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A REVIEW OF EFFORTS TO PREVENT
AND TREAT TRAUMATIC BRAIN INJURY
MONDAY, MARCH 19, 2012
House of Representatives,
Subcommittee on Health,
Committee on Energy and Commerce,
Washington, D.C.

The subcommittee met, pursuant to call, at 3 p.m., in Room 2123, Rayburn House Office Building, Hon. Joe Pitts [chairman of the subcommittee] presiding.

Present: Representatives Pitts, Burgess, Shimkus, Blackburn, Guthrie, Upton, (ex officio), and Pallone.

Staff Present: Brenda Destro, Professional Staff Member, Health; Debbie Keller, Press Secretary, Peter Kielty, Associate Counsel; Ryan Long, Chief Counsel, Health; Carly McWilliams, Legislative Clerk; Katie Novaria, Legislative Clerk; John O'Shea,

Professional Staff Member, Health; Monica Popp, Professional Staff Member, Health; Alli Corr, Democratic Policy Analyst; Elizabeth Letter, Democratic Assistant Press Secretary; Karen Nelson, Democratic Deputy Committee Staff Director for Health; and Anne Morris Reid, Democratic Professional Staff Member.

Mr. Pitts. The subcommittee will come to order. The chair recognizes himself for 5 minutes for an opening statement.

As many of you know, March is brain injury awareness month. According to the CDC, an estimated 1.7 million people sustain a traumatic brain injury each year. And of that figure, 1.365 million, or 80 percent, are treated and released from the emergency room; 275,000 are hospitalized; and 52,000 will die. TBI affects everyone. It is not restricted to one race, gender, or socioeconomic group.

While children age 4 and under and adults over the age of 75 are particularly at risk, brain injury affects soldiers, athletes, and even Members of Congress, like our former colleague Gaby Giffords.

The annual cost of TBI is estimated at \$48 billion, but dollars alone do not paint a complete picture of the scope of these injuries. It does not take into account the suffering of a person with a brain injury who may be disabled for life, or the strain of loved ones that TBI places on family members who are so often the caregivers.

Federal efforts to address TBI began with the Traumatic Brain Injury Act of 1996. The act aimed to identify and increase awareness of TBI through new research and programs. The TBI Amendments of 2001 amended the 1996 law by extending the authorization to include the implementation of a national trauma brain injury education and awareness campaign.

The Traumatic Brain Injury Act of 2008 reauthorized the program. It also authorized CDC and NIH to conduct a study to examine the information gathered by HHS, assess appropriate interventions, and

develop practiced guidelines. I look forward to the results of the study which will come out in November of this year.

The 2008 act also focused on the incidence and prevalence of TBI, uniform reporting, and linking individuals with TBI to support services and academic institution to conduct research.

I would like to hear an assessment from each of our witnesses of these Federal programs. What have we learned about the causes, the diagnosis, the treatment of TBI through HHS' efforts? How is that knowledge being applied in real-world situations? And I would also like to hear their ideas about where we should go from here.

I would like to say a special hello to Dr. Flaura Winston from the Children's Hospital of Philadelphia. CHOP is a wonderful institution that has served many of my constituents. And I would also like to welcome those with us today who have TBI, as well as their families and caregivers who make enormous sacrifices every day, and we are glad that you are all here.

I yield the balance of my time to the vice chairman, Dr. Burgess.

[The prepared statement Mr. Pitts follows:]

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Dr. Burgess. I thank the chairman for the recognition. Today's hearing is of vital importance, as the Center for Disease Control estimates that over 1-1/2 million people sustain a traumatic brain injury annually and over 52,000 of them do not survive. Of those that do survive, 11,000 are children. This makes pediatric-acquired brain injury the number one cause of death and disability for children. There exists no viable reparative therapeutic option for patients, and all of the interventions are designed to prevent progression of the injury or secondary injury.

In order to successfully treat traumatic brain injuries, we must equip healthcare professionals and researchers with the resources needed to achieve the goal of improving outcomes and quality of life for those affected. Although there are numerous research projects underway across the country, including the University of Texas and North Texas Brain Injury Model System, a TBI center, a centralized and coordinated research approach that avoids duplication is lacking. And a Government Accountability Office report released this January entitled "Coordinating Authority Needed for Psychological Health and Traumatic Brain Injury Activities," it emphasized the need for coordination of care and coordination of services in traumatic brain injury in patients in the Department of Defense. They noted that conducting their research, there was no central location to obtain accurate and timely information on traumatic brain injury and they had to use a variety of resources in order to obtain their data.

I believe we will not achieve our goals to better coordinate

research and support services if we don't get a grasp, and this hearing is designed to do that on funding in projects that are meant to address traumatic brain injury.

H.R. 2600 would lead State centers, like the Center for Brain Health at the University of Texas at Dallas, the country's lead virtual center category for pediatric-acquired brain injury, to continue benefiting individuals with evidence-based systems of care. Additionally, the money will be allocated from the available discretionary funds and will be on hand to advance our knowledge of the brain over the next several years.

Thank you, Mr. Chairman, for the recognition. I will yield back my time.

Mr. Pitts. The chair thanks the gentleman.

[The prepared statement of Dr. Burgess follows:]

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Mr. Pitt. And now recognizes the ranking member of the subcommittee, Mr. Pallone, for 5 minutes for an opening statement.

Mr. Pallone. Thank you, Mr. Chairman. Today this committee will have the opportunity to hear from some of the leading experts in the traumatic brain injury community about an update on the current landscape of traumatic brain injury prevention, research, and treatment.

As we all know, traumatic brain injuries are a very serious spectrum of disease that can have devastating outcomes. When I was chairman of the subcommittee, we held a field hearing regarding pediatric sports-related concussions in New Jersey, and today I look forward to an informative hearing that takes a broader perspective on this critical issue.

According to the CDC over 1.7 million people are subjected to a traumatic brain injury each year. Furthermore, traumatic brain injuries account for one-third of all injury-related deaths. These statistics only tell part of the story, as currently it is unclear how many people are misdiagnosed or don't receive treatment after a traumatic brain injury.

Traumatic brain injury also affects many sectors of our population. These injuries continue to plague primarily our young people and the elderly, some of the most vulnerable members of our society. Traumatic brain injuries also have a profound impact on our military and the sports community. In addition, I would be remiss, as my chairman said, if I didn't mention how a member of our own body,

Gaby Giffords, was also a victim of traumatic brain injury while performing her congressional duties.

Consequently, we must prioritize this issue in our prevention and research efforts. It is my understanding that the overwhelming majority of people that suffer a traumatic brain injury do not die from their injury. However, that also means that these patients are at risk of developing the long-term implications that can develop from an even mild traumatic brain injury. Patients can suffer from cognitive impairments like memory loss, impaired communication skills, mental illness, epilepsy and are even at risk of developing Parkinson's Disease or Alzheimer's Disease. These complications can create devastating disability and hinder an individual's productivity. They also create a tremendous emotional and financial burden to families and society as a whole. Ensuring that these patients have access to innovative and vital treatments and social services is a great challenge that we must all work together to achieve.

Since the passage of the Traumatic Brain Injury Act of 1996 and subsequent reauthorization, several Federal agencies have led efforts to understand, prevent, and treat traumatic brain injury. Most recently, these efforts have undergone formal coordination through the Federal Interagency Committee on Traumatic Brain Injury. This committee, which includes HHS agencies and nonHHS agencies, will hopefully accelerate and coordinate developments in traumatic brain injury initiatives, and I look forward to hearing more about their proposed plans and activities.

I would also like to highlight the importance of Federal partnerships with the States in addressing this important cause. I greatly appreciate the presence of Mr. William Ditto who hails from the great State of New Jersey. Mr. Ditto is the recently retired director of the New Jersey Traumatic Brain Injury Program and also represents the National Association of State Head Injury Administrators. Mr. Ditto along with his colleagues have made great strides in leveraging their limited Federal and State funds to coordinate and provide services for individuals with traumatic brain injury. Strengthening partnerships like these will improve the outcomes of the families and patients affected by traumatic brain injury.

So I look forward to today's testimony. And Mr. Chairman, I would like to ask -- as I think you know, Congressman Bill Pascrell, my colleague from New Jersey, has really been a leader on this whole issue. And I know he is not a member of the committee, but he asked if I could by unanimous consent -- I will ask unanimous consent to include his statement into the record.

Mr. Pitts. Without objection, so ordered.

[The prepared statement of Mr. Pascrell follows:]

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Mr. Pallone. Thank you, Mr. Chairman. As I said, I look forward to the testimony, and I appreciate the fact that you held this hearing today. Thank you.

Mr. Pitts. The chair thanks the gentleman. And I now recognize the chairman of the full committee, Mr. Upton, for 5 minutes for an opening statement.

Chairman Upton. Well, thank you, Mr. Chairman. According to a recent report from the CDC, at least 1.7 million folks sustain a traumatic brain injury every year. We don't have to look very far to see the profound effects of a major TBI. Children injured by caretakers or car accidents, athletes impaired by multiple concussions, or soldiers disabled from war -- and even one of our colleagues wounded at a constituent event in Arizona last year.

With efforts being undertaken at the Department of Veterans Affairs, the Department of Defense, and several agencies at the Department of HHS, it is incumbent upon us to examine these activities so that they can work in a coordinated and efficient manner. And I proudly serve on the Congressional Brain Injury Task Force and encourage bipartisan support for TBI research and rehabilitation. And with that support, I am confident that the committee will make even greater strides to help patients living with the aftermath of TBI.

So I want to extend a warm welcome to the families attending today's hearing as part of Brain Injury Awareness Month, and I look forward to your testimony. And I yield back to the chairman.

Mr. Pitts. The chair thanks the gentleman.

[The prepared statement of Chairman Upton follows:]

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Mr. Pitts. Today we have four witnesses on our panel: Dr. Bonnie Strickland, Director, Division of Services for Children With Special Healthcare Needs, U.S. Department of Health and Human Services; Mr. William Ditto, Director of the New Jersey TBI Division, New Jersey Department of Health; Dr. Flaura Winston, Children's Hospital of Philadelphia; and Dr. Mark Ashley, President, Centre for Neuro Skills.

Your written testimony will be made part of the record. We ask that you summarize your opening statements in 5 minutes.

STATEMENTS OF BONNIE STRICKLAND, PH.D., DIRECTOR, DIVISION OF SERVICES FOR CHILDREN WITH SPECIAL HEALTHCARE NEEDS, HEALTH RESOURCES AND SERVICES ADMINISTRATION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES; WILLIAM DITTO, MSW, DIRECTOR OF THE NEW JERSEY TBI DIVISION, NEW JERSEY DEPARTMENT OF HEALTH/ FLAURA WINSTON, M.D., PH.D., PROFESSOR OF PEDIATRICS UNIVERSITY OF PENNSYLVANIA SCHOOL OF MEDICINE, SCIENTIFIC DIRECTOR, CENTER FOR INJURY RESEARCH AND PREVENTION, CHILDREN'S HOSPITAL OF PHILADELPHIA; AND MARK J. ASHLEY, SCD, PRESIDENT, CENTRE FOR NEURO SKILLS

Mr. Pitts. And Dr. Strickland, you are recognized at this time for 5 minutes to summarize and make your opening statement.

STATEMENT OF BONNIE STRICKLAND, PH.D.

Ms. Strickland. Chairman Pitts, Ranking Member Pallone, and members of the subcommittee, thank you for the opportunity to testify today on the Department of Health and Human Services Traumatic Brain Injury Programs. I am Dr. Bonnie Strickland, Director of the Division of Services for Children With Special Healthcare Needs in the Maternal and Child Health Bureau at the Health Resources and Services Administration, Department of Health and Human Services.

HRSA and our HHS colleagues appreciate your interest in our work, and HRSA welcomes this opportunity to discuss our TBI program with you and to provide some highlights of other HHS activities.

Congress has charged HRSA with implementing a grant program to States and American Indian consortia to improve access to rehabilitation and other services. The NIH has responsibility in the areas of research, and the CDC has responsibility for prevention and surveillance. SAMHSA also conducts activities through the authorities provided under the Public Health Service Act.

HRSA's TBI program consists of two distinct grant programs: State implementation partnership grants and protection and advocacy grants. State partnership grantees are required to have or develop a statewide needs and resource assessment and a comprehensive statewide

action plan. With these tools, States have made remarkable progress in increasing access to TBI services and supports through a TBI screening program, training health professionals and service coordination. HRSA's protection and advocacy programs provide specialized legally based services to help recipients understand laws to facilitate self-advocacy. Training in self-advocacy ensures that individuals with TBI and their families can pursue needed services, even if outside representation is unavailable.

NIH has primary responsibility for TBI research. The breadth of NIH research reflects the complexity of the problems that TBI represents, both immediately and in the aftermath of the injury. For example, NIH supports studies of the mechanisms of damage, development of diagnostics and therapies, clinical trials and research on brain plasticity and recovery. NIH also leads a broad range of research related to TBI rehabilitation, falls in the elderly, and disorders that often co-occur with TBI, such as posttraumatic stress disorder.

CDC is responsible for TBI prevention and surveillance. The agency disseminates and implements evidence-based TBI educational materials and clinical guidelines, informed evidence-based policies through activities such as the Heads Up Initiative, and educates health departments and community-based organizations on shaken baby syndrome.

CDC also worked with national experts to produce the field triage guidelines for the injured patient, which provides uniform standards for emergency medical service providers and first responders to ensure that patients with TBI are taken to hospitals best suited to address

their particular injuries.

SAMHSA focuses primarily on behavioral health aspects of TBI. SAMHSA maintains strong partnerships with the VA and DOD to prepare community behavioral healthcare systems to provide services that reflect an understanding of military culture, servicemember's experiences, and the range of potential post-trauma effects. This is primarily accomplished through SAMHSA Servicemembers, Veterans, and their Families Policy Academics. Additionally, SAMHSA has developed training materials for behavioral health providers who encounter veterans or servicemembers with TBI.

In 2011 HRSA convened the first meeting of the Federal Interagency Committee on Traumatic Brain Injury in order to share information, facilitate collaboration, and minimize duplication across agencies.

To facilitate this purpose, the committee plans to create a centralized on-line clearinghouse of Federal resources. The current representatives on the committee are the Departments of Defense, Education, and Veterans Affairs, the Social Security Administration, and with NHHS, the Agency for Health Care, Research and Quality, the Indian Health Service, CDC, NIH, SAMHSA and HRSA.

Our agencies complement each other's work. For example, CDC surveillance may identify an abnormally high incidence of TBI in child athletes in a particular State and they may develop educational materials to address the issue. HRSA's State grantee might then use the CDC material to conduct a statewide education campaign for students, parents, and schools about the risks and consequences of TBI.

Likewise, HRSA's grantee might utilize a screening protocol that was informed by NIH research in order to implement a student athlete TBI screening program. In addition to education and screening, HRSA would connect students and families with needed resources.

Strategies like these allow HRSA State grantees to leverage resources of other agencies to identify and serve children with or at risk of sustaining a TBI. Opportunities for such a collaboration is a key focus of the interagency committee. HRSA committed to ensuring that individuals with TBI and their families have accessible and appropriate services and supports.

NIH, CDC, and SAMHSA are making strides in the respective areas of research prevention and surveillance and behavioral health. We are working together to ensure that our efforts are complementary and to achieve cross-departmental coordination and strategic leveraging of resources to address the full spectrum of needs of individuals and families impacted by TBI.

Mr. Chairman, this completes my prepared remarks. Once again, thank you for the opportunity to testify today and provide an overview of our TBI program.

Mr. Pitts. The chair thanks the gentlelady.

[The prepared statement of Ms. Strickland follows:]

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Mr. Pitts. And recognizes Mr. Ditto for 5 minutes for your opening statement.

STATEMENT OF WILLIAM DITTO, MSW

Mr. Ditto. Thank you very much, Chairman Pitts and Ranking Member Pallone from New Jersey. Just to clear things up, I am the retired director of the Division of Disability Services in the New Jersey Department of Human Services, since I have been given a variety of interesting previous titles when I was introduced. But I am really here today not so much in that role, but more in my role as the Chair of the Public Policy Committee for the National Association of State Head Injury Administrators, better known as NASHIA.

We are the only nonprofit organization that represents State government agencies and services who are involved in the provision of short- and long-term rehabilitation and community services for individuals with TBI and their families. And I am pleased to give you an opportunity to understand where State government stands with regard to serving these individuals.

The big item here that I want to emphasize is that no two individuals with TBI are the same, and neither are any two States the same with regard to the extent that they are able to address these needs. The one thing that is the common thread throughout this country is that brain injury is, in fact, the leading cause of disability not only in the State of New Jersey, but all across the country.

And I think this has not been recognized and not been recognized well. And if you go out on the street and ask folks what is the most significant disability, you will get mental retardation, cerebral palsy, autism, all sorts of different things; but in truth, it is, in fact, head injury. And head injury is such a disability because it is cradle-to-grave. It affects people in all age categories. And as a result, individuals with this type of disability have to interface with a lot of different governmental programs over their time as a survivor of brain injury. And as someone on the panel has already -- someone on the committee has already mentioned, individuals with brain injuries are, in fact, surviving and they are thriving to the extent that they can get services that they need.

In the early 1980s, families began advocating for States to provide rehabilitation in other services, and there are so many different needs for people with brain injuries. There really are no two individuals with brain injuries who are just the same. We also have the mild, moderate, and severe classification of brain injury, which makes it in my experience a little less clearcut. In many other forms of disability, we can quite clearly state what the extent of the disability is through clinical observation and medical evaluation. This is not true with brain injury. Not only that, but there was for a long time a feeling that people with brain injury could only achieve a certain plateau, a certain level, and nothing would happen after that.

Research has proven that individuals even ten years post brain injury can make significant improvements when given the right services.

About 20 States administer Medicaid home- and community-based services programs for individuals with disabilities that are intended to provide for service in lieu of a more extensive institutional or long-term care. What our big concern at this point is that the systems need to be coordinated and they need to be available to people of all ages. We have found from the CDC, who has moved brain injury up to the top of its list of concerns -- and it was not always at the top of this list -- we have found from them that the leading cause right now is falls, falls in individuals over the age of 75. And I think we are all familiar with the baby boomers and where we are headed with that. I myself am one of them. And then in addition to that, it is in children under 4.

So look at that age spectrum we have there of people suffering from brain injuries throughout the progression of life. It is not just the typical younger adult male crash victim or the returning servicemember, it is really a large number of people. And individuals with brain injuries and their families are specifically looking to States for help and support.

We would propose in terms of the Federal HRSA-TBI grants program that the grants be shifted away from short-term projects to allow States to maintain and expand initiatives. We would ask that States are given additional flexibility to use funds for case management and other services, that States can target their grant requests on populations which they identify as underserved, and that the program move from a competitive grant program to a formula-funded approach, contingent

upon the availability of Federal funds, to allow each State to receive a predictable amount of funding.

Right now the program is competitive in nature. I believe 21 States are receiving grants. The rest of the States are not receiving grants, and they are relying totally on their own resources to be able to do that. So just as States are required to coordinate and maximize State and Federal programs and resources, NASHIA supports the Federal Interagency Task Force that HRSA has created to promote Federal coordination of all resources.

We look forward to that time when the task force will invite stakeholders such as NASHIA, the Brain Injury Association of America, the National Disability Rights Network, as well as individual TBIs and their families to provide input as we develop a national plan and priority for TBI. Thank you.

Mr. Pitts. The chair thanks the gentleman.

[The prepared statement of Mr. Ditto follows:]

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Mr. Pitts. And recognizes Dr. Winston for 5 minutes for an opening statement.

STATEMENT FLAURA WINSTON, M.D., Ph.D

Dr. Winston. Good afternoon. Thank you Chairman Upton, Chairman Pitts, Vice Chair Burgess, Ranking Member Pallone, and distinguished members of the subcommittee for calling this hearing and inviting me to testify. I am encouraged to see the increased focus on child traumatic brain injury, or TBI, along with the emerging emphasis on prevention. My name is Dr. Flaura Koplin Winston. I serve as Scientific Director for the Center for Injury Research and Prevention at the Children's Hospital of Philadelphia, or CHOP, as well as Professor of Pediatrics at the University of Pennsylvania. In addition to being a doctorly trained bioengineer, I am a board-certified practicing pediatrician and a public health researcher.

The Children's Hospital of Philadelphia is the Nation's largest pediatric healthcare network and is home to one of the largest pediatric research programs in the U.S. I am humbled by the commitment and skill that the hospital brings to pediatric injury, much of which is enabled by investments from the Federal Government.

I came to care about TBI early in my training. When I would hear the trauma transport helicopter, I felt a sense of dread for the family whose life would be changed by their child's TBI. Every day more than

125 of our Nation's children are hospitalized or die from TBI. Car crashes, sports, falls, and child abuse are the likely causes, largely preventable events, at great cost to families and to society. Annually estimated, TBI costs are more than \$29 billion for children who die and \$53 billion for those who are hospitalized. Therefore as a Nation, I propose that our primary success metric should be annual reductions in pediatric traumatic brain injuries.

To reduce the TBI burden, I propose three priority areas: one, prevention; two, timely state-of-the-art acute care; and three, optimal recovery. I hope to demonstrate the importance of research and its translation, professional training and coordinated efforts. Together we can address child TBI so that our children and grandchildren can reach their full potential. The good news is that we know how to avoid TBI. Protect the brain from blows and jolts. Prevention is the best medicine. If you get your grandson into a car seat, or your daughter's sports league to adopt safe play, you can reduce the chance of TBI. Unfortunately, many safety strategies were designed for adults, not for children.

Let me demonstrate how we can do better. At CHOP we found that early air bags in cars designed to save adults could fatally injure a child. A research-supported effort by government and industry to improve air bag design, policies and education, and now child air bag deaths are rare. Dramatic success like these require strong science and collaboration. The National Science Foundation has provided us with opportunities to work with partners to protect our children's

brains in a world designed for adults.

Research funded by NIH, CDC, HRSA and DOT taught us another important lesson. When it comes to TBI, child age affects the brain's response to impact and recovery. For example, we now know that infants with severe TBI have the worst prognosis. We also know that when compared to adults, older children with milder TBI recover more slowly with more physical, emotional, and cognitive challenges.

Federal-funded biomechanics and other foundational research is teaching us why. Sadly, given the limits of current prevention efforts, TBI will continue.

Our next level of defense is timely and proficient acute care. Over the past decade the CDC, HRSA, and many others have raised awareness about early recognition and response to TBI. Children with severe TBI require highly specialized aggressive care in the hours after impact. Children with more mild TBI require cognitive and physical rest within the first 48 hours. Federal investments in basic and translational research are leading to improved strategies for those on the front line. And I suggest taking this to the next step by including industry in our partnerships.

Unfortunately, the reality is that there are limits to current prevention and treatment. This is why recovery is our third line of defense. One of the 15 children who suffers a TBI today could have been your child or mine, and they now face the long road ahead to recovery. We need to be empowered with the best tools to restore vital cognitive function and help our loved ones recover fully. HRSA funding

enabled innovative partnerships between schools and clinicians. These need to continue.

I want to close by looking forward. Recently I was selected as a hero by a local elementary school's children because I work to save lives. They too want to save lives, but I worry that their dreams may be stunted. We need to shore up the necessary training and funding opportunities that young people will need to become tomorrow's investigators, inventors, innovators, and clinicians in pediatric injury.

Mr. Chairman, Ranking Member Pallone, and members of the subcommittee, as policy members please know I am grateful for your role in helping to save children's lives. I thank you for inviting me to testify and look forward to answering your questions. As you consider this issue I want to leave you with one thought: The average medical cost for children hospitalized for TBI is \$40,000. That is a lot of helmets.

Mr. Pitts. The chair thanks the gentlelady,.

[The prepared statement of Dr. Winston follows:]

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Mr. Pitts. And recognizes Dr. Ashley for 5 minutes for an opening statement.

STATEMENT OF MARK J. ASHLEY, SCD

Mr. Ashley. Good afternoon, Chairman Pitts, Ranking Member Pallone, and members of the subcommittee. Thank you for the opportunity to testify today. My name is Dr. Mark Ashley. I am the President and CEO of the Centre for Neuro Skills which operates brain injury rehabilitation programs in California and Texas. I also serve as the Chairman Emeritus of the Brain Injury Association of America, which represents the 5.3 million children and adults in the U.S. who have long-term disability as a result of traumatic brain injury.

In 1972 my brother Steve sustained a catastrophic brain injury while in the Navy. For 8 years he lay incontinent, unable to move, unable to speak, communicating through eye blinks only. When I completed my professional training in 1980 I co-founded the Centre for Neuro Skills and admitted my brother. After 18 months of intensive rehabilitation, Steve regained continence, speech, movement in all extremities, and was able to actually feed himself.

I hope to provide you today with several key points. The first is that traumatic brain injury affects people of all ages and is more prevalent than new diagnoses of all cancers in the U.S. There are over 4,000 people who will sustain a brain injury every day in the United States. The injury is heterogeneous and unpredictable. Treatment is

very complex and highly specialized. Treatment, particularly rehabilitation in post-acute settings, is clinically effective and cost efficacious. There is significant variability in access to medically necessary health care for patients with traumatic brain injury. And research funding is not adequate to match the significance of this public health threat.

TBI is not an event or an outcome, it is a catastrophic condition, and it is the start of lifelong disease, causative and disease accelerative processes. In the early weeks after an injury, the brain's metabolism stabilizes and improves. This allows the brain to find and use undamaged alternate pathways to perform tasks; a workaround, if you will. To maximize recovery, however, the brain must grow new neurons, new glial cells, new synapses, and new vascular structures. In short, grows new brain. The process is demand-induced and is rate-limited. It occurs slowly. For children and adolescents, early recovery gives way to later deficits in behavior, new learning, and in skill acquisition. There is not a single pathway or course of treatment for catastrophic traumatic brain injury. Instead, care is provided across a spectrum of settings, including nonhospital-based rehabilitation facilities that evolved in response to demands for less costly treatment.

When my brother was injured 40 years ago, his initial hospital stay was over 12 months and his rehabilitation, initiated 8 years later, lasted 18 months. More recently, ABC News journalist Bob Woodruff and Congresswoman Gabriel Giffords made miraculous recoveries

after a year or more of intensive rehabilitation. Today, however, most patients with moderate to severe brain injuries average just 19 days in the hospital and just 26 days or less in post-acute rehabilitative treatment.

What surprises most people is that today many patients do not receive complete rehabilitation. They include older patients, minorities, those who have no insurance or who are covered by Medicare and Medicaid, even many who have insurance. The consequences of this shortsighted approach include more medical complications, greater permanent disability, family dysfunction, job loss, homelessness, impoverishment, medical indigents, suicide, and involvement with the criminal or juvenile justice system.

Inadequate treatment leads to lost productivity and greater use of medication, durable medical equipment, income maintenance programs, and long-term care and institutionalization. In contrast, the consequences of adequate medical treatment -- that is, rehabilitation of sufficient scope, timing, and duration -- are well documented but are not well known in the general medical community or among payors, patients, or families. Proper acute and post-acute treatment and disease management help to restore maximum levels of function, reduced long-term disability and suffering, rather than merely accommodating for it.

My company provides post-acute treatments by physicians, licensed therapists, and other allied health professionals in assisted living facilities, like many other companies. Therefore, we are not

eligible to be a Medicare provider. And because we do not have a Medicare provider number, we cannot accept TRICARE patients through a normal admissions process.

Currently my company is participating in the VA's assisted living traumatic brain injury pilot project. However, we are voluntarily supplementing the care paid for by the VA with more frequent and intensive therapies, because after 32 years of clinical practice I know that is what our service members need and firmly believe it is what they deserve. TBI can change how you move, talk, think and feel, it can change the length of your life and its quality. Individuals with brain injury, and their loved ones, are rarely able to advocate for themselves. They rely on policymakers to invest wisely in prevention, treatment, including medically necessary rehabilitation, and in research.

In 2011 the NIH spent \$81 million on traumatic brain injury research, as compared to \$5.4 billion in cancer. The disparity is enormous, given the similarity in annual incidents and higher societal costs associated with brain injury.

The Brain Injury Association supports basic science research as envisioned by the One Mind Campaign. Investment in epidemiologic research by the CDC strongly advocates for more rehabilitation research for children and adults by the National Institute on Disability and Rehabilitation Research. We cannot sacrifice care while the field works toward a cure; therefore, BIA strongly supports reauthorization of the TBI Act. We urge policymakers to move away from time-limited

project-oriented grants, to formula funding so that all States and territories can build a sustainable infrastructure to address this growing public health problem.

Finally, as you have learned today, administering treatment at the proper time and with the right scope, intensity, and duration by a well-skilled workforce yield significant cost savings in both the public and private sectors and vastly improves outcomes, functional independence, and life satisfaction.

We hope you will take action leading to better health, enhanced employment and education, and more fairness in equality for this vulnerable population. Thank you.

Mr. Pitts. The chair thanks the gentleman and thanks each of you for your opening statements.

[The prepared statement of Mr. Ashley follows:]

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Mr. Pitts. I will now begin the questioning, and I will recognize myself 5 minutes for that purpose.

Dr. Strickland, the committee applauds your efforts to convene an interagency working group, to maximize resources and coordinate Federal efforts related to traumatic brain injury. Would you please review the goals of the working group, and what is the role of the stakeholders within the group and how do they receive public input?

Ms. Strickland. Thank you. The purpose of the Federal Interagency Coordinating Council is, as I said in the testimony and in my statement, to facilitate greater collaboration and coordination across the agencies that are working on TBI activities. We want to maximize the activities and we want to minimize duplication of effort. We also want to create a common vision across the multiple programs that are going on not only in HHS, but across government, around traumatic brain injury. And above all, we want to be able to collaborate and leverage each other's resources.

One of the ways that we are doing that is through a clearinghouse of Federal tools. We are hoping, and we are just throwing this out now, we are hoping that we will be able to include tools produced by all of the Federal programs in one place that would be accessible to the public and to each other so that we wouldn't duplicate effort and that we could use our scarce resources to launch out into new areas.

Mr. Pitts. Thank you. Dr. Winston, we have always heard of the plasticity of young brains and their remarkable ability to adapt to the surgical removal of part of the brain. Yet in your testimony, you

mention that young brains are actually harmed more than the brains of older individuals. Would you elaborate on this difference?

Dr. Winston. Yes. Children differ from adults biomechanically, cognitively, emotionally, socially, and these differences affect injury and its recovery. Just think about normal children and the amazing changes that occur as your children grow up. Think about when you held your baby, think about when you taught your older child how to ride a bike or your teenage how to drive. Just as they are different on the outside, their brains are different on the inside. And new research is showing that this fundamental knowledge of the brain and its response to injury is yielding some surprises.

We used to think that children were more resilient, their brains were more resilient to impact. But in fact, let me give you three examples. Adult skulls fracture on impact, infant skulls bend, and when they bend it presses on the brain and can cause damage. Another is that infants have stiffer brains. People used to think that that was protective. But in fact, they injure at much lower levels of impact and energy. And then finally, some new research that was done by -- the first research was done by Dr. Susan Margulies at the University of Pennsylvania.

New research that was done by Dr. Fred Rivera at Harborview shows that for mild traumatic brain injury, we start to see that there are disabilities that emerge that might not have been thought to be the case. And here there is a slight difference. It is the teenagers who have more disability from the same level of mild traumatic brain injury.

And I think that this really shows that we are just beginning to truly understand the biomechanics of brains, the biology of what happens in the event of an injury, and this knowledge and this furthering of our understanding of our scientific foundation is going to help us to come up with better helmets, better prevention strategies and better therapies and, I hope, better recovery.

Mr. Pitts. You mentioned the short-term and the long-term effects of brain injury in children. Can you have long-term effects without noticing any short-term injury?

Dr. Winston. I think that you usually will see something early on. But there are some subtle differences. Children are continuing to develop as we go forward. I often talk about children as an unfinished painting, right. We don't know where they are going to go, we don't know what their potential is going to be. And so as they get older there might be need for certain -- certain cognitive abilities that weren't needed early on, and they will come through.

Again, there was a study that was recently done that showed that at 36 months after a traumatic brain injury, children with moderate to severe brain injury had much poorer function than they did at baseline and that they had no improvement between 24 and 36 months. And so this really gives us pause that we don't know enough about how to optimize therapy and optimize recovery, but we really need this in order to better inform our future interventions.

Mr. Pitts. The chair thanks the gentlelady, and recognizes the ranking member, Mr. Pallone, 5 minutes for questions.

Mr. Pallone. Thank you, Mr. Chairman. I wanted to start with Mr. Ditto. It is my understanding that the treatment of traumatic brain injury is very complex and, unlike other diseases, the treatment of course has to be tailored for each individual and the outcomes can be variable as well. And I realize there is a great importance in an interdisciplinary approach towards treatment and management of patients. Particularly those with severe diseases may require a broad range of services, including health care, education, vocational rehab, and housing. And State health departments like yours or like the New Jersey Department of Health, play a critical role in serving as access points.

Can you tell us more about the importance of an interdisciplinary approach in case management in the treatment? In addition, can you highlight ways that you have been successful in providing these services in New Jersey?

Mr. Ditto. Of course. Again, I am from the Department -- I was previously with the Department of Human Services. We have got to get that health out of there. Not that I don't like health. But I do want to say that it is very true that one of the most critical services for individuals with brain injury, regardless of the age at which the brain injury occurred, is the ability to get service coordination and multidisciplinary intervention into the picture, because it requires a lot of different folks with a lot of different specialties to be able to help people, because no two people, as I said before, are alike.

And so when we look at this, the important element is to have one

central coordinating individual -- and that is usually a case manager -- that the family and the individual can work with to structure the kind of individualized service package and then follow along. Case management isn't successful if you just say to somebody, oh, well, there is a treatment place over here that you could go to, they are open on Monday and Wednesday. You need to not only tell them about it, maybe you need to go there with them the first time to get them introduced. Maybe you need to follow up. Maybe you need to check with the program to see if their attendance has dropped off. You need to have someone who is measuring progress.

Case managers look at where they start with their clients and they move forward. And case management can come from a variety of sources. The Title 5 Maternal and Child and Health Program provides States with funds to provide case management to children with diseases and disabilities. And I can tell you in the State of New Jersey, it is a highly effective program that works very well in terms of providing that level of intervention helping families negotiate.

It is harder in the adult system for us to offer those kinds of services because there are not entitlement programs that we can turn to. So for the individual with an adult onset brain injury, States have developed things like State trust funds. And we did that in New Jersey, a surcharge on motor vehicle registrations. Those of you in New Jersey know that we register and reregister our cars every year and pay a fee for it. And we got them to take a dollar of that fee and put it aside into a trust fund, and we use that trust fund money

to help support education, outreach, awareness, and direct services.

The most requested service in the State of New Jersey by people of all ages, from children through 99-year-old people was case management, was someone to help them negotiate and navigate the system, and somebody with sufficient training to be able to understand the subtle differences between people with brain injury.

If you see someone who has had a severe brain injury and they are in a wheelchair, you obviously see, oh, they have physical impacts from it. But so often for people with brain injury they don't look any different than you and I do, but they have the problems of cognitive dysfunction, they have the problems of impulsivity, aggressiveness, they have impaired processes that lead to social problems. And one of the things States are very concerned about is a lot of individuals who have brain injuries end up in our justice system, end up in our prisons. And I hate to tell you, but it is true, they end up in State psychiatric hospitals. And frankly, a State psychiatric hospital is not a place for an individual with brain injuries to be.

I spent a good deal of the last 10 years of my professional career trying to get people out of inappropriate placements and back into the community. But the funding for this is very, very difficult. There is more funding available on the child side than there is on the adult side. We are trying to tap into the aging piece of this and get more help from the Administration on Aging. But it comes back to the issue of really seeing that this is a lifelong disability that impacts people of all ages, and we have to look carefully at what systems have already

been put in place out there that we can knit together to provide a comprehensive service. And even if we can't afford to buy all the treatment we need for people, at least if we can give them case management services and get them somebody who can help to coordinate their medical care with their rehabilitation care, with their education program, with community supports and services, can make a tremendous difference.

And again, as I say, when I look back on our TBI fund in New Jersey, which was very successful, the most frequently requested service was case management beyond all others. And we offered a very broad range of home modifications and treatment services and all sorts of things, and people opted -- the thing that was most opted for was case management.

But it is not equal across the country. When you go from State to State, and that is the luxury of working in a national organization like I do, when you go from State to State, there is such a big variation in what is available to people. And really this is a lifelong disability from which people, in my view -- and I know not everyone likes this term -- but they survive. I am not sure they recover. They survive. They learn compensatory strategies, they learn how to cope with the world, they learn how to make their way and improve their social interaction and minimize, hopefully, their involvement with the legal system. But it is a lifelong disability. You don't just wake up one day and say, oh, I don't have a brain injury any longer, everything is back to normal and I am perfectly fine. It is there forever. Thank

you.

Mr. Pitts. The chair thanks the gentleman, and recognizes the vice chairman of the committee, Dr. Burgess, 5 minutes for questions.

Dr. Burgess. Thank you, Mr. Chairman. Dr. Winston, along that line, do you have a sense as to -- I mean, clearly States are doing things differently among the several States. Do you have a sense as to whether or not there is any coordination at the State level as to adopting the best practices, what is working in one location might be transferrable to another location, is there communication along these lines, are States looking at what programs are working in other areas?

And then I want to go to Dr. Strickland as to what the Federal oversight of that is. But do you get a sense there are States that are doing it right and States that show room for improvement?

Dr. Winston. Well, I have to say that it is not my expertise to look at what States are doing, so I can't really give you a full answer. I can speak to one program that HRSA funded that is in Pennsylvania that might be of help to you. In Pennsylvania, there is this group -- there is a program that is called Brain STEPS to try to reintegrate children into the school system; because, understand, that is the job of children is to go to school and to get back in there. And now every school district in Pennsylvania has been trained in traumatic brain injury and there is coordination between these school districts and the local health care teams.

So I think that there are some models. I was hearing them from the panel members here. We need to build the collaboration. And,

again, I want to reiterate, it is not just within the public sector, it is also with the private sector. It is really important to keep them together. So I would like to actually give my time over to Dr. Strickland.

Dr. Burgess. Let me just ask you one follow-up on that before we leave it. Then, what type of coordination do you see between the schools and the Department of Education in this regard, because obviously the schools may become the de facto rehabilitation center for children with brain injury. How do they integrate with the State Departments of Education or the Federal Department of Education?

Dr. Winston. I can tell you that one of the main things I do for children, as a practicing pediatrician for children with special healthcare needs, is to try to get them into an individualized educational plan to get them the medical care that they need at the schools. And this does require a tremendous amount of coordination.

Dr. Burgess. And how receptive is the Department of Education, the State Department of Education to those?

Dr. Winston. Well, they are limited by their budgets as well. Clearly we have challenges to fund our public education system. But I can tell you that that is a part where the State and the school districts are really trying to make this better for children. But it is a very challenging thing to provide the kind of care that these children need day in and day out at school. They also need wraparound services with someone who is there with them in school to deal with their emotional outbursts, to deal with other things. So it is a really

challenging situation.

Dr. Burgess. I am sure it is. Dr. Strickland, let me just ask you a question. The total budget for HRSA in the President's fiscal year budget for this year?

Ms. Strickland. 9.76.

Dr. Burgess. 9.76?

Ms. Strickland. Million.

Dr. Burgess. For the total of HRSA?

Ms. Strickland. I would have to get back with you on that. You mean of all related activities?

Dr. Burgess. Yes.

Ms. Strickland. Everything related? I would have to check with our colleagues and see. But through the Traumatic Brain Injury Act, our program receives --

Dr. Burgess. Within your division of the agency, the budget is?

Ms. Strickland. \$9.76 million.

Dr. Burgess. No, no. The total HRSA budget. It is going to be in excess of \$8 million, is it not?

Ms. Strickland. Oh, for everything?

Dr. Burgess. Yes.

Ms. Strickland. In HRSA? Oh, yes, \$700 million.

Dr. Burgess. Did the President's request increase last year to this year?

Ms. Strickland. Yes.

Dr. Burgess. About how much, again, for the total of HRSA?

Ms. Strickland. I don't remember.

Dr. Burgess. The figure I have been given is \$228 million. Does that sound about right?

Ms. Strickland. I would have to get back with you.

Dr. Burgess. And then we are spending on traumatic brain injury how much?

Ms. Strickland. \$9.76 million.

Dr. Burgess. I mean, that just seems thin given the total HRSA budget, does it not?

Ms. Strickland. We do a lot with the resources that we have. We can always do more with more.

Dr. Burgess. It seems thin, given the requested increase. Now, I grant you Congress is supposed to do the budget, and Congress does the appropriation, so there is always a disconnect between what the President's request is and what the actual dollars are. But it just almost seems out of line, it seems out of kilter there. Is it because you are not asking for enough? I mean, Frank, he loves to give you money, so ask him. He will do it, he will write the check himself; I have seen him do it on this committee when he was chairman, subcommittee chairman.

Well, I guess my point is it seems like there is a disconnect between the level of funding for traumatic brain injury and HRSA and all of the other many things that HRSA does, however great and wonderful they are. And I am just asking as we go through this, that is something we might spend a little time and a little attention to see if there

are places where perhaps other funds could be freed up in other areas and delivered to this very pressing need.

Thank you, Mr. Chairman, for the indulgence. I yield back.

Mr. Pitts. The chair thanks the gentleman. The other members seem to have stepped out, so we will begin round two of questioning.

Dr. Strickland, the GAO just found that NIH, DOD, and VA each lack comprehensive information on health research funded by the other agencies. GAO raised concerns about the potential for unnecessary duplication and urged the agencies to find ways to coordinate their efforts.

Question: How is TBI research that is conducted by NIH, DOD, and VA coordinated among the three agencies?

Ms. Strickland. Well, I would reiterate that both DOD and VA are members of the newly established Interagency Coordinating Council. We will have our second meeting actually at the end of this week. But specifically, NIH has partnered with the DOD in building a central Federal interagency brain injury research database that will allow access to researchers across the multitude of research done by both agencies. This is important, because that helps us establish better TBI classification systems, better diagnostic criteria for mild TBI, predictive markers for dementia, and a host of other activities that can only really be achieved through that type of collaboration. So I think that the acronym is FITBIR. The Federal Interagency Traumatic Brain Injury Research database I think is going to be a real facilitator.

Mr. Pitts. So you are working to improve access to databases --

Ms. Strickland. Right.

Mr. Pitts. -- and electronic information on the funded research?

Mr. Ditto, how are the States working with returning servicemembers or veterans, and how do States coordinate these services with the veterans organizations.

Mr. Ditto. Well, actually the States have had an interesting opportunity over the last several years. The Veterans Administration actually established a program in conjunction with the Department of Health and Human Services that is called Consumer Directed Home and Community-Based Veterans Services.

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[4:01 p.m.]

Mr. Ditto. And it was modeled after a program that was done in a number of States in which individuals were given an individual budget and then allowed to decide how to use that money to meet their specific needs. And so the States have gotten involved -- it is a slow process, but it is taking off -- in getting involved in understanding that the returning service people, once they have had the acute care and they go through the acute rehabilitation phase through Veterans Affairs, they then need sort of a stepdown after that. They are not ready to just go back into their communities and live. They need an environment, a therapeutic environment, not as intense as intense physical rehab is, but something that is more a day-to-day living, kind of getting adjusted program.

And so I think we are making headway with that, because before, to be perfectly blunt, in most States the Department of Defense was placing individuals in long-term care facilities and nursing homes. And so we are getting away from that.

I think also the States are reaching out to their Veterans Administration agencies to network with them and to become involved with them and to open up the doors to what the State may have to offer in terms of helping out with this. Many times Veterans employees are just not aware of the scope of brain injury programs and, frankly,

because this has become the signature injury of this war, this is the first time that people started looking at these other programs that were out there dealing with people who had acquired their brain injuries in a different way other than combat.

Mr. Pitts. Thank you. Dr. Ashley, you described the variability and post-acute care for TBI patients. What are the factors that cause this variability? And also would you -- I only have so much time -- describe the difference in rehab and rehabilitation of children's versus adults?

Mr. Ashley. Yes, sir. The first part of your question is what accounts for the variability. It begins the lack of understanding of the condition itself. As I mentioned earlier, in the general medical community and in the payer community, there is not a good understanding of the neurophysiologic and neuroanatomic principles of neuroplasticity as a recovery mechanism for brain injury. It used to be thought that what you see at 6 months is what you get. Today we understand that what we do in the environment by creating appropriately structured demand, reprograms existing cells to take over function or induces growth in the brain for development of new structures to take on function.

So without the proper knowledge in the medical community or in the payer community that underlies this, it is treated as though it is a broken bone. A broken bone takes 6 weeks to heal, and we get 2 weeks or so in rehabilitation for the brain. Wholly inappropriate.

We also have rehabilitation policy insurance plans that was

designed for musculoskeletal and orthopedic rehabilitation 4 decades ago when it first came into being. It has not morphed into covering the rehabilitation needs that we now see with surviving neurologic injuries. So we spend a great deal of money to keep a person alive and we basically spend no money to give them any quality of life afterward. The injustice here is that we actually have the ability to do it. So we are simply withholding this care and calling it something other than medical treatment and constraining it in policy by either licensure restriction or by benefit restriction. One or both.

I apologize, the second part of your question? Oh, the difference between children and adults.

Mr. Pitts. Yes.

Mr. Ashley. Euphemistically it is said that children are not little adults. I think Dr. Winston touched on it very nicely when she indicated the pathophysiology of a child's brain is substantially altered with an injury and differs substantially from adults. One of the areas that we have to really investigate has to do with the onset of lifelong disease processes that arise from the changes in the brain metabolically and neurophysiologically. Once altered, it is difficult to know if these changes actually revert to normal or not.

There is great suspicion, for example in pediatric injury, that neuroendocrine abnormalities contribute to a failure of the system to further mature appropriately. As a consequence we have to really call into question the role of even occult brain injury, much less more

obvious brain injury in conditions that might lead to dyslexia, agraphia, dyscalculia, difficulties with reading, writing, math, and so on that we have bundled under learning disabilities as an example.

Further, as we see the difference in children, we have medication differences, pharmacologic interventions that are not effective with children, or put children at risk that can be used in adults. And then of course, we have the real social dilemma in terms of how we treat these children. It is difficult to amass them in a single environment and take them out of their cultural surroundings -- family, school, et cetera. So unfortunately, because of vagaries of rehabilitation coverage, the schools do end up being the de facto rehabilitation setting. It is not what they are trained for, it is not what they are prepared for. They certainly have stepped up and tried to address the problem, but the medical rehabilitation of children really ought to be left to medical professionals.

Mr. Pitts. The chair thanks the gentleman and recognizes the ranking member for 5 minutes for questions.

Mr. Pallone. Thank you, Mr. Chairman. I want to ask Dr. Winston, you described how the majority of research is focused on traumatic brain injury in adults and that the scientific foundation for pediatric brain injury is limited. And you mentioned the need for focused research investments to inform new safety products, programs, and policies that will better prevent and reduce the severity among children.

It seems that you believe there is an important role for NIH and

other Federal agencies and Congress to build upon existing research on pediatric brain injury. But could you just share your perspective on specific pediatric research questions that could be further -- or should be further explored?

Dr. Winston. Thank you very much for asking that question. We need to build up our scientific foundation so that we can improve and be more efficient in how we deliver our care. I like to think about it in five categories: first, to improve the prevention strategies, we need to understand the who, what, where, when, how, and why of pediatric injury, using biomechanics, behavioral science, epidemiology and the like. We need to improve our methods and measures for studying, diagnosing, and following the course of TBI. Biomarkers are also important. We need to conduct -- work to know what works and what doesn't, how to improve on therapies that are currently done, how to deliver it in the best ways possible. We need to know how to get state-of-the-art to the field, to the frontline. And we need to support innovation research for the development of new safety products, biomarkers and therapeutics. And we must not forget to train our next generation to be scientists of pediatric injury.

There are two resources I call the committee's attention to that would be able to give you more complete answers. I am trying to be brief here. The first is a very exciting initiative that I was part of -- actually both I was part of -- that would be released by the CDC, I think next month, and it is a national action plan for child injury prevention that provides action steps in research, data, education,

health systems, communication to prevent child injuries from occurring. It also seeks to incorporate child injury prevention into existing systems and strategies at the national, State and local level.

A second very exciting initiative is the National Institute of Childhood Health and Development is interested in childhood injury, and I applaud leadership for their interest in this. The Society for Advancement of Violence and Injury Research under the direction of the President. Dr. Fred Rivera tapped into experts in the field and enumerated important next steps in child injury research. And I recommend that you get ahold of that as well.

From the personal perspective, there is a range, a wide range, whatever we need to do. I think we can prioritize and we should.

Mr. Pallone. Thank you very much. Dr. Ashley, in your testimony I am struck by the continuous care that is needed for people with traumatic brain injury. And you stated that those Americans who have experienced moderate to severe traumatic brain injury, their recovery often extends beyond their hospitalization and requires ongoing extensive rehab.

You also testified that it is the start of a disease-causative and disease-accelerative process. Can you elaborate on the extent to which more serious brain injuries are lifelong conditions? I know you mentioned that, but if you want to talk about it a little more.

Mr. Ashley. Yes, sir. The difficulty that we see, of course, is that anything and everything that a human being does is mediated by the brain. So when the brain is injured, the potential for impacting

any and every organ system in the body and its function exists. At the most basic level, when a brain cell is injured -- and you have 100 billion of them -- that begins a neurodegenerative process, the end of which we are not sure exists. In fact, a few hours after an injury to the brain, we see inflammatory processes around the body initiated. In about a third of all individuals late in life, we will see those same processes reinitiate. So we change how the brain's biochemistry works. The brain functions in various degrees of bioenergetic crisis following a brain injury, almost indefinitely.

As a result what happens is the metabolic demand creates tremendous stress within the system that triggers a number of degenerative processes. So we are beginning to reconsider lifelong diseases or diseases we have known lifelong as Parkinson's, amyotrophic lateral sclerosis, multiple sclerosis, Neimann Picks, Huntington's chorea, and so on, as lipid metabolic disorders that may have an origin in alteration in the brain's neurophysiology after a brain injury. You see this made manifest in the recent press over retired athletes with repetitive concussions from the Sports Legacy Institute and the work being done at Boston University on the posthumously donated brains of retired professional athletes. We see the changes in the brain in a condition called chronic traumatic encephalopathy that has been identified as a single example of these lifelong conditions and progressive conditions.

Mr. Pallone. Thank you. Thank you, Mr. Chairman.

Mr. Pitts. The chair thanks the gentleman and recognizes the

gentleman from Illinois, Mr. Shimkus, 5 minutes for questions.

Mr. Shimkus. Thank you, Mr. Chairman. I appreciate the panel being here. I apologize for not being here for opening statements. I was giving a tour of Wounded Warriors in the Capitol, and they just left and it gave me time to get back here. And so in that venue, obviously, some of my questions will be asked.

Just at the outset, Dr. Strickland, we think it is applaudable for us to try to organize these agencies and try to maximize the focus. We know that you have got the Federal Interagency Committee, the Federal Clearinghouse for TBI, the Federal Interagency for TBI Research database, the Center for Neurosciences and Regenerative Medicine. How are you going to try to coordinate these groups? I think everyone knows and the President has also said we have got to get efficient and we have got to pare down redundancies. How are you going to go about doing that?

Ms. Strickland. Well, I should clarify that the interagency committee that HRSA is convening is really not to achieve that intraagency --

Mr. Shimkus. Do you think that is an important thing to do?

Ms. Strickland. I think it is very important thing to do within each agency. Ours is more of an informal group so that we can be aware of what our agencies are doing and better align what we are doing with our scarce resources with the resources of others. There is certainly still a need for agencies to coordinate their activities within their own agencies and on dedicated activities of similar interest and

similar focus.

Mr. Shimkus. And I think we are going to try policy-wise and budgetary-wise to really streamline this process, not just in this area, but healthcare research dollars because we do seem to have sometimes multiple agencies doing similar things, but they are not coordinated and they are not feeding back the same information and there is not one clearinghouse. So we are not sure we -- we are getting a return on that investment. The question is: Are we getting as big a return on investment as we should? That is not even in the Agency, that is some of the healthcare research in the Department of Defense, as you know, and the like.

Let me go to Mr. Ditto. How many States are working with returning servicemembers or veterans?

Mr. Ditto. Give me a quick number? Probably about 15 or 20, from what we are aware of. Now, some States are very advanced in this. The State of Massachusetts, for instance, has a very involved, elaborate program that they have been working on for years, but they had a lot of commitment of resources at the State level that helped to bring this collaboration together and to work on it.

What I am worried about from the standpoint of our organization and representing State government is that we just don't have every State working on this, but every State has returning service people. So right away we are in sort of a difficult position, because we are really not necessarily reaching people.

The other thing is, and I am sure it is no surprise to you, most

of the public entitlement programs across the country, especially like Medicaid, become the payer for long-term services for people with various disabilities, including brain injury. And most States are seeking to reduce and decrease their expenditures under the Medicaid program for various reasons, for obvious reasons.

And it worries me because what is happening is in some respects people with brain injuries are just being mixed in or lumped in in States with other groups of people with disabilities, and yet as you have heard from the experts, the treatment and management of these individuals is quite different. We are looking at quite a different approach to doing something. And because it is a lifelong disability and because the impairments persist over time, over a long period of time, it really requires a lot of resources. And States are not -- I don't think States don't want to do the right thing, I just think they are having a very difficult time with the funding. And with constrictions in programs and with the small amount of money that HRSA gets to support, through the TBI Act, what needs to be done, this system is not -- the amount of money that is being given to HRSA is not reflective of the magnitude of the problem of brain injury. That is the simplest way I can say it.

Mr. Shimkus. And we appreciate that. What about in your coordination with States? And how are the veterans organizations linked in at all?

Mr. Ditto. Veterans organizations are linked in. In fact, we have have some very interesting developments in a number of States where

the National Guard came to the State and said, We would like to do something with the people we are sending out to combat. And so they were pretested before they left on assignment with a base measure of their brain function, et cetera. And then when something happened to them, they were sent home and retested. Because of baseline, there was an ability to determine whether or not any brain damage had been sustained. And if so, then plan an appropriate treatment. So both the local service organizations as well as the State veterans service organizations, as well as the Federal veterans department, Veterans Affairs, I think are all very interested in this. NASHIA has tried to work with these organizations and encouraged our States to work with them. But when we ended up with 21 States getting grants from HRSA, it made it difficult for the rest of the States to get replacement funding from the legislature and the Governor to fill the void of trying to continue the momentum of this.

Mr. Shimkus. My time has expired. I appreciate the answers. I will just finish on this, especially your last point, because as Members of Congress, one of things that we do numerous times is we do constituent service and we do a lot of Veterans Affairs issues, and have a baseline on disability and percentages, and be able to get through that system sooner rather than later, instead of reinventing the wheel -- and some of the lag time, it is just really abysmal -- that would be helpful too. So appreciate the testimony. Thank you, Mr. Chairman.

Mr. Pitts. The chair thanks the gentleman. Dr. Winston, I didn't get to you, so I have just one follow-up, if you would. In your

testimony you discuss the importance of the golden window. In acute treatment, are you aware of any studies of treatment of children with TBI during the golden window?

Dr. Winston. Yes. So the question is about the golden window, it used to be called the golden hour. We are now learning that it is important to have aggressive care for a longer period of time, as we heard terrific testimony on. You know, the fact is it is very difficult to do acute care research. And I think there is work out there to try to start bridging together emergency departments in hospitals to try to build networks where this kind of research can be done.

Just beginning -- I personally could get back to you on specific information -- but I know of a very exciting study with adults that just came out from the University Pennsylvania found that early, aggressive, expensive care had important long-term consequences. I think that we give, and I think you would agree, too little too late. And sometimes too late, too little, even late. We really need to get in there, particularly for very serious injuries, we need to get in there and work with the brain's ability to heal and reduce the secondary injuries that might occur from hypoxia or from low oxygen or a low blood flow.

I think for mild traumatic brain injury, the window is a little bit longer, it is 48 hours. And I applaud the CDC and others to try to get that awareness out there that early recognition response is needed.

But I want to challenge, if I may give you a challenge that we

are experiencing, the growing awareness for early recognition has really turned into some real challenges by parents who want some sound answers. They want to know things like after how many concussions should my child be removed from contact sports? How long are injured brains vulnerable to a second impact? Does the risk differ by age? And why did my child get a concussion when they were wearing a helmet? Our science today does not answer these questions.

Clinicians on the front lines are also asking questions. I think you might find this interesting. Visits for concussions, because of awareness, have skyrocketed at the Children's Hospital of Philadelphia's Care Network, increasing 458 percent since 2009. We are struggling to meet the demand. We need research and leadership to provide evidence-based recommendations. It can't be this broad-brush because we just can't afford it and we don't have enough trained providers.

I know that, Chairman Pitts, you have been very, very helpful in trying to make sure that we shore up the training that is necessary for this specialized care that children need. Thank you very much for that. We need better standards for safety equipment, biomarkers for traumatic brain injury so we can follow the course of care; better tools to use in the field and in the clinics, evidence-based and tested protocols. These don't exist right now.

And just to reiterate, for the young athlete in particular, their job is not playing on the field, it is actually learning. And we can't forget that. We need to make sure that we protect their brains so that

they can become the leaders in society that many of them hope to become.

Mr. Pitts. Thank you. And that effort for the Children's Hospital GME training was bipartisan. My colleague, Mr. Pallone, was a great advocate of that as well. Do you have any follow-up?

Mr. Pallone. No. Mr. Chairman, first of all, thank you for what you just said and your comment about concussions in sports. I agree. I wanted to ask unanimous consent to submit the statement of our full committee ranking member, Mr. Waxman.

Mr. Pitts. Without objection, so ordered.

[The prepared statement of Mr. Waxman follows:]

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

Mr. Pitts. That concludes our hearing. The members may give you questions. We ask that you respond to those questions once you get them promptly. And I remind members that they have 10 businesses days to submit questions for the record and that means they should submit their questions by the close of business on Monday, April the 2nd.

[The information follows:]

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

Mr. Pitts. Excellent hearing. Wonderful testimony. We thank our expert panel for your very important testimony and answers to our questions.

Without objection, the subcommittee is adjourned.

[Whereupon, at 4:25 p.m., the subcommittee was adjourned.]