

## **Documents for the Record – 02/14/2024 HE Hearing**

### **Majority:**

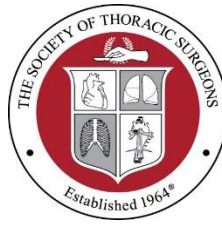
- February 12, 2024 Letter from The Society of Thoracic Surgeons
- February 13, 2024 Letter from American Society of Health System Pharmacists
- February 13, 2024 Letter from American Society of Health System Pharmacists, Dr. Lorna Breen
- February 13, 2024 Letter from Brain Injury Association of America, National Association of State Head Injury Administrators, and United States Brain Injury Alliance
- February 13, 2024 Statement from Rep. Pascrell
- February 13, 2024 Statement from Children's Hospital Association
- February 13, 2024 Statement from The American College of Physicians
- February 13, 2024 Letter from the American Speech Language Hearing Association
- February 13, 2024 Letter from Cure SMA
- February 13, 2024 Letter from the Oncology Nursing Society
- February 13, 2024 Coalition letter supporting H.R. 5012
- February 14, 2024 Letter from Rep. Cammack
- February 14, 2024 Letter from the American College of Emergency Physicians
- February 14, 2024 Letter from the Alzheimer's Association and Alzheimer's Impact Movement H.R. 6160
- February 14, 2024 Letter from the Alzheimer's Association and Alzheimer's Impact Movement H.R. 620
- February 14, 2024 Letter from the Alzheimer's Association and Alzheimer's Impact Movement H.R. 7218
- February 14, 2024 Letter from the Alzheimer's Association and Alzheimer's Impact Movement H.R. 619
- February 14, 2024 Statement from the Alzheimer's Association and Alzheimer's Impact Movement
- February 14, 2024 Article submitted by Rep. Griffith

### **Minority:**

- January 11, 2024 Coalition letter on H.R. 6960
- February 12, 2024 Letter from National Down Syndrome Society
- February 13, 2024 Statement from Debbie Jaine Vijayvergiya on the SHINE for Autumn Act
- February 13, 2024 Letter from Figs, Inc.
- February 13, 2024 Coalition letter supporting H.R. 5012
- February 14, 2024 Statement from Rep. Cohen
- February 14, 2024 Letter from American College of Emergency Physicians

- February 11, 2024 Letter from Cheri Davies on BOLD
- February 14, 2024 Statement from Brain Injury Association of America, National Association of State Head Injury Administrators, and United States Brain Injury Alliance
- February 14, 2024 Statement from the Children's Hospital Association
- February 14, 2024 Statement of Molly Guthrie, VP of Policy and Advocacy, Susan G. Komen
- February 14, 2024 Statement from GO2 for Lung Cancer
- February 14, 2024 Letter from Rep. Boyle
- February 14, 2024 Statement from Rep. Pascrell
- February 14, 2024 Statement from HEAL Trafficking

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February 14, 2024

The Honorable Brett Guthrie  
Chair  
House Committee on Energy and Commerce  
Subcommittee on Health  
Washington, DC 20515

The Honorable Anna Eshoo  
Ranking Member  
House Committee on Energy and Commerce  
Subcommittee on Health  
Washington, DC 20515

Dear Chair Guthrie and Ranking Member Eshoo,

On behalf of The Society of Thoracic Surgeons (STS), I write to provide feedback on the important issues raised during the Subcommittee's hearing "Legislative Proposals to Support Patients and Caregivers" on February 14, 2024. Founded in 1964, STS is a not-for-profit organization representing more than 7,700 surgeons, researchers, and allied healthcare professionals worldwide who are dedicated to ensuring the best possible outcomes for surgeries of the heart, lungs, and esophagus, as well as other surgical procedures within the chest.

We thank you for holding this hearing to deliver bipartisan solutions to improve the health and wellbeing of our physicians and our patients. STS remains fully committed to improving the quality, safety, and efficiency of care for all patients and we strongly encourage the Committee to consider enacting the following legislation.

H.R.7153, Dr. Lorna Breen Health Care Provider Protection Act Reauthorization

STS supports efforts to reauthorize the Dr. Lorna Breen Health Care Provider Protection Act. Since its enactment, this legislation has provided healthcare workers with education and training to mitigate stress and burnout on the job. Access to mental health support and treatment is more available for the healthcare workforce than ever before. Despite this progress, healthcare professionals still face greater and increasing rates of mental and behavioral health conditions, suicide, and burnout than other professions. This law must be reauthorized to ensure the healthcare workforce has continued access to the necessary mental health services, without fear of loss of licensure, loss of income, or other meaningful career setbacks. By protecting our providers, we ensure that patients have access to optimal care.

H.R. 7189, Congenital Heart Futures Reauthorization Act of 2024

The Centers for Disease Control and Prevention (CDC) Congenital Heart Defect Program represents the federal government's commitment to better understanding congenital heart defects (CHD), the most common birth defect, and raises awareness of this condition. STS urges the Committee to advance this legislation to help reduce the devastating effects of CHDs. The knowledge gained through this program

enhances physicians' ability to diagnose and treat these conditions while contributing to improved patient outcomes for the 40,000 lives affected by CHD. Reauthorizing this program is crucial to continuing the CDC's positive impact on the lives of those affected by these complex congenital cardiac conditions.

#### H.R. 6829, Cardiomyopathy Health Education, Awareness, Research, and Training in the Schools (HEARTS) Act of 2023

STS supports the Committee's consideration of the HEARTS Act of 2023. This legislation authorizes the creation and dissemination of cardiomyopathy education and risk assessment materials to identify at-risk families and authorizes research and surveillance activities relating to cardiomyopathy. If enacted, the legislation would provide training information on automated external defibrillators (AEDs) and cardiopulmonary resuscitation. It would also provide schools and childcare centers with recommendations and tools to implement a cardiac emergency response plan.

STS encourages the Committee to also consider the Access to AEDs Act, which would similarly play a crucial role in reducing the devastating impact of sudden cardiac arrest (SCA) in schools by awarding grants to local educational agencies, to promote student access to defibrillation in elementary and secondary schools. SCA is a leading cause of death in the United States, affecting over 356,000 individuals annually. Of these, an estimated 7,000 to 23,000 young people are stricken by SCA each year. SCA often occurs without warning and can quickly lead to irreversible brain damage or death if not treated immediately. AEDs provide a critical intervention for SCA victims, as they can shock the heart back into a normal rhythm and improve the chances of survival.

Both pieces of legislation would help ensure that these lifesaving devices are available in schools around the nation and provide critical funding for AED procurement, training, and maintenance. By increasing the availability and proper use of AEDs, we can significantly improve survival rates for SCA victims and reduce the long-term health complications associated with delayed treatment.

#### H.R. 4534, Women and Lung Cancer Research and Preventive Services Act of 2023

STS is a strong proponent of the Women and Lung Cancer Research and Preventive Services Act, which would accelerate research and investigate possible ways to decrease the number of women affected by lung cancer.

Lung cancer is the leading cause of cancer-related death among women, and women face disparate rates of lung cancer compared to men. The gender disparity is not well understood and is particularly stark among non-smokers: approximately two-thirds of non-smokers who are diagnosed with lung cancer are women. It is critical that we gain a solid understanding of women's access to and knowledge of preventive services, since covered services like low-dose computed tomography screenings have proven effective. This legislation is an important step towards utilizing all available data and best practices to save lives.

#### H.R.4758, Accelerating Kids' Access to Care Act

While not listed for review during this hearing, STS would encourage the Committee to consider the Accelerating Kids' Access to Care Act which reduces barriers to families and children receiving lifesaving out-of-state care. Specifically, this legislation would establish a voluntary pathway for qualified providers providing specialized care to children that is not available locally to enroll in other states' Medicaid or CHIP programs without burdensome or delayed screenings.

Congenital and pediatric cardiothoracic surgeons treat children who live with complex medical needs such as congenital heart disease. Families of these children often struggle to access and coordinate specialized care and must travel out-of-state to seek necessary lifesaving treatment. When a child's medical needs cannot be met by providers in their home state, the State Medicaid Agency and/or Medicaid Managed Care Organization authorizes such care with an out-of-state provider which requires additional screenings and enrollment. Currently, there is no federal pathway to streamline this process which means providers are often required to be screened and enrolled every time they treat a child from out-of-state. This process can be onerous, redundant, and cause significant delays in time-sensitive care. For these reasons, we need policies that ensure timely access to care for children and families with complex medical conditions.

#### H.R. 3226, the Prematurity Research Expansion and Education for Mothers who deliver Infants Early (PREEMIE) Reauthorization Act of 2023

Given the Committee's interest in congenital heart defects, STS would like to flag this bill which aims to prevent preterm birth and its consequences, including being the leading contributor to infant death. Our specialty treats many of the challenges presented by premature infants, particularly those grappling with neonatal cardiac diseases, pulmonary hypertension, chronic lung disease, and airway disease. These conditions not only pose significant health risks but also contribute to financial burdens and emotional stress for affected families. There is an urgent need for continued targeted research in this critical area of neonatal care. The PREEMIE Act signifies a vital step toward improving the outcomes for premature infants, reducing the associated healthcare costs, and advancing our collective understanding of preventable measures.

#### H.R. 4189, the Creating Opportunities Now for Necessary and Effective Care Technologies (CONNECT) for Health Act

Access to telehealth has become one of the essential mechanisms with which patients can receive care. This important legislation builds upon actions already taken by Congress to ensure patients can maintain a stable relationship with their healthcare provider via telehealth services. Currently, many essential Medicare telehealth flexibilities are set to expire on December 31, 2024.

The COVID-19 public health emergency (PHE) illustrated how valuable a tool telehealth can be for all communities, including those that are in rural or underserved communities. Access to telehealth services has been shown to improve access to healthcare. Virtual care has provided unprecedented access for patients, but the future of telehealth medicine remains uncertain. According to a 2022 study by the Centers for Disease Control and Prevention (CDC), 37.0% of all adults had utilized telehealth medicine in the past 12 months.<sup>1</sup> Important legislation like this would ensure that all communities,

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<sup>1</sup> <https://www.cdc.gov/nchs/products/databriefs/db445.htm>

including rural and underserved areas, will not go over a “telehealth cliff” and lose access to critical services.

Thank you for the opportunity to provide these comments. Please contact Molly Peltzman, Associate Director of Health Policy, at [mpeltzman@sts.org](mailto:mpeltzman@sts.org) or Derek Brandt, Vice President of Government Affairs, at [dbrandt@sts.org](mailto:dbrandt@sts.org), should you need additional information or clarification.

Sincerely,

A handwritten signature in black ink, appearing to read "Jennifer C. Romano". The signature is fluid and cursive, with the first name being the most prominent.

Jennifer C. Romano, MD  
President



February 14, 2024

The Honorable Chairman Brett Guthrie  
House Energy and Commerce Committee  
Health Subcommittee  
2434 Rayburn House Office Building  
Washington, DC 20515

The Honorable Ranking Member Anna Eshoo  
House Energy and Commerce Committee  
Health Subcommittee  
272 Cannon House Office Building  
Washington, DC 20515

**Re: Energy and Commerce Committee, Subcommittee on Health, hearing entitled “Legislative Proposals to Support Patients and Caregivers.”**

Dear Representatives Guthrie and Eshoo:

Thank you for holding a hearing on legislative proposals to support patients and their caregivers, and in particular the Reauthorization of the Dr. Lorna Breen Health Care Provider Protection Act (H.R. 7153). We appreciate the Committee’s attention to patient and caregiver issues, and this impactful legislation aimed at supporting the mental health and well-being of the healthcare workforce. The American Society of Health-System Pharmacists (ASHP) is the collective voice of pharmacists who serve as patient care providers in hospitals, health systems, ambulatory clinics, and other healthcare settings spanning the full spectrum of medication use. The organization’s more than 60,000 members include pharmacists, student pharmacists, and pharmacy technicians.

ASHP has been addressing workforce well-being within our organization and the profession of pharmacy for decades. Our commitment is embedded within ASHP’s strategic plan, vision statements, policy positions, standards, resources, and programming. Consistent with this commitment, we urge reauthorization of the Dr. Lorna Breen Health Care Provider Protection Act in 2024 to sustain its impact since its initial passage in 2022. Thanks to that legislation, ASHP is one of 44 organizations selected to receive funding from the Health Resources and Services Administration (HRSA). Through the HRSA Health and Public Safety Workforce Resiliency Training grant, we have reached over 4,300 pharmacists, pharmacy technicians, pharmacy residents, and student pharmacists in a curriculum-based, virtual learning community that aims to empower local action to mitigate occupational burnout and create cultures of well-being in healthcare organizations.

ASHP thanks you for taking action to protect the mental health and well-being of the healthcare workforce. We look forward to continuing to work with you on this issue. If you have questions or if ASHP can assist in any way, please contact Frank Kolb at [fkolb@ashp.org](mailto:fkolb@ashp.org).

Sincerely,

Tom Kraus  
American Society of Health-System Pharmacists  
Vice President, Government Relations



The Honorable Susan Wild  
1027 Longworth House Office Building  
Washington, DC 20515

The Honorable Earl L. “Buddy” Carter  
2432 Rayburn House Office Building  
Washington, DC 20515

The Honorable Debbie Dingell  
102 Cannon House Office Building  
Washington, DC 20515

The Honorable Jennifer A. Kiggans  
1037 Longworth House Office Building  
Washington, DC 20515

February 13, 2024

**Re: ASHP support to reauthorize the Dr. Lorna Breen Health Care Provider Protection Act (H.R.7153)**

Dear Representatives Wild, Carter, Dingell, and Kiggans:

Thank you for your role in introducing the reauthorization of the Dr. Lorna Breen Health Care Provider Protection Act (H.R. 7153). We applaud your efforts to acknowledge the critical role of the healthcare workforce in protecting patient and public health and to advance initiatives that support healthcare workforce mental health and well-being. The American Society of Health-System Pharmacists (ASHP) is the collective voice of pharmacists who serve as patient care providers in hospitals, health systems, ambulatory clinics, and other healthcare settings spanning the full spectrum of medication use. The organization’s more than 60,000 members include pharmacists, student pharmacists, and pharmacy technicians. For more than 80 years, ASHP has been at the forefront of efforts to improve medication use and enhance patient safety.

Unfortunately, the pharmacy workforce, like the rest of the healthcare workforce, is experiencing alarming rates of occupational burnout, moral injury, and stress. ASHP has been addressing workforce well-being within our organization and the profession of pharmacy for decades. Our commitment is embedded within ASHP’s strategic plan, vision statements, policy positions, standards, resources, and programming. Consistent with this commitment, we support reauthorization of the Dr. Lorna Breen Health Care Provider Protection Act in 2024 in order to sustain its impact since its initial passage in 2022. Thanks to that legislation, ASHP is one of 44 organizations selected to receive funding from the Health Resources and Services Administration (HRSA). Through the HRSA Health and Public Safety Workforce Resiliency Training grant, we have reached over 4,300 pharmacists, pharmacy technicians, pharmacy residents, and student pharmacists in a curriculum-based, virtual learning community that aims to empower local action to mitigate occupational burnout and create cultures of well-being in healthcare organizations.

ASHP thanks you for taking action to protect the mental health and well-being of the healthcare workforce. We look forward to continuing to work with you on this issue. If you have questions or if ASHP can assist in any way, please contact Frank Kolb at [fkolb@ashp.org](mailto:fkolb@ashp.org).



ASHP support for Reauthorization of the Dr. Lorna Breen Health Care Provider Protection Act  
February 13, 2024  
Page 2

Sincerely,

A handwritten signature in black ink, appearing to read 'Tom Kraus', with a stylized flourish at the end.

Tom Kraus  
American Society of Health-System Pharmacists  
Vice President, Government Relations

**Written Testimony for the Record**  
**House Energy and Commerce Committee**  
**Legislative Proposals to Support Patients and Caregivers**  
**Support of the Traumatic Brain Injury Reauthorization Act**

**Submitted by**  
**Brain Injury Association of America**  
**National Association of State Head Injury Administrators**  
**United States Brain Injury Alliance**

**February 14, 2024**

Thank you for the opportunity to submit Testimony for the Record to the hearing entitled *Legislative Proposals to Support Patients and Caregivers*, which includes discussion on the Traumatic Brain Injury (TBI) Reauthorization Act (H.R. 7208). The Brain Injury Association of America, National Association of State Head Injury Administrators, and United States Brain Injury Alliance appreciate the opportunity to submit joint Testimony for the Record. Today, we stand united in advocating for the reauthorization of the Traumatic Brain Injury Act in 2024 with modest improvements to the bill.

### **The Brain Injury Challenge**

Brain injuries are considered a significant public health issue in the United States and the leading cause of death and disability in both older adults and youth.<sup>1</sup> Brain injury was dubbed the signature injury of the wars in Iraq and Afghanistan. More than 2.5 million veterans serving after September 11, 2001, have sustained a TBI and 80 percent of these injuries are non-combat related.<sup>2</sup> Motor vehicle and motorcycle crashes (on and off base), military training accidents, fights and falls, recreational and organized sports, exposure(s) to blast from improvised explosive devices, gunshot wound(s), exposure to overpressure from use of high powered weapons, and more may contribute to brain injury in veterans. Additionally, the incidence continues to increase among our nation's civilian population. Every year, 2.5 million Americans experience a brain injury with some degree of severity, resulting in an estimated 5.3 million individuals living with lifelong disabilities. Approximately 200 Americans die from brain injuries each day, and countless others face long-term consequences of brain injury with cognitive, physical, and behavioral challenges as a result of their brain injuries. Furthermore, 15% of high school youth report sports or recreation-related concussions annually.

Most estimates come solely from data collected through emergency department admissions, which is not reflective of the total population. The Center for Disease Control and Prevention (CDC) Injury Center recently conducted a pilot of the National Concussion Surveillance System, which found that adult respondents reported more than 30 times as many TBIs in the past 12 months compared to current estimates, while children and adolescents reported approximately 17

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<sup>1</sup>[https://www.cdc.gov/traumaticbraininjury/get\\_the\\_facts.html#:~:text=TBI%20is%20a%20major%20cause%20of%20death%20and%20disability&text=That's%20about%20190%20TBI%2Drelated,health%20problems%20after%20the%20injury.](https://www.cdc.gov/traumaticbraininjury/get_the_facts.html#:~:text=TBI%20is%20a%20major%20cause%20of%20death%20and%20disability&text=That's%20about%20190%20TBI%2Drelated,health%20problems%20after%20the%20injury.)

<sup>2</sup> <https://health.mil/Military-Health-Topics/Centers-of-Excellence/Traumatic-Brain-Injury-Center-of-Excellence/DOD-TBI-Worldwide-Numbers>

times as many TBIs in the past 12 months. Unfortunately, the number Americans who sustain a brain injury continue to increase each year due to a variety of factors. Recent studies have found that COVID-19 increases the risk of long-term TBI through Long-COVID, which is estimated to impact at least 65 million people.<sup>3</sup> Intimate partner violence also increased following lockdowns, leading to an increase in brain injury due to blows to the head and/or strangulation.<sup>4</sup> Similarly, substance use disorder greatly increased during the COVID-19 pandemic, which can lead to a brain injury when an individual loses oxygen to the brain. These data combined underscore the significant prevalence and growing challenge of TBI in the U.S.

Research demonstrates that there is a dramatic convergence of co-occurring conditions among people with TBI. For example, people with TBI are 10 times more likely to die from accidental poisoning as a result of substance misuse, including opioids, and 70-80% of people with brain injuries leave inpatient rehabilitation with a prescription for opioids. As high as up to 50% of people with TBI experience mental health challenges,<sup>5</sup> as high as 82% of individuals involved with the justice system are people with TBI,<sup>6</sup> compared to 8% in general population, and 50% of the unhoused have a past history of TBI.<sup>7</sup> Because of these needs and the high occurrence of co-occurring conditions, people with TBI need a wide range of supports to maximize their function and independence.

TBI has come to be acknowledged as a chronic condition that changes over the lifespan of the individual, rather than a one-time occurrence, characterized by enduring functional impairment, cognitive deficits, comorbid health conditions, and psychosocial challenges across the lifespan.

### **Significance of the TBI Act**

Since 1996, the TBI Act has served as a beacon of hope, driving the development of state-based systems of care for individuals with brain injury and their families. Through its repeated reauthorization, the Act has provided essential funding for civilian brain injury programs, addressing the evolving medical and social needs of people with brain injuries. These state programs do not provide direct services, but, rather, identify individuals with brain injuries and link them to resources within the state to address their brain injury-related challenges. The Act has been reauthorized in 2000, 2008, 2014, and 2018, with the upcoming 2024 reauthorization being pivotal in ensuring continued progress. Our collective organizations have a particular focus on ensuring continued success of, and improvement to, the TBI State Partnership Program at the Administration for Community Living and the TBI Program at the CDC, including the National Concussion Surveillance Program.

#### *TBI State Partnership Program*

Because of the high co-occurrence of TBI with other challenges, people looking for services and supports often enter state service systems at varying agency points. There is often no obvious state program for services for people with TBI within a given state. The purpose of ACL's TBI

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<sup>3</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10179128/>

<sup>4</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8543566/>

<sup>5</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2536546/>

<sup>6</sup> <https://doi.org/10.1016/j.pnpbp.2011.01.007>

<sup>7</sup> [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(19\)30188-4/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(19)30188-4/fulltext)

State Partnership Program is to ensure that there is one central program coordinating state systems to improve access to resources for people with TBI, and their families, with the goal of improving long-term outcomes. Research proves that people with brain injury who live in states with State Partnership Program Grants have better overall long-term outcomes than those living in states without the grants.

States have utilized this funding to support a variety of challenges that people with brain injury may face. For example, states have focused on forging partnerships to raise awareness and promote education for veterans with a history of TBI, addressing the critical co-occurrence of brain injury and suicide while actively participating in national initiatives to prevent veteran suicides. Other states have built up capacity to support youth who sustain sports-related concussions, while others have enhanced support for job seekers with brain injuries. Others have focused on identifying and assisting specific populations, such as those with co-occurring brain injuries and behavioral health disorders, addressing brain injuries resulting from intimate partner violence, supporting native populations, and implementing comprehensive models within the criminal justice system. These diverse approaches underscore the flexibility and impact of these resources across states.

#### *CDC TBI Program and National Concussion Surveillance System*

The CDC TBI Program is responsible for assessing and reporting on the incidence and prevalence of TBI in the United States. The 2018 TBI Reauthorization Act created a National Concussion Surveillance System (NCSS) as part of the CDC to support better data collection on TBI, particularly concussions. Unfortunately, existing national data underestimate the prevalence of brain injury across the country. The pilot program of the NCSS, as described above, was a one-time survey that evaluated the methodology of collecting self-reported brain injury information and validated a brain injury case definition. Additionally, CDC has added questions to the National Health Information Survey, which will provide national data that is necessary but is limited in the questions it is able to ask. Therefore, the CDC needs to continue the NCSS on an annual basis to develop a more accurate understanding of the incidence and prevalence of brain injury across the country. This program is supported by a wide variety of partners, including the American Academy of Pediatrics, all of the national brain injury organizations, and a variety of sports organizations.

We strongly support the two programs outlined above and call for their reauthorization. As we consider the evolving medical and psychosocial needs of people with brain injury, the brain injury community recommends these consensus-based changes to the TBI Act to further strengthen these important programs.

#### **Proposed Changes for Strengthening the TBI Act**

##### *Brain Injury as a Chronic Condition*

We suggest language in the legislation to emphasize that brain injury is a chronic condition that can impact individuals with brain injury across the lifespan. A brain injury is not a one-time, static event, but the beginning of a process that can lead to the development of recurring,

persistent, and/or dynamic effects in a significant segment of brain injury survivors. While many people who sustain a brain injury experience only temporary symptoms or neurological impairment, others experience permanent changes and are impacted throughout their lifespan. This evidence-based update, influenced by how brain injury is perceived by the public at large, and based on what is known by the clinical community, will more accurately reflect what is occurring in practice with respect to the lifelong impact and treatment of brain injury.

#### *Increase Authorization Level for the TBI State Partnership Program*

We propose an increase in the authorization level to \$19 million per year for fiscal years 2025 to 2029 for the TBI State Partnership Program. Currently, only 31 states have TBI Act grant programs, and research indicates that these programs are effective in ensuring access to brain injury care. An increase in the authorization level aligns with the brain injury community's annual appropriations requests and enables more states to be funded, and such funding to be increased, leveraging the current small size of these grants in order to serve a larger population.

#### *Definition of TBI under State Partnership Program*

We also recommend that Congress modify the definition of "traumatic brain injury" to be very clear that systems of support for people with anoxic or traumatic brain injury can be supported under the TBI State Partnership Program Grant. Due to the increases in brain injury from loss of oxygen to the brain (i.e., "anoxic" brain injury) from intimate partner violence, substance use disorder, and other causes, many state programs are serving systems that support both traumatic and non-traumatic brain injury. While the current definition does include both traumatic and nontraumatic/anoxic brain injury, the definition could be updated to be more inclusive of all types of brain injury. This update in language will clarify the current intent of the law and reflect what is occurring in practice. It will also focus state program officials at helping individuals in need, rather than spending time determining the etiology of an individual's brain injury.

#### *State Match for State Partnership Program Grant*

For a state to receive a federal grant, it must contribute funds, matching the federal outlay with a 50 percent contribution. Due to this 50 percent match requirement, many states have not been able to take advantage of these grants due to a lack of available state funding. A state match of some kind can ensure that the state is committed to the project and help leverage dollars even further, which is why we support some match requirement. However, the current match requirement level can serve as a barrier to states that do not have the resources to meet the significant 50 percent commitment. Unfortunately, these are often the states that need the funding the most. Additionally, many of ACL's other programs that serve people with disabilities have substantially lower match requirements. A reduced match will provide more equity to ACL's other programs, while still requiring the match to ensure that states are bought into the program and are committed to focus on brain injury.

#### *Support the TBI Programs at CDC, including the National Concussion Surveillance System*

As mentioned above, the CDC's TBI Program, including the National Concussion Surveillance System, plays a crucial role in assessing and reporting on the incidence and prevalence of TBIs across the country. Ongoing authorization of funding for this important legislation is vital for improved data collection, especially considering the underestimation of brain injury prevalence based solely on emergency department admissions.

#### *ACL Protection and Advocacy Program*

We suggest an increase in the authorization level of Protection and Advocacy TBI programs to \$6 million. We also support allowing Protection and Advocacy systems access to federal facilities such as federal prisons and Veterans Affairs facilities through 2029. Enhanced federal funding and access to federal systems for Protection and Advocacy will empower states to better serve individuals with TBI, ensuring increased independence and community participation.

#### **Conclusion**

The reauthorization of the TBI Act in 2024 is a pivotal opportunity to strengthen our nation's response to the significant prevalence and complex challenges associated with brain injury. We urge Congress to consider these proposed improvements, informed by consensus within the brain injury community, to ensure that every individual affected by a brain injury receives the care and support they need to live functional and independent lives.

We appreciate the Energy and Commerce Committee's consideration of this legislation and look forward to including improvements to the legislation through the markup process. Thank you for your attention and commitment to advancing the well-being of those living with brain injuries in the United States and their families.

The Honorable Bill Pascrell, Jr. Testimony before House Energy and Commerce  
Subcommittee on Health  
Legislative Proposals to Support Patients and Caregivers  
2123 Rayburn House Office Building  
February 14, 2024

Chair McMorris Rodgers, Ranking Member Pallone, Chair Guthrie and Ranking Member Eshoo, thank you for holding today's hearing and including my legislation, H.R. 7208, to reauthorize Traumatic Brain Injury programs.

First authorized in 1996, the TBI Act has been the major federal program to support the medical and societal needs of 5.3 million individuals living with lifelong disabilities due to TBI. In fact, 2.5 million Americans experience a brain injury annually. Since the bill's introduction, I have heard from stakeholders seeking important amendments to this measure and would like to suggest some proposed changes to the program in my testimony.

Over two decades ago, I co-founded the Congressional Traumatic Brain Injury Task Force. The issue of Traumatic Brain Injury (TBI) became a personal matter to me early in my first term when I met with one of my constituents, Mr. Dennis John Benigno. Dennis's 15-year-old son, Dennis John, was critically injured the summer of 1984 after being struck by a car. Dennis John suffered a severe brain injury that left him totally disabled. Before then, I had no intimate knowledge about TBI nor its terrible impact on families. This became the impetus behind my passion for championing the cause in the Congress.

The Benignos helped me to become acutely familiar with the issue of traumatic brain injury as their son was unable to communicate or care for himself. As the family struggled to find a cure for Dennis John, it became clear to them that there existed very little awareness and treatment for TBI. Dennis and his wife Rosalind chose to act in promoting TBI awareness. Dennis's courage, dedication, and love became my primary inspiration to try and make a difference in the fight for Americans living with TBI.

Thereafter, I began championing Dennis's cause by working with other external stakeholders along with my colleagues in Congress. Two important steps were taken in our effort to address this silent epidemic: First, in the 106th Congress, thanks to this committee we passed the Children's Health Act of 2000 [P.L. 106-310], which included important amendments to the Traumatic Brain Injury Act of 1996. This bill created a new education and awareness campaign run by the Centers for Disease Control and Prevention (CDC) and required the U.S. Department of Health and Human Services (HHS) to make grants to states to create TBI registries that aided in critically important data collection. Secondly, in 2001, I along with Congressman Jim Greenwood (PA-8) co-founded the Congressional Brain Injury Task Force. Today, I am proud to report that the Task Force has grown to nearly 70 bipartisan, bicameral Members working across the aisle on behalf of the 5.3 million Americans living with a permanent traumatic brain injury.

The primary mission of our Congressional TBI Task Force is to: (1) *increase awareness of the incidence and prevalence of brain injury in the United States*; (2) *explore research initiatives for rehabilitation and potential cures*; (3) *study and address the effects such injuries have on*

*families, children, education and the workforce*; and (4) *bring improved services to individuals with brain injury*. We held our first Task Force congressional briefing on June 27, 2001. Twenty-three years later, our Task Force serves to inform fellow Members of Congress and their staff about cutting-edge research, findings from recent studies on rehabilitation, and the challenges faced daily by those with brain injuries.

Regrettably, Dennis John passed away on January 29, 2024, after a 40-year battle with TBI. One of the best ways to thank him for his being the inspiration for our task force, and all the change and progress it was inspired, is memorialize his legacy in perpetuity by renaming H.R. 7208 to be the ***Dennis John Benigno Traumatic Brain Injury Reauthorization Act of 2024***.

My second priority as we negotiate H.R. 7208 in Committee is to ***Increase the Authorization Level for the TBI State Partnership Program from \$7.321 million to \$19 million for fiscal years 2025 to 2029***. Realizing that we are under the strict budget rules, the increase in authorization closely aligns with the brain injury community's annual appropriations requests to ensure that every state is funded at an adequate level. Presently, there are 31 states participating in the Administration for Community Living's (ACL) State Partnership program given the 50:50 matching requirement (see attached.) There are 19 states that do not participate.

We have learned that states participating in ACL's State Partnership grant had higher levels of community participation and life satisfaction on average for people with living with TBI. Conversely, the non-participating states cannot afford the state matching funding that is required to accompany federal dollars, resulting in poorer health outcomes for TBI patients<sup>1</sup>. ACL's State Partnership Program was created to aid survivors of a TBI with person-centered, culturally competent systems of services to support maximum independent living. This federal initiative helps states to access technical assistance for brain injury programs, allowing for ACL to integrate brain injury focus into their other programs. Other areas of focus include mental and behavioral health as well as those persons with a dual diagnosis, older adults, and independent living. I urge you to increase the authorization funding levels to \$19 million for fiscal years 2025 to 2029.

Third, the next priority for the 2024 Traumatic Brain Injury Reauthorization Act is to ***Designate Brain Injury as a Chronic Condition***. The reason for this request is to help standardize a medical definition that denotes the long-term effects of persons living with a brain injury. Currently, our U.S. health care system and the public often view brain injuries as a one-time event. However, this medical condition should be viewed as the beginning of a process of recurring and/or persistent effects that can lead to the development of recurring, persistent, and/or dynamic effects in a significant segment of brain injury survivors.

While many people who sustain a brain injury experience only temporary symptoms or neurological impairment, other people experience permanent changes and are impacted throughout their lives. This evidence-based update on how brain injury is perceived in the clinical community and the public at large will help further clarify what is occurring in practice with respect to the lifelong impact of TBI, as well as the chronic treatment of brain injury over the lifespan. As such, I am requesting that the Committee, through the mark-up process, amend language to address this issue as follows: *"In collaboration with the Director of the Centers for Disease Control and*



*Prevention (CDC), the Secretary shall examine the evidence base for designating brain injury as a chronic condition that can impact individuals with brain injury across the lifespan.”*

Fourth, I am requesting that the Committee prioritize **Clarifying Service Eligibility for the TBI Act**. Particularly, within the Brain Injury community, there are two types of injuries to note: **external force**, through a force that constitutes a traumatic brain injury, and **internal force**, through a loss of oxygen to the brain deemed as acquired (ABI). ABI is a classification of brain injury based on a non-traumatic event which includes, but is not limited to stroke, tumor, arteriovenous malformation, and aneurysm. In contrast, TBI is manifested by an external force resulting from the following events including, but not limited to car crashes, falls, and assaults.

The current definition of “*traumatic brain injury*” within the legislation is inclusive of both traumatic and nontraumatic/anoxic brain injury, which has caused confusion about the target of developing services. Due to the increases in brain injury from loss of oxygen to the brain (anoxic brain injury) from intimate partner violence, substance use disorder, and other causes, many state programs are serving systems that support both traumatic and non-traumatic brain injury. While the current definition does include both traumatic and nontraumatic/anoxic brain injury, this definition is more inclusive of all types of brain injury and is recognized and accepted by many of the major brain injury organizations. This update in language will clarify the current intent of the law and reflect what is occurring in practice.

Fifth, I am requesting that the Committee amend H.R. 7208 to **Continue to Authorize the CDC TBI Programs and National Concussion Surveillance System**. Specifically, our proposed recommendation would be to reauthorize the CDC TBI Programs, including the National Concussion Surveillance System (NCSS) through 2029 at the current authorization level of \$11.75 million annually with \$5 million allocated to the National Concussion Surveillance System. This would equal total funding of \$58.75 million over five years, which is the same as the current authorization level.

The justification for this increase is predicated upon CDC’s TBI Program, which is responsible for assessing and reporting on the incidence and prevalence of TBI in the United States. The 2018 TBI Reauthorization Act created a NCSS as part of the CDC to support better data collection on TBI, particularly concussions. Unfortunately, existing national data underestimate the prevalence of brain injury across the country. Most estimates are projected solely from data collected through emergency department admissions, which is not reflective of the many individuals who do not seek care for concussions, receive care outside of emergency departments, or those who are not reported from the emergency room.

Recently, the CDC conducted a pilot program to validate its methodology for better data collection of this condition. The pilot of the NCSS has indicated much higher levels of brain injury than are currently reported, with adult respondents reporting more than 30 times as many brain injuries in the past 12 months compared to estimates using emergency department data from national datasets. Children and adolescents reported approximately 17 times as many brain injuries in the past 12 months, as compared to estimates using emergency department visits from national datasets. The NCSS needs to be fully funded at \$5 million for CDC to continue its vitally important work in this area.

Lastly, on behalf of the Brain Injury community, I am requesting amended language for inclusion of the **ACL Protection and Advocacy Program**. Specifically, we are proposing an increase in the authorization level to \$6 million and to allow Protection and Advocacy access to federal facilities (e.g., VA Hospitals and federal prisons) through 2029. The TBI Act currently authorizes every state to have a Protection and Advocacy for Individuals with Traumatic Brain Injury program, funded at a minimum of \$50,000 per state. Effective Protection and Advocacy services for people with a TBI can lead to increased independence and community participation. This increased federal funding and access to federal facilities for Protection and Advocacy would create greater access for the states.

Thank you for your considering the TBI Act reauthorization. From vehicle accidents to youth sports to servicemembers wounded in combat, the causes of brain injuries are diverse and those suffering with the after affects need our attention and federal resources to combat this silent epidemic. I hope this committee will consider including the suggested policy changes we have been in collaboration with key stakeholders including the Brain Injury Association of American, the National Association of Head Injury Administrators and the United States Brain Injury Alliance. Thank you for your help advancing this important measure.

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<sup>i</sup> Corrigan, J.D., Vuolo, M., Bogner, J., Botticello, A.L., Pinto, S.M., & Whiteneck, G.G. (2021). Do state supports for persons with brain injury affect outcomes in the 5 years following acute rehabilitation? *ScienceDirect*, 72. Retrieved from <https://doi.org/10.1016/j.healthplace.2021.102674>



# Children's Hospital Association Statement for the Record

## U.S. House Committee on Energy and Commerce Hearing “Legislative Proposals to Support Patients and Caregivers” February 14, 2024

On behalf of the Children's Hospital Association (CHA), representing over 200 children's hospitals nationwide, we appreciate the opportunity to submit this statement for the record for today's Energy and Commerce Subcommittee on Health hearing titled “Legislative Proposals to Support Patients and Caregivers.”

We commend the Subcommittee for its dedication to addressing crucial issues impacting the well-being of our nation's children and families. CHA strongly supports the following four bills slated for discussion during the hearing:

- H.R. 6960 – Emergency Medical Services for Children (EMSC) Reauthorization Act:** We wholeheartedly endorse H.R. 6960, the Emergency Medical Services for Children (EMSC) Reauthorization Act. This critical legislation demonstrates a strong commitment to pediatric emergency care by authorizing essential funding of \$22.3 million through fiscal year 2024 and \$24.3 million annually from 2025 through 2029. We all understand that children are not little adults and need specialized care, especially in emergency situations, such as child-appropriate equipment in ambulances and emergency departments. This funding is instrumental in guaranteeing that the EMSC program continues to work with states to expand and improve emergency medical services for children so they have pediatric-focused and pediatric-appropriate care no matter where they live. By providing financial support to this critical program, the bill ensures that pediatric patients, irrespective of their location, receive prompt and effective emergency medical attention, addressing the unique needs and vulnerabilities of our nation's youngest and most fragile population. This investment is pivotal for sustaining and enhancing emergency medical services dedicated to children, ultimately contributing to improved health outcomes and the overall well-being of our pediatric communities, including those served by children's hospitals across the country. Thank you, Reps. Carter, Castor, Joyce, and Schrier for introducing this vital legislation for kids.
- H.R. 5012 – SHINE for Autumn Act:** We wholeheartedly support H.R. 5012, the SHINE for Autumn Act, sponsored by Reps. Kim, Castor, Joyce, and Kelly. This legislation seeks to authorize \$5 million annually for fiscal years 2024-2028, providing grants to states for the enhancement of stillbirth data collection and reporting. This initiative is crucial for understanding the root causes of stillbirths and developing prevention strategies through comprehensive risk factor analysis, particularly benefiting children and families served by our nation's children's hospitals.
- H.R. 7153 – Dr. Lorna Breen Health Care Provider Protection Reauthorization Act:** CHA strongly supports H.R. 7153, the Dr. Lorna Breen Health Care Provider Protection Reauthorization Act, sponsored by Reps. Wild, Kiggans, Carter, and Dingell. The Dr. Lorna Breen Health Care Provider Protection program is a first-of-its-kind program to bolster the mental health and well-being of our nation's health care

workforce. It provides crucial grants to health care organizations to enable the delivery of essential behavioral health services to reduce burnout amongst front-line health care providers. The program also supports a national campaign supporting hospital leaders in promoting worker well-being and provides grants for employee education and peer-support. Reauthorization of this program is paramount for fostering a resilient health care workforce and underscores a commitment to the mental health and well-being of those at the forefront of health care delivery and a sustainable and robust health care workforce that positively impacts the quality of care provided to children and families served by our nation's children's hospitals.

4. **H.R. 7300 – Family-to-Family Reauthorization Act:** CHA stands in firm support of the reauthorization of the Family-to-Family Health Information Centers (F2F HICs) program through HR 7300. These family-led and staffed centers play a vital role in providing essential guidance and support to families of children with special health care needs navigating the health care system and critical supports. By extending funding for an additional five years, this bill ensures families can access critical information about health care resources, treatments, and services for their children facing health care challenges. We appreciate Reps. Sherrill and De La Cruz for introducing H.R. 7300.

These bills collectively address critical gaps in pediatric health care and demonstrate a commitment to improving the overall well-being of children across the nation. We are confident that the subcommittee's consideration of these legislative proposals will lead to positive outcomes for pediatric patients and their families.

We are also grateful you are taking up the Dr. Lorna Breen program reauthorization and encourage you to look at additional ways to support the mental and physical health and safety of health care providers.

Thank you for your continued bipartisan efforts in championing policies that directly influence the health and well-being of our nation's children and the health care workforce. CHA is enthusiastic about the prospect of collaborating with the subcommittee and other stakeholders to advance legislation that prioritizes child health, ensuring access to quality care, promoting healthy development, and fostering an environment conducive to the overall happiness and prosperity of our youngest citizens. Together, we can actively contribute to shaping a brighter and healthier future for the children and families across our nation.



February 13, 2023

The Honorable Cathy McMorris Rodgers  
Chair  
Energy and Commerce Committee  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Brett Guthrie  
Chair  
Energy and Commerce Health Subcommittee  
U.S. House of Representatives  
Washington, DC 20515

Dear Chairs Rodgers and Guthrie:

On behalf of the American College of Physicians (ACP), I would like to express our strong support for the Dr. Lorna Breen Health Care Provider Protection Act (H.R. 7153). This bill would reauthorize essential programs to further prevent and reduce incidences of suicide, mental health conditions, substance use disorders, and long-term stress, sometimes referred to as burnout amongst the physician workforce. We appreciate your recognition of the need to strengthen services to address the mental health needs of our nation's physicians and fight the stigma around seeking necessary treatment and support. Thank you for convening a legislative hearing on February 14<sup>th</sup> in the subcommittee entitled "Legislative Proposals to Support Patients and Caregivers," which includes consideration of this important legislation. ACP requests that this letter be inserted into the official hearing record.

ACP is the largest medical specialty organization and the second largest physician membership society in the United States. ACP members include 161,000 internal medicine physicians, related subspecialists, and medical students. Internal medicine physicians are specialists who apply scientific knowledge, clinical expertise, and compassion to the preventive, diagnostic, and therapeutic care of adults across the spectrum from health to complex illness.

Since the Dr. Lorna Breen Health Care Provider Protection Act became law in 2022, access to mental and behavioral health support and treatment has improved for physicians across the country. The College supports H.R.7153, which would build on the progress the law made by further strengthening critical programs to prevent burnout and improve access to resources for mental and behavioral health services – key factors to help address the current physician workforce shortage.

In a 2021 [physician survey](#) conducted by the American Medical Association, almost 63 percent of physicians reported symptoms of burnout. This number is up from 38 percent in 2020. America's physicians are at a critical breaking point that must be urgently addressed. The 2024 Medscape Physician Burnout & Depression Report showed that [53 percent](#) of physicians who reported feeling burned out and/or depressed have not and will not seek professional help. Many physicians reported barriers such as stigma and the professional risks associated with disclosing their treatment activities to the medical board as factors for not seeking help. This is very alarming given that avoidance of treatment could lead to worsening depression and even suicide. In fact, physicians in the United States face higher incidents of suicide than almost any other profession.



The College endorses this legislation, which would ensure that physicians across the country will continue to have access to education and training on effective strategies to prevent stress and burnout before the need becomes dire. This reauthorization bill would prioritize grant funding for communities with a shortage of health care workers, rural communities, and those experiencing burnout due to administrative burdens. Further the bill would reauthorize and expand the scope of a national education and awareness campaign that would provide hospital and health system leaders with evidence-based solutions to reduce health care worker burnout.

ACP strongly supports the Dr. Lorna Breen Health Care Provider Protection Act (H.R. 7153), and we thank you for your leadership in bringing this important legislation before the subcommittee. If you have any questions, please contact Vy Oxman, Senior Associate of Legislative Affairs, at 202-261-4515 or via email at [voxman@acponline.org](mailto:voxman@acponline.org).



February 13, 2024

The Honorable Brett Guthrie, Chair  
The Honorable Anna Eshoo, Ranking Member  
Committee on Energy and Commerce  
Subcommittee on Health  
United States House of Representatives  
2125 Rayburn House Office Building  
Washington, DC 20515

RE: Energy & Commerce Health Subcommittee Legislative Hearing, “Legislative Proposals to Support Patients and Caregivers.”

Dear Chairman Guthrie and Ranking Member Eshoo:

I am writing to share the American Speech-Language-Hearing Association’s strong support for H.R. 7153, the Dr. Lorna Breen Health Care Provider Protection Reauthorization Act, which would reauthorize grants to establish, enhance, or expand evidence-informed programs or protocols to promote the mental health of health care providers.

The American Speech-Language-Hearing Association (ASHA) is the national professional, scientific, and credentialing association for 228,000 members and affiliates who are audiologists; speech-language pathologists (SLPs); speech, language, and hearing scientists; audiology and speech-language pathology assistants; and students.

Audiologists and SLPs work tirelessly to meet the needs of their patients, while navigating the numerous personal and professional stressors health care providers experience—which were further worsened by the COVID-19 pandemic. Many ASHA members feel overwhelmed and burned out from excessive caseloads, mountains of paperwork, inadequate reimbursement, and unrealistic productivity standards. Due to these challenges, maintaining a healthy work-life balance is difficult, and many health care providers don’t know where to turn for help, or can’t find it when they try.

ASHA believes H.R. 7153 will help address the profound impact of these challenges on providers’ mental health by reauthorizing grant funding—distributed by the Health Resources and Services Administration to hospitals, clinics, and medical professional associations—to improve awareness of risk factors for mental health crises, establish evidence-based programs for preventing suicide, and enhance peer-support programs.

Every health care provider, including audiologists and SLPs, should have access to the mental health care services they need and deserve, without fear of losing their license, potential loss of income, or other adverse repercussions. We appreciate your continued commitment to improving the mental health of the health care workforce and ensuring that patients have the highest quality care and support.

Thank you for considering ASHA's support of H.R. 7153. If you or your staff have any questions or would like additional information, please contact Josh Krantz, ASHA's director of federal affairs, health care, at [jkrantz@asha.org](mailto:jkrantz@asha.org).

Sincerely,

A handwritten signature in black ink, appearing to read "Tena L. McNamara". The signature is fluid and cursive, with the first name "Tena" being more prominent and the last name "McNamara" following in a similar style.

Tena L. McNamara, AuD, CCC-A/SLP  
2024 ASHA President





Make today a breakthrough.

February 13, 2024

The Honorable Brett Guthrie  
Chairman, Health Subcommittee  
Energy and Commerce Committee  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Anna Eshoo  
Ranking Member, Health Subcommittee  
Energy and Commerce Committee  
U.S. House of Representatives  
Washington, DC 20515

Dear Chairman Guthrie and Ranking Member Eshoo,

In advance of your hearing to examine ways to support patients and caregivers, **Cure SMA is pleased to preview findings from an upcoming national report on the caregiving needs of children and adults with spinal muscular atrophy (SMA).** We hope this information will help inform your hearing and future legislation to address the caregiving crisis faced by families impacted by SMA and other disabilities across the country.

SMA is a rare degenerative neuromuscular disease that robs individuals of their physical strength, greatly impacting their ability to walk, sit without support, transfer independently, and perform other essential functions of everyday life. Cure SMA is the national organization that represents individuals with SMA and their families in your districts and across the country. **On Friday, National Caregivers Day, Cure SMA will release a [national report](#) that chronicles the caregiving needs and challenges of people with SMA,** many of whom require in-home caregivers, whether a paid personal care attendant (PCA) or family caregiver, to assist in their daily lives. *"I rely on caregivers for all of my activities of daily living, including bathing, transfers, grooming, cooking, dressing, transportation, and bathroom breaks,"* said **an adult with SMA.**

Individuals with SMA who require in-home support reported needing 100+ caregiving hours a week, on average, to assist with their activities of daily living. Most individuals with SMA depend on 1-3 caregivers for this essential caregiving assistance, of which half are paid through Medicaid or other sources and half are uncompensated family caregivers. *"I receive 42 hours a week of caregiving hours through the state, which is not nearly enough for what I need. It's why I still live at home with my parents, who assist me during hours when I don't have paid caregiving,"* said **an adult man with SMA.** Another **adult with SMA** said, *"I only get about 6 hours per day of paid caregiving, which essentially covers a morning caregiver to come and shower me and get me into my wheelchair so I can go to work and then one to come at night to put me into bed. The lack of hours means I am without paid support during the day for toileting and eating."*

According to Cure SMA's upcoming caregiving report, **79 percent of individuals with SMA relied on at least one unpaid family caregiver,** which can include parents, grandparents, partners, siblings, and other relatives. Some family caregivers play a primary role in their loved one's lives, providing daily and weekend help with everything from transferring in and out of bed and wheelchairs to assistance with dressing, grooming, meal preparation, and bathroom support. *"I couldn't do it without the help I get from my spouse,"* said a **married adult with SMA.** Other family caregivers serve as backup for hours uncovered by other caregivers or when the paid caregiver is unavailable. *"Because of the worker shortage, my parents often have to cover when my caregiver calls in sick or during planned days off,"* said **an adult with SMA.**



**Cure SMA is pleased that the Health Subcommittee will examine the important role and needs of family caregivers.** Many individuals with SMA worry about what will happen to them if their family caregiver becomes unavailable due to health, injury, or other reasons. For many adults with SMA, the challenge is even greater given the age of their family caregivers. *My parents are getting older and the physical and mental aspects of caregiving is getting more challenging for them,*” said an **adult woman with SMA**. Another **adult with SMA** said, *“My mother helps me when I don’t have a PCA, but I worry about the toll it takes on her health given she is in her 60s.”*

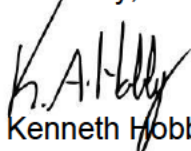
Several studies have chronicled the detrimental health effects of family caregiving, which can include stress, depression, physical ailments, poor diets, and missing their own healthcare appointments.<sup>i</sup> Family caregivers of individuals with SMA provide, on average, about 45 hours per week in unpaid caregiving services, according to Cure SMA’s *Understanding the Caregiver Experience* report, which is significantly higher than the 23.7 hours per week of all caregivers.<sup>ii</sup> Respite is one strategy to help provide temporary relief to family caregivers. However, many family caregivers are unaware of or unable to access respite care in their state.<sup>iii</sup> **Cure SMA supports the Lifespan Respite Care Program, which provides funding to states to help improve and expand the availability of respite care services for their residents.** Cure SMA supports the reauthorization and expansion of this critical program so that all family caregivers, including those who support individuals with SMA, can access these services.


We appreciate the focus on respite care at this hearing. However, the caregiving needs and challenges of the SMA community are greater and more chronic. As highlighted in our upcoming report, individuals with SMA and their families face many caregiving challenges, including:

- lack of clear information about caregiving options available in the state,
- eligibility requirements that are restrictive, penalize savings, and limit work,
- state caregiving hours do not meet actual caregiving needs,
- difficulty in recruiting and retaining direct care workers, and
- concern over the health, age, and availability of backup family caregivers.

Cure SMA encourages the Health Subcommittee to continue its important work to examine and address the challenges that are causing the caregiving crisis in this country. Cure SMA welcomes the opportunity to meet with your staff to share our report and its findings, which we hope will help inform your work in addressing the direct care workforce shortage and other caregiving challenges. Your staff can reach out to Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at [maynard.friesz@curesma.org](mailto:maynard.friesz@curesma.org) or 202-871-8004, for the report or for any questions.

Sincerely,

  
Kenneth Hobby  
President  
Cure SMA

  
Maynard Friesz  
Vice President of Policy & Advocacy  
Cure SMA

Cc: Members of the U.S. House Energy and Commerce Health Subcommittee



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<sup>i</sup> Physical and Mental Health Effects of Family Caregiving, NIH, 2009, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2791523/>

<sup>ii</sup> Caregiving in the U.S., AARP, 2020, <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>

<sup>iii</sup> Economic consequences and lack of respite care, 1999, <https://pubmed.ncbi.nlm.nih.gov/10672749/>



## Oncology Nursing Society

125 Enterprise Drive • Pittsburgh, PA 15275-1214  
Toll Free: 866-257-4ONS • Phone: 412-859-6100 • Fax: 412-859-6165  
[help.ons.org](http://help.ons.org) • [www.ons.org](http://www.ons.org)

February 14, 2024

The Honorable Brett Guthrie  
Chairman  
Energy & Commerce Health Subcommittee  
2434 Rayburn House Office Building  
Washington, D.C. 20515

The Honorable Anna Eshoo  
Ranking Member  
Energy & Commerce Health Subcommittee  
272 Cannon House Office Building  
Washington, D.C. 20515

**RE: H.R. 3916, *Screening for Communities to Receive Early and Equitable Needed Services (SCREENS) for Cancer Act***

Dear Chairman Guthrie and Ranking Member Eshoo:

Oncology nurses are privileged to support people with cancer through the entire cancer experience, from diagnosis and treatment into survivorship or as they face their end-of-life journey. The mission of the Oncology Nursing Society is to lead the transformation of cancer care and promote excellence in oncology nursing and quality cancer care. As such, we write to thank you for including H.R. 3916, the *SCREENS for Cancer Act*, in the upcoming hearing hosted by the House Energy & Commerce Health Subcommittee. As you are aware, this critical legislation would reauthorize the lifesaving National Breast and Cervical Cancer Early Detection Program (NBCCEDP) through 2028.

An estimated 300,590 people in the United States will be diagnosed with breast cancer and nearly 44,000 will die from the disease in 2023 alone. An additional 11,500 new cases of cervical cancer are diagnosed each year across the nation, and approximately 4,000 women will die of this cancer. For more than 30 years, the NBCCEDP has provided timely access to breast and cervical cancer screening and diagnostic services for women who have low incomes and are uninsured and underserved. Oncology nurses are the health professionals involved in the administration and monitoring of chemotherapy and managing the associated side effects cancer patients may experience. Every day, we see the pain and suffering caused by cancer and understand the physical, emotional, and financial challenges that people with cancer and their families face throughout their diagnosis and treatment.

ONS and its members stand ready to work with you and your staff to reduce and prevent suffering from cancer. We would be happy to discuss ways in which ONS may be of assistance in advancing this proposal and would encourage you to contact Jaimie Vickery, ONS' Director of Government Affairs and Advocacy, at [jvickery@ons.org](mailto:jvickery@ons.org). We look forward to engaging in an ongoing dialogue to address issues of importance to our cancer patients and ways in which we can promote public health.

Sincerely,  
The Oncology Nursing Society

February 13, 2024

The Honorable Cathy McMorris Rodgers  
Chair  
Energy & Commerce Committee  
Washington, DC 20515

The Honorable Frank Pallone  
Ranking Member  
Energy & Commerce Committee  
Washington, DC 20515

The Honorable Brett Guthrie  
Chair  
Energy & Commerce Health Subcommittee  
Washington, DC 20515

The Honorable Anna Eshoo  
Ranking Member  
Energy & Commerce Committee Health Subcommittee  
Washington, DC 20515

Dear Chair McMorris Rodgers, Ranking Member Pallone, Chair Guthrie, and Ranking Member Eshoo,

As 300 organizations committed to improving maternal and child health, we are writing to express our sincere gratitude for the inclusion of the bipartisan and bicameral Stillbirth Health Improvement and Education (SHINE) for Autumn Act (H.R. 5012/S. 2647) in the upcoming Energy and Commerce Health Subcommittee hearing on “Legislative Proposals to Support Patients and Caregivers”. Reintroduced by Congresswoman Young Kim (R-CA), Congresswoman Kathy Castor (D-FL), Congressman David P. Joyce (R-OH), and Congresswoman Robin Kelly (D-IL); there are currently [71 bipartisan cosponsors](#).

Stillbirth is a public health crisis, with more than 21,000 stillbirths every year in the United States. Many of these deaths are preventable, and are happening in otherwise healthy, low-risk pregnancies. While stillbirth is a risk for all pregnancies, there are persistent and longstanding racial and ethnic disparities. Women who experience a stillbirth are also more likely to die after delivery and severe morbidity is nearly five times more common than in women whose babies are born alive. Despite these numbers, stillbirth has not been afforded the same attention as other critical areas of public health.

The SHINE for Autumn Act aims to lower the staggering rate of stillbirth by taking critical steps to invest in research, training for perinatal pathologists, education and awareness, and improved data collection required to better understand stillbirth so that we can begin to identify strategies for prevention. With the bill’s provisions for increased awareness and education, improved data collection, and more research, the U.S. can begin to seek effective long-term solutions for stillbirth prevention. Without progress in these areas, the U.S. will remain greatly limited in its understanding of stillbirth causes, and what we can do to combat this crisis.

As you know, during the 117<sup>th</sup> Congress the SHINE for Autumn Act (H.R. 5487) passed the House of Representatives, under suspension with overwhelming support (408-18), highlighting the urgency and bipartisan nature of this issue. Now more than ever, we owe it to the families of this great nation to work harder to protect them. Passage of the comprehensive SHINE for Autumn Act is a critical step forward in this noncontroversial, life-saving work. We sincerely hope that 2024 is the year the SHINE for Autumn Act finally becomes law.

We appreciate your attention to this critical issue by including this comprehensive, lifesaving bill in the upcoming Subcommittee on Health hearing. Thank you for your time and consideration.

Sincerely,

1st Breath  
2 Degrees Foundation  
4th Trimester Arizona  
A Better Balance  
Aaliyah in Action  
ACOG Vermont  
Adalyn Rose Foundation  
Advocates for Children of New Jersey  
AFE (Amniotic Fluid Embolism) Foundation  
Alana Rose Foundation  
Albuquerque Area Indian Health Board, Inc.  
American Academy of Pediatrics  
American Academy of Pediatrics - Vermont Chapter  
American College of Nurse-Midwives  
American College of Obstetricians and Gynecologists (ACOG)  
American College of Osteopathic Obstetricians and Gynecologists  
American Society for Clinical Pathologists  
Angels Born Still  
Ashlie's Embrace  
Association of Maternal & Child Health Programs (AMCHP)  
Association of Perinatal Networks (APN)  
Association of Schools & Programs of Public Health  
Association of Women's Health, Obstetric, and Neonatal Nurses (AWHONN)  
ATIME  
AWHONN NY  
Babies Remembered  
Baby Loss Family Advisors  
Barrett's Bears Ministry  
Bay State Birth Coalition  
Bereaved Parents of Madison, Inc.  
Birth Equity & Justice Massachusetts (BEJMA)  
Birth In Color RVA  
Birthmark Doula Collective  
BirthNet  
BirthWell Partners Community Doula Project  
Buffalo Prenatal Perinatal Network, Inc.  
Building Bright Futures  
Centering Healthcare Institute  
Central Jersey Family Health Consortium  
Children's Bereavement Center of South Texas  
Coalition of Oklahoma Breastfeeding Advocates (COBA)  
Community Care Network of Kansas  
Community Health Council of Wyandotte County  
Conscious Moms  
COPE  
Cradling Memories - The Milo James Coe Foundation  
Cribs for Kids, Inc.  
Denver Share

Doula Trainings International, LLC  
Dr Shalon Maternal Action Project  
Durham's Maternal Stress Free Zone DH Inc.  
Early Childhood Alliance  
Emalyn's Angels  
Empty Arms Bereavement Support  
Empty Arms Vermont  
Every Baby Guilford  
Every Breath Coalition  
Every Mother Counts  
Expecting Health  
Families Forward Resource Center  
Families of Color Seattle  
Families USA  
First Candle  
First Step Family Support Center  
First Year Cleveland  
Foundation for a Healthy Kentucky  
GAPPS (Global Alliance to Prevent Prematurity and Stillbirth)  
Granny's Birth Initiative  
GriefHaven  
Griffin Cares Foundation  
Groundwork Ohio  
Group B Strep International  
GROW Prenatal & Family Center  
Healing Our Hearts Foundation  
Health Action New Mexico  
Healthier Moms and Babies Inc.  
Healthy Birth Day, Inc.  
Healthy Black Pregnancies  
Healthy Mothers, Healthy Babies - The Montana Coalition  
Healthy Mothers, Healthy Babies Coalition of Georgia  
Healthy Start Coalition of Hardee, Highlands and Polk Counties, Inc.  
Held Your Whole Life  
HER (Hyperemesis Education and Research) Foundation  
I Was Supposed To Have A Baby  
I Will Carry You: Birth & Bereavement Doula Services  
In The Arms of Jesus Remembrance Photography and Grief Support  
Infant Loss Resources  
Jace's Journey  
Jamir's Heart  
Julianna Grace Ministry  
JustActions  
Kansas Academy of Family Physicians  
Kansas Action for Children  
Kansas Birth Equity Network  
Kansas Birth Justice Society  
Kansas Breastfeeding Coalition

Kansas Infant Death and SIDS (KIDS) Network, Inc.  
Kansas Section of American College of Obstetricians and Gynecologists (ACOG)  
Kentucky Primary Care Association  
Kindred Beginnings  
Krista Gervon Doula Care  
Liam Lives Foundation Inc.  
Lifeline for Families Center and Lifeline for Moms Program at UMASS Chan Medical School  
Little Love Foundation Project  
Louisiana Public Health Institute  
Loved by Lincoln  
Loving Tanner  
M.A.M.A. Mom's Advocate & Maternal Advisor, LLC.  
M.E.N.D. - Chicagoland Chapter  
M.E.N.D. - Columbus Chapter  
M.E.N.D. - Dallas-Fort Worth Chapter  
M.E.N.D. - East Valley Area Chapter  
M.E.N.D. - Greater Houston Chapter  
M.E.N.D. - Mid-Michigan Chapter  
M.E.N.D. - Northwest Washington Chapter  
M.E.N.D. - Southwest Missouri Chapter  
M.E.N.D. - Tulsa Chapter  
M.E.N.D. (Mommies Enduring Neonatal Death)  
Maddie's Footprints  
Maine Children's Alliance  
Maine Mother + Company  
Maine Public Health Association  
March for Moms  
March of Dimes  
Mass. PPD Fund  
Maternal and Family Health Services  
Maternal Mental Health Leadership Alliance  
Maternity Care Coalition  
Mattie's Memory Inc.  
Measure the Placenta  
Melanin Mass Moms  
Melinated Moms  
Mera's Mission  
Middlesex Regional Black Nurses  
Midwives Alliance of Hawaii  
Mikayla's Grace  
Minnesota Center for Stillbirth and Infant Death  
MISS Foundation  
Missing Pieces Support Group  
Mom Congress  
MomsRising  
Mother IS Supreme, Inc.  
Mothers & Babies Perinatal Network of South Central New York, Inc.  
National Association of Nurse Practitioners in Women's Health



National Association of Pediatric Nurse Practitioners  
National Birth Equity Collaborative  
National Blood Clot Alliance  
National CMV Foundation  
National Council of Jewish Women  
National League for Nursing  
National Perinatal Association  
NCJW, Jersey Hills Section  
NechamaComfort  
Neighborhood Birth Center  
New Brunswick Area NAACP  
New Futures  
New Jersey Health Care Quality Institute  
New Mexico Doula Association  
New Mexico Voices for Children  
New York State Perinatal Association  
Now I Lay Me Down to Sleep  
Nurture KC  
Oklahoma Institute for Child Advocacy  
Oklahoma Midwives Alliance  
Oklahoma Mothers' Milk Bank  
Open Arms Perinatal Services  
Parent Trust for Washington Children  
Parents as Teachers National Center  
Partnership for Maternal and Child Health of Northern New Jersey  
Patient Safety Movement Foundation  
Pennsylvania Partnerships for Children  
Perinatal Health Equity Initiative  
Perinatal Support Washington  
Policy Center for Maternal Mental Health (formerly 2020 Mom)  
Postpartum Resource Center of New York  
Postpartum Support International  
Postpartum Support International-Utah  
PPROM Foundation  
Preeclampsia Foundation  
Propa City Community Outreach  
Providing Mothers Joy Inc.  
Public Health Solutions  
PUSH for Empowered Pregnancy  
Quietly United in Loss Together  
R Baby Foundation  
REACH CNY, Inc.  
Remembering Rowan  
Reproductive and Placental Research Unit, Yale University  
Return To Zero: HOPE  
Rising Hope Counseling and Wellness  
Ryker's Rainbow  
Sankofa Reproductive Health and Healing Center

Saul's Light  
Seleni Institute  
Shades of Blue Project  
Shafia Monroe Consulting/Birthing CHANGE  
Share of Idaho  
Share Parents of Utah  
Share Pregnancy & Infant Loss Support, Inc.  
Share Support Group of Colorado Springs  
Society for Maternal-Fetal Medicine (SMFM)  
Society for Pediatric Pathology  
Society for Reproductive Investigation  
Southern New Jersey Perinatal Cooperative  
Speaking of Birth  
St. George Share  
Star Legacy Foundation  
Star Legacy Foundation - Chicago Chapter  
Star Legacy Foundation - Idaho (Statewide Chapter)  
Star Legacy Foundation - Kansas City Chapter  
Star Legacy Foundation - Maine (Statewide Chapter)  
Star Legacy Foundation - Maryland (Statewide Chapter)  
Star Legacy Foundation - Minnesota (Statewide Chapter)  
Star Legacy Foundation - Montana (Statewide Chapter)  
Star Legacy Foundation - Nebraska (Statewide Chapter)  
Star Legacy Foundation - New York Metro Chapter  
Star Legacy Foundation - Orlando Chapter  
Star Legacy Foundation - San Antonio Chapter  
Star Legacy Foundation - San Diego Chapter  
Star Legacy Foundation - San Francisco Bay Area Chapter  
Star Legacy Foundation - Sandhills Chapter  
Star Legacy Foundation - South Florida Chapter  
Star Legacy Foundation - Triangle Area Chapter  
Star Legacy Foundation - West Michigan Chapter  
Star Legacy Foundation - Western New York Chapter  
Star Legacy Foundation - Western Washington Chapter  
Start Healing Together  
Step By Step Family Support Center  
Stillbirth Advocacy Working Group (International Stillbirth Alliance)  
SUDC Foundation  
Support Group For Mothers  
Sweet Grace Ministries  
The Butterfly Suite  
The Center for Black Maternal Health and Reproductive Justice  
The Compassionate Friends Honolulu Chapter  
The EMA Project  
The Finley Project  
The Healing Place  
The Iris Fund  
The Little Timmy Project

The Marigold Foundation  
The Massachusetts Center for Unexpected Infant & Child Death  
The New Orleans Maternal & Child Health Coalition  
The Orsini Way  
The Shane Foundation  
The Skylar Project  
The Slade Thomas Foundation  
The Still Remembered Project  
The Tara Hansen Foundation  
The Tatia Oden French Memorial Foundation  
The TEARS Foundation  
The TEARS Foundation - Alabama (Statewide Chapter)  
The TEARS Foundation - Alaska (Statewide Chapter)  
The TEARS Foundation - Arizona (Statewide Chapter)  
The TEARS Foundation - Central California  
The TEARS Foundation - Central Texas  
The TEARS Foundation - Colorado (Statewide Chapter)  
The TEARS Foundation - Delaware (Statewide Chapter)  
The TEARS Foundation - District of Columbia Chapter  
The TEARS Foundation - Florida (Statewide Chapter)  
The TEARS Foundation - Georgia (Statewide Chapter)  
The TEARS Foundation - Hill Country  
The TEARS Foundation - Idaho (Statewide Chapter)  
The TEARS Foundation - Illinois (Statewide Chapter)  
The TEARS Foundation - Indiana (Statewide Chapter)  
The TEARS Foundation - Maryland (Statewide Chapter)  
The TEARS Foundation - Massachusetts (Statewide Chapter)  
The TEARS Foundation - Michigan (Statewide Chapter)  
The TEARS Foundation - New Hampshire (Statewide Chapter)  
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The TEARS Foundation - Washington (Statewide Chapter)  
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The University of Vermont Health Network  
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Wisconsin Center for Stillbirth and Infant Death  
Wisconsin Doula Association  
Wisconsin Grief Collective  
Wisconsin Guild of Midwives  
Worcester Healthy Baby Collaborative  
Zeal of Xander, Inc.

CC:  
Members of Energy & Commerce Committee  
The Honorable Young Kim  
The Honorable David P. Joyce



February 14, 2023

The Honorable Kat Cammack  
2421 Rayburn House Office Building  
Washington, DC 20515

The Honorable Debbie Dingell  
102 Cannon House Office Building  
Washington, DC 20515

**RE: NDSS letter of support for the Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 2706/S. 1183)**

Dear Congresswoman Cammack and Congresswoman Dingell:

The National Down Syndrome Society (NDSS) empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions. We write today in strong support of the *Charlotte Woodward Organ Transplant Discrimination Prevention Act* (H.R. 2706/S. 1183). This legislation is named for Charlotte Woodward, NDSS education programs associate and an adult woman with Down syndrome who received a heart transplant in 2012. For more than a decade, she has advocated tirelessly to ensure others with disabilities have the same access to organ transplants.

Despite existing civil rights protections, individuals with disabilities continue to face both willful and unintended discrimination in organ transplantation that threatens their ability to access health care when they need it most. A 2019 report from the National Council on Disability (NCD), an independent federal agency that advises Congress and the executive branch on disability policy issues, found that people with disabilities, especially intellectual disabilities, have been denied access to organs because of subjective judgements about the value of a life with a disability, assumptions about their quality of life, and misconceptions about their ability to comply with post-operative care. Furthermore, the report found that some organ transplant programs have policies that exclude people with disabilities as candidates for a transplant – some with categorical exclusions based on disability, refusing to even evaluate a person’s medical suitability for an organ transplant because of their disability.<sup>1</sup>

The Charlotte Woodward Organ Transplant Discrimination Prevention Act upholds, clarifies, and builds upon rights established in the Americans with Disabilities Act of 1990, Sec. 504 of the Rehab Act, and Sec. 1557 of the Affordable Care Act to prohibit covered entities from determining that an individual is ineligible to receive a transplant, deny an organ transplant or related service, refuse to refer the individual to an organ transplant center, refuse to place an individual on a waiting list or decline insurance coverage for a transplant or related service based solely on the fact that the individual has a disability. This crucial bill also recognizes the importance of auxiliary aids and services, the ability of an individual’s support network to help with post-operative care, and the need for reasonable modifications to policies and procedures to make organ transplant systems and facilities more accessible to people with disabilities. At the same time, the bill respects the professional judgment of health care providers by clarifying how disability should properly be considered in an individualized treatment plan. Finally, this bill provides access to expedited review through the Office of Civil Rights at the Department of Health and Human Services to ensure that there is timely relief for those who have been discriminated against.

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<sup>1</sup> National Council on Disability. (2019). *Organ Transplant Discrimination Against People with Disabilities*. [https://ncd.gov/sites/default/files/NCD\\_Organ\\_Transplant\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf)



To date, 40 states have passed state-level legislation prohibiting discrimination based solely on disability in the organ transplant system; however, this patchwork system of protections leaves those in states without legislation vulnerable to discrimination and denial of lifesaving care. Federal action is needed to ensure that individuals with disabilities have access to an organ transplant system free from discrimination.

We urge Congress to support the Charlotte Woodward Organ Transplant Discrimination Prevention Act and we thank you for your leadership regarding this important piece of legislation.

Sincerely,

A handwritten signature in black ink that reads "Kandi Pickard". The signature is fluid and cursive, with a large, looping "O" at the end.

Kandi Pickard  
President and CEO  
National Down Syndrome Society

**The following national organizations have endorsed the Charlotte Woodward Organ Transplant Discrimination Prevention Act:**

American Academy of Developmental Medicine & Dentistry (AADMD)  
American Association of People with Disabilities (AAPD)  
Association of Organ Procurement Organizations (AOPO)  
Autism Society  
Autism Speaks  
Communication First  
Conquering CHD  
Disability Rights Education and Defense Fund (DREDF)  
Down Syndrome Affiliates in Action  
Family Voices  
GiGi's Playhouse Down Syndrome Achievement Centers (GiGi's)  
Global Down Syndrome Foundation (GLOBAL)  
Global Liver Institute (GLI)  
LuMind IDSC Foundation  
National Association of Councils on Developmental Disabilities (NACDD)  
National Down Syndrome Congress (NDSC)  
National Fragile X Foundation  
Northwest Kidney Kids  
The Arc of the US  
Transplant Families  
United Network for Organ Sharing (UNOS)

February 14, 2024

The Honorable Brett Guthrie  
Chair  
Committee on Energy and Commerce  
Subcommittee on Health  
2434 Rayburn House Office Building  
Washington, DC 20515

The Honorable Anna Eshoo  
Ranking Member  
Committee on Energy and Commerce  
Subcommittee on Health  
272 Cannon House Office Building  
Washington, DC 20515

Dear Chairman Guthrie and Ranking Member Eshoo,

On behalf of the American College of Emergency Physicians (ACEP) and our nearly 40,000 members, thank you for holding today's legislative hearing to consider a wide variety of legislative efforts to support patients and caregivers. In particular, ACEP thanks you for including the "Dr. Lorna Breen Health Care Provider Protection Act" (H.R. 7153) on today's agenda, and we offer our deep appreciation for Representatives Susan Wild (D-PA), Jennifer Kiggans (R-VA), Debbie Dingell (D-MI), and Buddy Carter (R-GA) for their leadership on this critical and bipartisan effort. We are also grateful for the inclusion of the "Emergency Medical Services for Children Reauthorization Act" (H.R. 6960), as well as legislation to reauthorize poison control programs, both of which are vital components of our health care safety net.

As you know, H.R. 7153 is named in honor of emergency physician and longtime ACEP member Lorna Breen, MD, FACEP, who died by suicide in April 2020 after treating COVID-19 patients and contracting the virus herself. Dr. Breen was the chair of the Department of Emergency Medicine at the New York Presbyterian Allen Hospital. She had been an ACEP member for 15 years and served on our Emergency Medicine Practice Committee where she spearheaded the development of a Point of Care tool for patients with Autism Spectrum Disorder. Dr. Breen was also active in her state chapter and served on the New York ACEP Board of Directors from 2007 to 2010. Most importantly, she was a sister, a daughter, a friend, and a colleague.

As you well know, the stigma surrounding mental illness is a well-known barrier to seeking care among the general population, but it can have an even stronger impact among health care professionals who even still face greater and increasing rates of mental and behavioral health conditions, suicide, and burnout than other professions. For most physicians and other clinicians, seeking treatment for mental health sparks legitimate fear of resultant loss of licensure (some state licensing boards continue to ask questions about clinicians' mental health histories or past treatment), loss of credentialing at your site of employment (for similar reasons), loss of income, or other meaningful career setbacks as a result of pervasive stigma. Such fears have deterred many from accessing necessary mental health care, leaving them to suffer in silence, or worse. However, thanks to the work of many physicians, health care workers, organizations, and other stakeholders, there have been several successful efforts to eliminate some of the barriers related to licensure, certification, and registration for physicians, and numerous efforts continue on this front at the state level.

The law that bears Dr. Breen's name honors her life and legacy, and as of today more than \$100 million has been distributed to 44 organizations to improve access to mental health services and resources for physicians and health care providers across the nation. H.R. 7159 reauthorizes the law's critical programs through fiscal year 2029 and sets them on a traditional five-year authorization process, ensuring necessary and continued support for health care workers' well-being. We urge Congress to swiftly take up and pass this vital legislation.

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800-320-0610  
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With regard to the “Emergency Medical Services for Children Reauthorization Act” (H.R. 6960), the Emergency Medical Services for Children (EMSC) program helps ensure emergency departments and ambulances have the equipment, supplies, and medications necessary to treat children and helps develop pediatric treatment protocols. As the exclusive federal initiative focused on enhancing emergency services for the pediatric population, EMSC has been pivotal in transforming pediatric emergency care across the United States and has directed crucial focus and funding towards a group that was once overlooked and has unique health considerations and needs. Providing continued stability and certainty for EMSC means that emergency physicians can help ensure that emergency departments and EMS systems are equipped with child-appropriate medical equipment, health care workers are well-trained in pediatric care, and research and policies are directed towards optimizing emergency care for children.

Finally, we appreciate your efforts to reauthorize critical poison control programs. ACEP strongly supports the availability of high-quality, fully funded, certified poison centers. This legislation will provide critical support for the nation’s poison centers and to all Americans who rely upon the excellence, experience, and resources of these centers during an emergency. Emergency physicians witness first-hand the consequences of intentional and accidental access to poisons and other lethal substances, and we strongly support the work done by our colleagues in poison control centers throughout the country.

Once again, we appreciate your attention to these critical issues and we are grateful for the opportunity to share our support. Should you have any questions or require any further information, please do not hesitate to contact Ryan McBride, ACEP Congressional Affairs Director, at [rmcbride@acep.org](mailto:rmcbride@acep.org).

Sincerely,

A handwritten signature in black ink, appearing to read 'A Terry'.

Aisha T. Terry, MD, MPH, FACEP  
ACEP President





The Honorable Cathy McMorris Rodgers  
Chair  
United States House of Representatives  
Committee on Energy and Commerce  
2125 Rayburn House Office Building  
Washington, D.C. 20510

The Honorable Frank Pallone  
Ranking Member  
United States House of Representatives  
Committee on Energy and Commerce  
2322A Rayburn House Office Building  
Washington, D.C. 20510

The Honorable Brett Guthrie  
Chair  
United States House of Representatives  
Committee on Energy and Commerce  
Subcommittee on Health  
2434 Rayburn House Office Building  
Washington, D.C. 20510

The Honorable Anna Eshoo  
Ranking Member  
United States House of Representatives  
Committee on Energy and Commerce  
Subcommittee on Health  
272 Cannon House Office Building  
Washington, D.C. 20510

February 14, 2024

Dear Chairs Rodgers and Guthrie, and Ranking Members Pallone and Eshoo:

On behalf of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued leadership on issues and legislation important to Americans living with Alzheimer's and other dementia, and to their caregivers. The Alzheimer's Association and AIM write today to thank the Subcommittee for holding a hearing on legislative proposals to support patients and caregivers, including the Lifespan Respite Care Reauthorization Act (H.R. 6160), which would reauthorize and extend the Lifespan Respite Care Program that assists family caregivers in accessing affordable and high-quality respite care.

The burden of Alzheimer's on individuals and families continues to grow. Today, more than 6 million Americans aged 65 and older are living with Alzheimer's dementia, and by mid-century, this number is expected to nearly double. Total payments for all individuals living with this disease are estimated at \$345 billion (not including unpaid caregiving). Medicare and Medicaid are expected to cover \$222 billion, or 64 percent of the total health care and long-term care payments for people with Alzheimer's or other dementia. Total payments for health care costs, including hospice care, for people with Alzheimer's and other dementia are projected to increase to nearly \$1.1 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

Eighty-three percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers. Compared with caregivers of people without dementia, caregivers of those with dementia indicate more substantial emotional, financial, and physical difficulties. The Lifespan Respite Care Program plays a crucial role in supporting caregivers and enhancing the overall quality of life for individuals with chronic conditions or disabilities, such as Alzheimer's or other dementia. By providing funding opportunities to states and programs, these programs offer caregivers a temporary break from the heavy physical, mental, and financial tolls associated with caregiving that, all too often, go unnoticed. This can, in turn, improve the quality of life for both caregivers and individuals living with chronic illness. Reauthorizing this program through the Lifespan Respite Care Reauthorization Act will maintain a public health infrastructure that has been shown to help alleviate caregiver burden and further enhance care quality for individuals with chronic illness.

The Alzheimer's Association and AIM deeply appreciate your continued leadership on behalf of all Americans living with Alzheimer's and other dementia, and we look forward to working with you to advance this important bipartisan bill. If you have any questions about this or any other legislation, please contact Sarah Tellock, Director of Congressional Affairs, at [stellock@alz-aim.org](mailto:stellock@alz-aim.org) or at 202.638.8676.

Sincerely,

A handwritten signature in black ink that reads "Rachel M. Conant". The signature is written in a cursive, flowing style.

Rachel Conant  
Vice President, Federal Affairs, Alzheimer's Association  
Executive Director, Alzheimer's Impact Movement



The Honorable Cathy McMorris Rodgers  
Chair  
United States House of Representatives  
Committee on Energy and Commerce  
2125 Rayburn House Office Building  
Washington, D.C. 20510

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United States House of Representatives  
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Subcommittee on Health  
272 Cannon House Office Building  
Washington, D.C. 20510

February 14, 2024

Dear Chairs Rodgers and Guthrie, and Ranking Members Pallone and Eshoo:


On behalf of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued leadership on issues and legislation important to Americans living with Alzheimer's and other dementia, and to their caregivers. The Alzheimer's Association and AIM write today to thank the Subcommittee for holding a hearing on legislative proposals to support patients and caregivers, including the bipartisan Alzheimer's Accountability and Investment Act (H.R. 620/S. 134), which would continue the requirement for the National Institutes of Health (NIH) to submit a Professional Judgment Budget (PJB) to Congress, among other provisions.

As you know, the burden of Alzheimer's on individuals and families continues to grow. Today, more than 6 million Americans aged 65 and older are living with Alzheimer's dementia, and by mid-century, this number is expected to nearly double. Total payments for all individuals living with this disease are estimated at \$345 billion (not including unpaid caregiving). Medicare and Medicaid are expected to cover \$222 billion, or 64 percent of the total health care and long-term care payments for people with Alzheimer's or other dementia. Total payments for health care costs, including hospice care, for people with Alzheimer's and other dementia are projected to increase to nearly \$1.1 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

Since its passage in 2015, the Alzheimer's Accountability Act has allowed Congress to hear directly from the scientists at the NIH on how much research funding is needed to fully pursue scientific opportunities to prevent and effectively treat Alzheimer's. In turn, the Alzheimer's Accountability and Investment Act would continue the requirement for NIH to submit a PJB to Congress describing the annual funds needed to make progress in the fight against Alzheimer's disease for an additional decade. The legislation has strong bipartisan, bicameral support in Congress, and the Subcommittee action today builds upon Senate momentum, following the Senate Health, Education, Labor, and Pensions (HELP) Committee's June 2023 markup of the legislation. Swift passage of the Alzheimer's Accountability and Investment Act would help further our understanding of the risk factors, genetics, and mechanisms of dementia, helping diversify and de-risk the therapeutic pipeline and expand research on dementia care and care partner support.

The Alzheimer's Association and AIM deeply appreciate your continued leadership on behalf of all Americans living with Alzheimer's and other dementia, and we look forward to working with you to advance this important bipartisan bill. If you have any questions about this or any other legislation, please contact Sarah Tellock, Director of Congressional Affairs, at [stellock@alz-aim.org](mailto:stellock@alz-aim.org) or at 202.638.8676.

Sincerely,

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Rachel Conant  
Vice President, Federal Affairs, Alzheimer's Association  
Executive Director, Alzheimer's Impact Movement



The Honorable Cathy McMorris Rodgers  
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2125 Rayburn House Office Building  
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February 14, 2024

Dear Chairs Rodgers and Guthrie, and Ranking Members Pallone and Eshoo:

On behalf of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued leadership on issues and legislation important to Americans living with Alzheimer's and other dementia, and to their caregivers. The Alzheimer's Association and AIM write today to thank the Subcommittee for holding a hearing on legislative proposals to support patients and caregivers, including the bipartisan BOLD Infrastructure for Alzheimer's Reauthorization Act of 2024 (H.R. 7218/S. 3775), which would reauthorize and extend a nationwide Alzheimer's public health response that will help further population-level improvements, achieve a higher quality of life for those living with the disease and their caregivers, and reduce associated costs.

And, as of 2023, an estimated 6.7 million Americans aged 65 and older are living with Alzheimer's dementia. Total payments for all individuals with Alzheimer's or other dementia are estimated at \$345 billion (not including unpaid caregiving) in 2023. Medicare and Medicaid are expected to cover \$222 billion or 64 percent of the total health care and long-term care payments for people with Alzheimer's or other dementia, which are projected to increase to more than \$1.1 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

As scientists continue to search for a way to prevent, cure, or slow the progression of Alzheimer's through medical research, public health plays an important role in promoting cognitive function and reducing the risk of cognitive decline. The BOLD Infrastructure for Alzheimer's Reauthorization Act of 2024 would reauthorize the bipartisan 2018 Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406), which is assisting state, local and tribal public health departments in increasing early detection and diagnosis, reducing risk, supporting the

needs of caregivers, and supporting care planning for people living with the disease. The BOLD Act has led to great progress in strengthening the Alzheimer's public health infrastructure nationwide. Since 2018, the BOLD Act has allowed the Centers for Disease Control and Prevention (CDC) to establish three Public Health Centers of Excellence, each focusing on a priority public health area of need: dementia risk reduction, early detection of dementia, and dementia caregiving. Public Health Centers of Excellence play a key role in identifying and disseminating research findings and population-level best practices and providing technical support to state, local, and tribal public health officials. The CDC has also provided 66 awards to 45 state, local, and tribal public health departments to promote brain health, address dementia, and support people living with dementia and their caregivers. Extending this law through the BOLD Infrastructure for Alzheimer's Reauthorization Act will allow this infrastructure to continue advancing public health action on Alzheimer's and dementia care.

The Alzheimer's Association and AIM deeply appreciate your continued leadership on behalf of all Americans living with Alzheimer's and other dementia. We look forward to working with you to advance this important bipartisan bill. If you have questions about this or any other legislation, please contact Sarah Tellock, Director of Congressional Affairs, at [stellock@alz-aim.org](mailto:stellock@alz-aim.org) or at 202.638.8676.

Sincerely,

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Rachel Conant  
Vice President, Federal Affairs, Alzheimer's Association  
Executive Director, Alzheimer's Impact Movement



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United States House of Representatives  
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Ranking Member  
United States House of Representatives  
Committee on Energy and Commerce  
2322A Rayburn House Office Building  
Washington, D.C. 20510

The Honorable Brett Guthrie  
Chair  
United States House of Representatives  
Committee on Energy and Commerce  
Subcommittee on Health  
2434 Rayburn House Office Building  
Washington, D.C. 20510

The Honorable Anna Eshoo  
Ranking Member  
United States House of Representatives  
Committee on Energy and Commerce  
Subcommittee on Health  
272 Cannon House Office Building  
Washington, D.C. 20510

February 14, 2024

Dear Chairs Rodgers and Guthrie, and Ranking Members Pallone and Eshoo:

On behalf of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued leadership on issues and legislation important to Americans living with Alzheimer's and other dementia, and to their caregivers. The Alzheimer's Association and AIM write today to thank the Subcommittee for holding a hearing on legislative proposals to support patients and caregivers, including the bipartisan NAPA Reauthorization Act (H.R. 619/S. 133), which would extend the work of the National Plan to Address Alzheimer's Disease, among other provisions.

As you know, the burden of Alzheimer's on individuals and families continues to grow. Today, more than 6 million Americans aged 65 and older are living with Alzheimer's dementia, and by mid-century, this number is expected to nearly double. Total payments for all individuals living with this disease are estimated at \$345 billion (not including unpaid caregiving). Medicare and Medicaid are expected to cover \$222 billion, or 64 percent of the total health care and long-term care payments for people with Alzheimer's or other dementia. Total payments for health care costs, including hospice care, for people with Alzheimer's and other dementia are projected to increase to nearly \$1.1 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

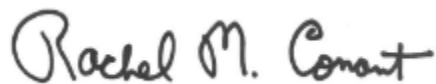
In 2011, Congress passed the bipartisan National Alzheimer's Project Act (NAPA) (P.L. 111-375), resulting in the landmark [National Plan to Address Alzheimer's Disease](#) (The National Plan). The National Plan, which is updated by the Department of Health and Human Services (HHS) annually, continues to drive meaningful action, creating and implementing strategies to address Alzheimer's and other dementia on both national and state levels. NAPA also led to the creation of the Advisory Council on Alzheimer's Research, Care, and Services, which is a panel of federal and non-federal experts that convene regularly to provide recommendations and annually update the coordinated strategic National Plan. While the National Plan has driven enormous progress in research, clinical and long-term care, and public awareness, we still have much work to do.

The NAPA Reauthorization Act would continue the great progress of the National Plan to Address Alzheimer's Disease through 2035 and would add several federal seats to the Advisory Council on Alzheimer's Research, Care

and Services, including the Department of Justice, Federal Emergency Management Agency, and Social Security Administration. The bill also adds language to help address healthy aging and risk reduction for Alzheimer's disease to reflect the new sixth goal of the National Plan. The legislation has strong bipartisan, bicameral support in Congress, having recently surpassed 100 cosponsors in the House of Representatives. The Subcommittee action today builds upon Senate momentum, following the Senate Health, Education, Labor, and Pensions (HELP) Committee's June 2023 markup of the legislation. Swift passage of the NAPA Reauthorization Act would provide HHS the certainty and stability to continue both immediate and long-term planning for a strategic nationwide approach to Alzheimer's and other dementia.

The Alzheimer's Association and AIM deeply appreciate your continued leadership on behalf of all Americans living with Alzheimer's and other dementia, and we look forward to working with you to advance this important bipartisan bill. If you have any questions about this or any other legislation, please contact Sarah Tellock, Director of Congressional Affairs, at [stellock@alz-aim.org](mailto:stellock@alz-aim.org) or at 202.638.8676.

Sincerely,

A handwritten signature in black ink that reads "Rachel M. Conant". The signature is written in a cursive, flowing style.

Rachel Conant  
Vice President, Federal Affairs, Alzheimer's Association  
Executive Director, Alzheimer's Impact Movement





## **Alzheimer's Association and Alzheimer's Impact Movement Statement for the Record**

### **United States House of Representatives Committee on Energy and Commerce, Health Subcommittee Legislative Hearing on "Legislative Proposals to Support Patients and Caregivers."**

**February 14, 2024**

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the House Energy and Commerce, Health Subcommittee legislative hearing on "Legislative Proposals to Support Patients and Caregivers." The Association and AIM thank the Subcommittee for considering four key pieces of legislation that have been instrumental in prioritizing our nation's response to the widespread and growing impact of Alzheimer's disease on over 6 million Americans, their 11 million caregivers, and society as a whole. The Association and AIM are proud to support the **NAPA Reauthorization Act (H.R. 619/S. 133)**, the **Alzheimer's Accountability and Investment Act (H.R. 620/S. 134)**, the **BOLD Infrastructure for Alzheimer's Reauthorization Act (H.R. 7218/S. 3775)**, and the **Lifespan Respite Care Reauthorization Act (H.R. 6160)**. We are grateful to the Subcommittee and the champions leading these bipartisan bills for their timely consideration today. Congress must reauthorize these laws now to ensure our country continues to advance policies that improve the lives of people living with dementia, and their families.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Our mission is to eliminate Alzheimer's and other dementia through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. AIM is the Association's advocacy affiliate, working in a strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and the development of approaches to reduce the risk of developing dementia.

As too many of us know from personal experience with family or friends, Alzheimer's is a progressive brain disease that damages and eventually destroys brain cells, leading to a loss of memory, thinking, and other cognitive functions. Ultimately, Alzheimer's is fatal. We have yet to celebrate the first survivor of this devastating disease. By 2050, an estimated 13 million Americans will be living with Alzheimer's, and total payments for all individuals with Alzheimer's or other dementia are projected to increase to more than \$1.1 trillion. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

#### **The NAPA Reauthorization Act (H.R. 619/S. 133) and the Alzheimer's Accountability and Investment Act (H.R. 620/S. 134)**

In 2011, Congress passed the bipartisan National Alzheimer's Project Act (NAPA) (P.L. 111-375), resulting in the landmark [National Plan to Address Alzheimer's Disease](#) (The National Plan). The National Plan, which is updated by the Department of Health and Human Services



(HHS) annually, continues to drive meaningful action, creating and address Alzheimer's and other dementia on both national and state the creation of the Advisory Council on Alzheimer's Research, Care, and Services, which is a panel of federal and non-federal experts that convene regularly to provide recommendations and annually update the coordinated strategic National Plan, including Dr. Joanne Pike, president and Chief Executive Officer of the Alzheimer's Association and Chief Executive Officer of the Alzheimer's Impact Movement.

While the National Plan has driven enormous progress in research, clinical and long-term care, and public awareness, we still have much work to do. For the first time, Alzheimer's patients have treatments that slow disease progression. The FDA's approval of these therapies was a historic moment for the Alzheimer's community and, as research continues, the scientific community expects better and more effective treatments. Patients are having difficulty accessing these new therapies, which only underscores the need for a clear, consistent, and updated national strategy to reflect the strides the field has made and the progress we need to protect.

The bipartisan NAPA Reauthorization Act (H.R. 619/S. 133) would extend this important work through 2035 and modernize the law to reflect strides the field has made in understanding the disease, such as including a new focus on promoting healthy aging and reducing risk factors. The bill would also add new federal representatives to the Advisory Council, including those from the Social Security Administration, Department of Justice, and Federal Emergency Management Agency. These representatives can provide unique insight and focus on timely issues, like Social Security Disability Insurance, elder abuse and law enforcement training, and disaster preparedness, for this vulnerable population. Adding these Agencies to the Advisory Council now is critical to ensuring the federal government addresses these issues in a coordinated way at the national level. Reauthorizing NAPA ensures the continuity of vital initiatives, fostering advancements in understanding, treatment, and care for individuals living with Alzheimer's disease and other dementia.

The 2015 Alzheimer's Accountability Act (P.L. 113-235) complements NAPA's efforts by ensuring the National Institutes of Health (NIH) receives the funding and resources essential to making meaningful research progress in the fight against Alzheimer's. The law requires the NIH to annually submit a professional judgment budget, or bypass budget, which is an estimate of the investment needed to reach the goals of the National Plan. Strong funding for Alzheimer's research is vital for advancing scientific research, developing effective diagnostics and treatments, and improving the quality of care and support available to those affected by the disease. This annual bypass budget has been a crucial blueprint for Congress, enabling historic increases in Alzheimer's research investments and leading to a more than seven-fold increase in Alzheimer's funding at NIH over the past decade.

The approval of new Alzheimer's treatments is amplifying the urgency of detecting the disease early. Blood biomarker tests will revolutionize the detection and diagnosis of Alzheimer's, and these funding increases over the past decade have enabled groundbreaking advancements, including improved blood biomarker test accuracy. These blood-based biomarkers indicate the likelihood of amyloid or tau accumulation in the brain and track changes in protein levels in response to treatment. NIH investment is also advancing researchers' understanding of the risk factors, genetics, and mechanisms of dementia, diversifying and de-risking the therapeutic



pipeline, and expanding research on dementia care and care part must continue as there is much farther to go and the population of the only continues to grow.

Reauthorizing this law through the bipartisan Alzheimer's Accountability and Investment Act (AAIA) (H.R. 620/S. 134) will reinforce Congress' commitment to prioritizing the resources needed to address the multifaceted challenges posed by Alzheimer's and other dementia. AAIA would ensure NIH continues to submit an Alzheimer's annual bypass budget to Congress and the President through 2035.

The NAPA Reauthorization Act and AAIA have strong bipartisan, bicameral support in Congress. Enacting these bills now would provide HHS the certainty and stability to continue both immediate and long-term planning for a strategic nationwide approach to Alzheimer's and other dementia. The Subcommittee action today builds upon Senate momentum, following the Senate Health, Education, Labor, and Pensions (HELP) Committee's June 2023 markup of the bills. During that process, NAPA was modified to highlight the importance of including representation from the Down syndrome community in Alzheimer's clinical, research and service efforts, given the increased prevalence of the disease in this population. According to the National Down Syndrome Society, individuals with Down syndrome have a lifetime risk of developing Alzheimer's disease that is higher than 90 percent. Scientists believe this increased risk of dementia results from the extra genes present. Today, people with Down syndrome are living longer than at any other time in the past. When NAPA was signed into law more than a decade ago, we did not know that individuals with Down syndrome were disproportionately at risk for developing Alzheimer's. We look forward to working with the Subcommittee on similar changes as these bills move through the legislative process in the House of Representatives.

### **The BOLD Infrastructure for Alzheimer's Reauthorization Act (H.R. 7218/S. 3775)**

We are also grateful to Subcommittee Chairman Brett Guthrie and Committee member Congressman Paul Tonko for their leadership on the 2018 Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406), and recent efforts to reauthorize this important law. The BOLD Act has enabled communities nationwide to implement public health strategies that promote brain health, increase early detection, address dementia, and support people living with dementia and their caregivers. The BOLD Act provides an avenue for the activation of advances in knowledge to be integrated into our public health infrastructure. Public health can integrate brain health messages into existing, relevant public health campaigns, acknowledging the growing evidence that healthy living can reduce the risk of cognitive decline and may reduce the risk of dementia. Public health can also undertake public awareness campaigns to promote early detection and diagnosis, and can educate medical professionals about assessment tools, which is critical to ensuring access to treatment. Public health can also increase access to care and services by ensuring providers are trained in evidence-based care guidelines, and people living with dementia and their caregivers have the support and resources they need in their communities.

Since its enactment, the CDC has made 66 awards to 45 state, local, and tribal public health departments. These award recipients are working to implement public health strategies tailored to local populations as well as create, update, and operationalize state plans to address Alzheimer's disease. The CDC has also awarded funding to three Public Health Centers of



Excellence each focusing on a priority public health area of need: detection of dementia, and dementia caregiving. Together, these strategies from [The Healthy Brain Initiative: State and Local Road Map for Public Health](#) and [Healthy Brain Initiative Road Map for Indian Country](#), which provide a framework for BOLD award recipients to lead with urgency and act for impact in their communities to improve brain health across the life course and support caregivers.

The BOLD Act continues to make a significant impact on communities across the country. For example, in Kentucky, BOLD funding is increasing the state's capacity to operationalize its Kentucky State Alzheimer's Plan. Kentucky's initial investment in Alzheimer's disease and other dementia led to the creation of a full-time state agency Dementia Services Coordinator staff position which was a catalyst for their application to the BOLD Program award. In September 2023, the Kentucky Department for Public Health was awarded a BOLD Public Health Program Component 1 award to develop strategic statewide strategies to address Alzheimer's disease. This funding is already allowing the state to support the work of Kentucky's Office of Dementia Services.

Using the HBI Road Map, the state of Washington has expanded its public health infrastructure to increase the populations served and discuss dementia throughout the continuum of disease, from risk reduction to the late stages of the disease. For example, the Washington State Department of Health released guidance to local health departments on effective ways to use the HBI Road Map and conducted an internal agency evaluation to assess its ability and identify potential gaps in addressing Alzheimer's and caregiving needs. The state has also allocated funding to support the statewide expansion of dementia-specific public awareness efforts at the Memory and Brain Wellness Center at the University of Washington and to other state-led public awareness efforts aimed at reducing the stigma surrounding dementia as well as educating physicians about the importance of the early detection and diagnosis of Alzheimer's. This work led to the CDC awarding the Washington State Department of Health with the state's BOLD Public Health Program Component 2 award in September 2023, which will allow the state to expand upon these actions.

In September 2020, Wisconsin received a BOLD Public Health Program Component 1 award, and, through this grant, the Wisconsin Department of Health Services is utilizing existing public health infrastructure to increase early detection and diagnosis, reduce the risk of developing dementia, and support dementia caregiving. Wisconsin is in the process of implementing the Wisconsin State Dementia Plan: 2019–2023, its third state dementia plan. The current state plan has four areas of focus: care provided in communities where people live; improving how health care providers diagnose and care for people with dementia; responding to crises involving people with dementia; and care provided in assisted living, nursing homes, and other residential facilities. Further, a steering committee, led by the Department of Health Services, was established to ensure the state plan is implemented with the assistance of four "leadership teams" (work groups) that are responsible for assisting the Steering Committee in each of the four focus areas: care in the communities, health care, crisis response, and facilities-based care. The CDC awarded Wisconsin with its second BOLD award in September 2023, which will allow the state to continue building upon the great progress made thanks to its first award in 2020.



California recognized its need for a comprehensive Alzheimer's public health approach and used the resources provided by the federally funded Healthy Brain Initiative (HBI) as a framework to establish the California Healthy Brain Initiative. For this, six local health departments across the state produced action plans, and educational outreach materials and conducted 101 media campaigns for the public. Furthering implementation of the actions in the [2018 HBI Road Map](#), California appropriated funds to the state Medicaid program to establish [Dementia Care Aware](#) in 2021, a statewide program providing primary care providers with the information and tools needed to successfully administer cognitive health assessments and determine the appropriate next steps for the patients. In 2020, the County of Los Angeles received a BOLD Public Health Program Component 1 award, and in September 2023, the county received a BOLD Public Health Program Component 2 award to continue this work. The California State Department of Public Health received its first BOLD Public Health Program Award in September 2023, when the CDC awarded the state with a BOLD Public Health Program Component 2 award to amplify its existing efforts to address Alzheimer's disease.

The Vermont Department of Health received a BOLD Public Health Program Component 2 award from the CDC in September 2020, and, in September 2021, the department launched a virtual Project ECHO series to help build capacity for dementia diagnosis and care. Over 80 participants joined the first session of this monthly telementoring program run through the Area Health Education Center at the University of Vermont's (UVM) Larner College of Medicine. The Department of Health also offers monthly "Dementia Corner Consults" for primary care providers and their teams, led by the medical director of the UVM Memory Program. Additionally, in October 2021, the Vermont Department of Health published a data brief on Risk Factors for Subjective Cognitive Decline in Vermonters. The CDC awarded Vermont with its second BOLD award in September 2023, which will allow the state to continue building upon the great progress made thanks to its first award in 2020.

Underscoring the importance of a public health approach to addressing Alzheimer's and dementia in our communities, while New Jersey does not currently receive BOLD funding, the state is active in developing Alzheimer's public health initiatives. For example, the New Jersey Alzheimer's Disease Study Commission was established in 2011 to study the current and future impact and incidence of Alzheimer's within the state. The New Jersey Alzheimer's Disease Study Commission Report was published in August 2016 and examined services within the state to meet the needs of those affected by Alzheimer's. Most recently in 2023, the New Jersey Department of Health participated in a public health program called Data for Action, a project of the HBI designed to support the integration of data on brain health and caregiving into public health planning efforts. This has allowed the health department to produce state-specific data on risk factors for Alzheimer's and other dementia as well as identify links between cognitive changes and other chronic conditions and health behaviors. New Jersey now plans to use their work to educate members of the public and inform key decision-makers on how to advance public health action on brain health.

These are just a few of the many examples of the innovation stemming from Alzheimer's investment across the country. BOLD has clearly led to great progress in building and



strengthening the Alzheimer's public health infrastructure nationwide program is set to expire this year. The bipartisan BOLD Infrastructure Reauthorization Act of 2024 (H.R. 7218/S. 3775), introduced by Subcommittee Chairman Brett Guthrie and Committee member Congressman Paul Tonko, would extend this important law until 2029 and authorize \$33 million annually for five years, to reflect the program's current appropriated level. It is vital that Congress passes this bill and continues to invest in a nationwide Alzheimer's public health response that will help further population-level improvements, achieve a higher quality of life for those living with the disease and their caregivers, and reduce associated costs.

### **The Lifespan Respite Care Reauthorization Act (H.R. 6160)**

Finally, we thank the Subcommittee for considering ways to help support caregivers of people living with chronic conditions, such as Alzheimer's and other dementia. Eighty-three percent of the help provided to all older adults in the United States comes from family members, friends, or other unpaid caregivers. Compared with caregivers of people without dementia, caregivers of those with dementia indicate more substantial emotional, financial, and physical difficulties. In 2022, caregivers of people living with Alzheimer's or another dementia provided an estimated 18 billion hours of unpaid care, a contribution valued at \$339.5 billion. The Lifespan Respite Care Program, administered by the Administration for Community Living, continues to play a crucial role in helping support these caregivers and enhancing the overall quality of life for people with chronic conditions or disabilities. The program provides funding opportunities to states that offer caregivers a temporary break from the heavy physical, mental, and financial tolls associated with caregiving that, all too often, go unnoticed. The Lifespan Respite Care program has also been very valuable for dementia care by providing caregivers with Alzheimer's and dementia education and training sessions. This can, in turn, improve the quality of life for both caregivers and their loved ones living with chronic conditions.

The Lifespan Respite Care Reauthorization Act (H.R. 6160) would extend this important program until 2028, which is essential for sustaining a supportive infrastructure that has been shown to help alleviate caregiver stress and enhance care quality for people with chronic conditions.

### **Conclusion**

The Alzheimer's Association and AIM appreciate the Committee's steadfast support and commitment to advancing issues important to the millions of individuals living with Alzheimer's and other dementia, as well as their caregivers. We look forward to working with the Subcommittee and other members of Congress in a bipartisan way to reauthorize and extend these laws through the BOLD Infrastructure for Alzheimer's Reauthorization Act (H.R. 7218/S. 3775), NAPA Reauthorization Act (H.R. 619), the Alzheimer's Accountability and Investment Act (H.R. 620), and the Lifespan Respite Care Reauthorization Act (H.R. 6160). The swift reauthorization of these four important laws will underscore Congress' sustained commitment to a strategic approach to combating Alzheimer's disease and supporting caregivers nationwide and will enable further strides in understanding, treating, and ultimately preventing Alzheimer's and other dementia. Doing so will provide much-needed hope for the millions of families affected by this devastating disease.

# Virginia was the first state to protect doctors' mental health. Now the effort is going national.

Dr. Trudy Shahady was feeling burnt out. It was during the height of the pandemic, and three unvaccinated patients had died of COVID-19 in the span of one week.

She needed help, she decided. So she called a program that existed nowhere else in the country — one that allows doctors to seek therapy without putting their careers in jeopardy.

For years, doctors have feared that if they seek help for stress, depression or anxiety, they will be labeled unfit to do their jobs and lose their licenses. Lawyers could also use the information against them in a medical malpractice lawsuit.

Virginia was the first state to change these laws, ensuring that doctors and other health care workers can seek help without fear. Now, the initiative is going national. The Medical Society of Virginia has expanded it to other states, hoping to fight the shortage of health care workers besetting the industry.

It was "life-changing" not having to choose between her career and her mental health, said Shahady, a family medicine doctor at the Forest-based Central Virginia Family Physicians.



*Dr. Trudy Shahady, a family medicine doctor at the Forest-based Central Virginia Family Physicians, said it was “life-changing” not having to choose between her career and her mental health.*

*Paige Dingler, The News & Advance*

## Physician burnout

Burnout in health care was a problem long before the pandemic. The Medical Society of Virginia began seeing an uptick in 2018 — increased administrative tasks, patient quotas and uneven work-life balances were cited as causes.

But doctors are reluctant to seek counseling or therapy, because licensing applications in Virginia and elsewhere asked doctors whether they had any conditions that could affect their work and if they ever sought therapy. It was too big a risk to be diagnosed as “depressed.”

“It came down to fear,” said Melina Davis, CEO of the Medical Society of Virginia.

One doctor from Virginia, Lorna Breen, died by suicide in 2020. A member of her family told Congress that Breen was sure she would lose her license or face ostracism from colleagues for receiving mental health treatment. One study determined that doctors have the [highest suicide rate](#) of any profession in the country.

Burnout has only increased since the pandemic as many hospital staffs remain depleted.





*Melina Davis is CEO of the Medical Society of Virginia, which created the Safe Haven program.*

"We are losing providers left and right," Davis said.

There are three ways in which the Medical Society of Virginia sought to protect doctors' mental health records. The society did not want such information getting in the hands of employers, boards of licensure or lawyers taking civil action against doctors.

To address employers, the society asked health systems to stop asking about mental health treatment on credentialing applications. HCA Healthcare, the nation's largest for-profit chain, agreed to do so. The other two forms of protection required legislative action. Virginia changed those laws in 2020 and 2023.

Now, licensing applications ask doctors if they have any reason to believe they would pose a risk to the well-being of their patients and if they are able to perform the essential functions of their jobs.

"The fact that there's a law that protects us, that's the game changer," Shahady said.

## **A discreet form of help**

To give doctors a place to discreetly receive help, the medical society created Safe Haven. Participants pay \$400 a year and can receive counseling visits, peer-to-peer advice and a concierge that helps manage work-life balance. The concierge can schedule an appointment to change a car tire or book airline tickets.

The program is staffed by a national practice called Vital Work Life that specializes in well-being for health care organizations. Employers often have their own versions of these programs, but they are rarely utilized because the employer may have access to the information.

More than 8,000 health care workers in Virginia have signed up for Safe Haven. Health systems and practices can pay for their employees to join, or workers can sign up as individuals. While a patient



## SAFEHAVEN CLINICIAN WELL-BEING PROGRAM

*Rediscover meaning, joy and purpose in medicine.*

SafeHaven ensures that you can seek support for burnout, career fatigue and mental health reasons without the fear of undue repercussions to your medical license.

### RESOURCES FOR YOU AND YOUR FAMILY MEMBERS

SafeHaven includes Clinician Well-Being Resources from VITAL WorkLife—confidential and discreet resources designed to reduce stress and burnout, promote work/life integration and support well being for you and your family. These resources include:

### WE PROTECT PHYSICIANS AND PAs

SafeHaven was launched in 2020 after recognizing a greater need to provide physicians and PAs the support needed to stay well and prevent burnout. It was established when HB115 (Hope) and SB120 (Barker) successfully passed both chambers and were signed by Governor Northam. **SafeHaven provides:**

The old Virginia law that exposed mental health records of doctors still exists in many states. Now, the Medical Society of Virginia is going state by state, working to change their laws and introduce Safe Haven. Health care workers are licensed at the state level, so there's no push for federal legislation.

So far, Kentucky, Illinois, Michigan and South Dakota have followed Virginia's lead. Six other states are moving in that direction.

The medical society also expanded Safe Haven for physician assistants, nurse practitioners, nurses, pharmacists and students.

There has been some pushback, and some have asked if bad actors will fly under the radar. The medical society determined that if a doctor who receives therapy is deemed a threat to himself or others, the doctor will be reported. That is the same standard counselors are held to with all their patients.

These doctors will be required to stop practicing and undergo evaluation. They can return with certain conditions after gaining approval.



*Dr. Trudy Shahady received training on how to use the Safe Haven program and became the chief wellness officer for the roughly 100 providers at her practice.*

*Paige Dingler, The News & Advance*

Though the pandemic has ended, staff shortages persist in hospitals, and the rate of violence in health care settings has increased. Burnout remains a problem.

To make sure her colleagues are getting the help they need, Shahady received training on how to use Safe Haven and became the chief wellness officer for the roughly 100 providers at her practice.

When she used the program for her own therapy, she explained how the three patients refused to be vaccinated despite her pleas. She explained how they died, how she dreaded waking up in the morning and going to work, and how she was not enjoying practicing medicine anymore.

The person on the line responded, "I'm hearing this all day every day. You're not alone."

Shahady had felt responsible for her patients' deaths, but the counselor encouraged her to let go of that guilt.

"It helped me to process that and cope with that and move forward in a way that was healthy mentally," Shahady said.



January 11, 2024

The Honorable Buddy Carter  
United States House of Representatives  
2432 Rayburn House Office Building  
Washington, DC 20515

The Honorable Kathy Castor  
United States House of Representatives  
2052 Rayburn House Office Building  
Washington, DC 20515

The Honorable Dr John Joyce  
United States House of Representatives  
152 Cannon House Office Building  
Washington, DC 20515

The Honorable Dr Kim Schrier  
United States House of Representatives  
1110 Longworth House Office Building  
Washington, DC 20515

Dear Representatives Carter, Representative Castor, Representative Joyce, and Representative Schrier:

As organizations that care deeply about the health and safety of children, we offer our strong support for the *Emergency Medical Services for Children Program Reauthorization Act of 2024*. The EMSC program has made landmark improvements to the emergency care delivered to children all across the nation. As the only federal program dedicated to improving emergency care for children, EMSC has brought vital attention and resources to this important population.

Just this year, 30 million children will visit the emergency department, and emergencies involving children can occur anytime, anywhere.<sup>i</sup> Children have unique physiological, emotional, and developmental characteristics that require specialized emergency care. Research shows that taking steps to prepare for children's unique health needs in emergency departments is associated with 60-70% fewer deaths.<sup>ii</sup> The EMSC program is designed to improve emergency care for children and adolescents – no matter where they live, attend school, or travel.

Through EMSC, all states and territories have received state partnership grants to expand and improve their capacity to reduce and respond to emergencies. EMSC funding is used to equip hospitals and ambulances with the tools they need to treat pediatric emergencies, to provide pediatric training to paramedics and first responders, and to improve the systems that allow for efficient, effective pediatric emergency medical care. Additionally, EMSC funding has helped to improve pediatric capacity and transport of pediatric patients and address emerging issues such as pediatric emergency care readiness through the National Pediatric Readiness Project and pediatric emergency medical services in rural and remote areas.

Initiated in 2016, the EMSC Innovation and Improvement Center (EIIC) is working to accelerate improvements in the quality of care and outcomes for children who are in need of urgent or emergency care through an infrastructure that ensures routine, integrated coordination of quality improvement activities. The EIIC was invaluable during the surge in pediatric respiratory illnesses seen in late 2022 that strained healthcare facilities, staff, and resources across the U.S. EIIC created recommendations and resources to support the immediate response to the surge of pediatric patients and to guide planning and preparation for future surges.

EMSC has been successful in improving care for children. Emergency departments and pre-hospital EMS personnel have more appropriate medication, equipment, training, and systems in place to treat children. For example, doctors and nurses are better able to manage pediatric emergencies such as traumatic brain injuries, pediatric seizures, and bronchiolitis. The majority (90%) of EMS agencies in the US have consistent availability to online medical direction when treating a pediatric patient and 85% have off-line medical direction that includes protocols inclusive of pediatric patients. In the hospital setting, almost two thirds (67%) of hospitals have interfacility transfer agreements and 50% have interfacility transfer guidelines that incorporate recommended pediatric components. Looking ahead, EMSC aims to ensure all EDs are ready to care for children through the implementation of the National Pediatric Readiness Project, a national quality improvement initiative to ensure EDs have the essential guidelines and resources in place.

Your bill would reauthorize the EMSC program to continue its vital work for an additional five years. We thank you for your leadership in authoring this critical legislation for children and appreciate your long-standing commitment to the quality of the emergency care children receive. We look forward to working with you in support of enactment of this legislation.

Sincerely,

Academic Pediatric Association  
American Academy of Pediatrics  
American Ambulance Association  
American College of Emergency Physicians  
American College of Surgeons  
American Pediatric Society  
Association of Maternal & Child Health Programs  
Association of Medical School Pediatric Department Chairs  
Children's Hospital Association  
Children's Hospital of Philadelphia  
Emergency Nurses Association  
First Focus Campaign for Children  
March of Dimes  
National Association of Emergency Medical Technicians (NAEMT)  
National Association of Pediatric Nurse Practitioners  
National Association of State EMS Officials  
National League for Nursing  
Nemours Children's Health  
Pediatric Policy Council  
Society for Pediatric Research  
The National Alliance to Advance Adolescent Health  
The Paramedic Foundation

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<sup>i</sup> Newgard CD, Lin A, Malveau S, et al. Emergency Department Pediatric Readiness and Short-term and Long-term Mortality Among Children Receiving Emergency Care. *JAMA Netw Open*. 2023;6(1):e2250941.  
doi:10.1001/jamanetworkopen.2022.50941

<sup>ii</sup> [https://media.emscimprovement.center/documents/Pediatric\\_Readiness\\_Outcomes\\_-\\_2023\\_Q5q8cow.pdf](https://media.emscimprovement.center/documents/Pediatric_Readiness_Outcomes_-_2023_Q5q8cow.pdf)



February 12, 2024

The Honorable Susan Collins  
413 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Shelley Moore Capito  
170 Russell Senate Office Building  
Washington, DC 20510

The Honorable Jerry Moran  
521 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Lisa Murkowski  
522 Hart Senate Office Building  
Washington, DC 20510

The Honorable Christopher Smith  
2373 Rayburn House Office Building  
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The Honorable Edward Markey  
255 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Mark Warner  
703 Hart Senate Office Building  
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The Honorable Robert Menendez  
528 Hart Senate Office Building  
Washington, DC 20510

The Honorable Debbie Stabenow  
731 Hart Senate Office Building  
Washington, DC 20510

The Honorable Paul Tonko  
2369 Rayburn House Office Building  
Washington, DC 20515

The Honorable Maxine Waters  
2221 Rayburn House Office Building  
Washington, DC 20515

**RE: NDSS letter of support for the Alzheimer's Accountability and Investment Act (H.R. 620/S. 134)**

Dear Senators Collins, Markey, Moore Capito, Warner, Moran, Menendez, Murkowski, and Stabenow, Congressmen Smith and Tonko and Congresswoman Waters:

The National Down Syndrome Society (NDSS) empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions. We write today in support of the *Alzheimer's Accountability and Investment Act* (H.R. 620/S. 134) which would ensure Alzheimer's and dementia research is funded at the levels needed to achieve the goals in the National Plan to Address Alzheimer's Disease.

Individuals with Down syndrome are uniquely situated in the Alzheimer's landscape because they have an extra copy of chromosome 21. The 21st chromosome carries the amyloid precursor protein (APP) gene, which is strongly associated with the formation of amyloid peptides and plaques, a hallmark of Alzheimer's disease. As a result, individuals with Down syndrome have an elevated lifetime risk for developing Alzheimer's disease, upwards of 90%, with the onset of symptoms coming earlier and progressing faster than in the general population. In fact, Alzheimer's disease is the number one cause of death for individuals with Down syndrome.



Given the critical nature of this disease to the Down syndrome community, NDSS has facilitated sustained engagement with the National Alzheimer's Project Act (NAPA) Council which oversees the National Plan. An NDSS staff member or a representative of the Down syndrome community has shared [remarks](#) at every quarterly NAPA council meeting since October 2021. Furthermore, NDSS has also played an active role in advocating for the NAPA Reauthorization Act, as amended by the Senate HELP Committee, to ensure the important work of the NAPA council continues and is inclusive of the Down syndrome community. Our unequivocal support of the Alzheimer's Accountability and Investment Act builds upon these efforts.

Ensuring that Alzheimer's and dementia research is funded at the levels needed to achieve the goals in the National Plan to Address Alzheimer's Disease is paramount to supporting communities experiencing Alzheimer's disease and related dementia at markedly higher rates, such as the Down syndrome community. We urge Congress to pass the Alzheimer's Accountability and Investment Act and we thank you for your leadership regarding this important piece of legislation.

Sincerely,

A handwritten signature in black ink that reads "Kandi Pickard". The signature is fluid and cursive, with a large loop at the end.

Kandi Pickard  
President and CEO  
National Down Syndrome Society



**Hearing before the Energy & Commerce Subcommittee on Health:  
Legislative Proposals to Support Patients and Caregivers**

**Written testimony of Debbie Haine Vijayvergiya, Autumn's mom  
Stillbirth Health Improvement and Education (SHINE) for Autumn Act  
H.R. 5012/S. 2647**

**February 13, 2024**

Honorable Chair McMorris Rodgers, Ranking Member Pallone, Health Subcommittee Chair Guthrie, Health Subcommittee Ranking Member Eshoo, and members of the Committee, thank you for including the bicameral and bipartisan Stillbirth Health Improvement and Education for Autumn Act in the Subcommittee on Health legislative hearing to support patients and caregivers. I am immensely grateful for your steadfast leadership and for the opportunity to shed light on the U.S. stillbirth crisis and how the SHINE for Autumn Act serves as the solution.

**Debbie and Autumn's Story:**

My name is Debbie Haine Vijayvergiya, and I am a stillbirth parent advocate.

Ever since I was a young girl, the one and only thing that I was certain of was that I wanted to be a mom. My first pregnancy was completely textbook and resulted in a healthy, picture-perfect baby girl. However, things took a dramatic turn a week later when a late presentation of Group B Strep went undiagnosed and nearly killed me. I subsequently had two miscarriages, the second of which resulted in an ambulance ride, ten traumatic hours in the emergency room, and a broken heart. At that point, I didn't think things could get much worse.

The following year, when I found out I was pregnant for my fourth time in four years, I allowed myself to believe that everything would be okay. Once I successfully made it through my first trimester, I was able to take a deep sigh of relief and immediately began to embrace my pregnancy.

Unfortunately, luck wasn't on my side. On July 7th, 2011, I was suddenly thrust into any expectant mother's worst nightmare when, without warning, my obstetrician could not detect my daughter Autumn's heartbeat during a routine second-trimester checkup. As I lay stunned on the examination table, my whole world came crashing down around me.

Much of what happened after this is a blur. Except for Autumn's birth. Her stillbirth. Nothing can ever prepare you to birth your lifeless baby. It has been over 12 years, and I still find words inadequate to describe the experience. The silence at her delivery still haunts me. Time stopped moving for me that day, and my life has never been the same since.

The months following Autumn's death were excruciating. I became a tortured soul. In my mind, I had failed not only Autumn but both my husband and young daughter. The expectations and plans that we had for Autumn, for our family of "4", were gone.

I was thoroughly broken, leaving my husband unable to grieve himself because he was too busy trying to put me back together. My heart still aches when I think back to how my 3.5-year old's life was turned upside down. She was expecting a baby sister and instead all she got was a broken mommy. I began to question my ability to be a mom, as I couldn't keep one child alive and was completely incapable of being there for the other when she needed me most.

Hearing from my doctors that losing Autumn was as rare as being struck by lightning (something I now know not to be true) made me feel so ashamed—like I somehow had something to do with her death. Even worse, I suffered in silence because no one, not even me, knew how to talk about Autumn's stillbirth. I was drowning in my grief, barely able to keep my head above water. The only thing saving me was my anger: over her death, over my blissful ignorance, and over the fact that I couldn't save her. While my anger consumed me, it is also what kept me afloat and fueled my incessant search for answers, explanations, and assurances. I couldn't understand how, as a woman who had been pregnant three times, had successfully birthed one child, never knew what stillbirth was or that something so profoundly devastating could happen to me.

Before long, I came to realize that stillbirth is far more common than lightning strikes, and that it is among the most common adverse pregnancy outcomes. I soon learned that Autumn was one of more than 25,000 babies who were stillborn in the United States that year; and was dumbfounded by how little was being done to improve outcomes and save babies lives. While I couldn't bring Autumn back, I knew I could not sit idly by and let others suffer as we had. I had to find a way to put stillbirth on the map in the U.S.—not only for Autumn, but for all the other babies gone too soon, for those who love them, and for the families of tomorrow who deserve to be able to leave the hospital with their babies safe in their arms.

## **Stillbirth in the United States**

Stillbirth is a neglected public health crisis that tragically accounts for the deaths of over 21,000 babies every year in the United States. That is approximately 42,000 parents whose lives are irrevocably changed by these deaths, as they return home emptyhanded after the stillbirth of their much-wanted babies. Each of those numbers represents a life lost, and a family that has been forever changed. At least 1 in 4 stillbirths are preventable, and the vast majority of stillbirths are happening in healthy, low-risk pregnancies.

The annual number of stillbirths far exceeds the number of deaths among children aged 0-14 years from preterm birth, SIDS, accidents, drownings, guns, fire, and flu combined. U.S. families are losing approximately 60 babies every day, the equivalent to losing 3 classes of kindergarteners every day for an entire year.

While stillbirth is a risk for all pregnancies, there are persistent and longstanding racial and ethnic disparities, and those who suffer a stillbirth are more likely to experience material morbidity or mortality than those whose babies are born alive. Sadly, stillbirth has not been afforded the same attention as other critical areas of public health. We have a responsibility to understand *why* babies are dying at this rate and *what* we can do to start saving their lives.

From 2000 to 2021, the U.S. stillbirth rate declined by a negligible 0.9% per year. As [ProPublica](#) noted: “That figure lands the U.S. in the company of South Sudan in Africa and doing slightly

better than Turkmenistan in central Asia. During that period, Australia's reduction rate was more than double that."

Australia, Ireland, and the UK have made stillbirth prevention and care national priorities. Some of these efforts include the implementation of national guidelines for providing holistic care following a stillbirth, improvements in stillbirth data collection and reporting, and prioritizing research and clinical practice to reduce stillbirth rates. Similar efforts are much needed and long overdue in the United States.

The United States has seen significant improvements in infant mortality rates (the death of a child anytime between delivery and their first birthday) reflecting concerted efforts to address a wide range of contributing factors. These efforts include initiatives targeting preterm birth reduction, folic acid supplementation to prevent neural tube defects, advancements in caring for infants with congenital heart defects, and comprehensive safe sleep campaigns.

Since Autumn died in 2011, the infant mortality rate declined by 10.4% - with an impressive 16.7% decline in deaths due to SIDS, or Sudden Infant Death Syndrome. While these are laudable achievements, they highlight just how little progress has been made in reducing stillbirth rates in the U.S. with only a 6.2% reduction during this same time frame.

According to public health experts, the stillbirth rate is a critical measure of a population's health. If that's the case, what does this say about the well-being of our nation? No matter how you slice the data, we cannot deny that we have a legitimate problem. Despite all this evidence, stillbirth has remained one of the most understudied and underfunded public health issues to date in our country.

## **Stillbirth Data in the United States**

One of the greatest obstacles to reducing U.S. stillbirth rates is the lack of accurate and timely data.

Unlike other countries, the United States does not have a national system to report and investigate stillbirths. Instead, national stillbirth data come from vital records (in the form of fetal death certificates), which is administered at the state-level. The U.S. Centers for Disease Control and Prevention provides guidance to states for stillbirth reporting; however, stillbirth definitions and the quality of data vary from state-to-state. These data suffer from poor quality: not all stillbirths are registered, not all requested information is provided, and not all information is correct. Since fetal death certificates are often filed weeks before families receive any testing results, the cause of death is rarely noted.

Substantial effort has gone into improving the quality of *birth* certificate data – with great success. Similar efforts, supported with adequate financial and personnel resources, are needed to make progress in improving stillbirth data quality.

We cannot make progress in reducing stillbirth rates if we do not have a clearer picture as to why babies are dying. Better data will ultimately help us to understand the underlying causes of stillbirth and help guide prevention strategies. **With better data, the U.S. will have better outcomes.**

## **Stillbirth: Hidden in the Shadows**

There are several reasons why stillbirth hasn't received the public health attention and action that it deserves, and two of these reasons stem from dangerous misconceptions about stillbirth: a belief they don't happen often in the U.S., or that when they do, they were inevitable and linked to some genetic abnormality. We know that at least one in four stillbirths are preventable, and genetic causes are known to only account for about 10% of stillbirths. If the U.S. could match the stillbirth rates of countries with the lowest stillbirth rates, as many as 75% of stillbirths could be prevented.

For many families, finding out why their baby has died is of the utmost importance—for closure, to help address immediate health needs of the mother, and to provide guidance on how to manage subsequent pregnancies. Unfortunately, as many as *half* of stillbirths have no identified cause of death: that is over 10,000 families annually enduring the tragic death of their child, with no answers as to why they died. This is unacceptable.

**The first time someone hears of stillbirth, should not be when they are on the receiving end of this life-changing, devastating news.** Sadly, this is the case more often than not.

The stigma surrounding stillbirth is both harmful to families experiencing loss and hinders public health efforts to prevent future tragedies. Many families are led to believe that they will bring home a healthy baby once they have cleared the first trimester, but for tens of thousands of families every year in this country, that's not true. Most are aware of the realities of miscarriage, but stillbirth is rarely discussed. Pregnant moms are rarely educated about stillbirth, let alone the warning signs that something could be wrong with their baby. The laundry list of dos and don'ts that expectant parents receive during pregnancy tell them what to do to "protect their baby," but never explain what they are protecting them *from*; stillbirth is left out of these messages. Knowledge is power. Healthcare providers must empower parents with the information that they need to better understand the risks and realities of stillbirth and evidence-based recommendations on monitoring pregnancies to prevent stillbirths.

It is because of these gaps in data quality and awareness that the stillbirth rate has remained frustratingly stable for the twelve plus years since Autumn was born still. Even more disappointing is the stark contrast to the improvements and advancements in obstetrical and neonatal care that have greatly reduced infant mortality.

Research has shown that there is a tremendous return on investment for reducing stillbirths. Efforts to improve stillbirth rates will also lead to a reduction in maternal morbidity and mortality, as well as other complications of the newborn. To put it simply: it's a win/win.

## **The Solution: The SHINE for Autumn Act**

Stillbirth rates have remained the same over the past 30 years —efforts are much needed and long overdue. With increased awareness, better education, enhanced data collection, and dedicated resources, we can achieve the goals that stillbirth advocates, health providers, and researchers have been working towards for far too long.

Congress, and the public, must recognize that with minimal investment we *can* do something about stillbirth right now— with the bipartisan and bicameral Stillbirth Health Improvement and

Education (SHINE) for Autumn Act, H.R. 5012/S. 2647. SHINE would create the first comprehensive, federal-state partnership to reduce the incidence of stillbirth in the United States. This vital piece of legislation *aims to lower the staggering rate of stillbirth* by taking critical steps to invest in research, training for perinatal pathologists, education and awareness, and improved data collection required to better understand stillbirth so that we can begin to identify strategies for prevention. SHINE is the beginning of a longer-term solution towards the prevention of U.S. stillbirths.

As you may recall, incredible progress was made in the 117<sup>th</sup> Congress when the SHINE for Autumn Act (H.R. 5487) passed the House of Representatives, *under suspension*, with overwhelming support (**408-18**) in 2 months' time— highlighting both the urgency and bipartisan nature of this issue.

It was also tremendously validating having the Eunice Kennedy Shriver National Institute of Child Health and Human Development's Stillbirth Working Group's [final report](#), which was published in March 2023, call for improved efforts around the quality of data collected, more research, and increased awareness and education; which are all the exact elements that the SHINE for Autumn Act would address.

The SHINE for Autumn Act would put us on a path to begin tracking the U.S. stillbirth crisis and identifying opportunities to prevent future deaths. With minimal investment, the bill's provisions for increased awareness and education, improved data collection, and more research can begin to seek long-term solutions for stillbirth prevention. Without progress in these areas, the U.S. will remain greatly limited in its understanding of stillbirth causes, and what can be done to combat this crisis. Passage of the comprehensive SHINE for Autumn Act is a critical step forward in this noncontroversial, life-saving work.

## Closing

Despite my best efforts to sound the alarm on the U.S. stillbirth crisis since Autumn died, over 300,000 babies have been stillborn. That is **600,000** more parents that have endured the same devastating, life-altering pain; **600,000** parents who anticipated the birth of their child, only to grieve their death. **600,000** parents who celebrated their pregnancies with family and friends, assembled cribs, installed car seats, spent months anxiously and excitedly awaiting the arrival of their baby, only to leave the hospital with a small box of mementos and a pamphlet on grief. With each passing day, the number of babies lost to stillbirth continues to rise.

For the past twelve years, I have dedicated my life to raising stillbirth awareness, tirelessly advocating for change, and pushing for action. While the pain of losing Autumn will never fully heal, I find solace knowing that our tragedy can serve as a catalyst for positive change, and that through my efforts, I can protect other families from experiencing the same heartbreaking devastation.

My healing journey led me to stillbirth advocacy. It has provided me and countless others the opportunity to channel our heartache and pain into undeniable purpose. The bereaved families that make up the growing U.S. stillbirth community, are fiercely committed to breaking the silence that plagues stillbirth and to creating meaningful change in honor their baby and all babies gone too soon. We hope more than anything, that 2024 is the year the SHINE for Autumn

Act finally becomes law; for Autumn, all other babies lost too soon, their families, and future families.

To that end, please join me in putting stillbirth on the map in the United States. Stillbirth will never be made a priority issue without the leadership of Congress. Your support is truly invaluable in making a significant difference in the lives of countless families nationwide.

I strongly commend the bipartisan support for the SHINE for Autumn Act and look forward to working with the Committee to advance this lifesaving comprehensive bill. Thank you again for including SHINE in today's hearing and for the opportunity to provide written testimony.

Sincerely,

Debbie Haine Vijayvergiya, Autumn's mom



2834 Colorado Ave, Suite 100  
Santa Monica, CA 90404

February 13, 2024

The Honorable Susan Wild  
The Honorable Jen Kiggans  
U.S. House of Representatives  
Washington, D.C. 20515

The Honorable Buddy Carter  
The Honorable Debbie Dingell  
U.S. House of Representatives  
Washington, D.C. 20515

Dear Representatives Wild, Kiggans, Carter and Dingell,

FIGS is a founder-led, direct-to-consumer healthcare apparel company that seeks to celebrate, empower and serve current and future generations of healthcare professionals. We are fortunate to have 2.6 million healthcare professionals as customers—we call them “Awesome Humans” because they are the very best among us. It is in the spirit of serving them that we write to express our deep appreciation to you for your leadership in introducing the *Dr. Lorna Breen Health Care Provider Protection Reauthorization Act* (H.R. 7153). The original Act and this reauthorization importantly recognize – and seek to address – the incredible stress that the nation’s healthcare workforce is under – strain from which they have been suffering since long before the COVID-19 pandemic. FIGS is pleased to support this important measure.

When Congress enacted the *Dr. Lorna Breen Health Care Provider Protection Act* almost two years ago, it created grants to improve mental health services and supports for healthcare professionals. Under the Act, the Health Resources and Services Administration has awarded \$103 million awards through 45 grants across the country. These grants are funding important efforts in rural and underserved communities to help establish a culture of mental wellness among healthcare workers to ensure that those caring for the nation’s patients are caring for themselves too. These initiatives are important first steps. Yet, the nation’s healthcare workers are uniquely burdened by endless new administrative requirements that take them away from patient care. As such, we very much appreciate that your measure expands the types of entities eligible for grants and contract to include those that “focus on the reduction of administrative burden on health care workers.”

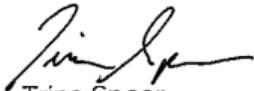
We stand ready to work with you and your colleagues to ensure that H.R. 7153 is enacted this year. However, we believe that much more needs to be done given the U.S. Surgeon General’s [assessment](#) of “the long-standing crisis of burnout, exhaustion, and moral distress across the health community.” **We feel strongly that Congress must take a comprehensive approach to solving the healthcare workforce shortage problem at its root causes.** Therefore, we call upon you and your colleagues to take additional steps specific to improving healthcare workers’ mental health including:

- Establish a national epidemiologic tracking program to measure health worker and learner well-being, distress, and burnout, as called for in the National Academy of Medicine’s (NAM) [National Plan for Health Workforce Well-Being](#),
- Expand funding for mental health programs at the HRSA including:

- Promoting Resilience and Mental Health Among Health Professional Workforce
- Health and Public Safety Workforce Resiliency Training Program
- Health and Public Safety Workforce Resiliency Technical Assistance Center
- Incentivize states to end punitive policies for healthcare workers seeking mental health care, particularly when it comes to credentialing, licensing and accreditation.
- Study the impact of the intense demands on medical residents and consider incentivizing Graduate Medical Education (GME) programs to reduce alarming levels of resident burnout.

Thank you for your commitment to helping protect and improve the mental well-being of our healthcare professionals. We look forward to working with you on passage of the *Dr. Lorna Breen Health Care Provider Protection Reauthorization Act* to reduce and prevent suicide, burnout, and behavioral health disorders among our nation's healers. We welcome the opportunity to work with you on this and other efforts to support our healthcare workforce. If we can be of any assistance to you and your staff on this or other matters, please do not hesitate to contact Jordan Vivian, FIGS Director of Advocacy ([jjvivan@wearfigs.com](mailto:jjvivan@wearfigs.com), 310-504-3709 Ext. 824).

Sincerely,



Trina Spear  
Co-Founder and CEO  
FIGS, Inc.

CC: Members of the House Energy and Commerce Health Subcommittee



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**Congress of the United States**  
**House of Representatives**  
**Washington, DC 20515-4209**

COMMITTEE ON THE JUDICIARY

COMMITTEE ON TRANSPORTATION  
AND INFRASTRUCTURE

COMMISSION ON SECURITY AND  
COOPERATION IN EUROPE (U.S.  
HELSINKI COMMISSION)

**Testimony in Support of H.R. 7224, the Stop, Observe, Ask, and Respond (SOAR) to  
Health and Wellness Reauthorization Act of 2024**

**House Committee on Energy and Commerce's Subcommittee on Health  
"Legislative Proposals to Support Patients and Caregivers"**

**February 14, 2024**

I would like to thank the Chair and Ranking Member of this Subcommittee for including the Stop, Observe, Ask and Response (SOAR) to Health and Wellness Reauthorization Act in today's legislative hearing.

I sponsored the Stop, Observe, Ask, and Respond (SOAR) to Health and Wellness Act, which was signed into law on December 31, 2018. This bill authorized a program known as 'Stop, Observe, Ask and Respond to Health and Wellness Training' to train health care professionals to identify and assist victims of human trafficking, and help close the gap in health care settings without plans for treating trafficking victims. The training teaches health care providers at all levels so that they can:

- Identify potential human trafficking victims;
- Implement protocols and procedures for working with law enforcement to report and facilitate communication with human trafficking victims;
- Implement best practices for referring victims to health care and social or victims service agencies or organizations; and,
- Provide victims care that is coordinated, age-appropriate, culturally relevant, trauma-informed, patient-centered, and evidence-based.

The program has been successful. Between September 2017 and September 2023, the Office of Trafficking in Persons hosted 222 events through which they trained 263,157 health care professionals. After receiving the training, 91.4% of the participants indicated that they had "high" or "very high" confidence in their ability to identify and respond to human trafficking.

The SOAR to Health and Wellness Program has made tremendous strides to train health care workers on the signs of human trafficking and appropriate steps to take once a victim has been identified. As Members of Congress, we should continue to support this program so that more people can be trained to properly assist victims of human trafficking.

I commend those who have overseen the SOAR to Health and Wellness Program over the past few years and request the support of the members of this subcommittee for the reauthorization of this program through the passage of my bill, that I was pleased to introduce with Representatives Ann Wagner, Tony Cardenas and Buddy Carter. I appreciate your consideration of this important legislation.

The Honorable Anna Eshoo and The Honorable Brett Guthrie

House Energy and Commerce, Subcommittee on Health

February 11, 2024

Dear Representatives Eshoo and Guthrie,

I am writing to express my support for the BOLD Infrastructure for Alzheimer's Act and The National Alzheimer's Project Act, both of which are due for reauthorization. To continue to make progress towards a world without Alzheimer's, your support and leadership are needed to change the trajectory of this life altering disease.

My family is one of the millions of families directly impacted by this devastating diagnosis. My husband Chris was 51 years old when he was diagnosed with Younger Onset Alzheimer's. In that moment our lives were changed in a way that can never be adequately summed up in words. Our son was just graduating High School, we were both working full time and had a rich and fulfilling life with family and friends. We worked hard to achieve the American Dream. Chris was a retired law enforcement officer, and I was a social worker working with elementary special education students. My husband was a dynamic and vibrant man who loved the outdoors: mountain biking, camping, fishing, and hiking the Adirondack High Peaks were his favorite activities.

As Chris's Alzheimer's has decreased his ability to live fully independently, I had to leave my full-time job and work part time. I became a caregiver at the age of 51. Nothing prepares you to watch your husband slowly lose his memory and his future. Despite all the challenges that come with Alzheimer's, we have benefitted directly from the programs that are up for reauthorization. We were fortunate to have two Centers for Alzheimer's Excellence within an hour of our home. Chris was diagnosed early in his disease because of the high-quality care we received at this Center. This is no small thing. We were afforded more time to live out some of our dreams: dreams we planned for our retirement that will no longer be a part of our future. The support I received as a caregiver was a life changing measure that was a direct result of the funding our Center received. Their support for families is one of the six goals of the NAPA Act.

Living with a terminal illness without a cure is something that no family should ever have to go through. But if my voice can raise awareness of why these legislations are so important in the fight to end Alzheimer's, then something good will have come from our grief and pain. I want to see a world where my son will not have to face the same devastating loss of his memory, his ability to live independently and then the inevitable loss of his life due to Alzheimer's.

I urge you and your colleagues to continue to fight for families across the United States who find themselves watching their parents, siblings, spouses, and adult children succumb to this horrific disease. This is why The NAPA and BOLD Acts need to be reauthorized: so future generations will have hope for a cure. I have hope that the first survivor is out there, and you can help make that happen. Thank you for being at the forefront of this important legislation.

Sincerely,

Cheri Davies    Moreau, New York

**Susan G. Komen**

Statement of Molly Guthrie, Vice President of Policy and Advocacy

Prepared For

the House Energy and Commerce Subcommittee on Health

hearing titled

“Legislative Proposals to Support Patients and Caregivers”

February 14, 2024

Susan G. Komen (Komen) is the world’s leading nonprofit breast cancer organization representing the millions of Americans who have been diagnosed and are living with breast cancer. Komen has an unmatched, comprehensive 360-degree approach to fighting this disease across all fronts – we advocate for patients, drive research breakthroughs, improve access to high-quality care, offer direct patient support and empower people with trustworthy information. Komen is committed to supporting those affected by breast cancer today, while tirelessly searching for tomorrow’s cures. We advocate on behalf of the estimated 313,510 people in the United States who will be diagnosed with breast cancer and the almost 44,000 who will die from the disease in 2024 alone. **Komen is grateful for the inclusion of the Screening for Communities to Receive Early and Equitable Needed Services (SCREENS) for Cancer Act (H.R.3916/S.1840) in this legislative hearing and requests that the Subcommittee and full Committee soon hold markups of the legislation so that it can proceed to the House floor for a vote.**

The bipartisan and bicameral SCREENS for Cancer Act reauthorizes the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which provides lifesaving breast and cervical cancer screening, diagnostic and treatment services to low-income, uninsured or underinsured people in all 50 states, the District of Columbia, two U.S. territories, five U.S.-Affiliated Pacific Islands and 13 tribes or tribal organizations. NBCCEDP also provides patient navigation services to help them overcome barriers and get timely access to quality care. It is time for Congress to act and recommit to this legacy program and the access to early detection it provides.

Since its founding in 1991, NBCCEDP has served more than 6.2 million people detecting nearly 78,000 invasive breast cancers, more than 24,000 premalignant breast lesions, more than 5,000 cervical cancers, and over 240,000 premalignant cervical lesions. The program, which is a partnership between the Centers for Disease Control and Prevention (CDC) and state health departments, provides public education, outreach, patient navigation and care coordination to increase breast and cervical cancer screening rates and reach underserved, vulnerable populations. More statistics on the number of women served by the program in each state are available [here](#).

A reauthorization of the NBCCEDP remains as crucial as ever as the nation continues to recover from the COVID-19 pandemic and is experiencing the effects of the Medicaid unwinding. Last reauthorized in 2007, NBCCEDP has a legacy of reaching underserved populations and providing high-quality care, giving people across the country access to needed breast and cervical health services. NBCCEDP funding supports interventions which help address inequities in cancer screening and diagnosis, placing special

emphasis on women who are geographically or culturally isolated or who identify as racial or ethnic minorities.

The COVID-19 pandemic highlighted the broad systemic trends that exist within almost every public health crisis: consequences disproportionately affect and are more severely experienced in low-income, underserved and marginalized communities. Black women in the United States have a breast cancer mortality rate about 40% higher than white women. Similarly, Hispanic/Latina and American Indian/Alaska Native women are 30% more likely to be diagnosed with advanced stage breast cancer compared with white women. NBCCEDP focuses on factors at the interpersonal, organizational, community and policy levels that influence screening access. This approach is particularly useful as grantees can serve a wide variety of communities from remote, rural communities to urban population centers and are able to navigate differing needs.

Additionally, data show that the COVID-19 pandemic has caused people to delay or forego life-saving cancer screenings, which will lead to more advanced cancers, and increase related mortality. At the beginning of the pandemic, screenings declined by over 80%<sup>i</sup> and for breast and cervical cancer, studies show that screening prevalence decreased by 6% and 11%, respectively, between 2018 and 2020.<sup>ii</sup> Research suggests that those postponed breast screenings appeared to disproportionately affect women of color: Non-Hispanic white women had 17% fewer breast cancer diagnoses, while the year-over-year decline was 53% for Asian women, 43% for Hispanic women, and 27% for Black women.<sup>iii</sup> Data released as recently as earlier this month<sup>iv</sup> confirm that the decline in screening rates persisted throughout the pandemic and rates have still not returned to normal levels.

Exacerbating the problem, last year states began redetermining eligibility for Medicaid and disenrolling individuals for the first time since the start of the COVID-19 public health emergency. As of February 1, 2024, the KFF Medicaid Enrollment and Unwinding Tracker shows that over 16 million individuals have lost Medicaid coverage and many of those individuals would depend on access to the services provided by the NBCCEDP should they become uninsured or underinsured as a result.

The NBCCEDP has a long road ahead of not only reaching new populations that may have become eligible for services due to these factors, but also retaining those who were already eligible but may not have returned yet for regular screening. The SCREENS for Cancer Act will help address these alarming trends.

The legislation would provide greater flexibility to NBCCEDP grantees, allowing for a deeper emphasis on implementing innovative, evidence-based interventions and aggressive outreach to underserved communities through media, peer educators and patient navigators. Current requirements regarding how NBCCEDP grantees can utilize money are outdated and reflect practices that were successful when the program was last reauthorized in 2007. Much has changed in how we approach cancer screening and how we approach communities in the last 17 years and the statutory authorization needs to be modernized to reflect those changes.

The flexibilities called for in the SCREENS for Cancer Act will allow NBCCEDP grantees to implement evidence-based and evidence-informed strategies, such as the utilization of social media and patient navigators to reach underserved populations in their state, that are the most appropriate for their own communities. The needs of a rural community may differ greatly from those of a more urban setting and NBCCEDP grantees should have the ability to respond to those dynamic needs.

The SCREENS for Cancer Act not only benefits those eligible to receive services but all the communities across the country who are served by NBCCEDP. The availability of the NBCCEDP impacts every taxpayer and individuals in every congressional district, as the uninsured will eventually seek care at our states' hospitals with later-stage disease, putting an even greater strain on the patients, the health system and government budgets. NBCCEDP is key to ensuring that low-income, uninsured and underinsured women across the country maintain access to vital screening services, health education and patient navigation services, as well as enabling proper monitoring of state and local breast cancer patterns and trends.

Early detection is a sound investment and the SCREENS for Cancer Act preserves access to vital public health infrastructure that has a 30-year track record of improving cancer screening rates in vulnerable populations. Reauthorizing NBCCEDP will enable cancer screening in underserved communities, leading to more people being screened, more cancers being diagnosed at earlier stages and ultimately better outcomes for people at lower costs for our health care system.

After a long lapse, we urge the Committee to exercise its authority to reauthorize NBCCEDP. The SCREENS for Cancer Act allows us all to recommit to the investment and determination required to actualize the promise of early cancer detection for all patient populations. Komen thanks Representatives Morelle and Fitzpatrick for leading the SCREENS for Cancer Act and the additional 44 members of the House of Representatives who have co-sponsored the legislation, including the four bipartisan members of the Energy & Commerce Committee. We stand ready to assist the Subcommittee, full Committee, and Congress in moving the SCREENS for Cancer Act forward.

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<sup>i</sup> Alexander M. Norbash. Early-Stage Radiology Volume Effects and Considerations with the Coronavirus Disease 2019 (COVID-19) Pandemic: Adaptations, Risks, and Lessons Learned. *J Am Coll Radiol*. 2020 Sep;17(9):1086-1095. doi: 10.1016/j.jacr.2020.07.001. Epub 2020 Jul 9. PMID: 32717183; PMCID: PMC7346772; and Hummy Song. Disruptions in preventive care: Mammograms during the COVID-19 pandemic. *Health Serv Res*. 2021 Feb;56(1):95-101. doi: 10.1111/1475-6773.13596. Epub 2020 Nov 4. PMID: 33146429; PMCID: PMC7839639.

<sup>ii</sup> Linda Wang. Working to Close the Cancer Screening Gap Caused by COVID. National Cancer Institute. May 17, 2022.

<sup>iii</sup> Kathryn P. Lowry. Breast Biopsy Recommendations and Breast Cancers Diagnosed during the COVID-19 Pandemic. *Radiology*. 2022 May;303(2):287-294. doi: 10.1148/radiol.2021211808. Epub 2021 Oct 19. PMID: 34665032; PMCID: PMC8544262.

<sup>iv</sup> Alba, Christopher, ZhaoNian Zheng, and Rishi K. Wadhera. 2024. "Changes in Health Care Access and Preventive Health Screenings by Race and Ethnicity." *JAMA Health Forum* 5 (2): e235058. <https://doi.org/10.1001/jamahealthforum.2023.5058>.



Confronting  
Lung Cancer  
Starts Here

**Statement by Laurie Fenton Ambrose, President & CEO, GO2 for Lung Cancer on H.R. 4534, Women and Lung Cancer Research and Preventive Services Act of 2023 as part of the Legislative Proposals to Support Patients and Caregivers Hearing.**

**Wednesday, February 14, 2024**

**Submitted for the record to the House Energy and Commerce Committee and Subcommittee on Health**

Thank you Committee Chair McMorris Rodgers and Subcommittee Chair Guthrie distinguished members and all who have contributed to the discussions that led to holding today's important hearing that includes H.R. 4535, The Women and Lung Cancer Research & Preventive Services Act of 2023, introduced in the House by Congressman Brendan Boyle (D-PA) and Brian Fitzpatrick (R-PA), on legislative proposals to support patients and caregivers.

On behalf of GO2 for Lung Cancer, the leading national lung cancer organization founded by patients, survivors, and caregivers, we are proud to provide for the record our strongest endorsement of H.R. 4535 and to offer additional comments on the importance of advancing this vital legislation – now – for the tens of thousands of women who are at risk for or have been diagnosed with lung cancer.

Most people are not aware that lung cancer is the leading cause of cancer death in women – more than breast and cervical cancers combined. It is now estimated that every day 162 women die from the disease – one woman every 8.9 minutes. It is also estimated that 234,580 new cases of lung cancer are expected this year, and an estimated 125,070 lives will be lost to the disease. This “hidden” women’s cancer is the least funded cancer, in terms of research dollars per death, of all the major cancers and one of the only cancers where patients are routinely blamed as responsible for their condition.

Reports continue to document how lung cancer develops differently in women and men within many facets of the disease including risk factors, clinical characteristics, progression, and length of survival.

For example, several years ago, a significant study by the National Cancer Institute (NCI) and the American Cancer Society (ACS) published in the [New England Journal of Medicine](#) on May 24, 2018, indicated that the incidence rates of lung cancer among White and Hispanic women born after 1965 are now higher than among their male counterparts, a reversal not correlated to changes in their smoking rates. The lung cancer incidence rates among young African American and Asian women were closer but do not yet exceed those

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of their male counterparts. This NCI-ACS study concluded by calling for more research into this disturbing precedent.

GO2 has witnessed lung cancer's unique and devastating impact on women. We placed an early spotlight on the need for increased research into women and lung cancer. Beginning in 2010, GO2 partnered with The Connors Center for Women's Health and Gender Biology at Brigham and Women's Hospital (BWH) after they released a study, "[Out of the Shadows](#)," which highlights the gaps in current knowledge about lung cancer's lethality, summarizes existing research on sex and gender differences in lung cancer, identifies shortcomings in current research funding that would provide better understanding of these biological differences, and recommends steps to reduce the burden of this disease in women and men.

In 2016, BWH released an updated report, "[Lung Cancer: A Women's Health Imperative](#)," as a follow-up to bring lung cancer in women "Out of the Shadows." This report brought even greater awareness of the need for a national strategy to address the study of sex- and gender-specific aspects of the disease. The report was released at a Congressional briefing on Women and Lung Cancer hosted by the Lung Cancer Alliance (now known as GO2 for Lung Cancer) in coordination with the Congressional Lung Cancer Caucus and ultimately became the basis of the bi-partisan, bi-cameral Women and Lung Cancer Research and Preventive Services Act, first introduced in 2016 and re-introduced in 2023.

It is our hope through H.R. 4534, the Women and Lung Cancer Research and Preventive Services Act of 2023, we will gain a better understanding of the roles that genetic, hormonal, behavioral, and environmental factors play in this lethal disease, uncover differences in incidence, prevalence, and survivability to identify treatment responses between men and women.

Increasing basic and clinical research knowledge of the disease will make the public aware of the vital need to create a national strategy that accelerates implementing lung cancer screening for women and bridge the gaps in lung cancer innovations.

Thank you for the opportunity to submit written testimony in support of people living with lung cancer. We share the obligation to serve the public and we stand ready to assist the committee and our bill sponsors to advance this legislation to passage, in this session of the 118<sup>th</sup> Congress.

Laurie Fenton Ambrose  
President & CEO  
GO2 for Lung Cancer



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February 14, 2024

The Honorable Brett Guthrie  
Chair  
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Subcommittee on Health  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Anna Eshoo  
Ranking Member  
Committee on Energy and Commerce,  
Subcommittee on Health  
U.S. House of Representatives  
Washington, DC 20515

Chairman Guthrie and Ranking Member Eshoo,

Today's hearing to analyze my bill, the Women and Lung Cancer Research and Preventative Services Act of 2023, is a step in the right direction for the estimated 234,580 Americans that will be diagnosed with lung cancer in 2024. I thank you for your strong leadership on this important issue. I have devoted much of my time in Congress to defeating this deadly disease and raising awareness for early screenings and diagnosis. I look forward to the opportunity to advance this legislation and continue efforts to address the ongoing health disparity.

The Women and Lung Cancer Research and Preventative Services Act of 2023 would require the Secretary of Health and Human Services, in consultation with the Secretary of Defense and Secretary of Veterans Affairs, to conduct an interagency review to evaluate research on women and lung cancer, access to lung cancer preventive services and conduct public awareness campaigns on lung cancer.

Despite the remarkable progress made by the medical community in preventing and treating lung cancer in recent decades, there exists a concerning disparity, particularly affecting women. Every 8.8 minutes, a woman in the U.S. loses her life to lung cancer. The decline in lung cancer rates among women lags behind that of men. This bill signifies a crucial stride toward ensuring that all Americans, regardless of gender, are shielded from the harrowing impact of this disease. The time has come for the federal government to confront this issue head-on, employing focused research and decisive action to address the urgent demands it presents.

Thank you again for your leadership on the important health matters that will be addressed in today's hearing. I am hopeful this is a step forward in a long journey of reducing instances of lung cancer and saving the lives of countless Americans.

Sincerely,

A handwritten signature in blue ink that reads "Brendan F. Boyle".

Brendan F. Boyle  
Member of Congress



Health Education, Advocacy, Linkage  
Because Human Trafficking is a Health Issue  
HEALTrafficking.org

**Statement to the Committee on Energy and Commerce, Subcommittee on Health  
In support of H.R. 7224, to reauthorize the Stop, Observe, Ask, and Respond (SOAR) to Health  
and Wellness Training Program**

***Reps. Cohen, Wagner, Cárdenas, and Carter***

**Written Testimony Hanni Stoklosa, MD, MPH**

**Chief Medical Office, co-founder, HEAL (Health, Education, Advocacy, and Linkages) Trafficking  
Emergency Physician, Brigham and Women's Hospital, Harvard Medical School**

The following testimony comes from a combination of my experiences on the frontlines of health care, the emergency department, as well as my national vantage point as Chief Medical Officer and co-founder of HEAL Trafficking.

*Juan, a laborer worked 19 hours a day to repay an insurmountable debt to his employer. When he fell off a 10-foot platform on a construction job, he broke his back. Emergency physicians treated him with painkillers but overlooked the fact that he was chronically malnourished with signs and symptoms of tuberculosis.*

*Kia, a 17-year-old went to an emergency department with a gunshot wound to the leg. Her male companion told the provider it was the result of a drive-by shooting. No further questions were asked about the cause.*

These are real-life stories of patients in the United States who were medically treated, but their human trafficking victimization was not “seen” by health professionals. (<https://www.aamc.org/news-insights/physicians-can-play-crucial-role-identifying-human-trafficking-victims>)

The majority of trafficked people in the United States access healthcare while being exploited.

What this means is that health care professionals must be equipped to respond when a victim comes through its doors. **The Stop, Observe, Ask, and Respond (SOAR) to Health and Wellness Training Program has been and continues to be vital in educating health professionals on how to respond to human trafficking.**

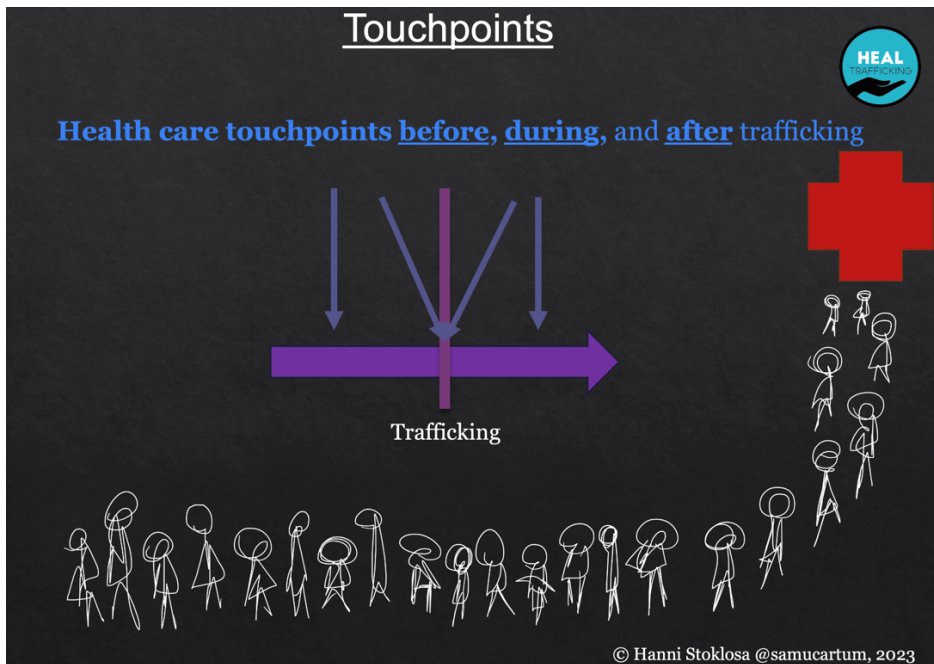
**About HEAL Trafficking**

For over a decade, HEAL Trafficking has led innovative health solutions to eradicate human trafficking in our communities worldwide. We do this through high level training and technical assistance and community building among practitioners. HEAL Trafficking's network encompasses over 4000 trafficking survivors and multi-disciplinary professionals in 50 countries. HEAL Trafficking brings together physicians, advanced practice clinicians, nurses, dentists, emergency medical services (EMS) personnel, psychologists, counselors, public health workers, health educators, researchers, clinical social workers, administrators, and other health professionals who work with and advocate for the health of survivors of human trafficking.

**Why educate health professionals on human trafficking? Trust and Touchpoints**

**Trained health professionals are the most powerful force to end human trafficking.** While trafficking survivors may have contact with other professions, such as law enforcement, they are unlikely to trust them. The majority of trafficked people in the United States access healthcare while being exploited. In fact, based on 2020-2023 data, National Human Trafficking Hotline data hears from more from Mental Health and Medical

Professionals than any other professional industry other than NGO representatives.



### **Why SOAR?**

Clinical responses to human trafficking are complex and nuanced. Real harm can occur to trafficking victims if health professionals are not properly trained. ([https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)32453-4/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32453-4/fulltext)) Therefore, it is not enough for all health professionals to be simply aware of trafficking, but rather they must be empowered with skills to provide education to patients, assess for trafficking, and to care for trafficked persons. Educating clinicians about trafficking is about training them to translate knowledge into practice with the ultimate goal of improving the health and well-being of trafficked persons.

The Stop, Observe, Ask, and Respond (SOAR) to Health and Wellness Training Program which is administered under the Administration for Children & Families (ACF), U.S. Department of Health & Human Services, helps accomplish just that. HEAL Trafficking, an initial advisor on SOAR curriculum content and design can attest to the essential resource it provides. SOAR serves as a high quality, free, continuing education resource for health professionals on trafficking that helps to bridge the gap between the millions of practicing clinician who have and have not been trained on trafficking. Moreover, it is easy to access by health professionals everywhere, whether they are practicing in a large urban hospital in Tennessee, a rural community health center in California, or a critical access emergency department in Missouri. Every health professional in the country can access the SOAR curriculum.

### **Why SOAR reauthorization?**

Every day, trafficking victims are coming through the doors of clinics and hospitals. Opportunities to intervene are being missed because not all health professionals have yet been trained on trafficking. The SOAR to Health and Wellness Training Program helps empower millions of health professionals across the United States with high quality training that can **literally save lives**.

*The opinions and conclusions expressed in this testimony are the author's alone and should not be interpreted as representing those of Mass General Brigham, Brigham and Women's Hospital or Harvard Medical School.*