



News from the States

Minnesota Brain Injury Alliance



The Minnesota Brain Injury Alliance hosted the Second Annual Statewide Stroke Conference on November 14, 2019. Attendees were enthusiastic about this year's lineup of presenters, including our Keynote Speaker, Dr. Magdy Selim, Professor of Neurology at Harvard Medical School. Dr. Selim presented on the pathophysiology of brain injury following an intracerebral hemorrhage and the results of clinical trials to improve patients' response to therapies. Bringing in experts like Dr. Selim, as well as the conference's other presenters, offered attendees the opportunity to hear about advancements in stroke research and care while also providing them with new perspectives on stroke care in general.

The Minnesota Brain Injury Alliance has made the difficult decision to cancel the 2020 Annual Conference for Professionals in Brain Injury out of concern for our

attendees and consideration for those facing increasingly tight travel restrictions. This is not a decision we made lightly; however, the downsides to continuing with the Conference greatly outweighed any conceivable advantages. Our first thoughts are for the health and safety of our attendees, presenters, and vendors as well as Earle Brown Heritage Center staff. If you have any questions or concerns, please contact the Minnesota Brain Injury Alliance at 612-378-2742.

Finally, the Minnesota Brain Injury Alliance recently was approached by two counties who wished to add themselves to our growing list of contracted Case Management counties: Anoka County, which started contracting with us in August of 2019, and Dakota County, which starts in February of 2020. This brings the number of counties we contract with to four: Hennepin, Ramsey, Dakota and Anoka. These are the four largest counties in Minnesota by population. Adding Anoka and Dakota to Case Management will significantly increase our ability to help people with brain injury across the state.

Brain Injury Alliance of Nebraska



Brain Injury Alliance of Nebraska (BIA-NE) has a couple of exciting partnerships rolling into 2020.

In October 2019, BIA-NE was awarded a small grant from the Nebraska Council on Developmental Disabilities to partner with the Lancaster County Youth Detention Center to provide brain injury training and screening. In the preliminary screening of 25 of the 28 youths in the program, 72% of the youths screened positive for brain injury. BIA-NE has shared this data with programs serving the juvenile justice population in the area. The preliminary results have sparked an interest and BIA-NE has begun to set up training for program partners.

The second partnership is with the Mental Health Association (MHA) of Nebraska. MHA is a nonprofit, peer-operated and participant-driven organization which serves and provides alternative programs to those struggling with mental health and/or substance use issues. In a pilot brain

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Spotlight on Minnesota's Citizen Advocate Program

By Jeff Nachbar, Public Policy Director & Mollie Clark, Public Policy Associate

The Minnesota Brain Injury Alliance has built a very successful and multifaceted public policy department and citizen advocate program over the past 20 years. We have clearly demonstrated the power that individuals with brain injury have to impact public policy decisions and bring positive change to services, supports and prevention of brain injury. From proactive funding for Resource Facilitation, to improvements to state Medicaid programs, injury prevention and many other issues, we and our volunteer citizen advocates have made the critical difference.

Our public policy department conducts both direct and grass-roots lobbying campaigns on specific policy priorities that are set by the Board of Directors each year. On the direct lobbying side of the equation, we meet regularly with legislators, help draft legislation and amendments, attend and testify at committee hearings, participate in coalitions and collaborate with other disability advocacy organizations, as well as conduct media advocacy and other issue awareness activities.



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Our real power comes from the grassroots lobbying activity we generate by educating and activating our Citizen Advocates. We conduct a yearly five-part Citizen Advocate Academy in preparation for the legislative session with classes every other Tuesday in the late summer. We educate and provide exercises for our advocates on topics including the specific issues we work on, the legislative process, how to lobby, telling your story, media advocacy, community organizing and many other topics.

However, just educating them is not enough. We continually strive to provide opportunities for advocates to put their learnings into action. We hold Town Hall Forums, set up one-on-one meetings with their own legislators, conduct Candidate Forums and other voter education campaigns, attend community events and participate in forums organized by others. During the Legislative Session, we are famous for our Tuesdays at the Capitol where we bring advocates to the Capitol every Tuesday. We help them meet with their legislators, show them how to lobby, have them attend and testify in Committee and of course we hold an annual rally in the Rotunda. Participating in their own government is an incredible and empowering experience for all involved. Minnesota Brain Injury Alliance Citizen Advocates are well known across the Capitol Complex by their purple tee-shirts and wide smiles.

We are certainly proud of the commitment and significant financial investment we have made to this program, and we well understand that not all have a significant level of resources to invest in political advocacy. However, we'll let you in on a little secret: anybody can do this! Maybe not all these things, but certainly some of them. Our advice is to start with a few people with brain injury and tell their stories!

Stories are at the very center of the work we do and for good reason - they're universal.

As policy advocates at the Minnesota Brain Injury Alliance, we are incredibly lucky to work with dozens of people with brain injuries to coordinate effective political messages that help push good ideas forward. The stories of individual advocates ground our policies in the day-to-day lives of people in our community and help keep our issues above the fray of usual political debates. The biggest part of our secret? You don't need a political science degree or any experience lobbying to start sharing stories with your legislators. Whether a policy expert, brain injury professional, or a citizen who cares greatly, anyone can make a difference by sharing their story and helping those around them share their stories.

Stories don't come in one shape or size, and that's important. Our role as professionals who work with people with brain injuries isn't to put words in people's mouths. People are nuanced and have complex experiences that often don't fit easily into a specific mold. When you work with someone to help draft their story, don't be afraid to let them take the lead and take ownership over the message they want to tell.

In our work, we have found many ways to adapt to meet the needs and abilities of a diverse range of individuals who all have their own stories to tell. For those who have difficulty with short term memory, we encourage bringing a written draft from which to read during a meeting with a legislator. For those who struggle with reading, we recommend creating a general outline for reference and practicing orally. For folks with difficulties writing, creating a draft as a voice memo or having someone help transcribe can help get the ball rolling. The key to supporting individuals in sharing their story is having flexibility in the ways we communicate.

Next, set up a meeting with them and their state legislator or call their local Congressional office and find out who the

staff person is that handles health care or brain injury, and set up a meeting with them. If you can, practice with them, attend the meeting with them, give them some feedback and bask in the feeling of political power you unleash!

Even if you don't have a specific policy agenda, policy makers will remember these meetings and will think about how their vote might impact a constituent or somebody they know.

This year Minnesota is looking to have an impact at the State Capitol on several critical issues and have set the following legislative priorities for 2020:

1. Improve Medical Assistance (MA) in Minnesota through changes to the MA Spend-down bill passed last year and to reduce the complexity of MA paperwork.
2. Increase Investment in Housing through significant bonding for affordable housing and additional policy reforms protecting people with disabilities.
3. Prevent Brain Injuries by raising awareness about e-scooter safety, supporting legislation to reduce DWIs and improve prevention and protections for individuals with disabilities experiencing gender-based violence.
4. "Cassie's Law" to promote neuropsychological testing during criminal sentencing to improve outcomes for people with brain injuries involved in the criminal justice system.

Of course, we do not win on our issues every year, but because of the sound foundation of citizen advocates and advocacy activities that we have built, we know we will always be making progress. You can too!

Minnesota Brain Injury Alliance Public Policy Staff are always willing to answer questions and help other Alliances that would like to do more advocacy. Give us a call at (612) 378-2742.

injury screening project done in 2019, BIA-NE found 77% of the staff screened positive for brain injury. Given this data MHA stated they would like to know about how to recognize and manage brain injury within their programs.

Brain Injury Alliance of New Jersey



Data has shown that New Jersey's pedestrian serious injury and fatality rates are higher than many other states

and seem to be slowly rising. The Brain Injury Alliance of New Jersey partnered with traffic safety community leaders to form the New Jersey Pedestrian and Bicyclist Safety Coalition to address how to improve the safety of the most vulnerable roadway users. In the one year that the coalition has been working, an online resource guide has been developed along with statewide social media messaging. Today, weekly social media posts are shared by over 150 community organizations.

The Brain Injury Alliance of New Jersey hosted another year of Adopt A Family in December, a gift drive program that benefits families who have been affected by brain injury. 2019 was the biggest year to date with 138 people adopted by 55 donors. This effort culminated in a party for the families involved where Santa handed out presents, families visited with therapy dogs, and children were able to do holiday crafts.

The annual free trainings for health and human service professionals, in collaboration with Community Oriented Correctional Health Services, will take place in two locations in New Jersey this spring. This year's topic is TBI in Detained Settings: Implications for Detained People, Correctional Staff, and Community Health Systems. Speakers include representatives from the New

York City Office of the Mayor, Incarcerated Nation Network, Urban Institute, Middlesex County Office of Adult Corrections and Youth Services, The Fortune Society and PINK Concussions.

BIANJ's Annual Seminar for Professionals, A 2020 Perspective: Improving TBI Outcomes in the Next Decade, is Tuesday, May 12th, and for the first time ever, BIANJ is hosting the Annual Professional Seminar VIRTUALLY!

You will still be able to learn from experts in the field, ask questions, interact with fellow attendees, and earn CEU's... all from the comfort of your home. Keynote Speaker John D. Corrigan, PhD, Professor, Ohio State University, Department of Physical Medicine and Rehabilitation, and Director, Ohio Valley Center for Brain Injury Prevention and Rehabilitation, will present TBI as a Chronic Health Condition. At the conclusion of Dr. Corrigan's presentation, participants will be able to describe change in function from rehabilitation discharge to five years' post-injury, explain conditions with the greatest excess mortality for persons receiving rehabilitation for TBI, and discuss issues to be addressed in developing a proactive approach to long-term management of moderate and severe TBI. More information on the virtual event can be [found here](#).

BIANJ has been invited by RWJBarnabas to be part of a Concussion Summit. Staff will present on current concussion-related legislation passed and in progress, and also on concussion management teams including definitions, structure, and technical assistance.

The Brain Injury Alliance of New Jersey is exploring the creation of an acquired brain injury (ABI) fund to help address financial burdens some people with ABI face. ABI is a broad term that includes, but is not limited to, brain injuries acquired as a result of arteriovenous malformation

(AVM), stroke, brain aneurysm, and brain tumor. Currently, New Jersey has a fund that is exclusively for people with traumatic brain injury. The purpose of the Fund, in part, would be to function as the payer of last resort, for the costs of post-acute care, services and financial assistance provided to qualifying persons in New Jersey who have survived ABI. The creation of an ABI Fund can be instrumental in addressing this need and keeping individuals in the home environment and out of costly institutional settings. The Alliance is working with stakeholders to address logistics associated with administering the would-be fund and seeks signers of a petition that calls upon elected officials in New Jersey to create an ABI Fund.

BIANJ now supports 16 affiliated groups in most New Jersey counties, all led by brain injury professionals and families who volunteer their time and expertise. During this quarter, an annual Support Group Satisfaction Survey was conducted. All support group participants and leaders had the opportunity to complete the anonymous survey. For the first time, the form was offered online as well as a printout at meetings, resulting in a total of 99 responses. Positive feedback included "The support group provided information on programs available and is an excellent place to gain perspective and meet people who 'get it'." And "I feel I am home with my people who share and understand brain injuries."

On November 14, 2019, 22 of BIANJ's volunteer support group leaders convened at St. Lawrence Rehabilitation Hospital in Lawrenceville, New Jersey. This year's Annual Meeting was notable for its record attendance and high level of engagement with participants. Speakers presented on Ticket to Work, services available through the Tri-State Advocacy Network, and statewide Centers for Independent Living. This event fostered a sense of community among the cohort of leaders

serving diverse groups in urban, rural, and suburban settings by providing a space to share information and celebrate their efforts. Post-event surveys were conducted reflecting positive experiences.

Brain Injury Alliance of Washington

The Brain Injury Alliance of Washington has had a great winter. We held our annual Brain Injury Gala on Saturday, November 3rd in Seattle. The theme this year was Unbreakable. It was a wonderful celebration and recognition of our unbreakable community of survivors of Brain Injury, their family members, and advocates.

In December, BIAWA kicked off the holiday season with over 100 survivors, caregivers, and supporters for our annual Community Holiday Party. We came together to celebrate a great year of expanded resources and support for those we serve and to share some fun, food, and song.

Despite the current crisis, we are already busy with 2020. March was a busy month for us with expanded outreach efforts throughout the whole state of Washington for Brain Injury Awareness month. We are also looking forward to an enjoyable year of activities and outings with those we serve like summer baseball games, day trip to the Skagit Valley tulip farms, and our annual Art Show later this fall.



USBIA Webinars

Management of TBI in Children

On Wednesday, February 12, Juliet Haarbauer-Krupa presented on the CDC's Report to Congress on the Management of TBI in Children (RTC). In consultation with the National Institutes of Health, the CDC conducted a review of scientific evidence related to brain injury management in children and reported it to Congress. Dr. Krupa is Senior Health Scientist on the Traumatic Brain Injury Team in the Division of Injury Prevention at the CDC. You may watch a video of the [webinar here](#).

Funding and Operations in a Time of Uncertainty

Geoff Lauer, Chair of USBIA, will soon host a web meeting for USBIA states with a panel of three to four Chief Financial Officers (CFOs), Chief Operating Officers (COOs), and CEOs from USBIA state affiliates to serve on a panel to discuss "Funding and Operations in a Time of Uncertainty." The target audience for this meeting will be USBIA Executive Directors, Chief Executive Officers (CEOs), CFOs, Board Chairs, Finance Committee Chairs, and Board Members. The format will consist of a 60- to 90-minute open conversation and a Question and Answer (Q&A) session with attendees. The webinar can be accessed from the USBIA [website](#).

Future USBIA Webinars

Community Brain Injury Services

Clubhouse

May 20, 2020

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OUR MISSION

The mission of the United States Brain Injury Alliance is to engage the community in preventing brain injuries and improving lives. We will accomplish this through awareness, prevention, advocacy, support, research, and community engagement.

www.usbia.org

Intimate Partner Violence in Nebraska

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Intimate Partner Violence (IPV) is defined as sexual violence, physical violence, stalking and/or Psychological aggression by a former or current intimate partner¹. World-wide, one in three women report experiencing IPV during their lifetime². Nationally in the United States of America (USA), approximately one in four women, and one in eight men, experience what is defined as severe physical and or emotional violence during their lifetime by an intimate partner. This includes sexual violence, as well as being burned, threatened with a weapon, hit, kicked and strangled.

In the USA, analysis of homicides of women by intimate partners revealed that in 2007, 45% of all homicides committed against women were at the hands of a current or former partner. Additionally, analysis of women who experienced IPV for the first time revealed that they tended to be younger, and perhaps less financially secure and prepared to manage their first episode of IPV independently. In Nebraska, during 2016 there were over 8,000 reports of domestic violence that were responded to by law enforcement. In the past ten years there have been over 54,000 reports of domestic violence that required response from law enforcement (www.ncc.nebraska.gov). However, it is also clear that rates of domestic violence are often underreported³.



Figure 1. Symptoms of persons with concussion and brain injury.

The consequences of experiencing IPV include a range of emotional and physical symptoms and disorders. Common emotional disorders include the experience of clinically significant symptoms of anxiety, which when severe, meet criteria for post-traumatic stress disorder (PTSD). PTSD is defined as a series of symptoms involving vivid and uncomfortable dreams about an event, intrusive and unpleasant thoughts of an event, and avoidance of locations, people and activities that are similar to those from the event. These symptoms are severe enough to interfere with activities of daily living. Chronic PTSD, defined as symptoms of this disorder which persist for more than four months, have been reported in approximately 47% of persons seeking shelter^{3,4}. Further, at least one other study has shown that of persons who experienced IPV for the first time and then sought shelter, 39% continued to experience symptoms of PTSD at a clinical elevation at 12 months post-assault. Untreated PTSD has been associated with poorer health, disrupted sleep/wake cycle, changes in working memory, changes in ability to sustain attention, and decreased cognitive stamina⁵. Additionally, many victims experience repeated victimization, which appear to increase the severity of the emotional and cognitive symptoms of PTSD⁶. It has been shown that the presence of PTSD in and of itself is sufficient to cause changes in

brain structure and function^{7,8}, as well as dysregulated stress hormone levels⁹, often impacting regions of the brain associated with both memory and reasoning/problem solving.

Unfortunately, IPV also often involves physical trauma and often to the head. In many cases, the result of this trauma is a brain injury. Brain injuries can be caused by an external force being exerted on the brain (i.e., a traumatic brain injury from being struck in the head), or can be the result of a non-forceful event that lead to injury (i.e., an acquired brain injury from being choked to the point of losing consciousness). These injuries are graded on a continuum from mild to moderate to severe. Mild injuries involve a loss of consciousness of up to 30-minutes and no apparent structural brain damage on imaging. Moderate injuries include a loss of consciousness from 31 minutes to 24 hours with evidence of structural damage/bleeding on the brain on imaging. A severe injury would involve loss of consciousness of over a day, with significant structural brain damage (biausa.org). Individuals with brain injury, whether traumatic or acquired, often display similar symptoms, depending on the severity of the injury. Figure 1 presents a table of commonly reported symptoms in individuals with a concussion or more severe brain injury. Note that there is

a large overlap of symptoms that could have both an emotional and physiological etiology or cause.

But how common is brain injury observed in persons who experience IPV and live in Nebraska? No one really knows for sure. However, a 2016 screening conducted by the Brain Injury Alliance of Nebraska at four regional women's programs revealed that approximately 60% of those surveyed screened positive for possible brain injury as a direct result of experiencing IPV. 42% of those surveyed indicated that they had been hit or strangled on more than six occasions. 66.3% of those surveyed indicated that they had experienced a loss of consciousness or felt dazed after an incident of IPV. Figure 2 demonstrates patterns of responding from the entire group of persons surveyed by site. While it is important to note that these data were obtained based on a screening tool and no

formal diagnosis of brain injury was made, the number of participants who endorsed a concerning level of symptoms is very high. Based on the initial screening that was completed in 2016, it is apparent that there are many hundreds of survivors of IPV in Nebraska experiencing cognitive change as a direct result of the violence they experienced.

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	Friendship Home (n=48)	The Bridge (n=5)	Domestic Abuse Program (n=8)	Center for Survivors (n=8)	Overall (n=69)
Headaches	87.5%	80.0%	87.5%	75.0%	85.8%
Dizziness	64.6%	60.0%	62.5%	37.5%	60.9%
Nausea	52.1%	60.0%	37.5%	37.5%	49.3%
Sensitivity to light	56.3%	40.0%	25.0%	25.0%	47.8%
Blurred or double vision	45.8%	20.0%	37.5%	37.5%	42.0%
Numbness or weakness in any of your limbs	41.7%	40.0%	12.5%	37.5%	37.7%
Insomnia, difficulty sleeping, or changes in your sleeping patterns	70.8%	60.0%	75.0%	62.5%	69.6%
Feeling irritable or impatient	68.8%	40.0%	25.0%	37.5%	58.0%
Feeling anxiety or depression	91.7%	100%	87.5%	75.0%	89.9%
Confusion	50.0%	20.0%	62.5%	50.0%	49.3%
Difficulty remembering	60.4%	0.0%	50.0%	75.0%	56.5%
Difficulty concentrating or focusing	77.1%	60.0%	75.0%	37.5%	71.0%
Challenges with going back to school or work and performing tasks you used to	58.3%	40.0%	50.0%	25.0%	52.2%

Figure 2. Symptoms endorsed by survivors of IPV in Nebraska, 2016