with this bill, this really does address other instances of sudden unexplained death in infancy and childhood that may be unrelated to the situation.

So to Ms. Zarecky's point about more research being needed, I think that is a really important point because there is a lot we don't know, particularly about the older infants and children.

Mr. Burgess. And that was going to be the point of my question, to widen the focus of what we are examining, not ignoring what perhaps may be the more vulnerable population but not to exclude populations that might also be vulnerable.

I do have to say, Madam Chair, and we, of course, have worked on issues related to maternal mortality in the last Congress, this Congress. Last Congress we passed the first stand alone bill dealing with maternal mortality that I have seen in my entire time in Congress. And it got signed into law, and that is a good thing. We have continued that work in this Congress, and that is a good thing.

But the hearing we had leading up to the bill that you referenced, we had Dr. Nelson from Parkland Hospital where I did my residency many, many years ago -- many, many, many years ago -- and I guess the point for Dr. Nelson's testimony was, here is a hospital that is basically an inner city hospital, serves basically a minority population, a low-income population, and they have very significantly good maternal mortality statistics.

So the point in all of that is, we know that it can be done well, and really I hope at some point, we will have some follow-on discussion where we might identify either the exposition of best practices or even, I dare say, do we need to talk about those institutions that are not doing as well.

But I think we owe it to the patient population to be able to -- it is hard to discern, it is hard to know when you are shopping for a hospital in which to deliver your baby. You don't basically go into the deep within the statistical part of it. Maybe that is something that we could look at in the future.

Mr. Mendez, I do want to say as someone who has lived with asthma my entire life, I appreciate your effort on that.

Mr. Mendez. Thank you.

Mr. Burgess. I know there is always more that we could be doing. I do worry some about things that we might mandate from this committee because then we always -- we tend to drive the price up of those products that we mandate, and that has been one of the down sides of some of the work we have done in the past. But I appreciate what your organization does and your work --

Mr. Mendez. Thank you.

Mr. Burgess. -- on that.

And Ms. Zarecky, sorry for your loss. I am glad you are here with us to share your story today. I hope that your presence here will be of benefit to people who might learn something from Dr. Beers' instructions that she so wisely gave us.

Thank you, Madam Chair. I will yield back.

Ms. Eshoo. The gentleman yields back. I would be happy to do follow-through on what you just raised.

Now, on the heels of the hearing that we had on maternal mortality, I raised the issue relative to hospitals, and today the accreditation board now includes what you described, but there is always more to be done.

But I think that that is a positive step because there has to be internal pressure by those that are in charge of and oversee hospitals so that we can weed out those that -- whose rates are deeply troubling, from those that are doing well, and learn from those that are doing well. So I will continue to work with you on that.

I now would like to recognize the gentleman from New Jersey, the chair of the full committee, Mr. Pallone, for his 5 minutes of questions.

The Chairman. Thank you, Madam Chair, and I want to thank all our witnesses including Ms. Zarecky for being here today. I can't imagine the pain and grief that you had to endure since losing Scarlett, but I thank you for your courage and for sharing her story with us, really.

This cause has long been something that I support. In 2014, President Obama signed into law the Sudden Unexpected Death Data Enhancement and Awareness Act, a law that I sponsored that required the Secretary to collect info on sudden unexpected infant death and sudden unexplained death in childhood, and educate the public, and collaborate with other agencies and State and local health departments to provide information for medical examiners and other individuals.

And thanks to this law, we now have a more clear vision of what is known and unknown about sudden unexpected infant death and sudden unexpected death in childhood. And our focus has to turn now, how can we take further action to prevent these tragedies and support families, care providers, and researchers when these tragedies occur.

One of the provisions of the Scarlett's Sunshine Act would provide grants for support services for families who have had a child die including grief counseling, home visits, and support groups.

So I wanted to ask you, Ms. Zarecky. No amount of support can ever replace what you or your families have lost, but can you tell us how support services can be helpful to families like yours in working through these tragedies?

Ms. Zarecky. Thank you so much for your question, and thank you for asking because it actually gives me the opportunity to focus on one of the strengths of the

House bill, and that, of course, is the support services.

I think when you have lost a child, there is a before and there is an after, and once you have crossed that line, oftentimes there is no -- there is no greater gift than being able to connect with another family who really truly understands. And it is the support services that we have received through national foundations as well as local foundations in Pittsburgh.

It has been absolutely critical in being able to live life after our loss. So, you know, bereavement support for families, of course, is very critical. It is very badly needed, and I truly don't know where I would be today if I didn't have the support of other families who have walked this journey before me.

And I thank you, Congressman, for your leadership on this issue and for working on it for many years.

The Chairman. Well, thank you. Let me just turn to Dr. Beers from a physician's point of view. In your testimony, Doctor, you discuss the difficulty your team faced when you could not identify timely and accessible grief counseling for a family who just lost a child.

As a physician, can you tell us about the appropriate forms of grief counseling and other support services that should be made available to families and how these services can help support the mental and emotional health of the family?

Dr. Beers. Absolutely. And I think as you and other members know, access to timely and accessible mental health services is a significant issue across the country, and so -- and grief counseling and grief services are particularly important for families. When you need them, you need them immediately. They are not services that you can wait 6, 8, 10 months for.

You need mental health providers who are specifically trained in addressing grief and bereavement issues. And what type of services is going to vary a little bit, depending on the family and their individual desires and needs. For some, individual therapy may be appropriate, and for others, group therapy and support groups may be appropriate as well, but certainly we should make sure that both of those things are available to families.

The Chairman. I wanted to thank you. I wanted to ask you one more question in the time remaining. Another important provision of the bill supports grants for infant safe sleep and efforts to decrease risk factors. You mentioned physicians began recommending positioning babies on their back for sleep starting in the 1990s. I remember that.

And after which we saw a decrease in cases of sudden unexpected infant death. However, as continued tragedies demonstrate, we still have a lot of work to do. So in your testimony, you suggested that we might need to reframe safe sleep recommendations to address cultural or socioeconomic considerations.

Can you explain what that means and how can we ensure that all families receive the benefit of these recommendations?

Dr. Beers. Absolutely. And perhaps the best way is to share a short example. I am close colleagues with a pediatrician and researcher who does a lot of research in this area, and we used to work together in Washington, D.C., and working with many low-income families who live in neighborhoods with high community violence.

And one of the things they learned through their qualitative research was that many of the families they talked to were not adhering to the safe sleep recommendations because they were fearful of people entering into their house or apartment and wanted their baby very close to them. And they felt like putting their baby in a crib was taking them too far away and was putting them at risk because they were living in unsafe and unstable housing.

And so being able to tailor those recommendations to address those very specific concerns of bringing the crib very close to the bed, making sure that you were set up and your room was set up so that the crib was away from the door, those things made an enormous difference. But the only way that we knew that was by asking those questions and really diving into what a family's specific concerns were.

The Chairman. Thank you.

Thank you, Madam Chair.

Ms. Eshoo. The gentleman yields back. A pleasure to recognize the gentleman from Michigan, former chairman of the full committee, Mr. Upton.

Mr. Upton. Well, thank you Madam Chair, and I appreciate the hearing, and I have asked that my name be added as a co-sponsor to H.R. 2271, so thank you very much for your testimony.

Dr. Beers, a quick question. Just for new moms, when they deliver often in a hospital, I mean, is it the standard operating procedure to, in fact, make sure that that new mom is aware of the safe sleep recommendations? I think it is pretty widespread belief about bumpers and stuffed animals, but blankets and -- I mean, for the first year?

I mean, is there a checklist? I mean, have you -- has it been pretty good in terms of your follow-up with hospitals across the country that, in fact, new moms are -- realize that information is pretty good to receive?

Dr. Beers. It is, and that is pretty standard education that is given in the hospital. I think one of the important things to remember is that when you are a brand new mother having just delivered a baby, you know, maybe 24 to 76 hours previously, you may not remember everything or absorb everything you are being told right in that moment.

So being able to continue that education is also very important.

Mr. Upton. Dr. Mendez, I was chairman of the committee when we passed and signed into law Leader Steny Hoyer's School Access to Emergency Epinephrine Act. Can you give us an update on how that bill is being implemented as well as the School-Based Allergy and Asthma Management Program Act --

Mr. Mendez. Sure. I would say, you know, it is a win-win when you look at the numbers and the results and the outcomes, that, you know, asthma is quite costly, and I think that we reduced by $23 billion the amount of cost to the healthcare system because what that Act has tried to do was provide upstream help in terms of interventions before you end up in the emergency room or the hospital.

I think for the National Asthma Control Program, $71 is saved for each dollar spent in the program. So to the extent that we can have forward-facing, more advanced protocols here to prevent asthma attacks or allergy attacks is really helpful. So continuing with this current bill, 2468, will help that by adding the asthma piece as well.

RPTR WARREN

EDTR HOFSTAD

[11:04 a.m.]

The Chairman. Well, I look forward to pushing that legislation forward. Appreciate your testimony.

And with that, Madam Chair, I yield back.

Ms. Eshoo. The gentleman yields back.

It is a pleasure to recognize the gentlewoman from California, Ms. Matsui, for her 5 minutes.

Ms. Matsui. Thank you very much, Madam Chair.

And I want to thank the witnesses for being here today.

You know, I was thinking about the fact that schools play a fundamental part in supporting the health and well-being of children, particularly with asthma and allergies, and given the rapidly growing prevalence of childhood food allergies, we must improve school allergy management programs to ensure the continued safety and inclusion of all students.

Moreover, I am particular on the risk factors for food allergies, and the reasons why these potentially life-threatening diseases are becoming increasingly common among kids are not fully understood at this time.

Further, 1 out of 13 children in the United States is living with food allergies. And my grandson is one of them. And if you have someone in the family, you immediately become sensitized to this. I know too well the serious health, social, and economic impacts that a severe food allergy and related adverse immune responses, like hives, asthma, and shock, can have on children and their families as well as their friends.

So we must do more to recognize and study food allergies, and that is why I have introduced the FASTER Act, legislation that updates labeling laws to include sesame and expands data collection of Americans' exposure to specific food allergens. My bill aims to improve the way we monitor, manage, and treat these complex and multifaceted diseases.

Mr. Mendez, thank you very much for specifically highlighting the growing prevalence and serious concerns related to childhood food allergies in your testimony.

Can you expand on some of the best practices for managing food allergies in schools? I am thinking about the fact that the school seems to be the environment that most children interact in, which means not only the personnel, it is the teachers, it is the parents. There are also fellow students too.

Mr. Mendez. Yes.

Ms. Matsui. So how does this legislation incentivize greater dissemination of these best practices?

Mr. Mendez. Yeah, sure. Thank you for that. And, you know, things have changed completely in the last 20 years when two of my three kids had food allergies, and we have come a long way since then, but there are still a lot of gaps and things that we need to do.

I think having -- and they are in the bill -- having trained personnel in acknowledgment of food allergies is really important in the school; an explicit anaphylaxis program so you have policy and procedures in knowing how to deal with an asthma attack or an allergy attack in the school, with instructions on administering the medication, having updated school records, having a school nurse involved in things; and then incident reports for usage and medication are really key. And then, again, stock medication and train personnel.

Ms. Matsui. Well, where do the greatest gaps in understanding food allergies, where do they still exist? And how can we best direct the future direction of food allergy research?

I remember, when my son was going to school, no one ever thought about this at all. We used to bring all kinds of cookies and cakes and things to school. Now it is so prevalent and it is something that everybody is aware of but not knowing quite what to do. And I want to understand where the future direction that you believe we are going in.

Mr. Mendez. Yeah, sure. I think continuing to increase that awareness level is really important. I mean, there is food allergy bullying that happens --

Ms. Matsui. Yes.

Mr. Mendez. -- in classrooms that we really have to be aware of. And to the extent that this bill, 2468, codifies an approach, then it recognizes that that is not okay, to have food allergy bullying.

I think the other thing is, on the clinical trial side, raising the awareness that they are out there and increasing diversity in clinical trials and recruiting more patients into clinical trials. I think that what we have found is that there is not a high degree of awareness in clinical trials, as well, for future research.

Ms. Matsui. Do you find that there -- in your understanding of schools, are there certain schools that -- I mean, I am sure that there are disparities --

Mr. Mendez. Yes.

Ms. Matsui. -- in where the schools are and the economic levels. Do you find that there is more emphasis on certain schools than other schools? And what can we do to ensure that everyone gets covered here?

Mr. Mendez. Sure. Well, it is clearly in the health disparities issue where that comes into play. And I think if you look at the ZIP Codes in some of those schools, those are the ones that are most challenged.

In our State Honor Roll report, we looked at those various school policies. There are 24 that have made that honor roll right now, but we could go a lot further.

This National Asthma Control Program is really important, and if we could expand that as well, in addition to your great work on the FASTER Act, I think it would really go a long way towards helping with asthma and allergies in the school community.

Ms. Matsui. I want to thank you.

And I am out of time, but, Ms. Zarecky, I think the greatest loss anyone can ever experience is a loss of a child. And thank you so much for being here. And know that we will do everything we possibly can to ensure that we find explanations and to continue our work on these issues. Thank you very much.

And thank you very much.

Ms. Eshoo. The gentlewoman yields back.

I know the gentlewoman has legislation -- and I look forward to taking it up -- relative to one of the allergies to sesame seeds. And that is not borne on labels. I did call the FDA, spoke to the person in charge of this issue, of that division of the FDA, trying to make the determination whether they could handle this administratively or we should move ahead legislatively. They said it would take between 5 to 7 years to label. So I think we have to get your bill going, Ms. Matsui.

Okay. It is a pleasure to recognize the gentleman from Virginia, Mr. Griffith, for his 5 minutes of questions.

Mr. Griffith. Thank you very much, Madam Chair.

And I, too, support the principles of Ms. Matsui's bill. My family are consummate label readers.

Ms. Zarecky, you know, you talked about -- and you got to me because you talked about those moments when you go in to listen to your child breathing, and I did that many times, particularly with my older son, who has lots of food allergies and breathing issues, including asthma. And so I know that feeling, and I am so sorry.

That being said, let me switch back to allergies, which is where I had planned on going, but, you know, your testimony is very compelling.

I like the bill. I do have some questions about it.

I will tell you that, you know, this is not something new, as you know. It has been around for a long time. My mother loves to still tell the story of, when I was 5 years old, I got in trouble for a brief period of time because I threw a cookie across the room. They did not understand. I had and still have a wheat allergy. I knew I couldn't eat that cookie. And back in the early 1960s, they didn't have rice cookies readily available or, you know, other flours. Everything had wheat in it. And I knew I couldn't have it, but the aide who had just been hired had no idea and kept handing me the cookie and said, "No, this is for you." And, finally, after having refused it several times, I tossed it across the room. I don't remember it, but my mother loves to tell the story.

Mr. Mendez. Uh-huh.

Mr. Griffith. Likewise, and as a part of what I was thinking about when you were testifying, one of the greatest days of my life was when my son, my older son -- he is now 14. He will be embarrassed and roll his eyes if he ever sees this. But he was about 2-1/2. We don't know to this day what he got a hold of, but something that we were eating at a restaurant, he got something he was allergic to. We don't know what it was. We heard the wheezing beginning.

Mr. Mendez. Yeah. Right.

Mr. Griffith. We had already turned the car around. My wife and I were already going to the hospital. And from the back came this little voice that said, "Mommy, I need to see a doctor." The self-awareness factor is so important.

And so I appreciate the bill that Phil Roe and Steny Hoyer have put in. And Phil has had similar bills in the past.

And they had actually had -- and one of my concerns with the bill is that they had actually had some requirements that you have medications in the schools, which I like. This one does not require that. Now, Virginia has epinephrine in the schools now. But, you know, if something were to happen, you know, that is step one, as you know.

But one of the questions that comes up is, the trained individuals, how much training would they need? Because I represent a district that has a -- we are 422nd in household income out of 435 in the U.S. House. The school systems don't have the money to necessarily have a school nurse, an R.N., in every building. They have one somewhere in the system most of the time.

Mr. Mendez. Sure.

Mr. Griffith. So what kind of training would those folks need? And would it be so extensive that it would be too expensive for poor communities like the ones that I represent to be able to afford?

Mr. Mendez. Yeah. I don't think so. And that is one of the things that we do with the CDC through their National Asthma Control Program. We publish materials on our website which are completely free for an asthma action plan, for an allergy action plan. So just having those -- they are easily downloadable. You could get them on a lot of doctor sites as well.

Then, in terms of training, there are videos that we produce that walk you through what an asthma attack looks like and how to address asthma.

So those --

Mr. Griffith. But somebody --

Mr. Mendez. -- are all free resources.

Mr. Griffith. -- some health teacher or somebody in the school could do these videos and qualify under the bill?

Mr. Mendez. That is absolutely right.

Mr. Griffith. All right. I appreciate that, because that would be a concern. I want those people trained, I want them to be aware, but I also don't want to, you know, price them out of the market or make it so that they can't meet the requirements.

Mr. Mendez. Yeah. I mean, the legislation is great because it comes full-circle. It creates incentives for schools to access some of the free materials that the CDC is working with other partners to address on a public health basis.

Mr. Griffith. Now, let me get this on the record too, because sometimes people will look at the language and then they will get carried away. It says in the bill on page 3 that the schools have to have efforts to reduce the presence of environmental triggers of allergies and asthma.

My son, my 14-year-old, is allergic to every tree in the East. I don't want anybody to interpret it and I don't think you mean to have it interpreted that they have to chop all the trees down around the school. Am I correct in that? Just make sure --

Mr. Mendez. Right. No, that is --

Mr. Griffith. -- that they have clean systems inside the school?

Mr. Mendez. Yeah, that is exactly right. There are some best practices that you could do by looking at your air filtration. I mean, there is indoor air, you know, rugs in the classroom, that kind of stuff, that you can manage. So it is not about cutting down trees.

But there is legislation locally that addresses idling school buses, for example, and idling cars. Those are things that you could do on a local basis to reduce fuel emissions that could trigger an asthma attack.

Mr. Griffith. I appreciate it very much.

My time is up, and I yield back.

Mr. Mendez. Thank you.

Ms. Eshoo. The gentleman yields back.

It is a pleasure to recognize the gentlewoman from New Hampshire, Ms. Kuster, for her 5 minutes of questions.

Ms. Kuster. Thank you very much. Great to be with you.

And, Ms. Zarecky, I am so sorry for your loss. And I just want to say that I am here today on behalf of my great-niece, Leah, who passed from SIDS just over a year ago. And as my niece has said, our family will never be the same. So Leah is with me always, every day. And I just -- the pain that my niece, Miley, and her husband, Dan, have gone through, and my sister, Debbie, and her husband, Peter, and our entire family. So I am with you every day. I appreciate your courage coming forward.

And I want to thank Dr. Beers and every pediatrician in this country. I find it extraordinary, when I went to do the research after losing Leah to understand the scope of this, it is quite an extraordinary public health success that we cut the number of unexpected infant deaths in half, I believe, from the "Back to Sleep" recommendations.

But I am troubled, having done the research -- my staff has given me some statistics. In my home State of New Hampshire, in the period between 2011-2018, 62 sleep-related infant deaths in my home State, 15 due to SIDS, 42 undetermined. But despite the recommendations that all infants be placed on their backs to sleep, the New Hampshire review group found that only 48 percent of cases reviewed had been placed on their backs.

And so I want to support -- and I have asked to cosponsor the legislation as well. I want to support the additional research from the truly unexpected, unexplained deaths, but I also want to focus on this issue of education and training.

In our case, my great-niece, Leah, died in a daycare setting. And so one of the questions I have for both of you is, what more can we be doing for training parents? And I think your point was very important about we need to ask why they are not able to comply; what is your fear, what is your worry? But, also, what can we do to be training childcare workers and providers?

Ms. Zarecky?

Ms. Zarecky. I think Dr. Beers would probably be best suited to answer that question. Scarlett's death was not an incident -- it was not related to unsafe sleep practices.

Ms. Kuster. Right.

Ms. Zarecky. We followed the same guidelines from the AAP. We followed them until Scarlett was 16 months old, well past the age -- so Scarlett's death is truly unexplained --

Ms. Kuster. Truly unexplained.

Ms. Zarecky. -- and unknown.

Ms. Kuster. Yes.

Ms. Zarecky. So I am really not qualified to answer that and would defer to Dr. Beers.

Ms. Kuster. And that is true in our case as well.

Ms. Zarecky. Yeah. Yeah.

Ms. Kuster. We followed -- my niece followed all of the protocols.

Ms. Zarecky. Yeah.

Ms. Kuster. So if you could comment, Dr. Beers, both as to the sleep protocols but also as to this unexpected, unexplained, what more we could be doing on research.

Dr. Beers. Absolutely. Absolutely. I would be happy to.

And I think your point about childcare is absolutely spot on, because, as pediatricians, we are providing education to parents and families but don't typically have the opportunity to provide direct education to childcare centers and childcare providers. And so that is a very important place. I think we need to be thinking about providing education to serve larger, licensed center-based childcares but also smaller, home-based and unlicensed childcare centers, because often that is another group that may slip through the cracks with education.

Certainly, you know, local jurisdictions can think about regulations to sort of require that kind of training, and then, as professionals, we can work to make that training available.

I do --

Ms. Kuster. Can I ask about, in the research that is happening so far -- and my niece and her husband are participating in the protocol at Boston Children's Hospital. And thank God they have had that support and that family support. Do we know from the research, is there an increased risk at the stage when a baby is beginning to roll over, and whether that is an issue to be concerned about?

Dr. Beers. Yeah, I mean, you do see a peak around 3 to 4 months of age, certainly, which is a bit before that period of time. But I do think it really does, then, come back to the point that Ms. Zarecky and others have raised, is that there was a tremendous public health success with the "Back to Sleep" campaign, and it has somewhat plateaued.

And what that tells us is that we really need more information and we need better information and more consistent information when, tragically, infants and children do die inexplicably. And so getting that information so that we can make those decisions is, I think, most important.

Ms. Kuster. And my time is over. I apologize. But I want to thank you for coming forward.

Ms. Eshoo. The gentlewoman yields back.

It is a pleasure to recognize the gentleman from Indiana, Dr. Bucshon, for his 5 minutes of questions.

Mr. Bucshon. Thank you, Madam Chairwoman. And thank you for having this hearing today with all of these very important bills. I was a physician before, a surgeon, so a lot of these are near and dear to my heart.

Mr. Mendez, as you highlighted in your testimony, roughly 5.5 million, or 1 in 13, American children currently live with asthma, a disease that is one of the leading causes of school absenteeism.

The Department of Education and the Department of Health and Human Services recommend that schools have comprehensive management plans in place to support children with asthma. However, many schools do not have such programs in place, as we have heard. I am proud that my home State of Indiana is a leader in addressing this growing health challenge and was named to the Asthma and Allergy Foundation of America's 2019 State Honor Roll list.

I know that you just talked with Congressman Griffith about the details of the legislation, but can you elaborate on how H.R. 2468, the School-Based Allergies and Asthma Management Program, would use a proven model to assist all States in experiencing the success we have seen in Indiana by ensuring better outcomes that result from a safe learning environment for every student?

Mr. Mendez. Sure. I mean, in Indiana specifically, I think you guys have done, through the National Asthma Control Program, school nurse trainings on asthma management, indoor air quality, and pest management. So what we have seen in many of the States is that, to the extent that you can have this training up front, it reduces asthma attacks, it reduces absenteeism because there is greater awareness among the families that have that and the caregivers.

So this act specifically asks for, you know, in an emergency situation, an asthma action plan or an allergy action plan. And we have seen that, with the asthma action plan implementation over time, it has reduced absenteeism, I think, by 20 percent or so, to the extent that we have increased the number of asthma action plans that have been delivered there.

So this legislation will help do that. There is a direct correlation between awareness and having an asthma action plan and now an allergy action plan to reducing missed school days.

Mr. Bucshon. Are there certain areas of the country that are more prone to the allergy situation? And it is seasonal, correct?

Mr. Mendez. Yeah. Yeah.

Mr. Bucshon. So, I mean, Indiana, we have seasonal allergies just like everywhere else, but something like this legislation, which would create some uniformity, would still be applicable to most States, correct, I mean, even though there are obviously differences in the environment?

Mr. Mendez. Yeah, no, that is correct. I mean, the idea here is to create the incentives for all States to work with the CDC. Because it is a competitive grant program. The CDC works with the public health departments in various States. So to the extent that we could expand that program by having States be more competitive in having these programs is really helpful.

There are belts, you know, that we have looked at. The central part of the U.S. -- we do an "Asthma Capitals" report, and the northeast corridor, I-95, and, kind of, the Midwest are areas that we have seen. And we do that "Asthma Capitals" report based on prevalence of mortality and emergency room visits. So we clearly see there are pockets of where asthma is more significant.

And we also do an "Allergy Capitals" report which looks at some different criteria. And you don't want to be at the top of that list either, because it means that, you know, you are struggling in those areas.

Mr. Bucshon. Yep. Thank you very much.

Madam Chairwoman, I yield back.

Ms. Eshoo. The gentleman yields back.

It is a pleasure to recognize a California colleague, Mr. Cardenas, for his 5 minutes of questions.

Mr. Cardenas. Thank you very much, Chairwoman Eshoo and also Ranking Member Burgess, for having this very critical and important hearing on these important matters.

And I would like to thank the panelists for coming forward and giving us your expertise, and especially Ms. Zarecky. Thank you for your bravery and your courage in continuing to make sure that all of us, us on this side of the room and everybody in the room and throughout this country, can benefit from knowledge and investment in efforts so that we can minimize these tragedies.

So thank you all very much.

In particular, I want to focus on the Healthy Start program. This important program addresses the infant mortality rate in America by providing grants to State and local community organizations that are in the greatest need. Now nearing its 30th anniversary, the program has created results -- good results. Communities receiving Healthy Start grants have, on average, reduced their infant mortality rate below the national average despite having a history of a higher infant mortality rate.

However, the national infant mortality rate in our great country is still far too high. It is clear that we need to do more to improve the programs and ensure the funds are getting to areas that have the greatest need.

Under current law, the Secretary of Health and Human Services is required to consider several factors that contribute to infant mortality rates when awarding grants, such as low birth weight. H.R. 4801, the Healthy Start Reauthorization Act, would require that the Secretary take other important factors into account, such as social determinants of health, and under consideration when awarding grants.

Dr. Beers, can you give us some examples of social determinants of health that might affect the health outcomes of pregnant women and newborns?

Dr. Beers. Absolutely. I think there are many examples; I will highlight a couple.

First would be food insecurity. If a family is living in a household where they do not have reliable access to food, that certainly is going to affect the health and nutrition of the mother and the developing baby. So that would be one example.

Housing insecurity is another issue, as we have talked a lot about, environmental toxins, environmental influences on health. And certainly same for a pregnant mother; if she is living in a housing situation where she is exposed to mold or other unsafe environmental influences, that can have an influence as well.

Transportation is another great example. If your OB-GYN care is across town and you have no way to get there, you are not going come to as many of those appointments. And so access to good, reliable, affordable transportation -- I have many patients who have to make a decision between buying diapers and bus fare. And so making sure that families have and mothers have transportation is important.

Mr. Cardenas. So all the top-line determinants that you just outlined -- and, as you mentioned, there are many more, but in the interest of time, thank you for sharing those with us -- is this exclusively a rural issue or a big city issue, or is it pretty much across the board, the things that you outlined?

Dr. Beers. It is really across the board. Sometimes, you know, I get asked this question a lot, living here in D.C., where we are very close together, but sometimes it is just as long to get to an appointment as it might be in a rural area. So it really is across all jurisdictions.

Mr. Cardenas. Is this a minority issue or is this an American issue across the board?

Dr. Beers. It is absolutely an American issue across the board. There are significant racial and ethnic disparities that do exist that we need to dive into, but it is an issue for all families.

Mr. Cardenas. Okay. Thank you.

Healthy Start grantees also coordinate with other evidence-based programs that serve infants and their families, including the Special Supplemental Nutrition Program for Women, Infants, and Children, or WIC, and the Early Childhood Home Visiting Program.

Dr. Beers, can you explain these programs, how they work together with the Healthy Start program to support newborns, and how coordination with these programs can be streamlined to improve healthy outcomes?

Dr. Beers. Absolutely. Absolutely.

I think one of the key points of the Healthy Start program is the focus on care coordination and individualized services, and so really, through the program, helping families to access all of those different services that you recommend that they may need. Families have an assessment done when they first enter the program to really target in on what those needs are and then help connect them to existing services to decrease duplication of programming and duplication of services.

Mr. Cardenas. So, again, I would like to clarify -- and the reason why I am having this clarification, because far too often, when we see communities in need in America, they tend to show minority communities, poor, inner-city communities, but I just would like you to help clarify, is this an issue that faces all Americans -- White, Black, brown, women, men, children? Is it pretty much across the board?

Dr. Beers. Yes, it is.

Mr. Cardenas. Okay. Thank you very much for your clarity and for your expertise.

I yield back.

Ms. Eshoo. The gentleman yields back.

It is a pleasure to recognize the -- is he here?

Oh, there you are, leaning back.

Mr. Shimkus. I don't have any questions.

Ms. Eshoo. You don't have any questions? Happy New Year to you, John. Lovely to see you.

All right. I will recognize the gentleman from Kentucky, Mr. Guthrie, for his 5 minutes of questions.

Mr. Guthrie. Thank you very much.

And I am sorry, there is another hearing of this same committee, a subcommittee, that I have been in this morning. And so I am actually going to kind of follow up with you, Dr. Beers, but Mr. Cardenas kind of asked some of the questions that I was going to ask.

But first I just want to thank Ms. Zarecky for being here. I have a cousin who has had a similar situation. I know how devastating it can be on families. And as we look at the infant mortality decline, about 14 percent, and we look at numbers, those are important, but it is also important to see faces. Because the ones that are still affected, it is -- so your willingness to come here at a difficult, emotional time, present to us, as we deliberate and make decisions. I can tell you, I look at faces I have met when I have to deal with issues like this far more than graphs that people put in front of you, so it is important that you do it. I know it has to be emotionally draining, but it is important and a good honor for your child.

But, Dr. Beers, as Mr. Cardenas was talking to you, I know that in your testimony you said between 2007 and 2017 infant mortality has dropped by 14 percent, which is good to know because we are actually spending a lot of time in this committee studying mother mortality, which has not has the same decrease, it appears.

So I know you were talking with Mr. Cardenas about things we need to do about the food insecurity and so forth. So what do you attribute the decrease to? And I think some of the things you mentioned before, can you kind of elaborate more? I know he kind of stepped on my questions, so -- but I think it is important to give you more time to elaborate on things we can. But why are we seeing the success? I am always like, let's look at success and see if we can replicate it.

Dr. Beers. Yes, absolutely. And I do also want to clarify, we have had tremendous success and still have a long way to go.

Mr. Guthrie. Right. Exactly.

Dr. Beers. That is, I think, an important point for us.

So I think there are a couple of things we -- there has been tremendous progress in terms of access to care for, you know, pregnant mothers and children. So we have had good progress there.

Families have had some growth in programs that allow them access to services focused on social determinants, such as Healthy Start, to really be able to connect families to those services that they need and those services that really help decrease the barriers to getting the care that they need and deserve.

We have grown quite a bit in our medical knowledge in terms of care of newborn infants and things like sudden infant death syndrome and sleep-related death issues, which contributes to that infant mortality rate.

So it really is a combination of a lot of different things. But some of things that really do remain, as I mentioned in my testimony, there are still tremendous and very troubling racial and ethic disparities in the infant mortality rate. And we need more information and we need to dive deeper and we need to seek community solutions for how we continue to address those.

Mr. Guthrie. Okay. Thank you very much.

And then switching a little bit, Mr. Mendez, there is also -- Congress is a snapshot of the American public. And I am a father of a daughter with a nut allergy and an uncle of a nephew who goes here at Georgetown but he was home in Kentucky over Christmas and ended up in the emergency room, eating something that had peanuts in it.

And so, as you are parents and you can -- in particular, I am talking about schools now -- you can control the environment. You read every label. You become obsessive about anything that might have traces of nuts in it. But then you send them off the school.

So that is why it is important that public policy plays a role in what is happening in schools. And I was in the Kentucky General Assembly, and we took steps. So, I guess, are States -- does it take the Federal Government having States do this? Or what are States doing now? I think we have a role, but what are States doing now in terms of allergies? Or what are good examples of States --

Mr. Mendez. It really depends on the State, but there are some -- for example, Delaware -- that have stocked epinephrine and they encourage that. I mean, there is always the sensitivity about whether or not you want to have mandatory medication in the classroom. That is kind of some of the issue.

But to the extent that you have training and an emergency action plan and there are trained personnel within the school to respond to those issues, that is really important.

I mean, anyone who has an allergy or asthma that is life-threatening should have medication and be working with their doctors and should bring it with them to their school and let the school know that they have this. And this legislation helps encourage that and create incentives for that. So that is really important.

Mr. Guthrie. Okay. Thank you.

And those are my questions, and I will yield back.

Ms. Eshoo. The gentleman yields back.

It is a pleasure to recognize the gentlewoman from California, Ms. Barragan, for her 5 minutes of questioning.

Ms. Barragan. Thank you.

Dr. Beers, thank you for mentioning the environmental influences. Oftentimes we oversee those or we don't discuss them -- don't discuss them enough.

I happen to represent a district, California's 44th. It includes the Port of Los Angeles. It is surrounded by three freeways and the port, and there are high air pollution rates there. These factors, being surrounded by highways, help to contribute to some of the worst air quality in the country.

Unfortunately, because of these factors, back home in Los Angeles asthma is an epidemic. A stunning 1 in 11 children in Los Angeles County have asthma. In my very own district, children walk around with inhalers around their necks. And even the doctor's office, they stock up on boxes and boxes of these asthma inhalers, expecting to see children come in. It is so heartbreaking to see, which is one of the reasons why I am so happy that we are trying to move legislation to address this, although there are a lot of steps that need to be taken.

The rates of asthma in communities of color are even worse. That is my very district. I have a district that is almost 90 percent Latino, African American. Some of the statistics say that 25 percent of African American children in L.A. County have asthma, and Hispanic children are one and a half times more likely to die due to asthma when compared with other non-Hispanic children.

Statistics such as these are one of the reasons that I am a cosponsor of the School-Based Allergies and Asthma Management Program. By incentivizing schools to maintain asthma management programs, students and parents can be assured that the child will be able to have the care they require in case of an emergency.

Mr. Mendez, can you elaborate a little bit on how this bill, H.R. 2468, will help to reduce some of the racial disparities that we see happening with asthma?

Mr. Mendez. Yeah, sure. I mean, you know, there is going to be a child with asthma or allergies in just about every school in the United States. So to the extent that this program creates incentives to have an asthma or an allergy action plan in the State will be really helpful to all those communities.

The CDC, which provides grants and works with the public health systems in each State, will favor whatever schools or whatever States have this kind of program. So, to the extent that this becomes legislation and creates incentives for schools and States to do this, then it will improve funding and their likelihood for getting funding to prevent asthma and allergy attacks and have the right systems in place.

Ms. Barragan. When I was a kid, I remember my father had a home that was right near the freeway. And I didn't know any better. I said, well, geez, if you live near the freeway, that must mean it is going to be faster to get to where you want, so it is a great place. And, of course, now knowing what I know and the allergies that I deal with --

Mr. Mendez. Yes, definitely.

Ms. Barragan. -- I know that there is a connection there.

Besides this bill, do you have any ideas on other things that we could be doing to address asthma, you know, in particular on a congressional level?

Mr. Mendez. Sure. I mean, you know, there are the outdoor environmental issues as well. I mean, to the extent that there have been rollbacks of some legislation that, you know, have contributed to more dirty air, I mean, that is certainly an area.

You are witnessing it in your district, and I think, in particular, they are trying to come up with specific standards for truck emissions. And, in particular, if you are in that window or that area where -- I think it is the port -- there is quite a bit of short-haul trucking, and there is quite a bit of pollution that is generated from that.

So there is the outdoor environmental issue, and then, you know, there are indoor environmental issues as well, having, you know, indoor air quality and being aware of that in the schools. I mean, kids spend the majority of their time either at school or at home. Those are areas that we could really be focusing on.

Ms. Barragan. Great. Thank you.

And, ladies, thank you for being here to talk about the infant mortality rates. Certainly in a community like mine that is majority minority, it is heavily impacted. In L.A. County, they have received over a million dollars and were able to invest in programs such at the MAMA's Neighborhood project, which provides tailored home visits during prenatal, labor, delivery, postpartum, and interconception periods up to 18 months following birth. These visits help reduce the rates of infant mortality.

With the last 10 seconds I have, do either one of you -- can maybe you comment on how else the Healthy Start program works to reduce the racial disparities in care?

Dr. Beers. I will give a 2-second answer, which is: I think that engagement with the community and the focus on community impact and collective impact is a really important component of it so that we are co-designing solutions together with families and communities who are most impacted.

Ms. Barragan. I yield back.

Ms. Eshoo. The gentlewoman yields back.

It is a pleasure to recognize my buddy from Indiana, the gentlewoman, Congresswoman Brooks --

Mrs. Brooks. Thank you, Chairwoman.

Ms. Eshoo. -- for your 5 minutes.

Mrs. Brooks. And I want to thank you and the ranking member for holding this critically important hearing, and I am really pleased that we are talking about all of these bills today.

While my colleague Dr. Bucshon talked about the progress that Indiana, our home State, is making on asthma, we are not really doing as well on infant mortality. It has been a huge problem in our State for a very long time. And, in fact, our 2017 statistics, we had 602 Hoosier babies die before their first birthday. So that is about 50 babies a month or 12 a week. I mean, it is a tragic loss.

And so your voice, Ms. Zarecky, on today, of all days, and sharing with us the tragic story of your daughter Scarlett, you are a voice for all of these families across the country. So thank you very much.

And I do want to ask you, though, because you do represent a much larger group of families than we all really appreciate, can you share with us a couple of things. Specifically -- and I know you talked about the foundation being such a lifeline, but is that where -- and the grief counseling that maybe they provided. How did you get connected to that foundation?

What are the mental health services that are needed? We are hoping that the H.R. 2271 -- focus on support services for families. But when I heard, you know, 5-1/2 months for you to get the autopsy results, can you -- briefly, because I also have a question for Dr. Beers about the review teams. What more do we need to be doing? Mental health. And what were your frustrations?

Ms. Zarecky. Thank you for your question.

First I would say that, you know, over 5 months is a very long time to wait, but I am also very grateful that the pathologist took the time to really thoroughly examine what happened to Scarlett. So, while it was excruciating, I am so thankful that they took all measures that they did --

Mrs. Brooks. Good.

Ms. Zarecky. -- to try to find out what happened to her.

The main reason that we allowed to have the legislation named after Scarlett is, of course, because we wanted to raise awareness of what happened to her. So many people are aware of children who pass away before, you know, their first birthday, but very few people realize how many of us there are, because children pass long after their first birthday, all the way up to the age of 18 years. So I certainly didn't know it could happen before it happened to me.

So, unfortunately, we -- I was lucky. I was connected with services relatively early. But it was through my own efforts and my own research that I was able to be connected to -- I actually learned about the foundation that I mentioned through a bereavement group, which is of course why bereavement groups are so important. But it would have been wonderful, you know, if even the term "sudden, unexplained death in childhood," if I had even learned of it earlier, you know, as soon as Scarlett passed away, then I could have found the --

Mrs. Brooks. And so, even though you dealt with, whether it was law enforcement or coroners or medical professionals, you had to do that on your own.

Ms. Zarecky. Yeah, I found my own bereavement support. And it was just sheer luck that I happened to go to a bereavement group where another mother who lost her 14-month-old was there who told me about it. So, yes, I mean, being able to be connected to those services is critical.

Mrs. Brooks. Thank you so very much for sharing.

And, Dr. Beers, I think what her story shows and her request for data and more information, I think, shows is that we need more protocols at all different levels, whether it is at the death scene investigations -- and I am curious about the child death review teams, which, of course, most of our States all have child death review teams.

How does the CDC's National Fatality Review Case Reporting System work with those review teams? And what more do we need to be doing to institute more protocols that can help make sure the death scene investigations are appropriate, to make sure that families get information they need? Can you share with us a bit more about national standards?

Dr. Beers. Yes, absolutely.

And I think your point is excellent, because it is very difficult to better understand what is happening with sudden, unexplained infant death and sudden, unexplained death in childhood when the data from across States is very inconsistent, and so it is difficult to get a full picture.

And so your point is very good, in that aligning those reviews with CDC standards, with consistent standards, is very important. I think there is a training piece of it -- right? -- where the review committees need to have clear and consistent training with resources that link into the registry, as well as a resource piece of it. Many of these review committees are under-resourced, and so the increased investment in that is also important.

Mrs. Brooks. Thank you.

And before I yield my time, Madam Chairwoman, I would like to acknowledge all these kids who are in the audience, who are incredibly well-behaved and quiet and so good.

And so kudos to you this far in.

So I yield back.

Ms. Eshoo. The gentlewoman yields back.

The reason they are quiet is because we put them to sleep.

It is a pleasure to recognize the gentlewoman from Illinois, Ms. Kelly, for her 5 minutes of questions.

Ms. Kelly. Thank you, Madam Chair. And I would like to thank you and the ranking member for us discussing this very, very important topic. It is just so astonishing to me when I hear about this, because I have worked 3 years on maternal mortality, and it is so similar, the issues.

And I want to thank all the witnesses and particularly you and your husband for sharing Scarlett's story. Thank you so much, because that takes bravery and courage. So we really, really appreciate it.

I wanted to know, Dr. Beers, could you speak to why it is not only important to reauthorize the program but why updates to the program are necessary and how that will contribute to the reduction of health disparities, such as the consideration of social determinants of health?

Dr. Beers. Absolutely. No, I appreciate that. And I think, as we have often talked about the importance of knowledge and research, we have more knowledge and research than when the program was initially authorized, and so incorporating that into the legislation is very important.

I think we have talked about this a bit, but the social determinants of and social influences on health are such key contributors to infant mortality and maternal mortality rates that really incorporating those into the legislation and into the program, I think, is critically important and will help us to continue to bring rates down and continue to move forward.

Ms. Kelly. As the chairwoman said, we were able to pass bipartisan legislation out of this committee on maternal mortality, but one thing we haven't done yet is after you have the baby and the importance of care not just for 2 months but the whole year, studies have found. So that is something that I am going to continue to pursue and push. In both cases was this so very, very important.

Ms. Zarecky, is there anything that you would like to say that we haven't asked you?

Ms. Zarecky. That is a tall question.

Ms. Kelly. Just, anything else?

Ms. Zarecky. Yeah. I guess I would just like to, you know, thank you for hearing Scarlett's sorry and recognize that Scarlett is one child but there are thousands of children out there who really need Congress. The families really need Congress's help to figure out what happened to them and stop it from happening in the future.

Ms. Kelly. Thank you so much.

And I yield back.

Ms. Eshoo. The gentlewoman yields back. We are all grateful to her. She is the resident scholar and leader on the issue of maternal mortality.

It is a pleasure to recognize the gentleman from Georgia, the only pharmacist in the Congress, Mr. Carter.

Mr. Carter. Thank you, Madam Chair. Thank you.

And thank all of you for being here, especially you, Ms. Zarecky. Thank you. I appreciate this very much.

Dr. Beers, I want to start with you. Let me ask you, are you familiar with Dr. John Snow? Did you ever read that book "Ghost Map"?

Dr. Beers. I did.

Mr. Carter. That is a great read. I hope you will get an opportunity. It is about cholera and how he, back in the mid- or early 1800s, how he finally used data to figure out what was causing that and actually was able to get it down to a single well where people were getting water, and that is how they were getting infected and that is how many people had died.

And that is what I want to concentrate on here, because I am from Georgia, and we are the number-one State in maternal mortality. And I still cannot understand that, for the life of me.

But I just want to ask you, how important is the data collection, and how important is it to make sure you are asking the right questions? And are we asking the right questions?

Dr. Beers. Thank you for that. And I agree that that story is a wonderful public health story and highlights the importance of data.

The data is very important in this. And we are asking some of the right questions, but I am not sure we are asking all of the right questions. And I am not sure we are always asking the right people the questions.

I think it is important for us to expand our data collection in this area to really be talking to affected families and to mothers who are receiving prenatal care and find what their barriers are, find where they are getting difficulty accessing services and/or what things they are running into.

And when we can match that qualitative data that we get from asking those questions with the, sort of, more number/quantitative data, that is going to give us a more full picture and help us further go down the line.

Mr. Carter. What kind of challenges are you having now in the way of data collection? What are your obstacles?

Dr. Beers. Yeah. So there are a number of things. I think, you know, we certainly have reasonable, I think, nationwide, reasonable access to, sort of, secondary data, hospital-based data, right? But it is harder to get data on some of the social conditions that families are living in. It is harder to get this more qualitative data. It --

Mr. Carter. But from what -- I don't mean to interrupt you, but from what I understand, with maternal mortality, the economic level doesn't really enter into it.

Dr. Beers. Correct. And it enters into it, but we see these racial and ethnic disparities despite socioeconomic levels. So it is kind of a "yes, and" situation.

But also recognizing that you can look at an entire neighborhood and every person and family in that neighborhood has a different experience and is living in different circumstances. And understanding those nuances better --

Mr. Carter. Uh-huh.

Dr. Beers. -- will help us then better understand how we address this.

Mr. Carter. Let me ask you something. Are death certificates uniform all throughout the Nation, or each State has a different one?

Dr. Beers. No, each State has a different one.

Mr. Carter. How much of a challenge is that?

I mean, I still question why Georgia is first. I just don't get it. I know we have south Georgia and rural areas, but I still don't understand. I mean --

Dr. Beers. Right.

Mr. Carter. -- the death certificates, should they be uniform? I mean, should we be asking the same questions all throughout the Nation?

Dr. Beers. Right. I think that certainly -- I think that would be one thing. I think, often, in these situations -- and we certainly see this in Washington, D.C., as well. We are not doing very much better than you are in Georgia. And the causes are really multifactorial.

Often you can address certain issues fairly easily, and then when you get to some of these really difficult, complex issues, the causes really are multifactorial. So it has to do with education and access to care and bias in healthcare and social determinants of health and how all those things interrelate. And that is a more difficult thing to tackle, and it requires a deeper investment to tackle it.

Mr. Carter. But you would agree that most probably not everyone is defining maternal mortality the same throughout the country? In other words, this very well may have been something that is not reported in one State but is reported in another State.

Dr. Beers. I don't know -- I am not 100 percent sure I would say the maternal mortality itself is being defined differently, but some of the, sort of, underlying things may be reported differently and different questions being asked that can help give us a full answer.

Mr. Carter. And, regardless, we still have to address it. I mean -- and this is a challenge. And I thank you for your work.

And I thank all of you for being here. Whether it be maternal mortality or sudden, unexplained death in childhood, God forbid, all of these things are extremely important. We just have to figure it out. And it is like it is right there in front of us and we just can't figure it out.

So thank you for your efforts, and thank you again for being here.

And I yield back.

Ms. Eshoo. The gentleman yields back.

Our subcommittee is blessed to have more than one physician as a member, and so it is a pleasure to recognize Dr. Ruiz for his 5 minutes of questioning.

Mr. Ruiz. Thank you very much.

As an emergency physician doctor, I have seen some very severe cases of asthma and asthma attacks. In fact, there is one child who I will never forget. He died in the emergency department. He was a young, 6- to 8-year-old, African American boy, playing games with his stepfather, and then suddenly just went into a dramatic asthma attack. He was brought into the emergency department. After a long and intensive resuscitative effort with multiple doctors, he was pronounced dead.

And I was in the room with the doctors -- this was during my training at the time -- when they told the parents, and it was so heartbreaking. And I am still haunted by that. And so I really respect the seriousness of asthma, because I have seen the end result of what can happen, especially for kids.

And, many times, it is preventable. It is preventable with the right knowledge, the right training, the right medications, the right follow-up, the right coverage. It is preventable.

So there is actually one area in my district that has a very severe asthma problem. They have three times the asthma rate in the State of California. In fact, they have the highest pediatric asthma hospitalization rate in the State of California.

And it is multifactorial. For one, we have a large body of water, the largest in

California, called the Salton Sea, and when it recedes, the dust is exposed to the children. Two, it is a very low-income -- low-income -- community, in the setting of very medically uninsured, where there is only 1 doctor per 9,000 residents in that part of my district. To give you perspective, it is recommended to have 1 to 2,000 in this country. One to 3,500 is considered medically underserved. So we are 1 to 9,000.

Then they live in underdeveloped areas, so they have dirt roads. Then they live in overcrowded, substandard housing and trailer parks, like I did in my first few years of life.

So all these point to the conditions that children live under, especially those with asthma. And so those kids are less likely to be able to manage their symptoms, more likely to end up in the emergency department, and more likely to be admitted as the result of an uncontrolled asthma attack, when it could be preventable.

So, Mr. Mendez, can you talk about the importance of the children's asthma treatment grant program for helping ensure that preventable asthma attacks are avoided?

Mr. Mendez. Sure. The grant program administered by the CDC, the National Asthma Control Program, takes a public health approach and tries to work with State health agencies in order to provide funding to have upstream remediation to issues like that.

And then, to the extent that this program could be rolled out more and have more States win these grants in the public health systems, then I think we will see on-the-ground improvements. Because we have seen, overall, in the various States that have it right now, reductions in emergency room visits, improvement in adherence to medication, reduction in hospitalizations. So, I mean, those three things are really helpful.

And, you know, with an $82 billion cost of asthma to the healthcare system, there are ways to reduce that through upstream programs like this for the National Asthma Control Program. I think that we increased the budget by a million dollars this year, or you voted for that, but to the extent that we could have even greater funding for it -- and I think Representative Engel, through the Elijah Cummings Family Asthma Act, is pushing towards that.

Mr. Ruiz. And can you walk us through how environmental factors and, by extension, the social determinants of health affect the overall public health?

Mr. Mendez. Sure. I mean, you know, there is some overlap here, but if you go into housing where there is mold, cockroaches, these are all triggers for asthma attacks. So I have been in housing situations or visited housing where I have gone in with a trained health worker who has basically said, you need to remove the carpeting, you need to work with your landlord in order to have them patch up the rodent holes, and then --

Mr. Ruiz. And how does poverty affect --

Mr. Mendez. It is significant.

Mr. Ruiz. -- the asthma?

Mr. Mendez. I mean, that is really part of it. So, to the extent that you can control or improve the indoor health environment, then it will have better outcomes for the patient.

Mr. Ruiz. It is also a matter of coverage. It is also a matter of being ensured and being able --

Mr. Mendez. Yeah.

Mr. Ruiz. -- to afford your proper asthma course. You know, most people think it is just the albuterol inhaler when you are having an attack --

Mr. Mendez. Right. That is the rescue.

Mr. Ruiz. That is the rescue, but --

Mr. Mendez. Yeah.

Mr. Ruiz. -- the prevention is the other medications.

Mr. Mendez. That is correct.

Mr. Ruiz. Thank you.

Ms. Eshoo. The gentleman yields.

It is a pleasure to recognize the gentleman from Missouri, Mr. Long, for his 5 minutes of questions.

Mr. Long. Thank you, Madam Chairwoman.

And thank you all very much for being here today on this very important topic.

I think the natural order of things is that, you know, our children are supposed to bury us and we are supposed to bury our parents, and when that doesn't happen, it is just heart-wrenching.

And I have a 30-year-old, now, daughter that was diagnosed with Hodgkin's lymphoma at 25. And when we were at the emergency room over here at G.W. and they said, "Your daughter has a large mass in her chest, and it is malignant," you immediately think that you are going to lose that child. She is 30 now, been through all the chemo. And we are very, very thankful to God and to doctors and the healthcare providers and everybody else that we still have her.

So, Ms. Zarecky, I can't fathom, you know, what you went through, to put a healthy baby down to bed and go in to check on the baby and the baby is deceased. So thank you for being here.

My oldest daughter is 33. She is a pediatrician. And I think I have one of her cards in my pocket. And, unfortunately, I think it is in my left pocket, so I have to figure out how to get it out. But I would like to give it to you, Dr. Beers. And just, if you wouldn't mind, just text her a little note or something and say, "I was with your dad today," because it is great honor to have the president-elect of the American Academy of Pediatrics with us, with my daughter being a pediatrician.

I just wish she didn't have a 6-month-old poodle. Because I was babysitting the poodle, and out under the gate it went, and you see the end result here. But I am advertising for somebody who is this doctor -- some sling provider, it looks like. But, anyway, that was my Christmas present to myself, was to break my shoulder on the Friday before Christmas wrangling her poodle. But the poodle did survive, I have to tell you.

Dr. Beers, as a pediatrician with a focus on community pediatrics, what has been your experience with the Healthy Start program and how it has been able to remove barriers to accessing healthcare?

Dr. Beers. Thank you very much. And I would be delighted to speak with your daughter. It is wonderful to hear of that connection, so thank you.

So, you know -- and we have Healthy Start here in D.C., so I have the privilege of having had families and patients who have participated in the program. And I think there are really a couple key pieces that highlight the importance of the program, in my experience.

One is the real patient- and family-centered nature of it. It is very individualized. It really takes the family's preference and needs into account and then really works to help connect the family to the healthcare services, to the other enabling services that can help support them in accessing the care they need to do the best they can for themselves and for their family.

I think it is also -- as a program, it is very connected and engaged with the rest of the community and the rest of the community-based services so that you are really utilizing all the resources available to you in your neighborhoods and in your community.

Mr. Long. Okay. How does the Healthy Start program support provider training?

Dr. Beers. It helps support provider training in a number of different ways. So by giving medical providers the education about how to access these services and about what needs families have and how to connect them to that. It also helps with provider training, nonmedical provider training, as well.

Mr. Long. Okay. And how does the Healthy Start reauthorization address the need for collaboration with these providers?

Dr. Beers. Yeah. Yeah. That is great. And I think, you know, one of the most important things that I have learned through my career and through working in the community is that we all work better when we work better as a team. I have my own set of skills and experiences. My colleagues and partners have their set of experiences. Our social workers have their experiences. Our WIC nutritionist has her skills and experiences. And so we do better for families when we all come together and work together as part of a team. And that is what Healthy Start helps promote.

Mr. Long. Okay.

You also mentioned the serious maternal mortality crisis that we are facing. And I am a member of the Black Maternal Mortality Caucus, and we are doing everything we can to figure out what is going on there. Can you discuss the role the Healthy Start program can have in reducing maternal mortality?

RPTR MERTENS

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[12:03 p.m.]

Dr. Beers. Absolutely. And it does, it comes back to some of these tenets of identifying what a family's needs and barriers are to accessing good-quality care and then helping to break down those barriers so that mothers can get there.

And so, you know, one of the first and most important things for a mother when she is pregnant is to be able to get to her OB-GYN care and access those services early and on a regular basis, and Healthy Start can help break down those barriers.

It can help identify what some of the social determinants and what some of the social needs may be that are getting in the way or, as we were speaking earlier, may be contributing to poor maternal health outcomes and start to address those things as well -- the food insecurity, the housing insecurity, things like that.

Mr. Long. Do you hear a tapping, or is it just me?

Dr. Beers. No, I do hear a little tapping.

Mr. Long. I yield back.

Ms. Eshoo. Tapping and clapping. How is that?

It is a pleasure to recognize the gentlewoman from Delaware, Ms. Blunt Rochester, for her 5 minutes of questions.

Ms. Blunt Rochester. Thank you, Madam Chairwoman, for recognizing me and also for this important hearing.

And I would also like to apologize; some of us may be going in and out because of a competing hearing, but this is a very important hearing.

And I would like to thank the witnesses for joining us as we consider legislation that aims to improve the health coverage of our constituents and also the health outcomes.

Ms. Zarecky, I want to personally thank you so much for taking the time, for sharing your story, and for honoring Scarlett. Having lost a spouse unexpectedly, I understand turning that pain into purpose. And so I thank you and I thank your family for being here today for something that is vitally important to our country.

Last year, I was proud to support the passage of H.R. 3172, the Safe Sleep for Babies Act. Today, we have an opportunity to continue those efforts by looking at H.R. 2271, Scarlett's Sunshine on Sudden Unexpected Death Act.

We need a strong, multifaceted public health approach in order to understand the causes of sudden, unexpected infant death, SUID, and sudden, unexpected death in childhood, SUDC, and how we can prevent instances of both. I am a cosponsor of H.R. 2271 because I believe this legislation achieves those goals. And I am thankful for my friend and my colleague, Congresswoman Gwen Moore, for introducing this legislation.

As the chairman pointed out, this multifaceted approach includes grant funding for State and local health departments, community-based organizations, and nonprofits so that they can provide support to families who have lost an infant or a child to SUID or SUDC.

And I am pleased to hear that the services had a positive effect on your family as well.

Ms. Zarecky, in your testimony, you shared the important policy priorities that we should be considering. And the strength of H.R. 2271, to me, is that it recognizes those priorities and it puts our money our where our mouth is. The bill authorizes $8 million to improve how we investigate and record the unexpected deaths of infants and children, $1 million to improve case reporting, and $15 million to help States develop and implement prevention strategies.

Ms. Zarecky, do you think that it would be difficult, challenging to make the progress that we need to make without including funding for these critical activities? I think that is an easy question.

Ms. Zarecky. Absolutely.

Ms. Blunt Rochester. Absolutely. Are there other sections of the House bill that you think make the House version strong?

Ms. Zarecky. Of course. One element of the legislation here in the House, of course, is the addition of the family support and the bereavement support. You know, it is a critical piece, I think, to being able to support families after their loss and their unique needs.

Ms. Blunt Rochester. Yes. Thank you.

Another public health issue facing children across the country and in Delaware is the rate of asthma amongst school-age children. In 2015, the Delaware Survey of Children's Health asked parents if their child had ever been diagnosed with asthma, and, in the responses, 17 percent of parents said that they had had an asthma diagnoses.

For this reason, we must have strong policies in place and equip our schools with the tools they need to support these efforts.

That is why I am proud that Delaware's public schools received an "A" on the Asthma and Allergy Foundation of America's 2019 State Honor Roll for meeting a key number of the 23 core policies laid out to protect students.

Mr. Mendez, how did the AAFA choose the standards used in their State Honor Roll of Asthma and Allergy Policies for Schools?

Mr. Mendez. Sure. We have been doing it for a while, but we have a medical and scientific board, and we work with the community, and these really are the best practices that we see as really important to prevent asthma and allergies. A lot of this bill, 2468, picks up on some of those policies that we recommend.

So congratulations to Delaware. I mean, you have some stock epinephrine laws, for example, that are really critical and that have been successful.

So 2468 really tries to include, again, asthma action plans, allergy action plans, how to deal with those kinds of emergency situations, in addition to looking at the environmental controls inside the classroom, where many of the kids spend much of their time.

Ms. Blunt Rochester. I am almost out of time. I have some additional questions that I will submit to the record.

[The information follows:]

******** COMMITTEE INSERT ********

Ms. Blunt Rochester. But I want to thank you all for your work and your commitment to the children and to the families of our country. Thank you so much.

And I yield back.

Ms. Eshoo. The gentlewoman yields back.

It is a pleasure to recognize the gentleman from Montana, Mr. Gianforte, for his 5 minutes.

Mr. Gianforte. Thank you, Madam Chair.

Ms. Zarecky, thank you for sharing your testimony today and your story. As a father of four, I can only imagine what you have gone through, and I am so sorry for your loss. And I applaud your bravery for being here to tell your story to honor Scarlett.

In your testimony, you said that we don't know how widespread instances of sudden, unexpected death in childhood are because there is a lack of specific ways to record these deaths. I was hoping you could share with us, from the perspective of a parent, what was the process like for you to determine your daughter qualified as an instance of sudden, unexpected death in childhood?

Ms. Zarecky. For us in particular, about a little less than 48 hours after Scarlett passed away, we heard the initial results of her autopsy, which is, of course, that it was undetermined, her cause of death. And then we waited a little over 5 months to get the full autopsy and the full gamut of tests back. And then, even then, her cause of death was considered undetermined.

So there are, you know, a lot of different terms that do relate to how these deaths are classified. And so that was -- you know, through that process and then being able to speak with other families who experienced similar losses, that is how we found that out.

Mr. Gianforte. And at a terrible time, where you wanted answers, there was really just no certainty for you.

Ms. Zarecky. Yes. And to this day, I mean, it is really, truly terrifying to know that I don't know what happened to my daughter. And you want answers, you know? You want to know what happened, but you also want to know that it is not going to happen again.

Mr. Gianforte. Uh-huh.

Ms. Zarecky. And living with that uncertainty for myself, for my subsequent daughter, for my husband, for my nephews and nieces, it is really -- you know, it has been 3 years today, and I am just reliving, you know, all of the triggers. And we just celebrated the second Christmas with my second daughter, and I was reliving Scarlett's second Christmas, which she died shortly after. So it has lasting impacts on me, just the trauma associated with it.

Mr. Gianforte. Again, thank you for your bravery and being here today.

Ms. Zarecky. Thank you.

Mr. Gianforte. On a related note, Dr. Beers, in your testimony, you discuss how important death review teams are in understanding how these terrible deaths occur.

Montana is a rural State. Could you talk about the challenges that death review teams have in rural parts of the country?

Dr. Beers. Yeah. It is very difficult -- right? -- because when your populations are smaller and more spread out, your expertise is a bit more spread out as well. It is there, but it is a bit more spread out and perhaps harder to access sometimes.

And so I think it does circle back to the importance of some of the things highlighted in this bill, of training, of standards, of support to be provided to death review teams across all States, regardless of the makeup, regardless of whether they are rural or urban. And so I acknowledge that it is a different challenge -- right? --

Mr. Gianforte. Yeah.

Dr. Beers. -- and, I think, you know, is one of the things that this bill helps to get at.

Mr. Gianforte. Yeah. Good.

And, also, Dr. Beers, Montana is home to eight federally recognized Native American Tribal governments. And it is incredibly troubling that SUID and SUDC are so common amongst Native American peoples. What can the Indian Health Service do to better prevent these deaths?

Dr. Beers. Yeah. No -- and I think it does -- and, again, it goes back to some of the services provided through Healthy Start: really taking the time and investing the resources to evaluate families, to do intake assessments, to really get to the heart of what challenges they are facing and what their needs are, and then providing that individualized support to help make sure they get there.

You know, you mentioned living in a rural State. Access to care can be more difficult in a rural State because you have to travel father and you don't have as easy access to public transportation or other things. And so really, kind of, diving into what those challenges and barriers are and helping to identify solutions.

Mr. Gianforte. Okay.

I have a couple seconds left. Also, Native American women, as you noted, face higher rates of maternal mortality. Is maternal mortality and infant mortality linked?

And how does fixing one affect the other?

Dr. Beers. Yeah. There certainly are linkages, in that the same influences on maternal mortality are very similar to the influences on infant mortality. And so, if we address those things, it will help both those issues.

Mr. Gianforte. Okay.

Thank you very much for your testimony.

And I yield back.

Ms. Eshoo. The gentleman yields back.

It is a pleasure to recognize the ever-patient gentleman from Massachusetts, Mr. Kennedy.

Mr. Kennedy. Thank you, Madam Chair. I am grateful for the opportunity.

Thank you to our witnesses.

And, Ms. Zarecky, thank you for being here as well. I echo the comments of my colleagues. I have a 2-year-old and a 4-year-old. Difficult to listen to your testimony this morning.

And I wanted to start by saying, about a month ago, I was at a coffee shop. I had just finished a meeting, and I was on my way out. And, that evening, it was dark and it was raining. And a gentleman, probably about my own age, maybe a couple years younger, just grabbed me and asked me to read a letter that he had scratched on a napkin as I jumped in the car.

And I got in and I started reading it, and it was a letter about his son, Luke, who was 18 months old -- my son at that point was about 22 months old -- who told your story. A beautiful, bright, healthy, chaotic baby boy, fully vaccinated, walking, talking, beautiful, who went to bed and didn't wake up.

And I went back inside, and we talked for about a half-hour or so. And listening to that young dad try to make sense out of what happened, wrestle with the stigma associated with the loss of a child and the judgment that came down on him and his wife for the perception of having done something wrong, and not be able to point to anything, and to still, as you articulated, search for answers.

His request was that I cosponsor your bill. And, luckily, I already had. But I think it highlights not just the obvious need to try to ensure that we do everything we can to make sure that this doesn't happen again but to make sure that parents get answers and families get answers.

And one of the things that stuck with me from our conversation was how he said, after searching for answers, they were fortunate to come across a research-based program in Boston that did help eventually diagnose a form of sudden, unexpected death in childhood that was consistent with an epilepsy pathway. But, still, largely unanswered.

What struck me was you had a young dad who was in tears who was talking about how fortunate he was to have come across a program that could help at least point him directionally to some explanation about what happened with his son.

I have a letter from his parents -- well, from Garrett and Megan that I wanted to introduce for the record, Madam Chair, as well.

Ms. Eshoo. So ordered.

[The information follows:]

**This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.**

******** COMMITTEE INSERT ********

Mr. Kennedy. But I wanted to thank you, Ms. Zarecky, for your courage and the strength that you show for Scarlett. So thank you.

I also wanted to turn briefly, in the time that I have left, to another story of a baby who will be turning a year old next month. He was born far away from Massachusetts, and the baby's esophagus is in two separate segments connected abnormally to the windpipe.

Boston Children's Hospital, Dr. Beers, is one of two places in the country that is capable of the surgery to correct that particularly complex and complicated case. And the family has been forced to reschedule that surgery three separate times since August because of their confusion within the baby's home State Medicaid vendor.

We know the diagnosis. We know we can treat it. We know there are people that can conduct the procedure. And yet the joint Federal-State nature of a Medicaid program prohibits that, oftentimes gets in the way.

Six months ago, the baby could have had surgery to relieve difficulty breathing and the pain that could result in trips to the ER. But confusion over those Medicaid regulations regarding out-of-State treatment for infants and children has prolonged that baby's suffering and that of countless others.

So I know you are aware of similar stories, and I apologize for not giving you a whole lot of time, but do you think it would be beneficial to help simplify Medicaid screening and enrollment for clinicians who are providing the highest quality care, specialist care, to children, enabling them to get access to treatment for rare illnesses that are only available at specialty centers across State lines?

Dr. Beers. I can be very brief: Yes, we do support that. Anything that can decrease the barriers to care and streamline access to coverage, I would support that.

Thank you.

Mr. Kennedy. Thank you.

Thank you for being here.

Madam Chair, thanks for the hearing.

Ms. Eshoo. The gentleman yields back.

We thought, Mr. Kennedy, that the ACE Kids Act was going to address the very situation that you just pointed out. So I want to work with you to make sure that it is working. We worked so long and so hard to get that legislation over the line, and that was the full intent of it, and it is more than disappointing to me to hear what you just said.

But at any rate, we need to work on that, because that is an impossible situation for a family to be in. No one can go up against these programs and the Federal Government and the bureaucracy and straighten them out themselves.

Now, the ever-patient, my pal, wonderful Member of Congress, your Representative, Ms. Zarecky. We are fortunate to have him in the Congress. We love Mike Doyle. So we are really pleased to welcome him to our subcommittee.

And you have your 5 minutes for questioning.

Mr. Doyle. I want to thank you, Madam Chair, for your kindness, and the ranking member, for allowing me to waive on to the subcommittee today.

Stephanie, I want to thank you and your husband, Ryan. And I saw Iliana walking down the hallway; she is a very active young lady. But your testimony and your courage to come here today -- this is a difficult day, but you are here. What you had to say touched every member of this committee.

This is a start of our regular order hearings. We will move into markups in subcommittee and full committee. I think it is safe to say, based on your testimony and the way you have touched every member of this committee, that this is a bill that will move quickly through the subcommittee and full committee process. And, hopefully, we can get this out to the floor and send this over to our colleagues in the Senate. And this is a great way to honor Scarlett's memory, and I just want to salute you for your courage in being here today.

I know we have spent a lot of time talking about sleep-related deaths, but what happened to Scarlett is different. And maybe Dr. Beers or Stephanie, can you help us understand the difference or the distinction between SUDC or SUID and other sleep-related deaths because of unsafe sleep procedures? Explain the difference, because I think a lot of people see this as some sort of, you know, unsafe practices in sleeping. So if you could take a moment to maybe just explain that.

Dr. Beers. Absolutely. Yes, absolutely. And I appreciate the question because I think it is an important clarification.

And I should say, I think often the reason that we talk more about sleep-related deaths is because we have more data and information on that and we are better able to articulate some of the reasons and causes behind it and what to do.

And I think that does, then, highlight one of the challenges for sudden, unexplained infant death that may not be sleep-related and/or sudden, unexplained childhood death, is that we don't have that data to be able to talk about -- as much of that data -- to be able to talk about how to prevent it.

And so SIDS, or sudden infant death syndrome that is sleep-related is an initially unexplained death in infancy that then is ultimately attributable to sleep positioning or to sleep practices --

Mr. Doyle. Right.

Dr. Beers. -- or sleep-related in some way. And that is often determined through the death scene investigation or death fatality review.

But there are many, many children who die unexpectedly in infancy or childhood for whom we don't identify a cause and that it is not sleep-related.

Mr. Doyle. Yeah. And maybe that just leads into my second. You know, what kinds of research are being done into SUID that can be expanded to also older infants and children?

Dr. Beers. Yeah. Yeah. No, I think it is a great question. I think Ms. Zarecky spoke, actually, to some of the most important things that are happening and then also highlighting that it is sometimes difficult to do research if you don't have the data.

And so this bill focusing in on making sure that we are starting with good data so that we can then build on that I think is a really important piece of it, and also making sure that we are investing resources to be able to do that research.

Mr. Doyle. And what kind of data is currently being collected on SUID? And how might that also apply to older children?

Dr. Beers. Yeah. Part of the challenge is that it is inconsistent. So there typically is data collected from autopsy results and/or from death scene investigation, but there is a bit of a lack of consistency in the way that is done across jurisdictions. And so that makes it, then, difficult to bring all those stories and cases together to start to draw some conclusions from them.

Mr. Doyle. And, Stephanie, I have 48 seconds. I want to give you a chance to add anything you would like to add or say --

Ms. Zarecky. Thank you.

Mr. Doyle. -- since I am the last speaker.

Ms. Zarecky. Thank you. The party is ours, right?

Thank you so much. And, you know, I thank you so much for being here. It means a lot to see a friendly face. This is very intimidating. And --

Ms. Eshoo. We all have friendly faces here.

Ms. Zarecky. Well, a face that is a little bit more well-known to me in my little town in Pittsburgh.

Ms. Eshoo. Yeah, that is all right. I am teasing you.

Ms. Zarecky. But I just want to thank everyone for listening to Scarlett's story.

And I do want to also thank you for pointing out the fact that, of course, Scarlett's death is a sleep-related death, but, as far as we know, it is unpreventable. We can't predict it, and we can't prevent it.

So, while we have made great strides in sleep-related deaths as related to potential hazards during sleep, we have barely scratched the surface -- barely scratched the surface on what is happening to these other kids. Like, there is a reason the numbers have gone down and then they have kind of stagnated.

So, on the back of my shirt right now, I have the names of hundreds of SUDC children who have been lost, and that is just a small fraction of the children representing the families who have just been shattered, who need answers. And we need systems in place to collect the data so that we can do the good research and we can figure out why this is happening. It really is an area of public health that has just not been addressed.

Mr. Doyle. Thank you. Well, we will get this done not only for you but for all those families that you have represented here today.

Ms. Zarecky. Thank you.

Mr. Doyle. Madam Chair, thank you so much.

Ranking Member, thank you for your indulgence.

Ms. Eshoo. Thank you, Mr. Doyle, for your persistence on the legislation and being so central in the life of Ms. Zarecky and her family.

I think almost all of us are parents here, and it just keeps running through our -- that it hasn't happened to us, that it could have, the unimaginable. These little angels, one moment they are breathing, and the next minute they are not.

Well, the first panel, thank you to you. And on behalf of all of my colleagues, I can't thank you enough for the excellent testimony that you have given to us and the expertise that you have shared with us. You can see that the committee was fully engaged, asked excellent questions. And you have now built a very sound foundation for the legislation. So thank you to you.

I want to ask the staff to prepare the witness table for the next panel. And we will get as much done as we can before we have to depart for the classified briefing on Iran and Iraq, which begins at, I believe, 1 o'clock in the Congressional Auditorium. So let's prepare the table as quickly as we can, please.

Thank you, first of all, for being here this morning and waiting and listening, but I am sure you have benefited from it, as did we.

So welcome to the second panel of witnesses.

Dr. Matthew Cooper is the director of kidney and pancreas transplantation at the MedStar Georgetown Transplant Institute.

Thank you for being here.

Mr. Kevin Koser, a patient advocate on behalf of the National Foundation for Ectodermal Dysplasias, thank you to you for being here.

And Mr. Fred Riccardi -- welcome to you -- president of the Medicare Rights Center.

Dr. Cooper, you are recognized for your 5 minutes of testimony.

## STATEMENTS OF MATTHEW COOPER, 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; AND FRED RICCARDI, PRESIDENT, MEDICARE RIGHTS CENTER

## STATEMENT OF MATTHEW COOPER, M.D.

Dr. Cooper. Thank you, Chairwoman Eshoo, Ranking Member Burgess, and members of this committee.

I will attempt to be brief. I know there are pressing issues that are before this committee. I will say, it is an absolute pleasure, a privilege, to be here. I am much more comfortable in a hospital, in an operating room, so this is outside of my boundaries, but I am --

Ms. Eshoo. This is our hospital and operating room.

Dr. Cooper. Yes, I understand.

I am representing hundreds of thousands of successful transplant recipients; several hundred thousands who, actually, are currently waiting for that call for the gift of life; hopefully several million in the future that will receive a lifesaving transplant; living donor families; those that have given the gift of life at the decision of their deceased loved ones; and countless transplant professionals around the country who care tirelessly for these groups of individuals.

My name is Dr. Matthew Cooper. As mentioned, I am a transplant surgeon. I do believe I have the best job in the world in participating in sharing of that gift of life. I actually serve as the director of kidney and pancreas transplantation for the MedStar Georgetown Transplant Institute here in the District.

I am also very much involved in a number of national societies and patient-centered organizations, including the American Society of Transplant Surgeons, the National Kidney Foundation, the American Association of Kidney Patients, whose voices are very important in this and who we have heard very loud and clear, and a spokesperson for Honor the Gift, which is a grassroots organization of professionals and patients who are looking to push this legislation through.

As mentioned in many of the introductory comments, this truly is a no-brainer. We believe that this bipartisan support is very encouraging. And unlike some of the very difficult conversations we had about maternal and fetal death -- again, back to some of the comments, almost Dr. Seuss-like, this is nonsensical. And so we really hope that, at the end of this, this is something that becomes very clear.

Organ transplantation is by far a medical success story for the patients that are able to receive an organ transplant. It increases not only their length of life but also their quality of life, not only for they but for their family. Important to recognize that kidney disease, kidney failure is not an individual problem; it is a family problem.

But, unfortunately, everybody who needs a kidney transplant does not receive one. The supply and the demand problem is real here in the United States. Over 100,000 people waiting for kidney transplants. Unfortunately, about 20,000 a year are transplanted. And, unfortunately, there remains, then, a dramatic shortage of organs.

Unfortunately, the current Medicare policy serves to exacerbate this issue. Under current policy, after that 36 months following a very successful transplant, Medicare coverage for immunosuppressive medication goes away. That becomes a significant problem for many patients, 80 percent of which are primary Medicare beneficiaries.

And I have witnessed this on a personal basis. I can give many examples. A very simple one, that several months ago, came through my doors a young mother of three who was covered by Medicare with a supplemental insurance, who was doing very well following transplant. Unfortunately, lost her job and, with that, lost her supplemental insurance. She was, therefore, only covered by Medicare. You can imagine where this story goes.

Three years following a successful transplant, she, unfortunately, was unable to pay for her medications. And while some might say that is her fault for not coming forward and letting us know that this was a problem, recognize that life goes on for these patients. They have families to care for, they have other bills to pay, and, unfortunately, they are a little bit embarrassed that they are unable to care for their own medications.

And so she lost her transplant. She is back on the list, and she is one of the potential only 10 percent of people that will receive a second transplant because of the sheer numbers of supply and demand.

And this is not an only story. Across the country, well over 70 percent of programs can talk about at least one patient who has lost their organ secondary to insufficient coverage.

From a medical standpoint, it makes no sense, and also from a financial standpoint, we have lots of information now that demonstrates that we can save Medicare money. This is it an absolute win for all of us. It costs about $86,000 a year for dialysis. Up-front costs for the transplant are around $100,000. But each year of immunosuppressive coverage is about $2,000, $2,300 a year; with generics and patient support programs, perhaps even less. And, again, this own government has recognized the cost savings perhaps being close to $300 million. That is a tremendous win for all of us.

And so, simply put, this legislation can potentially save kidneys, it can save lives, and it certainly saves the government money.

And I applaud Dr. Burgess not only for this but for all the things that you have done for kidney care. Please know that your efforts have not gone unnoticed.

And I would encourage Chairman Eshoo and the rest of this committee to please help us support this bill. Let's bring this across the finish line. It is time to put the exclamation point on this.

Thank you.

[The prepared statement of Dr. Cooper follows:]

******** INSERT 3-1 ********

Ms. Eshoo. Thank you, Doctor. This bill is going to move. It has to. And it really needs to be adopted by the Congress, both houses, and sent to the President for his signature. You are absolutely right; it will make all the difference in the world for not only patients but also, you know, the dollars that are attached to this. It is common sense. I never realized that this was the case. So thank you for your testimony and your patience today.

Mr. Koser, welcome. Thank you for your patience in waiting to testify. You have 5 minutes to do so.

## STATEMENT OF KEVIN KOSER

Mr. Koser. Wonderful. Good afternoon, Chairwoman Eshoo, Ranking Member Burgess, and distinguished members of this committee. I want to thank you for this opportunity to speak with you about a cause and bill that are very close to my heart.

My name is Kevin Koser, and I am a co-chair of the National Foundation for Ectodermal Dysplasias' Family Advocacy Committee. I am here to ask for your support in advancing H.R. 1379, the Ensuring Lasting Smiles Act, on behalf of the estimated 3 to 4 percent of Americans just like my 4-year-old son, Kannon, here in the audience, who are diagnosed with a congenital anomaly.

The bill currently has 266 bipartisan cosponsors, including 21 members of this subcommittee, and the identical Senate bill has 37 bipartisan cosponsors.

This bill will ensure that all private group and individual health plans provide coverages for Americans who are born with congenital anomalies and then require medically necessary treatments to restore function to missing or nonfunctioning body parts.

The intent of this bill might seem like common sense. It is. Health insurance should approve claims for medically necessary treatments of congenital anomalies.

In many cases, that is happening, especially when you think of the more well-known anomalies such as heart defects or spina bifida. The problem is that health insurance systematically denies or delays medically necessary treatments for a host of other congenital anomalies, such as those that affect the mouth, teeth, and the oral cavity.

Insurers call these treatments cosmetic and not medically necessary, despite a medical diagnosis and physician-approved care plan. Or insurers state that these are not covered benefits because they appear to be dental-related, even though they are directly linked to the underlying congenital anomaly. These loopholes must be closed.

My family's story serves as an example of this struggle. There were no signs that anything was wrong when Kannon was born. However, a doctor recognized some of the clinical traits of ectodermal dysplasia when he was 9 months old, and genetic testing at the age of 1 confirmed his diagnosis.

Ectodermal dysplasia is a congenital anomaly that affects development of the hair, skin, sweat and saliva glands, teeth, and sometimes other body parts. But it is specifically issues with the mouth, teeth, and oral cavity that has galvanized support from our families to lead the charge in advocating for this bill. Teeth are missing or completely absent. Their eruption is delayed, their enamel is weak, they are cone-shaped, and the jawbone and gum line recede and decay.

Kannon is now 4 years old and just sprouted his first tooth. X-rays indicate that he only has four total teeth. A child without ectodermal dysplasia typically grows about 20, and an adult grows between 28 and 32.

Now, please put yourself in Kannon's shoes and imagine the drastic impact this has on your health and daily life. Your diet is severely restricted. Therefore, you lack proper nutrition and are likely underweight or considered failure to thrive. You will choke, even on soft foods, because you cannot chew. Your inability to chew results in gastrointestinal and digestive complications. You struggle to speak properly. Your jawbone and gum line decay and recede from the lack of teeth. You will need a team of physicians across multiple medical disciplines, all of whom tell you that your health is suffering because you don't have a mouth full of functioning teeth.

While there is no cure, there are several common treatments that are medically necessary in order to manage these issues. These treatments are not optional: first, prosthetic teeth or dentures starting between the ages of 2 and 5 and replaced every 1 to 3 years as the mouth grows; second, surgeries to reconstruct and replace the decaying jawbone and gum line; and, third, dental implants that are surgically installed once an individual's mouth stops growing, usually around age 20.

Last Christmas, Kannon asked Santa Claus for teeth so he could, quote, "chomp big bites" of food like other kids in his preschool class. Now, please think about that. Our 3-year-old boy, who loves of dinosaurs, dragons, and superheroes, asked for teeth for Christmas.

We started pursuing dentures for him, but imagine the heartbreak when our health plan told us that, quote, "any services relating to his teeth or intraoral structure supporting the teeth are not a covered benefit" even though that same policy has mandated coverages for medically necessary treatments of congenital anomalies.

We are not alone. Aidan, a 14-year-old boy from Wisconsin, was first told that his oral treatments only served a cosmetic purpose, and other treatments were denied simply because they addressed issues in his mouth. Alli, a 13-year-old girl from Iowa, was told that her recent surgery to install implants was not a covered benefit due to the inappropriately applied dental exclusion. And Karl, a 47-year-old father from Minnesota, has fought for decades with his health insurance about the medical necessity of a fully functioning mouth, even when that same policy stipulates that accidental injuries to the mouth are covered benefits.

The financial burden of paying for this care 100 percent out of pocket is substantial, especially when our families are already paying for congenital anomaly coverages through our monthly premiums. So why are health insurers bypassing clauses within their own policies, and why are the mouth and teeth being separated from the rest of the body when directly related to a congenital anomaly?

We must close these loopholes that insurers use to bypass State congenital anomaly laws and their contractual obligations to approve claims for medically necessary treatments of congenital anomalies.

Thank you.

[The prepared statement of Mr. Koser follows:]

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Ms. Eshoo. Thank you for your testimony. Powerful testimony.

Mr. Riccardi, it is a pleasure to welcome you, and you have 5 minutes for your testimony.

**STATEMENT OF FRED RICCARDI**

Mr. Riccardi. Good afternoon. I am Fred Riccardi, president of the Medicare Rights Center. Medicare Rights is a national, nonprofit organization that works to ensure access to affordable healthcare for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives.

Thank you for the opportunity to speak with you today about two bipartisan bills that can help improve healthcare coverage and outcomes for people with Medicare.

One such bill, the BENES Act, introduced by Representatives Ruiz, Bilirakis, Walorski, and Schneider, would update Medicare enrollment rules for the first time in over 50 years to better empower beneficiaries to make informed coverage choices. These modernizations are needed due to major changes in how people experience their initial Medicare eligibility.

Today, as in 1965 when the program was created, most people are automatically enrolled in Medicare Part A, the hospital coverage benefit, and Part B, outpatient coverage, when they turn 65 because they are receiving Social Security benefits. However, as an increasing number of Americans are working longer and delaying Social Security benefits, in 2016 only 60 percent of Medicare-eligible 65-year-olds were taking Social Security, compared to 92 percent in 2002. That is a big difference.

Unlike those who are automatically enrolled, this growing cohort of employed older Americans must actively do so. Most can sign up for Part A at any time without a penalty, but enrolling in Part B is much more complicated. Enrolling requires that individuals understand when to sign up during Medicare's time-limited enrollment windows, how their current insurance might work with Medicare, and what penalties may result if they delay enrollment, even by honest mistake.

And the stakes are, indeed, very high. The consequences of any missteps can be significant and may include a lifetime Part B late-enrollment penalty. This penalty accrues at 10 percent for every year the individual should have been enrolled but wasn't. Currently, there are approximately 760,000 people who are paying a Part B late-enrollment penalty, and the average amount represents a 30-percent increase in the monthly premium.

They may also face harmful gaps in coverage and exposure to high out-of-pocket costs. Because Part B enrollment periods do not align, coverage starts later, and beneficiaries may have to wait several months before coverage begins. This is true for the initial enrollment period -- this is the window around someone's 65th birthday -- and then also for the general enrollment period, the period that we are in right now, where there is a larger gap in coverage of up to 7 months.

Americans who have other insurance when they become eligible for Medicare have even more to wade through, like whether Medicare will pay primary or secondary and whether they can delay Part B without a penalty.

The rules are so confusing that HR experts in employer benefits departments struggle to understand them. And clear advice from the Federal Government to those approaching Medicare eligibility would help, but no such notice is required at this point. As a result of this information vacuum, among the most frequent calls to our national consumer help line are those from people or on behalf of people with Medicare who are struggling to enroll into Part B and experiencing severe gaps in coverage.

Without immediate action, a growing number of Americans are going to experience these pitfalls in the current system. People are working longer and also delaying Social Security to collect their full retirement benefit, and more and more beneficiaries are going to face these critical Part B enrollment decisions.

Eight former CMS Administrators who served in both Democratic and Republican administrations endorse the BENES Act's commonsense solutions, which are needed now more than ever.

In part, the bill, for the first time, would require the Federal Government to notify individuals about eligibility, update enrollment timelines to eliminate unnecessary and harmful breaks in coverage, and inform future alignment strategies.

I would also like to take some time and speak to the H.R. 3935, the Protecting Patients Transportation to Care Act. Led by Representatives Carter, Cardenas, Graves, and Bishop, this bill would strengthen healthcare access for people with Medicaid, including some of the 12 million enrollees who are also eligible for Medicare.

And so, for these people with Medicaid, dual enrollees who also have Medicare, they tend to have very complex healthcare needs that require regular visits to medical appointments. And reliable transportation to and from these visits is absolutely crucial but not always readily available. In these instances, Medicaid's NEMT benefit can be a lifeline, facilitating access to needed care for those who have no other way to get to medical visits.

And in some States, like Georgia, there are innovative things happening where people are able to access prescription drugs. Codifying this benefit into Medicaid statute would ensure that enrollees have meaningful health coverage going forward.

Thank you.

[The prepared statement of Mr. Riccardi follows:]

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Ms. Eshoo. Thank you, Mr. Riccardi, for your testimony.

To each one of you, thank you.

And we are going to ask you for some patience. You can have a somewhat leisurely lunch. We are going to break now and attend the classified briefing. And I would say we will return -- the House is going to go back into session at 2:15, so I think that is a safe time for us to come back into session and give us time to get back from at least an hour of the classified briefing.

So we will see you in a bit. Have a nice lunch. Thank you.

[Recess.]

RPTR WARREN

EDTR ZAMORA

[2:30 p.m.]

Ms. Eshoo. Okay. Good afternoon again. Thank you to or second panel of witnesses for your patience in staying with us. We have now concluded the opening statements, your opening statements, and we will move to member questions. And I will recognize myself for 5 minutes to get the ball rolling on that.

Dr. Cooper, thank you again. You gave excellent testimony today. 11,000 Americans -- and you already know this, but I think it is important to state for the record that 11,000 Americans will die waiting for transplants this year. In the meantime, the Medicare program is putting people who are lucky enough to have a kidney transplant at risk by cutting off their coverage for immno -- immunosuppressive drugs. Why is that such a tongue twister?

Why do you think this has gone on for 50 years? I can't help but ask that question.

Dr. Cooper. Yeah. I knew you were going to ask me that question, and I wish I had answers for it.

Ms. Eshoo. I mean because there are advocates. There have been transplants, people waiting, people knowing that they were going to die because of the way this thing is set up. Why has it taken 50 years?

Dr. Cooper. Well, I think the easy answer, Madam Chairwoman, is that when you look at Medicare, I am not sure the As, the Bs, and the Ds sort of all communicate with each other all the time, and what is potentially a loss in one area is a gain in the other.

And, unfortunately, it probably took your examples and probably the voices of those many patient organizations that I talked about to continually bring this up, for folks to sit down and finally put all the numbers together in one place and recognize again, overall, this is a cost savings. But, again, beyond that, you know, this really is an ethical and moral obligation now.

Ms. Eshoo. It is. It certainly is.

Let me ask you this, because you are a transplant -- you do transplants. Do you think that -- the only hearing I ever remember since I came to Congress and have served on this committee was a hearing when I was in my second term. So that would have been 1995, 1996, and it was an examination of what are -- of the system that we have that allocates --

Dr. Cooper. Organs.

Ms. Eshoo. -- organs. Are you satisfied with how that works in our country?

Dr. Cooper. That is a great and very timely question, Madam Chairwoman. So the problem that we started this conversation with the supply and the demand that has sort of led to some --

Ms. Eshoo. Because there are very few that get one, get a part, get an organ.

Dr. Cooper. Yes, ma'am. And so I think we as a transplant community, we as the public, you know, continue to seek for better ways to make sure that that valued and cherished resource gets to the people that need them the most. There is currently afoot an effort to try and change the allocation system so that we remove geographic boundaries, which is currently the primary way in which organs are allocated, so that we, in fact, are getting the organs to where they need to get to.

We hope to eventually get to a point where we don't have that supply and demand problem, but until we get there, there is a need to continue to look at more ingenious ways to be able to assure that the organs are getting to the people that need them.

Ms. Eshoo. Do you think there should be an reexamination of the system that we have?

Dr. Cooper. Well, I think there -- it continually is a reexamination, Madam Chairwoman.

Ms. Eshoo. No, but -- at Congress.

Dr. Cooper. Oh, I actually think that the groups that have been contracted to oversee organ transplants through HRSA, UNOS, the SRTR actually recognize, again, that there is, you know, an opportunity for us to do better. We certainly would like to continue to have the support, things like the executive order, things like Congress to continue to move those initiatives forward, but I truly believe the passion that exists within the transplant community is fairly capable of moving things forward and looking at other ways to do things better, particularly the allocation.

Ms. Eshoo. Thank you.

Mr. Riccardi, one of the -- a problem you identified is that CMS doesn't notify soon-to-be eligible Medicare beneficiaries about enrolling in Medicare if they don't receive Social Security benefits. Seems to me that this could be fixed administratively. Why doesn't CMS do this notification now?

Mr. Riccardi. The practical, you know, solution to providing the notice involves not only CMS but also Social Security and the IRS.

Ms. Eshoo. Why can't they do it? Is there something that -- does there have to be a statute?

Mr. Riccardi. There has to be -- yeah.

Ms. Eshoo. There has to be a statute?

Mr. Riccardi. There has to a statutory change to provide this notice. And what we have observed over time, now that people are working longer and delaying their Social Security, people are --

Ms. Eshoo. They run into this.

Mr. Riccardi. -- missing their Medicare enrollment.

Ms. Eshoo. Yes. Another issue identified is that Medicare coverage is delayed until after the enrollment period ends. Why doesn't CMS begin Medicare coverage on the first of the month after a person enrolls, similar to how private business enrollment works?

Mr. Riccardi. Exactly. That is the most commonsense solution, and I think this is the point where the enrollment periods just need to be modernized. Most Americans are now used to enrolling in coverage and having it start the following month, and that is what this bill would do.

Ms. Eshoo. Right. Thank you very much.

The chair now recognizes Dr. Burgess, the ranking member of our subcommittee, for his 5 minutes of questions.

Mr. Burgess. I thank our witnesses for staying with us today, and these are important topics that we are talking about.

Dr. Cooper, you have referenced the passion in the transplant community. I just have to tell you, when I went to the President's executive order on kidney care, I didn't figure there would be many people that showed up for that. Who is going to be there? That place was packed, and it was packed with very passionate advocates and it was -- it really brought home to me, and although this has been a long-term fight that we have done on this immunosuppressive bill, it is important work and it needs to be done. It needs to get across the finish line.

Just in general, take us back to 1972 or when the End Stage Renal Disease Program started. Why was this -- why was this incorporated into the program this way?

Dr. Cooper. Again, I want to take the opportunity to thank you for everything you have done, Dr. Burgess. It has been, I understand, a very difficult and challenging battle for you, and I am hoping, again, together we can see this through to the finish line.

I think the answer to your question is that perhaps there wasn't the appreciated unintended consequences that would come about through this. Like I said, the way that Medicare was set up, the charges for the actual procedure and, you know, everything that came soon thereafter was not fully appreciated, you know, by another part of Medicare that paid for the long-term care of the post-transplant patient.

And like I said, you know, in the responses to Madam Chairwoman, I think we didn't really take time to sit down together and say how do we make this whole and recognize it as bring it all together we ultimately result in a cost savings for all this. So I think it was just we kept speeding forward with transplant. We kept demonstrating the successes and perhaps even the numbers that were shared earlier of the grafts that were lost from lack of immunosuppressive coverage did not fully appreciate the significance of the problem. There were several hundred. There is probably more like several thousand. And it really is now coming, I think, full circle, particularly with the voices, the patient organizations that said, you know, we have to recognize really the unintended consequences in how we are losing too many grafts from something that is absolutely preventable.

Mr. Burgess. And it is almost as if we were sugarcoating the issue when we talk about, you know, loss of a graft. I mean, this is a bad deal when it happens to someone. I mean, they have been lucky enough to get a transplant either from a living donor. Good news is God gave us each two kidneys and you can give one to someone else if you choose, or somebody got a cadaveric donor and they were on a waiting list. They waited a long time to get a match. Got a tissue match. They were able to go.

And now for want of -- I mean, cyclosporine now is, what, $250 a month? I mean, it is not a big expense. It is not like some of the other things we talk about in this committee where it is $65,000 a month to be on your medicine. This is relatively manageable, and yet for that small investment, the agency is letting these patients go into a -- into something for which they cannot recover without another surgery.

Dr. Cooper. I understand. We I think, unfortunately, look at the expression of gifts of life and don't really recognize that that is exactly what it is. This is a gift. It does provide new life for individuals, and the fact that we are unable to protect that gift with, like you said, something that is truly manageable and truly affordable and recognize, again, that with each graft lost, that potentially puts someone else on an already list that is overwhelming and prevents other people from potentially receiving a graft.

And so, again, if we just figure out that we can get out of our own way and protect a lot of the kidneys that are currently successful, being transplanted, we are going to make, I think, a potential effort towards the same thing that the President put forward on executive order of trying to increase the numbers of transplants by 2023.

Mr. Burgess. Now, you are a transplant surgeon. Do you do other transplants besides renal transplants?

Dr. Cooper. I do pancreas transplant also and combinations of the two, particularly those that have end-stage renal disease from type 1 or type 2 diabetes, another remarkable operation that changes people's lives.

Mr. Burgess. So somebody gets a transplant remote from the ESRD Program, somebody gets a heart transplant, what happens to them? Do they get -- I mean, I presume their regular health insurance will cover their antirejection drugs?

Dr. Cooper. Yeah. The majority of that, like I said, for kidney transplants, you know, far over 80 percent of our patients are Medicare primary. It is a little bit different for the other organs. Their private insurance is probably much better set up to take care of those organs. I think there is effort afoot after this gets approved to potentially make certain that we are not losing other organ systems through the cracks also. But primarily, number one, because of the volume of kidney transplants and the primary payer being Medicare do we see this as such a significant problem in the kidney population.

Mr. Burgess. Okay. So ironically we have may have disadvantaged people by setting up the ESRD Program who were covered by commercial insurance. Perhaps their immunosuppressant would be covered.

Dr. Cooper. That is certainly one way of looking at it, sir, yes.

Mr. Burgess. Okay. Mr. Riccardi, I just have to ask you, because it came to my attention in a constituent meeting last week, about the COBRA not being credible coverage and the gap that some people can fall into. You have kind of alluded to that. Can you speak to that a little bit?

Mr. Riccardi. Yes. Yes, I can. And this is another aspect of where the eligibility period for Medicare haven't been modernized now that there is the existence of COBRA. Currently, if somebody has Medicare part A and they enroll in COBRA, they will be continuing to pay their COBRA premiums, and then typically they will learn from either the health insurance plan or from a physician that the COBRA plan is no longer active or refuses to pay, and then they are locked out of coverage.

And it reminds me -- every day we are hearing from people who are calling our helpline, but it reminds me of one individual that I had worked with many years ago. She happened to be from Texas, and she had been paying her COBRA premium. And then when she was ready to enroll in Medicare, she realized that she couldn't. And she hadn't received any information about needing to enroll and was essentially misinformed by her employer, and this was a large company.

And typically we hear from people after they have already spoken to Social Security, Medicare. They have reached out to their elected officials, and they are desperate for needed assistance. And so we do increasingly over the last several years have more and more calls from people who are on COBRA. Either they have been paying these premiums, which is, if anybody has seen a COBRA premium, it is much more costly than a Medicare part B premium. And so most people are scrambling to get into Medicare, but then they are locked out of this punitive gap in coverage.

Mr. Burgess. Okay. I don't think we addressed that in this bill, but that is something we do need to take on at some point. I thank you.

I will yield back.

Ms. Eshoo. The gentleman yields back.

I am just stunned that no administration that I know of has ever come forward in these areas saying we need a statute to fix this. I think that is what is jaw-dropping to me. I have never had a constituent, in terms of organs and what we are trying to correct with the legislation, ever point this out to me. But what stands out is we are in Washington, D.C., is that no Secretary of Health and Human Services has ever come forward and said this needs to change and we need you to write a new statute.

I now would like to recognize the gentlewoman from California, Ms. Matsui, for her 5 minutes of questioning.

Ms. Matsui. Thank you. My microphone seems to be very powerful.

Older adults today face a challenging healthcare landscape with rising medical costs and fixed financial resources. It is unacceptable that Medicare's complex enrollment process often further exacerbates these challenges.

Mr. Riccardi, in your testimony, you note that modernization to the part B enrollment process are needed due to a shift in how people are experiencing their initial Medicare eligibility. Can you elaborate on some of the factors responsible for this shift?

Mr. Riccardi. Sure. As people are working longer and the Social Security eligibility age for full retirement benefits is now separate, the Medicare eligibility, Medicare eligibility, someone is eligible at age 65, and currently for someone who is retiring, they have to wait till age 66 to collect full retirement benefits and that age will increase to 67. So increasingly there are fewer people who are taking their Social

Security right now, and these people are going without an individual notice.

And what the BENES Act will do are three key things. First, there just will simply provide a notice about somebody's upcoming Medicare eligibility prior to age 65. They will -- it will inform people about the basic rules related to Medicare, including this late enrollment penalty. So it will prevent people from incurring a late enrollment penalty. And, lastly, it is going to eliminate this disastrous gap in coverage that I was just speaking about by ensuring that people who do enroll into Medicare and have their coverage start the following month or the current month.

Ms. Matsui. Right. Absolutely. And it is important to me that as we recognize the modern realities of how Americans are aging and transitioning through life stages, that we need to streamline part B to reflect these realities, and I think it is time to do that certainly.

Mr. Koser, thank you for your testimony today. I appreciate it very much. I am grateful you are here -- you are here today. It is so admirable you are advocating for many of the patients and children across the country.

Mr. Koser, can you tell us a little more about your journey and how you came to be involved in advocacy?

Mr. Koser. Thank you, Congresswoman. I appreciate that. So Kannon is 4 years old. We had no family history of ectodermal dysplasia. We had never heard of it until the doctor at University of Virginia mentioned it to us. It was at that point obviously I got heavily involved with the National Foundation for Ectodermal Dysplasias.

What I found there was that there was a systematic issue across this entire country where people affected not only by ectodermal dysplasia but other congenital anomalies were running into these issues, despite maintaining a full comprehensive health insurance plan.

For Kannon specifically we are very early in his treatment plan right now. We have started trying to pursue these dentures for him. Got rejected in the initial denial from insurance. We plan to pursue them further. We are going to end up having to pay 100 percent out of pocket for him probably in the next several months. We are waiting for his first tooth to fully erupt. That will cost thousands.

But I just wanted to not only represent Kannon and ectodermal dysplasia, but within the written testimony, you will see there is about 46 other organizations representing different disorders and congenital anomalies that are facing these same issues.

Ms. Matsui. And the health plans often deny these claims, right?

Mr. Koser. Correct.

Ms. Matsui. Okay. You know, although all 50 States already have some sort of congenital anomaly lot, it is really clear from your testimony that State regulation alone is not enough to ensure coverage for treatment. Can you expand on how somebody's shortcomings occur and how fair policy will help reenforce State protections for congenital anomalies?

Mr. Koser. Certainly. And thank you for that. I think it is important to understand the foundation of this bill. As you mentioned, all 50 States have statutes that already exist, many of them existing for decades, regarding that any insurance plan issued and regulated by the State must include medically necessary treatments of congenital anomalies. Those laws are written in open-ended ways as if all congenital anomalies are to be treated equally.

Those plans, otherwise known as fully insured plans, the State-regulated plans, there is only approximately 50 million Americans with such plans. The flip side and the other important piece here is to note that self-funded or self-insured plans which are regulated at the Federal level through ERISA of 1974, there are 110 million Americans with such plans. These are private employer-sponsored health plans get regulated at the Federal level. Beyond that, both types of plans, fully insured and self-funded, are both overwhelmingly telling us that within their policies we have mandates for coverage of medically necessary treatments related to congenital anomalies. It is just these loopholes. That is the only way that the insurers can bypass those things.

Ms. Matsui. Okay. Fine. Thank you very much, and I know how we must come forward to address these loopholes. And thank you very much for being here today. Thank you.

Ms. Eshoo. The gentlewoman yields.

It is a pleasure to recognize the gentleman from Florida who is sitting in the ranking member's chair, my friend, Mr. Bilirakis, for his 5 minutes.

Mr. Bilirakis. Thank you. Thank you, Madam Chair. It is an honor to sit in this chair next to you as ranking member, even though it is probably for only 2 minutes. I will take it.

Again, Mr. Riccardi, complex Medicare enrollment rules and lacking notification costs tens of thousands of older adults and people with disabilities that face lifetime fines, which I think is ridiculous, coverage gaps and other harmful consequences. With fewer people automatically enrolled in Medicare and 10,000 baby boomers aging into

Medicare each day, more people new to the Medicare must actively enroll in the program.

In your estimate, what percentage of seniors today have a proper understanding of their current Medicare eligibility and the enrollment process?

Mr. Riccardi. So thank you for your question. And, you know, currently as more and more people are working longer, you know, there are millions of people who are not well informed about their Medicare coverage because they are not receiving any notification about that. They are relying on information from HR departments, from benefit administrators, from commercial insurance brokers.

And so, currently, there are, you know, approximately only 60 percent of people are automatically enrolled into Medicare. So that is millions of people who are going uninformed about the -- these basic enrollment rules and the penalties, as you had mentioned, these lifetime penalties associated with them. And this problem is only going to snowball, as you mentioned, with, you know, 10,000 people every day turning 65.

Mr. Bilirakis. Yeah. So it looks like we have an easy solution here with this bill.

Mr. Riccardi. Yeah, very straightforward.

Mr. Bilirakis. Again, can you explain how seniors might confuse the merits of delayed enrollment into Social Security with late enrollment into Medicare? I mean, it is complicated.

Mr. Riccardi. It is very complicated.

Mr. Bilirakis. Yes.

Mr. Riccardi. And so, you know, the people who are receiving their Social

Security benefits, enrollment is automatic, and it is streamlined. People are automatically enrolled in part A and part B, and they can choose a drug plan or Medicare Advantage. For older adults who are continuing to work or who are waiting to collect their full retirement benefit, they have much more to consider, whether Medicare is going to be primary or secondary. And then they are juggling multiple enrollment periods -- an initial enrollment period, a special enrollment period, a general enrollment period -- and none of these periods are aligned.

So what the BENES Act will do, it will prevent many of these errors from occurring by providing a simple notification a few years out before someone turns 65 versus individuals kind of scrambling after they have turned 65 and realize that they have been working their entire life, they have had insurance, and then once they are eligible for Medicare, they are locked out of the program for several months. It is very unfair.

Mr. Bilirakis. As far as -- so, again, you know, obviously people have to have a sense of responsibility. But how are they going to be informed? We are talking about emails. We are talking about letters, hopefully with big letters, big font because I have a hard time. I need big font, and I will be a senior pretty soon.

Mr. Riccardi. Well, one thing that I have observed over the years and what we have heard from our helpline clients is that when Social Security or Medicare sends a mailing, people open it and they read it. And what the BENES Act will do, will provide notification as part of somebody's Social Security annual award statements. And for many of you, if you have spoken to someone who is near retirement or thinking about retirement, they are starting to wonder, well, how much can I collect at 62 and 65 and 67 and 70.

And so providing this information as part of that notice will ensure that people are obtaining it, and then they can make more informed decisions around whether they should enroll into Medicare part B.

Mr. Bilirakis. Thank you very much.

Madam Chair, the BENES Act is important to help individuals who are approaching Medicare eligibility, but as we all are aware, there are many issues that beneficiaries face once they are enrolled in Medicare -- and I am sure you will agree -- and begin accessing services and filing claims. Once those have to do with the -- one of those things that has to do with Medicare is reimburse in its secondary payer status. That is confusing too.

I cosponsored a bill with Congressman Kind, and it is called the -- what is H.R. 1375, the Provide Accurate Information Directly, or the PAID Act, that would help achieve efficiencies for beneficiaries, build better information sharing, again, through better information sharing. I would ask members of the committee to consider that particular bill and maybe cosponsor the bill.

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

Ms. Eshoo. The gentleman yields back.

I now would like to recognize the gentleman from Oregon, Mr. Schrader, for his 5 minutes of questions.

Mr. Schrader. Thank you very much, Madam Chair. I appreciate it.

Mr. Riccardi, thank you very much for taking the time to be here today and speaking with us on these important problems in Medicare. The BENES Act is a great piece of legislation. We are a big supporter of the BENES Act, and your testimony speaks to the reasons that we need to do legislative solutions.

I also have introduced a bill, bipartisan bill, with some of the colleagues here on the Energy and Commerce Committee, as well as others, dealing with the Medicare Enrollment Protection Act. It is much along the lines of what you and Chairman Burgess just discussed. I became personally aware of these types of situations shortly after I first got elected back in 2009. A constituent of mine, Bill Bergman, came to me, and like many Americans we have just talked about, he worked past the age of 65. He got COBRA coverage, a voluntary retirement package and COBRA through his employer. Felt he was in pretty good shape. Then, you know, fast-forward, he assumed -- he actually asked, could I switch to Medicare after getting off of COBRA. Was given inaccurate information, and he was really surprised when he faced lack of coverage when his COBRA terminated. And he tried to get Medicare because there was no enrollment period for him to get Medicare.

And that is a huge problem, one of the many problems that we have talked about here today. And he was subject to the late enrollment penalty as a result of that.

The bill I have introduced, H.R. 2565, with Mr. Bilirakis, Mike Thompson, and Vern Buchanan, provides a permanent remedy to folks who face barriers to enrolling in part D and penalties due to electing to utilize COBRA coverage after they are Medicaid eligible. Basically, what it does is at the conclusion of Medicare -- excuse me -- of COBRA coverage, that would be considered a qualifying event for a new enrollment period. So they would be able to enroll and get coverage within a month of, like we just talked about, is common in a lot of other plans.

I would hope that while the BENES Act goes forward, this would be a nice complement. And I wonder if you would agree that this is probably a nice complement to the BENES Act and perhaps could be a great amendment to work into this legislation to further deal with some of the Medicare enrollment problems that we are seeing.

Mr. Riccardi. Yeah. I agree that I think it is important to look for strategies and solutions to individuals who have other types of employer coverage, extensions of that coverage, like retiree insurance or COBRA coverage, to allow for a special enrollment period.

Again, these are many people who have done everything right. You know, they have worked a long time. They have had coverage through their employer. They have kept continual coverage, because as we age, you know, people do not want to have gaps in coverage or periods of time where they are uninsured, and then it is a surprise when they can't enroll.

It reminds me of a client that Medicare Rights had worked with many years ago who had worked for a very large company, and he was enrolled into a retiree insurance and was informed that he did not need to have Medicare part B because he was going to be taken care of. And so many of us can kind of look back and remember the time where if you did have insurance, you know, a company could guarantee it to you for life. Well, you know, for this individual, you know, eventually he developed stage IV cancer, and then the COBRA coverage began to deny payment and he was forced to, you know, personally take out a reverse mortgage to pay for his care to cover himself during that gap in coverage.

And I remember speaking to him and his daughter and how the family really struggled, and for him, he was less concerned about himself but more about the financial impact that it was going have on his wife.

Mr. Schrader. Very good. Very good story also.

So I would hope the leaders of the committee would take into consideration our legislation, along with the BENES Act, is one of many solutions that, when this bill gets marked up, be brought to the floor and hopefully pass and help our seniors get the coverage they deserve and think they have earned and especially after they have done all the right things.

And I yield back.

Ms. Eshoo. The gentleman yields back.

If I might make a suggestion, it seems to me, Mr. Schrader, that you need to get into a huddle with Dr. Ruiz. How is that? Friendly suggestion. Sounds like an amendment to a bill to me, but it is nice when everybody agrees.

I now would like to recognize the gentleman from Virginia, Mr. Griffith.

Mr. Griffith. Thank you, Madam Chair. I appreciate it.

I appreciate you all being here today. I know it has been a long day. As you know, we had a significant briefing that I think just about every member attended. It is the first time I have been to one of those where there was not enough seats, but it was important. It was good for all us to do that.

Mr. Koser, I am with you in principle. I am looking for ways we can tighten up that language to make sure that we are doing exactly what you want to do and not getting too carried away. And I think we are going to be able to work that out.

Mr. Koser. Thank you, Congressman.

Mr. Griffith. And I think we get that done, we can move forward on this.

Everybody else has had great testimony. I was here for the testimony. So I heard that and appreciate you all being here.

And with that, because I know it is late, I yield back.

Ms. Eshoo. Well, I called him a gentleman. Now he is a really timely one.

A pleasure to recognize the gentleman from California, Mr. Cardenas, for his 5 minutes of questions.

Mr. Cardenas. Thank you very much, Madam Chair, and ranking member as well. And I don't know how timely I am going to be, but hopefully I can be a gentleman.

I would also like to thank my colleague on the other side of the aisle, Congressman Carter, for working on the issue that I would like to bring up today, and also not to mention, we have a colleague who is not on this committee who is a champion on this issue, and it is Congressman Bishop from Georgia.

And I would also like to give a personal thanks to Mr. and Ms. Koser for coming and tirelessly advocating on behalf of not only your family but thousands and thousands of children and families across this country. And hopefully we can do some good work as a result of that, and so thank you for bringing your beautiful family with you.

I would like to talk about the importance of access to reliable transportation for Medicaid beneficiaries. As you said in your testimony, Mr. Riccardi, this benefit can be a lifeline for Medicaid beneficiaries who may not be able to afford other means of transportation. I think it is just common sense. If you can't get to your doctor, it doesn't matter if you have health insurance or not.

Mr. Riccardi, I would like to ask you a few questions about the folks who rely on this benefit and what sort of treatments they are using it for and what they are trying to get to with this transportation.

First, Mr. Riccardi, just to clarify, when we talk about nonemergency medical transportation, otherwise known as NEMT, we are talking about rides to healthcare providers, pharmacies and that sort of thing, not trips in and ambulance or to the ER. And so can you clarify what kind of access these people are getting when they utilize this transportation?

Mr. Riccardi. Yes. The NEMT benefit is a key Medicaid benefit that helps the most vulnerable Medicaid enrollees access medical services. This is not emergency care, say, ambulance rides to a hospital but for medical visits. And these people are any combination of elderly, have a disability, and very low income and have no other means of transportation.

And so this benefit allows people to receive both preventive care and a number of type of services. Many of our clients are receiving this benefit are using it for dialysis treatments and also for behavioral health and substance abuse disorder treatment and medical services.

I can think of one client who, you know, is unable to leave her home and without this benefit, she would not be able to receive her medical treatment. And, you know, she needs some assistance in leaving the home, and this benefit is crucial for her to get to her medical appointments.

And in many cases, people who are using this benefit are women and they are elderly and unable to, you know, drive or transport themselves, and this is why this benefit is so important.

Mr. Cardenas. Thank you.

And to clarify, and this is a benefit that benefits people in rural and inner city communities pretty much equally, right?

Mr. Riccardi. Equally.

Mr. Cardenas. It doesn't discriminate.

Mr. Riccardi. Yeah. So individuals in rural communities can access this benefit. And what is unique about this transportation benefit is our helpline is available for people with Medicare and Medicaid to call us up with questions and issues. And so many of the people that we speak to who are accessing this benefit are not calling us with complaints about NEMT; they are calling us with other Medicare-related questions, but we hear about the chronic conditions they have and how this transportation benefit allows them to receive the services that they need.

And the majority of our clients are receiving dialysis. What is great about this benefit -- and I know this -- States have flexibility with this benefit -- they are able to access this service, you know, 24 hours a day, and it really is a lifeline for them. Otherwise, if this benefit did not exist, people would not be able to stay and live independently and in the community.

Mr. Cardenas. And also I would venture to say -- and I will go on to my next question -- that without this benefit, the cost expense would exacerbate for the individual and for our system.

Mr. Riccardi, according to the Medicaid and CHIP Payment and Access Commission, about 42 percent of the people who use the NEMT benefit are dual eligibles, meaning they are eligible for both Medicaid and Medicaid. In your testimony, you said that these dual eligible individuals often have complex medical needs, that 60 percent have multiple chronic conditions, and 41 percent have at least one mental health diagnosis.

Is it fair to say that these individuals likely need a significant amount of Medicaid -- excuse me -- Medicare throughout the year?

Mr. Riccardi. So, yes, on average, someone who is dually eligible for Medicare and Medicaid can have anywhere from four to five chronic conditions and, additionally, at least one behavioral health issue. And increasingly more and more older adults are suffering from anxiety and depression, and so this benefit truly is crucial for people who are either elderly or disabled and low income where they are unable to afford transportation. So this really enables for them to receive their services and then also prevent either relapses or a worsening of a chronic condition.

Mr. Cardenas. Thank you very much. And I yield back the balance of my time.

Ms. Eshoo. The gentleman yields back.

It is a pleasure to recognize the gentleman from Oklahoma, Mr. Mullin, for 5 minutes of questions.

Mr. Mullin. Thank you, Madam Chair.

Dr. Cooper, the Medicare ESRD Program has saved lives but has a also impact on overall medical expenses. What are the easiest ways to reduce expenses connected with this program?

Dr. Cooper. Thank you, Congressman. So certainly on the one side, which is obviously transplant, and we spent a lot of time today talking about the value of a transplant and how it saves lives. The other part is identifying chronic kidney disease early and preventing people from ever needing the point where transplant is necessary.

And so -- and some of your efforts have certainly, I think, garnished a lot of interest in the kidney community of early identification and getting people the care they need for problems such as high blood pressure and diabetes so that they can receive the appropriate treatment for those and avoid kidney disease. But unfortunately, a lot of people without access to primary care eventually get to the need of a transplant. And I think that is why we are here today is to recognize transplant is the best treatment for end-stage organ disease. Dialysis is in many ways, we think, a stopover.

And, unfortunately, there is a lot of misperceptions about whether or not, number one, people can avoid dialysis altogether. They can and receive a transplant immediately, rather than go on dialysis. And also, who are the appropriate candidates for transplant? We are finding more and more myths exist about who is not a candidate for transplant, and we should spend more time recognizing that most people who have end-stage renal disease should be referred to a transplant program because it is the best treatment for end-stage renal disease.

Mr. Mullin. All right. Unfortunately, I have had my wife's grandfather and two good friends of mine who have passed away while they were on dialysis, awaiting a transplant, because in Indian Country it is disproportionately high, roughly 50 percent more likely to find themselves on dialysis, needing a transplant than any other groups. And so it is vitally important and it is something that we take to heart.

I can't simply drive any direction outside of our house, going to the big city of Tulsa, without passing a dialysis center. There is two within 30 miles of each other, and we are pretty rural for that to happen.

When you compare a transplant to dialysis, is a return on investment a short period of time? Is it noticed?

Dr. Cooper. Yeah. So there has been lots of studies that have demonstrated that people who undergo a transplant versus remaining on dialysis, at approximately 90 to 100 days after they receive their transplant, that they have a decreased risk of death versus remaining on dialysis. And so the return on the investment, to use your term, is actually very quick following transplant.

Now, that appreciates the fact that we do have some absolute contraindications and relative contraindications to being listed for transplant, albeit, like I said, those are getting shorter and shorter. But recognize again that the data has clearly shown that people should be transplanted who meet the criteria for transplantation because, again, their return on investment, not only from a length of life but from a quality of life, both for them and for their family, as I mentioned, it is an important consideration that end-stage renal disease not only affects the individual but affects their family and support system who often have to plan around three times a week dialysis and all of the rigors that are associated with suffering through end-stage renal disease.

Mr. Mullin. All right. And this is just more of a statement. This isn't a question, because I am supporter of H.R. 5334, but I am concerned to see that under section 2, individuals eligible for services in his, which is Indian Health Services, would be barred from this coverage under Medicare.

As I have stated before, American Indians and Alaska Natives are 50 percent more likely to have kidney failure compared to others. I know the bill sponsors are friends of Indian Country, and I look forward to continuing to work with them to ensure American Indians have the access to the medical services they need.

And with that, I will yield back.

Ms. Eshoo. The gentleman yields back.

I don't understand the reason why that is the case, but --

Mr. Burgess. May I address that?

Ms. Eshoo. Sure.

Mr. Burgess. Well, the bill was introduced by another Member of Congress. We did not have absolute editorial authority before it was introduced.

Mr. Mullin. Yes.

Mr. Burgess. I think that is something that can be remedied.

Mr. Mullin. And we understand that the sponsor is looking into it. We have clarification, but they have made us assured they are going to do what they can to --

Ms. Eshoo. Good. I would --

Mr. Mullin. -- amendment under the rule.

Ms. Eshoo. You obviously are already working with the authors of the legislation. And if anything, we want the tremendous benefits that the legislation brings about to have, I would say, you know, first and foremost in the Native American community to be --

Mr. Mullin. And I understand that his is last payer anyways, but it still has to be written in. That is the way I --

Ms. Eshoo. Exactly. Well, it can't be prohibited.

Mr. Mullin. Right.

Ms. Eshoo. That is where -- that is kind of chilling to me to draw a line and say, oh, you who need this desperately are definitely out.

Mr. Burgess. If I may offer, when this was an Energy and Commerce product, that did not happen. We will fix it.

Ms. Eshoo. Good. Okay.

Dr. Ruiz of California.

Mr. Ruiz. Thank you, Madam Chair, and thank you for considering my bill, H.R. 2477, the Beneficiary Enrollment Notification and Eligibility Simplification Act of 2019, otherwise known as the BENES Act.

I would also like to thank my friend and colleague, Mr. Bilirakis, on this committee for introducing this important piece of legislation with me.

I grew up in the Coachella Valley, and oftentimes, people think of Palm Springs, Indian Wells, Rancho Mirage with lush country clubs and that is a place where you go to retire and spend a lot of money playing golf and enjoying life, and that is definitely an option. However, the vast majority of seniors in my district are not so well off and they still struggle and they still have bills, and their Social Security doesn't cut it, and they still take care of their grandchildren, and they still have other bills that they need to pay and so they have to work. And when they work, they don't get the notification of automatic enrollment into Medicare part A, part B. Therefore, they miss out and they are late, and that has consequences, multiple consequences.

One is for every year that they are late, they incur a 10 percent lifetime penalty on their premiums. So let's say they work for 3, 4, 5 years. That is a 50 percent increase in premiums for the rest of their lives.

Second, when they don't enroll, they just don't have coverage. Simple as that. And some of these jobs don't offer that kind of insurance, and they just think that they are automatically going to get Medicare and they don't.

And then, finally, there are some innate enrollment coverage gap that is unacceptable, up to 6 months at times. And because they don't have insurance during that time, even after they enroll, then they have to pay those expensive bills. They have to get private health insurance, which has higher premiums than the Medicare. And we have seen how that can be detrimental, especially for those who have to decide between paying their bills, working, food, those that have to take reverse mortgages, those that simply go into extreme financial hardship, which adds to their sickness and ailments with anxiety.

And so this bill wants to prevent those -- not only prevent seniors from not having insurance once they turn 65, it also wants to prevent them from incurring the penalty for late enrollment, per se, after 65, but even closes those loopholes within the enrollment coverage gap that currently exist simply because it is outdated, it is complex, and people are really losing out.

So this bill really protects seniors and it is aimed for seniors by making sure they get notification, starting as early as the age of 60, every year when they are anticipating what they may be able to get in terms of their Social Security years later, even if they have to work. And it also aligns the enrollment period for part B with the other private insurance enrollment period so it is not as confusing. So it is just what they would normally -- when they would normally enroll, they would enroll.

So those two provisions will prevent them from making the mistake of not enrolling in a proper fashion.

And then, finally, the third thing is that it closes that nuanced systematic flaw, which has a loophole of an enrollment coverage gap by ensuring that, once they enroll, even those 3 months after they turn 65, but also when they do their first enrollment -- their first late enrollment, that they don't have to wait up to 6 months; that it can happen in the same month or soon after.

So let me ask you some questions. In your written testimony, you state that in 2018, approximately 760,000 Medicare beneficiaries were paying the late enrollment penalty. And many of the seniors I know can't afford their medicines or their Medicare premiums in the first place. They certainly cannot shoulder the additional burden of a penalty, and this is not to mention the potentially devastating effect of having a potential gap in coverage, especially when you are at most risk of getting sick. So these laws are over 50 years old, and healthcare has changed in the last 50 years.

Have the enrollment laws been amended since they were initially enacted, and how is the enrollment environment different today than it was back then?

Mr. Riccardi. So the --

Ms. Eshoo. We will allow Mr. Riccardi to respond, but your time is up.

Yes.

Mr. Riccardi. Thank you.

Ms. Eshoo. Please proceed.

Mr. Riccardi. The enrollment rules for the initial enrollment period and the general enrollment period have not changed in over 50 years.

And to speak to your point about the struggles that older Americans have with finances is that approximately 50 percent of older adults are living on $26,000 a year or less, and a quarter of them have less than $13,000 in savings and they simply cannot bear the burden of these late enrollment penalties and these gaps in coverage.

Our helpline hears, you know, approximately a quarter of our calls around these issues, and the worst call that we receive happens to be every year during the month of April after somebody misses the general enrollment period, because they would not be able to enroll for another approximately 18 months for coverage.

And so what is so important about the BENES Act is it will eliminate this punitive gap in coverage for people, as you have mentioned, who have had other types of insurance, in many cases have been paying more than what it costs -- what it would cost to be in the Medicare program.

And so this bill will prevent these errors from happening. It is very commonsense and practical that they would receive a notice from the Federal Government about the best decision for them to make.

Mr. Ruiz. Thank you. I yield back my time.

Ms. Eshoo. Wonderful. The gentleman yields back.

And I recognize the gentleman from Georgia, Mr. Carter.

Mr. Carter. Thank you, Madam Chair.

And thank all of you for being here. We appreciate this very much.

Madam Chair, I want to start by thanking you and thanking Chairman Pallone for including my bill, H.R. -- and Representative Cardenas' bill, H.R. 3935, the Protecting Patients Transportation to Care Act, in today's hearing.

H.R. 3935 is pretty simple. It just codifies what is already in rule, and that is important, and it codifies something that is beneficial and is helping us.

You know, I have been in the State legislature. I was in the State legislature for 10 years. I have been in Congress now for 5 years. One of the most difficult tasks I have had as a healthcare professional is explaining to some of my colleagues the value of and benefit of healthcare and well care, of making sure we are getting patients the care that they need and how it can actually save us money and save us a lot of money. But all this does is to just codify current regulations that the States have to offer nonemergency medical transportation for medically necessary services to patients who don't have access to transportation on their own.

Now, I represent a lot of south Georgia, a very rural area, and that is very important. However, it is important to note also that this could have an impact on people in urban areas just as well. There are certainly people who need this service in the urban areas just as we obviously need it in the rural areas.

Now, to tell you the truth, generally speaking, I am not in favor of mandating things and of codifying these type of things; however, the benefit outweighs the risk here. There is no question about it. The benefit of this far outweighs any risk.

And having said that, I will say that there are a number of my colleagues who have expressed some concern about fraud, waste, and abuse, and I get that and I understand that. This bill actually addresses that as well and actually puts some areas in place, some programs in place to make sure that we are checking on that. And we are going continue to work on that. It is extremely important.

But the lack of access to transportation can be a barrier across the country, and as I say, patients who use the nonemergency medical transportation benefit do it for a number of reasons, for a variety of reasons. Dialysis would be one. And that is a perfect example. Substance abuse, and let's talk about that for one second. This committee, in a bipartisan effort -- as I have always said, I think this is the most bipartisan committee in Congress, and I do believe that sincerely -- but what we have done for substance abuse and for addressing that situation, this is an extension of that. We need to make sure that people have access to those programs. So that is vitally important as well.

Mental health treatment, day support for patients with intellectual and developmental disabilities, physician services, pharmacy services, physical therapy, the list goes on and on. All of these are extremely important to making sure that we have a healthy citizenship, and that is very important.

So it is no surprise -- and just to give you one example -- it is no surprise that people who miss medical appointments due to a lack of reliable transportation experience worse health outcomes and are more likely to end up in the emergency room. You talk to any doctor, you talk to any hospital administrator, and they will tell you, where is the main cost? Emergency rooms. We got to keep people out of the emergency rooms. We have got to get them in the habit of primary care, getting them in the habit of making sure that they are not using the emergency room as their primary care physicians.

There is a study from Florida State University that found that if just 1 percent, 1 percent of nonemergency medical transportation trips prevented an emergency room visit, the State of Florida would receive a 1,108 percent return on investment. Now, who wouldn't take that? So I am just trying to show you the value of this, because I believe there is a great value here.

So as I said, we are going to be working on this as far as the fraud, waste, and abuse goes. Think about the future. Now we have got Uber. Now we have got Lyft.

We have got other things, and this requires the States to use prior authorization or some other form of utilization management to help cut down on bad actors, and we have bad actors in everything including this. We need to do that. So we have got stipulations in here for that.

Have I missed anything?

Mr. Riccardi. No, you haven't missed anything. But what was -- what I was thinking about was an individual, say, somebody who is frail and elderly. And as people are living longer and diagnosed with dementia and Alzheimer's, this benefit is cost effective and ultimately a cost saver, helping people stay in the home, reducing hospital visits, reducing ER visits, and allowing people to live in the community. And it is difficult to quantify what that would mean for someone's life, but this benefit, although it is not highly utilized, it is very important and vital to keeping people healthy and at home. So --

Mr. Carter. Great. Well, thank you. And I know I am out of time, but before I yield back, I would like to submit the following letters for the record, these are in support of this bill, from Generate Health, Access Living, Greater Hartford Legal Aid, Connecticut Legal Services, New Haven Legal Assistance Association, Together Colorado, Center for Health Progress, American Network of Community Options and Resources, Community Catalyst, and Georgians for a Healthy Future.

Ms. Eshoo. Thank you. Wonderful. So ordered.

[The information follows:]

******** COMMITTEE INSERT ********

Mr. Carter. Thank you. And I yield back, Madam Chair.

Ms. Eshoo. So ordered.

I would just like to say this about Mr. Carter's bill. I think it would be a godsend to people, in plain English, just a godsend.

I would like to submit the following statements for the record and request unanimous consent to enter them into the record: A statement from the National Kidney Foundation in support of H.R. 5534; a letter from the American Dental Association in support of H.R. 1379; a letter from the American Society of Plastic Surgeons in support of H.R. 1379; a letter from the Healthcare Leadership Council in support of H.R. 2477 and H.R. 3935; a letter from the American Network of Community Options and Resources in support of H.R. 3935; a letter from the March of Dimes in support of H.R. 4801; testimony of John Kahan, president of Aaron Matthews SIDS Research Guild of Seattle Children's in support of H.R. 2271; a letter from Food Allergy Research and Education in support of H.R. 2466.

This is really an honor roll of organizations, and kudos to all the authors and cosponsors of the seven bills that we heard today. This is quite something.

Testimony of the American Academy of Allergy, Asthma & Immunology in support of H.R. 2468; a letter from former CMS administrators -- well, that is nice -- in support of H.R. 5772; a list of 95 organizational supporters of H.R. 2477; a letter from 72 stakeholder organizations in support of H.R. 2477; a one-page summary of H.R. 2477 developed by the Medicare Rights Center. Thank you. An October 2018, New York Times article entitled, "Why you shouldn't wait to sign up for Medicare, part B." Well, I don't think very many people read it. So that is why we are here today. A December 2019 Wall

Street Journal article entitled, "Medicare Enrollment Can Be Confusing and Lead to Unexpected Costs"; a joint statement of Representatives Ryan, Underwood, and Stivers in support of H.R. 4801; a letter from Generate Health in support of H.R. 3935; a letter from Access Living in support of 3935; a letter from the Blue Dog Coalition in support of the NEMT benefit; a letter from the Congressional Black Caucus in support of the NEMT benefit; a list of 59 organizational supporters of 3935; a study on NEMT's return on investment prepared by the Medicare Rights Center. Thank you again. A statement from CVS Health in support of 5534.

Without objection, so ordered.

[The information follows:]

******** COMMITTEE INSERT ********

Ms. Eshoo. So to each of you at the witness table, on behalf of all of the members of this subcommittee, I want to thank you for your tremendous patience. You have been here since early this morning, and even though you weren't at the witness table, you stuck with it, and we sincerely appreciate it.

Hearings -- legislative hearings are foundational to strengthen bills, and so the expert testimony, the testimony of a parent describing what takes place in their day-to-day lives and informing us of what we need to do is always very powerful. You operate on people. We are listening. Your family experience strengthens our hand in terms of producing good legislation.

And, Mr. Riccardi, thank you for your work and the work of your organization. It really is superb, and I have confidence that -- someone said the magnificent seven, that we move these bills. I have every intention of doing so and because the American people will be bettered by them.

So thank you to all of you. I want to thank your families that are here, the little ones, these angels. We should have brought them up here and had them sitting with me, but one of them actually gave me a big hug. Isn't that something? That looks good. I feel like crawling in there with him.

With that, we thank all of you. And the subcommittee is now adjourned.

[Whereupon, at 3:27 p.m., the subcommittee was adjourned.]