Public Policy Update from the Chair of USBIA

Gavin Attwood
Brain Injury Alliance of Colorado

Dear USBIA Members,

As I am sure you are aware, the recent budget proposal by the President has cuts in areas that would significantly impact the BI community. There are threats to Medicaid, pre-existing conditions assurances in insurance, Essential Benefits in Insurance (including rehabilitation), as well as the TBI Act funding and other core federal funding for BI services, surveillance, prevention and research.

As a result of our deep concerns the USBIA Executive Committee decided to hire a lobbyist on a short term contract to ensure USBIA is represented in DC. The contract is with the Ridge Policy Group in DC. They have an excellent understanding of the landscape as it pertains to brain injury. Learn more about the Ridge Policy Group and the work they will be doing on behalf of USBIA, see their article on page 2 of this newsletter.

I have asked Geoff Lauer who is on both the executive committee and public policy committee to be the point person for the lobbyist and disseminate information and alerts to member states.

Please look out for updates from Geoff in the near future.

Member State Spotlight: Nebraska

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it is the only thing that ever has.”

Mother Teresa

Blazing Trails for Brain Injury 2017
Cathy A. Wyatt
Community Outreach Director

More than 300,000 individuals are living with a brain injury in Nebraska. An estimated 36,000 of them have a disability due to, in many cases, a circumstance or circumstances beyond their control.

Initially surrounded by professionals, the Meyer family eventually found themselves where many survivors and their caregivers do; at home, alone, wondering how they would make it through the day.

Fortunately, Marcie eventually found Brain Injury Alliance of Nebraska. And when she did, she didn’t hold back; making it very clear that she wanted to make a difference, she wanted BIA-NE’s help, and she wanted to do it right away.

During her first meeting with staff members, she brought a newspaper clipping from an out of state publication. It was about a walk, run, and roll. Marcie presented it to them and said, “How do we make this happen here?”

Less than one year later, on Sunday, June 11, Brain Injury Alliance of Nebraska hosted its first annual walk, run, roll: Blazing Trails for Brain Injury. The purpose: To create a fun and engaging experience for individuals of all ages and abilities to raise awareness and increase funding for brain injury. Like the logo above? Mike and Marcie’s daughter, Rachel, created it.

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Public Policy Updates

In response to the proposed cuts in federal funding for essential TBI programs and services, USBIA retained the Ridge Policy Group so the concerns of the brain injury communication can be heard on Capitol Hill. Learn more about the Ridge Policy Group below.

About the Ridge Policy Group

The Ridge Policy Group is a bipartisan, full service government affairs and issue management group with offices in both Washington, D.C. and Harrisburg, Pennsylvania. Since 1982, when Tom Ridge was first elected to the United States Congress, through his years as Governor of Pennsylvania, to his historic service as the Nation’s first Homeland Security Director, he has worked closely with senior advisors Mark Holman and Mark Campbell. Holman and Campbell have developed unmatched experience at the State and Federal levels, overseeing every aspect of government programs, policies, and budgets.

About Rebeccah Wolfkiel, Sr. Government Relations Specialist (DC Office)

Assisting USBIA on behalf of the Ridge Group will be Rebeccah Wolfkiel, who has extensive experience in brain injury issues. Rebeccah was intimately involved with the drafting and passage of the TBI Act reauthorizations in both 2008 and 2014, and she was integral in the TBI State Program’s transition from the Maternal and Child Health Bureau to the Administration for Community Living with the Department of Health and Human Services. She actively advocates for additional federal resources for individuals with brain injury and is instrumental in the organization of Brain Injury Awareness Day on Capitol Hill each March.

Representative Gallego Newest Face on Congressional Task Force

USBIA was thrilled to announce in June that Representative Ruben Gallego (AZ-7) is the newest member of the Congressional Task Force on Brain Injury. Gallego said that he joined because every year thousands of his constituents are impacted by brain injury, either personally or as a care partner. “I am confident that his advocacy for veterans’ issues can be applied toward advocacy of veterans with brain injury, a priority of the Congressional Brain Injury Task Force,” said Tom Grady, the Chair of the USBIA Public Policy Committee.

To find out if your member of Congress has joined the task force or to extend an invitation, please e-mail Erica Balderas, USBIA Public Policy Intern at policy@biaaz.org.

Balderas Named USIBA Public Policy Intern

Erica Balderas is completing a summer internship with the USBIA Public Policy Committee. Erica jumped right in working to increase the number of members on the Congressional Brain Injury Task Force and writing editorials on the impact of the President’s proposed 2018 budget.

The USBIA will be looking for a Fall 2017 Public Policy Intern to build on Balderas’ work. The intern could work from anywhere in the United States. If interested, please email policy@biaaz.org.

To register, visit usbia.org
Committee Reports

Membership & Development Committee

The Membership and Development Committee of the United States Brain Injury Alliance continues to work on strengthening the relationships with and between our member states. On May 11th, USBIA held another Leadership Call on the topic of Unmasking Brain Injury. Members shared their experiences with this amazing and powerful project while other participants had an opportunity to ask questions of the member states that have embarked on this journey.

Communications Committee

We have put on two webinars so far this year.

On February 23 Geoff Lauer presented “Riding a horse called ‘Chaos’: Navigating a challenging board chair or member.” The presentation was well received and there were great questions—e.g., “Do you have any strategies or suggestions as to how to ‘begin again’ after a rough start with a new leader?” Participants shared that they have similar challenges to the ones Geoff discussed.

Judy Dettmer and Drew Nagele presented “Improving school services: Update on the National Collaborative on Children’s Brain Injury.” The participants commented that the presentation was helpful as were the handouts. Note, you can learn more about NCCBI efforts on the NCCBI website.

The next webinar date is in August. The topic will be on web-based resources in brain injury, and Ann Glang and Laura Beck from the Center on Brain Injury Research and Training will present.

Spotlight on Nebraska, continued from page 1

“What a great morning,” said Peggy Reisher, Executive Director for BIA-NE. “More than 150 people turned out at Zorinsky Lake Park to participate and / or cheer on their loved ones; all while enjoying great entertainment and – for some – a newfound peace and assurance in knowing they weren’t alone.”

Michael & Marcie Meyer

“I think it’s wonderful,” said Marcie Meyer. “He (Michael) is the reason it started in the first place. I’m thrilled... just thrilled.”

A few days after the event, BIA-NE received a large bouquet of flowers. It was from Marcie and simply stated: “Thank you for turning our dream of an event like that into a reality.”

Needless to say, the organization is already gearing up for next year to, no doubt, blaze new trails in their quest to further a mission of creating a better future for all Nebraskans through brain injury prevention, education, advocacy, and support.

In the meantime, Mother Teresa was right.

One woman’s idea inspired a small group of professionals and community members to join forces and – together – shed light on brain injury and love on those living with one.

For more information on Brain Injury Alliance of Nebraska, we encourage you to go to www.biane.org.

Don’t miss USBIA’s next webinar!

Web-Based Resources in Brain Injury

Presented by Ann Glang & Laura Beck

Check the USBIA website for schedule!
BIAAZ hosted our annual Rays of Hope conference on May 14th. We had our biggest audience yet, with 350 survivors and care partners attending. Our keynote speakers were motivational speaker Steve Gamlin, forty-one year TBI survivor Jeff Sebell of Maine, Keith Watt, and Jason Westhoff. In May BIAAZ also hosted a panel of authors who have authored books on life after brain injury. Amy & Chris Hotaling, NFL-widow Cyndy Feassell, and Jeff Sebell walked our audience through what it takes to share your story after a brain injury. BIAAZ is just wrapping up a year-long grant that funded hospital outreach to raise awareness about our neuro-resource database. Camp Can Do is just around the corner as we prepare for our signature 4 day camp for adults with brain injury. The camp will be in August and you can find more information at campcandobiaaz.org. BIAAZ has also partnered with Seattle Mariners Evan Marshall and his wife Allison, to introduce the Butters Fund. The Butters Fund supports the pets of brain injury survivors and provides a clearing house of Arizona resources for those struggling to keep their pets maintained. More information is available at buttersfund.com.

A familiar face from Arizona has joined a congressional task force created to vet and advocate for legislation and to improve life for those living with traumatic brain injury. Congressman Gallego’s office announced that he has joined the Congressional Brain Injury Task Force. “Brain injury impacts over 50,000 Arizona residents every year,” said Representative Gallego from his Washington D.C. office. “I look forward to working on important legislation impacting veterans, caregivers, brain injury survivors, neuro professionals, and many of the residents of the Seventh District while serving on the Congressional Brain Injury Task Force.”

The Brain Injury Alliance of Arizona is thrilled that Congressman Gallego has lent his time and talents to this worthy cause. “When my son was injured and nearly died because of a brain injury from falling down the stairs while entering the subway in Boston, we had to Google traumatic brain injury because we had no idea what it was or the life-changing journey that we had just begun,” said Tom Nielsen, Board Chair of the Brain Injury Alliance of Arizona. “I know there are a million other families out there like mine, many in the Congressman’s district, and we are so thankful for his leadership on this issue.”

The United States Brain Injury Alliance, (USBIA), of whom BIAAZ is a chartered affiliate, expressed similar enthusiasm, noting that Congressman Gallego and the Congressional Brain Injury Task Force are a good and practical fit. “USBIA is pleased that Congressman Gallego has joined the Congressional Brain Injury Task Force,” said Tom Grady, the Chair of the USBIA Public Policy Committee. “I am confident that his advocacy for veterans’ issues can be applied toward advocacy of veterans with brain injury, a priority of the Congressional Brain Injury Task Force.” BIAAZ would also like to thank the Task Force Co-Chairs, Congressman Bill Pascrell of New Jersey and Congressman Thomas J. Rooney of Florida for their continued work on behalf of the traumatic brain injury (TBI) community. The Congressional Brain Injury Task Force was formed by Pascrell in 2001. Approximately 1.7 million Americans experience TBI each year and an estimated 3.2 million Americans are living with long-term, severe disabilities because of brain injury.
Over the years we have endured extreme heat and sun, rain, snow, wind, and lighting- sometimes all on the same day! Since 1986 there have been thousands of proud souls who will never forget the experience of braving the 13-mile hike 7,510 ft. elevation gain to the Pikes Peak Summit of 14,115ft! The opportunity for persons with brain injuries, their families, professionals, providers, and sponsors to join together for a common cause makes the PPC especially rewarding experience.

If you’ve never done it the Pikes Peak Challenge Fundraising Event, we would highly recommend it. It will change your life!

**BI 101 Trainings at Domestic Violence Shelters:** One of the ways BIAC strives to meet our vision (that all persons with a brain injury thrive in their community) is to raise awareness and increase knowledge among professionals. We do this by providing educational trainings throughout the state to groups such as police, mental health providers, homeless shelters, and other social service agencies. These presentations consist of an overview of brain injury, information about identification/screening, suggested accommodations/strategies, and connecting clients to resources. Recently we have been providing these trainings at a number of domestic violence shelters. Intimate partner violence is a common cause of brain injury in women. The head and face are often targets of intimate partner assaults, with victims suffering head or neck injuries. One research study of women in a shelter found that 75% had sustained at least one partner-related brain injury; 50% had sustained multiple. The more times they had been hit in the head or shaken, the more severe and frequent their symptoms. By providing education to staff at these agencies, we hope to build their capacity to better serve clients with brain injury. For more information, visit: https://biacolorado.org/education-for-professionals.

**Brain Injury Alliance of Idaho**

On May 20th we were able to gather as a board and have a face-to-face meeting. A lot of business was completed. BIA-ID reviewed the new website we have had on-line several months. Our ombudsman Virginia Galizia, PhD, reported she received 32 calls for BI information last year and has had 12 calls thus far this year. Russ Spearman identified there is no central data base in Idaho for people with BI whom call BIA-ID for assistance/information. Thus, the Brain Injury Alliance of Idaho will seek to develop a data base. Board members are investigating better ways to develop crossovers between Facebook and BAI-ID’s new website: www.biaid.org.

BIA-ID discussed fundraising efforts, including “Sip & Give,” at Telaya winery which has been extremely helpful/successful in the past, Idaho gives, Fred Meyer’s Rewards, and Amazon Smiles. In addition, Boise Brewing will be asked to arrange a raffle etc. The possibility of corporate donors will be explored in the future.

The TBI survey conducted by Idaho State University’s Russ Spearman was reviewed (“Executive summary–needs assessment of TBI in Idaho). Also reviewed was an educational brochure created by BIA-ID last year; changes were agreed upon, and more copies will be printed and disseminated to state universities to help students with BI better negotiate university study.

**Minnesota Brain Injury Alliance**

The Minnesota Brain Injury Alliance had a creative and fulfilling year with its “Unmasking Brain Injury In Minnesota” project leading up to Brain Injury Awareness Month during March. A statewide awareness effort that combined therapy, art and advocacy to share the stories of the hidden lives of people living with the effects of brain injury, more than 1,000 masks were created by people living with brain injury, their families, friends and the professionals who work with them. The
project culminated in a massive installation on April 1 at the Earle Brown Heritage Center in Brooklyn Center, Minnesota. “Unmasking” receive widespread media coverage from several local outlets over the year by featuring segments focused on individuals’ stories and ultimately a live broadcast the day of the event. Thousands of people attended the installation, which included several showings of Jed Schlegelmilch’s award-winning documentary “Unmasking” which followed the project from inception through to the end.

Overall, “Unmasking Brain Injury In Minnesota” achieved its goals by allowing over a thousand Minnesotans to share their unspoken feelings, by connecting people across the state and by raising public awareness of the subtle invisibility of brain injury.

In April, the Minnesota Brain Injury Alliance 32nd Annual Conference for Professionals in Brain Injury was held. Harvey E. Jacobs, PhD, CLCP and Uzma Samadani, MD, PhD presented the keynote speeches. A plenary on “Unmasking Brain Injury in Minnesota” featured a panel of participants in the project. And, a plenary with Janine Petracek covered her experiences as a TBI health care professional and as a parent of a child with a TBI.

Our 2017 Walk for Thought will take place on Saturday, September 23 at four locations around Minnesota.

**Brain Injury Alliance of Montana**

We are heading through 2017 at full speed doing what we can to reach and help more people. This fall will mark our 30th anniversary of creating better futures for those that have been impacted by brain injury.

This summer we will host our 9th annual helmet giveaway with the Missoula Osprey, one of four minor league baseball teams in Montana. Over the past 9 years we have expanded this event to include the Billings Mustangs and Helena Brewers. This year we will achieve our goal of working with all four teams by including the Great Falls Voyagers. These events are spread all over Montana so they give us an opportunity to meet new friends while expanding our outreach.

On October 14th, we will be hosting our annual conference; Unmasking Brain Injury in Montana: Facing the New Normal. The BIAMT is incorporating our partnership with Unmasking Brain Injury into the event and attendees will have the opportunity to decorate masks that represent their personal brain injury story. Montana is a large state so we are incredibly thankful for the survivors, caregivers, professionals and others that travel long distances to attend our conferences.

We have also partnered with the Injury Prevention department of the Montana DPHHS who has generously provided funds for us to advertise and share editorials in the Montana Senior News publication. With an estimated readership in excess of 100,000, the Montana Senior News is a great way to reach our states senior population. Our editorials have included survivor stories, the link between improving mental health and gardening and a spotlight on Liberty Place; an assisted living facility where “Freedom to Try” is the motto and the dignity of risk helps each person to explore their post-injury self to express the “courage to Sour” as new levels of independence immerge.

**Brain Injury Alliance of New Jersey**

The 11th Annual Gala was held on Thursday, March 16th at the Crystal Plaza in Livingston, New Jersey. The event honored Barbara Geiger-Parker, past President and CEO of the Brain Injury Alliance of New Jersey, John Tiene, CEO of Agency Network Exchange, and Benjamin Kurland, CEO of Allaire Health Care Group. The event served to raise awareness and funds critical to the services and supports BIANJ provides.

BIANJ is launching a new transportation safety website, JerseyDrives.com, to combine driver, passenger, cyclist, pedestrian, and motorcycle rider safety. The website and its counterpart social media accounts will be live by July 1.

The 35th Annual Seminar for Professionals was presented at iPlay America in Freehold, NJ. This year’s topic, “Making New Connections Following Brain Injury,” was dubbed the most successful yet by committee members and attendees. Keynote speaker, Dr. Kristen Dams-O’Connor, discussed Health and Neurodegeneration: A Continuum of Aging. The seminar was attended by nearly 200 professionals including occupational and physical therapists, cognitive rehabilitation therapists, case managers, social workers, nurses, school professionals, counselors, speech language pathologists, and others who work in the field of brain injury.

Camp TREK, (Together in Recreation, Exploration and Knowledge), BIANJ’s week-long summer camp for adults with a primary diagnosis of brain injury, will be from August 20-25, 2017 at the ARC of Gloucester in Williamstown, NJ.

BIANJ is presenting a Concussion Summit on Thursday, June 22nd in Sayreville, NJ. Keynote addresses include Gerard Gioia, PhD, presenting on Return to School, and Shannon Bauman, BS, BCSN, MD, CCFP, Dip. Sports Medicine, presenting Concussion Management: An Interdisciplinary Model. Peter Keating, Senior Writer at ESPN the Magazine will

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serve as Master of Ceremonies.

The 15th Annual Walk for Brain Injury Awareness will be on Saturday, October 7, 2017 in 4 locations including the usual Saddle River County Park, Mercer County Park, and Mt. Laurel Acres Park. New this year is a Jersey Shore location at Bradley Beach Boardwalk. Registration is now open at bianj.org/walk.

BIANJ’s teen safe driving program, Champion Schools, came to a conclusion on May 25, 2017. Students from 65 NJ high schools gathered to showcase their peer safe driving campaigns at Six Flags. After showcasing their projects, three schools were named Grand Prize Winners and awarded driving simulators for their schools courtesy of Founding Sponsor NJM. Winning schools included Nutley High School, Jackson Memorial High School, and Pitman High School.

Our Health and Human Services Professionals Trainings, held in two locations in New Jersey, were successful at the end of March. Each had over 100 people in attendance. The topic, “Managing Brain Injury in the Context of Medicaid,” was widely popular.

The Brain injury Alliance of New Jersey is working on several top priority public policy projects. First, the New Jersey General Assembly passed a resolution, Assembly Joint Resolution No. 115, which would designate the third Friday of each September as “Concussion Awareness Day.” Similarly, the New Jersey State Senate’s Health, Human Services and Senior Citizens Committee passed a companion resolution, Senate Joint Resolution No. 81. Both resolution are pending action by the full New Jersey State Senate. Second, the New Jersey Legislature passed Senate Bill No. 2348 which would add intramural sports to the State’s concussion management law. This bill is currently being considered by Governor Chris Christie. Third, the Brain Injury Alliance of New Jersey aims to pass a bill package, Senate Bill No. 3189 and General Assembly Bill NO. 4864, which would make permanent $140,000 in funding to provide specialized community-based brain injury services to benefit the brain injury community in New Jersey.

The last, but not least, top public policy project, the Brain Injury Alliance of New Jersey is working on is passing legislation, General Assembly Bill No. 2481, which would require public school students with concussion to be evaluated by licensed health care professionals before return to school; requires school districts to provide restrictions or limitations to student as needed. The New Jersey General Assembly passed this bill on September 29, 2016 and is pending consideration by the full New Jersey State Senate.

**Brain Injury Alliance of Oklahoma**

Allie Murie is hard at work on her current projects one of which includes a “Fashion Show” planned for next March to raise awareness on TBI. Allie also stays involved with her State Legislature watching all issues involving Brain Injury. She monitors not only Oklahoma but surrounding states to see what works and what does not so she can help build opportunities through her state lawmakers for the benefits of brain injury survivors.

**Brain Injury Alliance of Texas**

In Texas our big focus over the last quarter has been to serve at our state Capitol as advocates for brain injury rehabilitation. Two major issues came up during our state legislative session. First, our state agency that funds rehabilitation for brain injury, Comprehensive Rehabilitation Services, unexpectedly lost its funding stream due to a court ruling. The ruling found that it was unconstitutional to require people convicted of felonies to pay the fines that were funneled into the CRS trust. TXBIA and other advocacy groups scrambled to get new funding in the budget to allow CRS to remain in existence as an agency. Face to face meetings with legislators as well as calls and emails in support of funding for CRS went a long way in advocating for this much needed agency. Ultimately, funding was provided for both the ending of this fiscal year as well as the next biennium.

Next, the Texas House Insurance Committee put up a bill that would serve to wipe out all state mandates for coverage. Again TXBIA put out a call for advocacy, and our stakeholders and members strongly responded. We stood in the committee hearing and voiced our concerns and provided education regarding the needs of those with acquired and traumatic brain injury. A room full of advocates helped convince the committee not to move this bill up to the House floor for a vote. We really felt strongly that our voices made a difference!

We are looking forward to hosting our first resource fair and conference for pediatric brain injury in October at Dell Children’s Medical Center in Austin. And in December, we will have our 34th annual symposium providing educational opportunities for survivors and the professionals who serve them.

**Brain Injury Alliance of Utah**

Summer Greetings from the Brain Injury Alliance of Utah! Highlights of our recent activities include:

L. Michelle Sugerman, Ph.D., CIC, has been elected to the Board of Directors of the USBIA, and also recently became President of our local Board. Additionally, Alina K. Fong, Ph.D., has joined the USBIA Public Policy Committee. We are extremely proud of our association with these two outstanding individuals and greatly
appreciate their service to the USBIA, the Brain Injury Alliance of Utah Board of Directors, and the brain injury community.

Dr. Sugerman recently attended NeuroRehabilitation 2017, which was presented in association with Spaulding Rehabilitation Hospital and the Harvard Medical School Continuing Education Program. Many of the countries most experienced and committed neurorehabilitation experts presented cutting-edge clinical interventions, the latest findings, practical education, and hands-on methods to further expertise in guiding persons after CNS Trauma to their maximum level of function. During the conference, Dr. Sugerman had the opportunity to individually meet with Marilyn Price Spivak, the founder of the National Head Injury Foundation, which gave birth to the Brain Injury Alliance.

We are pleased to share, through a recent planned gift, the establishment of the Friends of Lacey Anne Picard Brain Injury Scholarship Fund. The fund is for brain injury survivors needing financial assistance in meeting the costs of post-injury treatment, and will be disbursed to qualifying individuals suffering from brain injury and/or spinal cord injury. Trust funds will be directed to providing services such as physical and cognitive therapies through appropriate sources, as well as the purchase of designated communication devices, medical or adaptive equipment for improved home mobility, and other assistive devices or therapeutic modalities. We are deeply grateful to the family and friends of Lacey Anne Picard for their foresight and generosity.

Over 350 people participated in our 23rd annual “Run, Walk & Roll” 5K held May 20, 2017. A beautiful, sunny morning was enjoyed by all. A big thank you to our new sponsors and to our historical sponsors who increased their support in 2017!

The BIAU has established new partnerships with Full Circle Yoga and Momentum Climbing in an effort to broaden our outreach and support to the brain injury community. Also, a new youth support group for children with brain injury, Story Time with Mrs. Bee, began this month. The yoga, climbing and story time sessions are each scheduled monthly. We will seek additional private funding to grow these valuable programs.

Throughout the summer we are traveling to rural community hospitals statewide to meet with case management staff, discharge planning teams, hospital administrators and other appropriate hospital personnel to inform and educate them about the Utah TBI Fund and the free services offered by BIAU.

We continue to cultivate our ongoing relationships with state representatives via meetings of the Utah Brain Injury Council (UBIC) and the TBI Fund Advisory Committee. Executive Director Glenn Lanham is serving as Chair of UBIC in 2017.

Upcoming Events in Utah: Our 28th annual Family and Professionals Conference will be held October 13, 2017. This year’s theme, “Building Connections for a Brighter Tomorrow,” comes from our collective efforts to remind everyone of the importance of community – that brain injury survivors and caregivers are not alone – and that there is always hope.

Brain Injury Alliance of Washington

We have had many wonderful opportunities so far this year to share meaningful experiences with our community. Our annual Brain Injury Awareness Dinner took place on March 14th. We had a fantastic group of survivors, their family and friends and professionals in the field come out to celebrate greater awareness for brain injury. The Walk, Run & Roll for Thought took place on April 2nd and was a tremendous success! Over 400 survivors, supporters, kids and dogs participated in this event to raise money for Brain Injury services. We also had the pleasure of taking a fun group of survivors and their caregivers to the Skagit Valley Tulip Fields on April 19th.

Follow USBIA on Facebook and Twitter!