**February 14, 2024**

House Committee Hearing

Energy and Commerce: Health Subcommittee

**Legislative Proposals To Support Patients And Caregivers**

On Wednesday, February 14, 2024, the House Energy and Commerce Committee, subcommittee on health, met to address legislative proposals that support patients and caregivers. Chair Cathy McMorris Rodgers (R-WA) and Subcommittee on Health Chair Brett Guthrie (R-KY) convened the hearing to address 19 bipartisan bills that support patients, caregivers, and healthcare providers.

“We’ll look at legislation to continue support for emergency medical services and health care providers, to reauthorize respite care resources for family caregivers…”, said Chair McMorris Rodgers.

The committee outlined the importance of informing policymakers on current programs that are providing positive results while filling gaps that exist and need to be addressed to improve access to high-quality levels of care.

“The bills in front of us today are designed to promote greater and improved access to care for Americans and their families. They are also complementary to our work on lowering healthcare costs for all Americans…”, said Rep. Guthrie.

Expert witnesses brought testimony on diverse issues and diseases including Cardiology, Alzheimer's, Down Syndrome, Cancer, Rural Health, Ambulatory care, and more.

Guthrie continued, “We’re considering legislation that will continue programs to detect, diagnose, and treat chronic diseases and health conditions at earlier stages, improve the quality of life for individuals with disabilities, help ensure Americans in rural communities have access to life-saving care, and provide additional resources to assist in the development of cutting-edge treatments for debilitating health conditions. “

Below is a listing of each of the bills addressed during the hearing:

* [H.R. 6160](https://d1dth6e84htgma.cloudfront.net/H_R_6160_Molinaro_Cardenas_55925ad00a.pdf), *To amend the Public Health Service Act to reauthorize a lifespan respite care program* (Reps. Molinaro and Cárdenas)
* [H.R. 7208](https://d1dth6e84htgma.cloudfront.net/H_R_7208_Pascrell_978a3ddaa2.pdf), *To reauthorize the Traumatic Brain Injury program* (Reps. Pascrell and Bacon)
* [H.R. 7251](https://d1dth6e84htgma.cloudfront.net/H_R_7251_Chavez_De_Remer_d1cc62d148.pdf), *To amend the Public Health Service Act to reauthorize certain poison control programs* (Reps. Chavez-DeRemer, J. Joyce, Davis, and Cherfilus-McCormick)
* [H.R. 7153](https://d1dth6e84htgma.cloudfront.net/H_R_7153_Wild_b4be03cdd5.pdf), *To reauthorize the Dr. Lorna Breen Health Care Provider Protection Act, and for other purposes* (Reps. Wild and Kiggans)
* [H.R. 6960](https://d1dth6e84htgma.cloudfront.net/H_R_6960_Carter_Castor_ea48317f74.pdf), Emergency Medical Services for Children Reauthorization Act of 2024 (Reps. Carter and Castor)
* [H.R. 4646](https://d1dth6e84htgma.cloudfront.net/H_R_4646_Joyce_Dingell_d63894102a.pdf), *SIREN Reauthorization Act* (Reps. D. Joyce and Dingell)
* [H.R. 7213](https://d1dth6e84htgma.cloudfront.net/H_R_7213_C_Smith_5c5b7b16a1.pdf), *Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024* (Reps. C. Smith and Cueller)
* [H.R. 7189](https://d1dth6e84htgma.cloudfront.net/H_R_7189_Bilirakis_92eb3fb0fd.pdf), *Congenital Heart Futures Reauthorization Act of 2024* (Reps. Bilirakis, Soto, Carter, Schiff, Salazar, and Cárdenas)
* [H.R. 7218](https://d1dth6e84htgma.cloudfront.net/H_R_7218_Guthrie_8c8b472b08.pdf), *Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act of 2024* (Reps. Guthrie, Tonko, C. Smith, and Waters)
* [H.R. 2706](https://d1dth6e84htgma.cloudfront.net/H_R_2706_Cammack_Dingell_87b88b0eb7.pdf), *Charlotte Woodward Organ Transplant Discrimination Prevention Act* (Reps. Cammack and Dingell)
* [H.R. 620](https://d1dth6e84htgma.cloudfront.net/H_R_620_Smith_Tonko_8a05715ec9.pdf), *Alzheimer’s Accountability and Investment Act* (Reps. C. Smith, Tonko, and Waters)
* [H.R. 619](https://d1dth6e84htgma.cloudfront.net/H_R_619_Tonko_Smith_6a224d92d7.pdf), *NAPA Reauthorization Act* (Reps. Tonko, C. Smith, and Waters)
* [H.R. 6829](https://d1dth6e84htgma.cloudfront.net/H_R_6829_Pallone_c933e0f9da.pdf), *Cardiomyopathy Health Education, Awareness, Research, and Training in the Schools (HEARTS) Act of 2023* (Reps. Pallone and A. Kim)
* [H.R. 7224](https://d1dth6e84htgma.cloudfront.net/H_R_7224_Cohen_68dc27331f.pdf), *To amend the Public Health Service Act to reauthorize the Stop, Observe, Ask, and Respond to Health and Wellness Training Program* (Reps. Cohen, Wagner, Cárdenas, and Carter)
* [H.R. 7300](https://d1dth6e84htgma.cloudfront.net/H_R_F2_F_Reauth_Sherrill_75bb2ba145.pdf), *Reauthorization of the Family-to-Family Health Information Centers* (Reps. Sherrill and De La Cruz)
* [H.R. 7268](https://d1dth6e84htgma.cloudfront.net/H_R_INCLUDE_Rodgers_78026379c3.pdf), *DeOndra Dixon INCLUDE Project Act of 2024* (Reps. McMorris Rodgers, DeGette, Cole, and Holmes Norton)
* [H.R. 5012](https://d1dth6e84htgma.cloudfront.net/H_R_5012_Kim_Castor_6807699a39.pdf), *SHINE for Autumn Act of 2023* (Reps. Y. Kim, Castor, D. Joyce, and Kelly)
* [H.R. 3916](https://d1dth6e84htgma.cloudfront.net/H_R_3916_Morelle_73fc7c58c4.pdf), *SCREENS for Cancer Act of 2023* (Reps. Morelle and Fitzpatrick)
* [H.R. 4534](https://d1dth6e84htgma.cloudfront.net/H_R_4534_Boyle_a0ba6193f9.pdf), *Women and Lung Cancer Research and Preventive Services Act of 2023* (Reps. Boyle and Fitzpatrick)

Each of the key witnesses portrayed the importance of continuing to fund, support, and build upon programs that support these vulnerable populations.

Listing of Key Witnesses in Speaking Order:

**Dr. Andy Shih, PhD**

Chief Science Officer

Autism Speaks

**Mr. Corey Feist, JD, MBA**

Co-Founder and CEO

Dr. Lorna Breen Heroes' Foundation

**Dr. Joanne Pike, DrPH**

President and CEO

Alzheimer's Association

**Dr. Gordon Tomaselli, MD**

Former President, American Heart Association; Marilyn and Stanley M. Katz Dean, Emiritus and Professor of Medicine, Albert Einstein College of Medicine; Adjunct Professor of Medicine, Johns Hopkins University School of Medicine

**Ms. Michelle Whitten**

President, CEO, and Co-Founder

Global Down Syndrome Foundation

**Mr. Randy Strozyk**

President

American Ambulance Association

**Dr. Christina Annunziata, MD, PhD**

Senior Vice President of Extramural Discovery Science

American Cancer Society

**Dr. Andy Shih, PhD:** In his testimony, Dr. Shih from Autism Speaks, highlighted the significant progress in the growth and understanding of autism over the past two decades. Numbers continue to grow with 1 in 36 children and 1 in 45 adults being diagnosed as falling on the autism spectrum. Dr. Shih documented disparities in healthcare, daily life support, services, and employment opportunities faced by autistic individuals, attributing this information to research funded by the [Autism CARES Act](https://www.congress.gov/bill/118th-congress/senate-bill/1333?q=%7B%22search%22%3A%22autism+cares+act%22%7D&s=3&r=1). Dr. Shih praised the Act for being a crucial driver of research investment and training programs, leading to advancements in understanding autism's biology and medical complexities. He urged the Committee to reauthorize the Autism CARES Act, emphasizing the need to address remaining gaps, reduce disparities, and support autistic individuals throughout their lives.

**Mr. Corey Feist, JD, MBA:** Corey Feist, CEO and co-founder of the [Dr. Lorna Breen Heroes’ Foundation](https://drlornabreen.org/), addressed the committee to advocate for the reauthorization of the Dr. Lorna Breen Health Care Provider Protection Act ([H.R. 7153](https://www.congress.gov/bill/118th-congress/house-bill/7153?q=%7B%22search%22%3A%22H.R.+7153%22%7D&s=1&r=1)). The foundation's mission is to reduce burnout among healthcare professionals and promote their well-being. However, despite progress, millions of health workers still lack access to mental health support due to systemic issues in the healthcare system. H.R. 7153 aims to address burnout, prevent suicide, and improve mental health conditions among health workers and is considered a lifeline for health workers and the future of healthcare in the country.

**Dr. Joanne Pike, DrPH:** Joanne Pike, President and CEO of the Alzheimer’s Association and CEO of the Alzheimer’s Impact Movement, highlighted the urgency of addressing the impact of Alzheimer’s on over 6 million Americans and their caregivers, emphasizing the need for reauthorizing critical legislation. Dr. Pike discussed the bipartisan NAPA Reauthorization Act ([H.R. 619](https://www.congress.gov/bill/118th-congress/house-bill/619?q=%7B%22search%22%3A%22NAPA+Reauthorization+Act%22%7D&s=2&r=2)/[S. 133](https://www.congress.gov/bill/118th-congress/senate-bill/133?q=%7B%22search%22%3A%22NAPA+Reauthorization+Act%22%7D&s=2&r=1)), which aims to extend and modernize the National Alzheimer’s Project Act (NAPA) until 2035.

In addition to this bill, Pike discussed the [Alzheimer’s Accountability and Investment Act](https://d1dth6e84htgma.cloudfront.net/H_R_620_Smith_Tonko_8a05715ec9.pdf) (H.R. 620/S. 134), which complements NAPA by ensuring NIH receives essential funding for Alzheimer's research. Strong funding is needed to advance scientific research, diagnostics, and treatments, and improve the quality of care for those affected by the disease.

Additionally, Pike addressed the [BOLD Reauthorization Act](https://www.congress.gov/bill/118th-congress/house-bill/7218?q=%7B%22search%22%3A%22BOLD+Reauthorization+Act%22%7D&s=3&r=1) (H.R. 7218/S. 3775), which extends the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act until 2029. BOLD funding has led to progress in public health strategies, brain health promotion, early detection, and support for people living with dementia and their caregivers.

**Dr. Gordon Tomaselli, MD:** In his testimony, Dr. Tomaselli, representing the American Heart Association (AHA), discussed two specific bills, the Cardiomyopathy Health Education, Awareness, Research, and Training in the Schools Act of 2023 ([HEARTS Act - H.R. 6829](https://www.congress.gov/bill/118th-congress/house-bill/6829?q=%7B%22search%22%3A%22HEARTS+Act+-+H.R.+6829%22%7D&s=5&r=1)) and the [Congenital Heart Futures Reauthorization Act of 2024](https://d1dth6e84htgma.cloudfront.net/H_R_7189_Bilirakis_92eb3fb0fd.pdf) (H.R. 7189). The HEARTS Act enhances school safety by coordinating educational efforts on cardiomyopathy, a leading cause of disability and sudden cardiac death among young people. The legislation proposes guidelines for AED placement in schools and childcare centers, CPR training, and the establishment of Cardiac Emergency Response Plans (CERPs). Dr. Tomaselli urged Congress to pass the Access to AEDs Act in conjunction with the HEARTS Act to ensure critical resources for implementing lifesaving policies.

In addition to the HEARTS Act, the Congenital Heart Futures Reauthorization Act of 2024, addresses the economic burden and human costs associated with congenital heart disease. Urgent action, considering the high prevalence of CHD and its lifelong impact on affected individuals, is essential.

**Ms. Michelle Whitten:**  Michelle Whitten, shared her journey as a mother of a daughter diagnosed with Down syndrome. Ms. Whitten emphasized the transformative impact individuals with Down syndrome have on their families and communities but highlighted the significant lack of funding for Down syndrome research at NIH, for several diseases. For example, individuals with Down syndrome are often excluded from Alzheimer's clinical research and face organ transplant discrimination.

To bridge this gap, NIH launched the INvestigation of Co-occurring Conditions across the Lifespan to Understand Down Syndrome (INCLUDE) Project. This project aims to advance research goals via clinical trials, data coordination, training, and the Down Syndrome Registry. In addition, the [Charlotte Woodward Organ Transplant Discrimination Prevention Act](https://www.congress.gov/bill/118th-congress/house-bill/2706?q=%7B%22search%22%3A%22Charlotte+Woodward+Organ+Transplant+Discrimination+Prevention+Act%22%7D&s=6&r=1) and Chair Rodgers' bill, the Protecting Health Care for All Patients Act address organ transplant discrimination and prohibit the use of discriminatory measures in federal health programs.

**Mr. Randy Strozyk:**

Mr. Strozyk, from the American Ambulance Association (AAA), emphasized the essential contribution of ground ambulance services to local and national healthcare and emergency response systems. Mr. Strozyk identified the challenges faced by EMS systems nationwide, particularly in rural areas, and supports legislative efforts, including the reauthorization of the [SIREN Act](https://www.congress.gov/bill/118th-congress/house-bill/4646?q=%7B%22search%22%3A%22SIREN+Act%22%7D&s=7&r=2), EMS for Children Program, Traumatic Brain Injury program, and Poison Control Programs. The AAA urges the Committee to swiftly consider these legislative measures. Additionally, Mr. Strozyk highlighted the importance of addressing below-cost Medicare reimbursement, advocating for the extension and increase of temporary urban, rural, and "super rural" add-on payments for ambulance services through the [Protecting Access to Ground Ambulance Medical Services Act of 2023](https://www.congress.gov/bill/118th-congress/house-bill/1666?q=%7B%22search%22%3A%22Protecting+Access+to+Ground+Ambulance+Medical+Services+Act+of+2023%22%7D&s=8&r=1).

**Dr. Christina Annunziata, MD, PhD:** Dr. Annunziata, addressed the committee and expressed her support from the American Cancer Society (ACS) and the American Cancer Society Cancer Action Network (ACS CAN) for the Screening for Communities to Receive Early and Equitable Needed Services for Cancer Act, known as the [SCREENS for Cancer Act](https://www.congress.gov/bill/118th-congress/house-bill/3916?q=%7B%22search%22%3A%22SCREENS+for+Cancer+Act%22%7D&s=9&r=2), and the [Women and Lung Cancer Research and Preventive Services Ac](https://www.congress.gov/bill/118th-congress/house-bill/4534?q=%7B%22search%22%3A%22Women+and+Lung+Cancer+Research+and+Preventive+Services+Act%22%7D&s=1&r=1)t. These bills can impact the reduction of the burden of cancer for women. Breast and lung cancer are leading causes of cancer incidence and mortality in women, and the legislation addresses disparities in cancer impact among women. The SCREENS for Cancer Act reauthorizes the National Breast and Cervical Cancer Early Detection Program through 2028, providing flexibility to grantees for innovative, evidence-based early detection and screening interventions. ACS CAN supports this program for its success in reaching women with limited incomes, being under or uninsured, and detecting breast and cervical cancers at early stages.

CTeL’s Analysis: What’s Next?

Each of these testimonies highlighted the importance of funding and authorization for programs that are working to positively impact the healthcare community, across a variety of specialties. From Alzheimer's research and care to early detection programs for cancer and anti-discriminatory acts for Down syndrome patients seeking organ transplants, there is no shortage of work Congress can be doing to continue to meet the needs of our communities. CTeL supports the reauthorization of bills and legislation which creates a wholistic, quality, and comprehensive healthcare environment.

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