



Uniting for Brain Injury



BRAIN INJURY AWARENESS TOOLKIT

National Association of State Head Injury Administrators

February 2018



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*The **National Association of State Head Injury Administrators** assists State government in promoting partnerships and building systems to meet the needs of individuals with brain injuries and their families.*

Introduction

For the first time, the **National Association of State Head Injury Administrators** (NASHIA) is engaging in a national theme for promoting March Brain Injury Awareness Month by providing materials, including a logo, that its members and partners may use to promote awareness. The theme, **Uniting for Brain Injury**, is to symbolize that as a national organization with state and local membership, together we are promoting awareness. Many state agencies, providers and state brain injury organizations plan activities to promote brain injury awareness, and some national and federal organizations and agencies employ a theme for the month. NASHIA recognizes the array of these activities and features a small sampling of these activities in this document and on its website.

This toolkit was developed with the intention of helping state agencies, councils or boards, and organizations who wish to help promote awareness in addition to other planned activities. Materials in this toolkit are also downloadable on NASHIA's website: www.nashia.org.

NASHIA will also publish special newsletters spotlighting activities and individuals with brain injury and their families who have received or are receiving services or participating in some way to improve service delivery through advocacy and participation on advisory boards/councils and associations in their state. NASHIA would love you hear from you. Do you have activities you wish to share? If so, please send to publicpolicy@nashia.org.

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Tips for Promoting Awareness

Promoting awareness can be as simple as putting something on your Facebook page or as sophisticated as having an awareness campaign, complete with a theme and planned events. Below are just ideas that can range the gamut. Whatever you choose, know your facts! A fact sheet is included in this toolkit with statistics from the Centers for Disease Control and Prevention (CDC). But, you may also have statistics with regard to your state. If you are giving a presentation or speaking to the media, be sure to know what the facts are in your state with regard to the number who are injured, causes, high risk groups, and so forth. If your advisory council/board or other agency is involved in service delivery efforts, be sure to know that and what the priorities are, as well as what is available in the state.

Some state programs may need to get approval from the agency's public information staff before embarking on an awareness campaign or may be able to enlist their support for promoting awareness by publishing a press release or have other means to be of assistance. Other ideas:

- Pick something that you can wear (a ribbon, for ex.) to wear all month or one day a week during the month to call attention to brain injury. But, make sure your office knows what you are doing.
- Place the NASHIA table tent, "I'm United for Brain Injury", or something similar on your desk at work.
- Give a short presentation during a staff meeting about brain injury and March Awareness Month.
- Add "Uniting for Brain Injury: March Brain Injury Awareness Month" logo or a tagline to your email signature.
- Place a poster or materials on the bulletin board in your office break room.
- Place an article in your department or division's newsletter, if you have one, and/or ask if March Brain Injury Awareness Month can be added to your agency's website.
- Circulate a flier or materials among other state agencies, such as intellectual/developmental disabilities, mental health, juvenile justice/corrections, Special Health Care Needs; Vocational Rehabilitation, noting March Brain Injury Awareness Month.
- Develop a "press release" calling attention to the month and upcoming activities, such as a conference or an advisory council/board meeting.
- Schedule presentations on brain injury and your state's resources at other agencies meetings/conferences, such as the state Developmental Disabilities Conference, State Independent Living Council, and state Assistive Technology Council.
- Arrange for a Governor's proclamation or House/Senate resolutions proclaiming the month as Brain Injury Awareness Month, if that has not been arranged by an association or affiliate.
- Ask a lawmaker to speak on brain injury on the House/Senate floor. An advisory council/board member or other family advocate may be able to do that if a state worker is unable.
- Tweet! Blog! Social media is a popular way to disseminate messages.
- Host an event. If you are a provider or organization, invite your legislators, community leaders and partners for a reception to bring attention to brain injury.
- Ask family members, individuals, professionals and others to write a "letter to the editor" or op-ed about brain injury, the incidence, causes and impact on the individual, family and community.

Partners and Collaborators

A number of organizations and agencies may already be promoting awareness either statewide or locally. The state brain injury association or alliance may be taking the lead in your state to promote awareness. In many states, they are sponsoring their annual conference during the month of March and may also be obtaining a Governor's proclamation and/or House/Senate resolution. But, there are other organizations to collaborate with or urge collaboration for a united approach for promoting awareness. Some of these agencies may be on the advisory council/board and will already be aware of March Awareness Month. These include:

- State injury and violence prevention programs are a natural to promote brain injury awareness, as well as other organizations, such as state/local domestic or family violence prevention, child abuse prevention, and falls prevention programs.
- Traffic safety state agency and organizations which promote traffic safety to reduce the number of deaths and injuries may include: ThinkFirst, Safe Kids, Community Traffic Safety Teams, Mothers Against Drunk Driving (MADD), all of which are natural partners to promote prevention to reduce injuries, including brain injury. They work in communities, schools, and other venues and may be willing to distribute brain injury materials or speak about brain injury, if they do not already.
- Disability organizations and agencies, including state Developmental Disabilities Council, Statewide Independent Living Council, Governor's Council on Disability, Assistive Technology Council, and others may be willing to distribute information regarding brain injury among their networks.
- Medical, TBI and disability providers, including hospitals, EMS, rehabilitation providers, Vocational Rehabilitation community providers, mental health, substance abuse, and providers offering community living and supports. Do they offer staff training? Do they have a newsletter? Would they be willing to put materials in their break rooms or in their entrances regarding brain injury. Are they already planning events that state programs may be aware of and can support with additional materials and information.
- Education organizations, such as local and state PTO/PTA, may also hold meetings or be an avenue to distribute information about TBI, especially with regard to concussions, return to play and return to learn, if they are not familiar with materials developed by CDC or your state agency.
- Occupational organizations, including farm organizations, which may be interested in farm-related or job related injuries in terms of prevention and treatment. Your state may have an occupational prevention agency within the labor or health department that collects statistics on job-related injuries.
- Aging organizations, including AAA's, state aging council/agency or home health care agencies, nursing homes, and so forth, which may be a place to distribute materials or engage in brain injury awareness.

These are just a few ideas if you are looking for partners or new partners to promote awareness. If you have developed such partnerships and wish to share about your collaboration, let NASHIA know and we will be happy to share your work with other states.

Know the Facts About Traumatic Brain Injury!

What is the Extent of TBI?

- According to the Centers for Disease Control and Prevention (CDC), about 2.8 million TBI-related emergency department (ED) visits, hospitalizations, and deaths occurred in the United States in 2013.
 - TBI contributed to the deaths of nearly 50,000 people.
 - TBI was a diagnosis in more than 282,000 hospitalizations and 2.5 million ED visits. These consisted of TBI alone or TBI in combination with other injuries.

What are the Leading Causes of TBI?

- Falls were the leading cause of TBI in 2013. Falls disproportionately affect:
 - the youngest – more than half of TBI-related ED visits, hospitalizations, and deaths were among children 0 to 14.
 - the oldest age groups – nearly 4 in 5 TBI related ED visits, hospitalizations, and deaths in adults aged 65 and older.
- Being struck by or against an object was the second leading cause of TBI.
- Among all age groups, motor vehicle crashes were the third overall leading cause of TBI-related ED visits, hospitalizations, and deaths (14%). When looking at just TBI-related deaths, motor vehicle crashes were the third leading cause (19%) in 2013.
- Intentional self-harm was the second leading cause of TBI-related deaths (33%) in 2013.

Is a Concussion a Brain Injury?

- Yes. While a medical professional may call it a “mild” brain injury, the effects can be serious.

What are the Symptoms of a Concussion?

- Symptoms may not show up immediately, sometimes it may be days later. But, symptoms may include headache, nausea, dizziness, and confusion. The individual:
 - May not be able to recall events *prior to or after* a hit or fall.
 - Appears dazed or stunned.
 - Forgets an instruction or is confused about an assignment.
 - Moves clumsily.
 - Answers questions slowly.
 - Loses consciousness (*even briefly*).
 - Shows mood, behavior, or personality changes.

About Traumatic Brain Injury (TBI) and The Role of State Government

What is a Traumatic Brain Injury (TBI)?

The federal TBI Act of 1996 (Public Law 104-166), as amended, defines a TBI as acquired injury to the brain that does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma, but may include brain injuries caused by anoxia due to trauma. The Centers for Disease Control and Prevention's (CDC) Injury Center further defines a TBI as is caused by a bump, blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain.

Not all blows or jolts to the head result in a TBI. The severity of a TBI may range from "mild," i.e., a brief change in mental status or consciousness to "severe," i.e., an extended period of unconsciousness or amnesia after the injury. States may define TBI more broadly to include other acquired brain injuries (ABI) or use ABI definition to include TBI for purposes of providing services and supports.

What are the leading causes of TBI?

The CDC reports that falls account for the vast majority of TBIs when factoring in emergency department visits, hospitalizations, or death. The age groups at highest risk are the very young and the very old. The second leading cause is being hit by a object (unintentional blunt trauma). Motor vehicle crashes are the leading cause of hospitalization for adolescents and persons ages 15 – 44 years of age. Other causes include assaults, sports-related injuries, and war-related injuries among the military. Alcohol is frequently a contributing factor.

What is the magnitude of TBI?

In 2010, about 2.5 million Americans were admitted to emergency department (ED), hospitals, or died with a TBI -- either alone or in combination with other injuries, according to the CDC. The CDC reports that from 2001 to 2009, the rate of ED visits for sports and recreation-related injuries with a diagnosis of concussion or TBI, alone or in combination with other injuries, rose 57%

among children (age 19 or younger). A TBI may have both short-term and long-term effects on individuals, their

families, and society due to the financial cost of treatment, rehabilitation and care. Further impact to society includes injury-related work loss and disability; and lost income from premature death.

What are the common symptoms?

Symptoms vary depending on the extent of the injury and the area of the brain that is injured. While some symptoms appear immediately, others may appear several days or even weeks or years later. A person with a TBI may or may not lose consciousness and loss of consciousness is not always a sign of a severe TBI. A TBI may cause problems with cognition, emotions, physical mobility affecting how a person is able to return to school, work, home and community.

What is the rehabilitation process after a person sustains a TBI?

Rehabilitation starts at the time of injury with care usually provided by emergency medical services (EMS) personnel who stabilize the person and provide pre-hospital assessment and treatment. Depending on the level of severity, the individual may be transported to a trauma center for further treatment and acute rehabilitation followed by post-acute rehabilitation. Following injury a person may need to re-learn how to dress, bathe, eat, walk, talk and other activities of daily living.

Post-acute rehabilitation may focus on cognitive, emotional, behavioral issues, as well as educational and vocational goals; and compensatory strategies to help individuals to reintegrate and to live as independently as possible in the community. These rehabilitation therapies may be provided in inpatient settings, outpatient settings, residential settings or in the home. Often the payment source, such as private insurance, will dictate the length of stay in programs, duration of rehabilitation, and rehabilitation settings.

What are the services and supports which may be needed after rehabilitation?

Individuals with TBI may require short-term, long-term, crisis, or intermittent supports and services. These services and supports may be formal (paid) supports or natural supports, which involve relationships that occur in everyday life, including family, co-workers, neighbors, church family and acquaintances. Services and supports may include therapies to maintain functioning; counseling; in-home supports; personal care; transportation; home and vehicle modifications; substance use treatment; vocational counseling and training; and independent living skills training. These services are all designed to help individuals to reintegrate into community living and to live as independently as possible. Individuals may also need assistance with compensatory strategies to accommodate cognitive and behavioral disabilities associated with a TBI.

Service coordinators, also known as case managers or care coordinators or resource facilitators, help individuals to plan for short-term and life-long goals and facilitate and coordinate resources necessary to achieve these goals. Service coordinators employ a person-centered planning approach, which empowers individuals to be in charge of defining the direction for their lives. It is an ongoing problem solving approach involving a "person-centered" team which meets to identify opportunities for individuals to develop personal relationships, participate in their community, increase control over their own lives, and develop the skills and abilities needed.

What is the role of State government with regard to services for individuals with TBI?

Families and individuals with TBI generally contact State government programs when their insurance has been exhausted or does not cover the types of assistance needed to assist with rehabilitation and day to day living. Finding that traditional State disability and health related programs did not address cognitive and behavioral needs associated with a TBI, States developed programs designed specifically for individuals with TBI-related disabilities in order to provide timely and appropriate services to help individuals to return to home, school, work and community living.

States may offer Information & Referral (I&R) services; administer service coordination programs to work directly with individuals in obtaining needed services and supports; and

contract with providers for an array of rehabilitative and community services. Through these efforts, States coordinate policies and administer funds to provide seamless services from hospital discharge to home and community.

How do States pay for TBI services and supports?

States use a variety of resources to assist individuals with TBI and their families, including Medicaid, Vocational Rehabilitation, mental health/intellectual and developmental disabilities; and State revenue. About half of the States provide long-term services and supports through Medicaid Home and Community-Based Services programs designed to prevent unnecessary institutionalization or nursing home care as the only alternative.

About half of the States have enacted legislation, generally referred to as a trust fund, which dedicates funding from a fine or fee, usually associated with traffic safety violation, for purposes of providing or supporting TBI services. Some States also receive general (State) revenue which is appropriated for TBI programs offering an array of services. Some States use as a combination of all of these funding resources. In addition, through the TBI Act of 1996, as amended, federal funds have been made available for competitive State grants to improve and enhance access to service delivery. Service coordinators also identify and access community and private resources and donations to assist an individual to live and work in the community.

References:

- **Basic Information About TBI and Concussion.** Centers for Disease Control and Prevention, National Injury Center for Prevention and Control webpage: http://www.cdc.gov/traumaticbraininjury/basic_s.html
- **NASHIA website:** www.nashia.org
- **"Understanding TBI: Part 3 - The Recovery Process".** Fact Sheet. Model Systems Translation Center: <http://www.msktc.org/tbi/factsheets/Understanding-TBI/The-Recovery-Process-For-Traumatic-Brain-Injury>



Recognizing the Needs

- At least 5.3 million Americans live with TBI-related disabilities.
- TBIs are a major cause of death and disability contributing to about 30% of all injury deaths.
- Every day, 138 Americans die from injuries that include TBI.
- Individuals who survive a TBI may experience impaired thinking or memory, movement, sensation (e.g., vision or hearing), or emotional functioning (e.g., personality changes, depression), all of which can impact his or her ability to return to home, work or school and resume living independently, without assistance, accommodations and supports (Centers for Disease Control and Prevention's Injury Center)

Building Systems

- About half of the States that have established TBI programs through state funding or trust funds established to dedicate funds derived from traffic fines, surcharges to drivers license and other sources.
- About half of the States administer brain injury Medicaid home and community-based waiver programs
- 19 States receive grants from the ACL TBI State Partnership Program, the *only* federal program assisting States in developing service capacity.

Promoting Partnerships

- NASHIA partners with federal agencies to promote federal resources and information through webinars, conferences, and website.
- NASHIA belongs to several coalitions promoting disability, health, research, and prevention policies and funding.
- NASHIA joins other partners to promote awareness and foster collaboration among national and federal agencies through the Congressional Brain Injury Task Force Awareness Day held each year during the month of March.

*The **National Association of State Head Injury Administrators** assists State government in promoting partnerships and building systems to meet the needs of individuals with brain injuries and their families.*

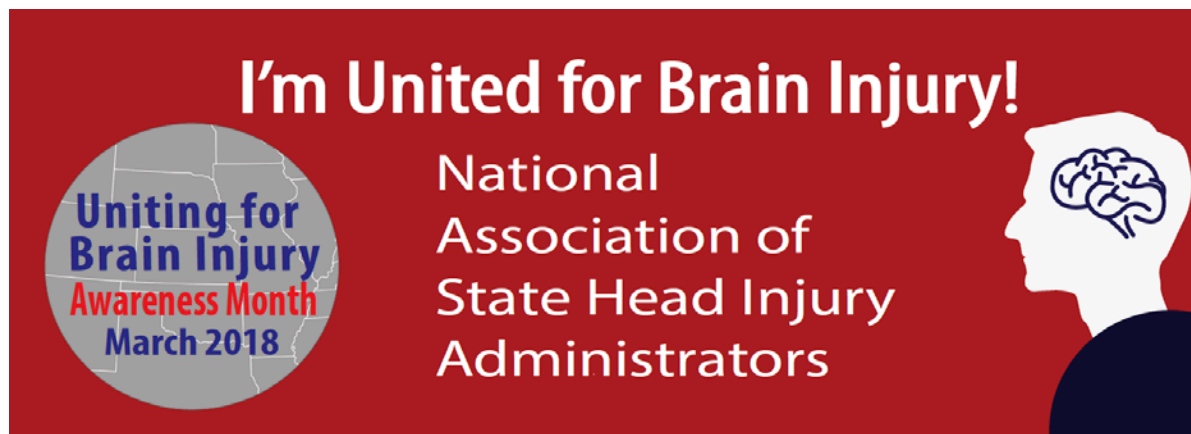
Logo; Table Tent; and Poster

With assistance from Nancy Noha, Coordinator for the Nebraska Assistive Technology Partnership, NASHIA developed the logo and theme, Uniting for Brain Injury, which can be accessed on NASHIA's website: www.nashia.org. Nancy developed the logo and accompanying materials which can be tailored to meet state and other organizations' needs. The poster has a place to add your name, as well as the table tent.

Logo:

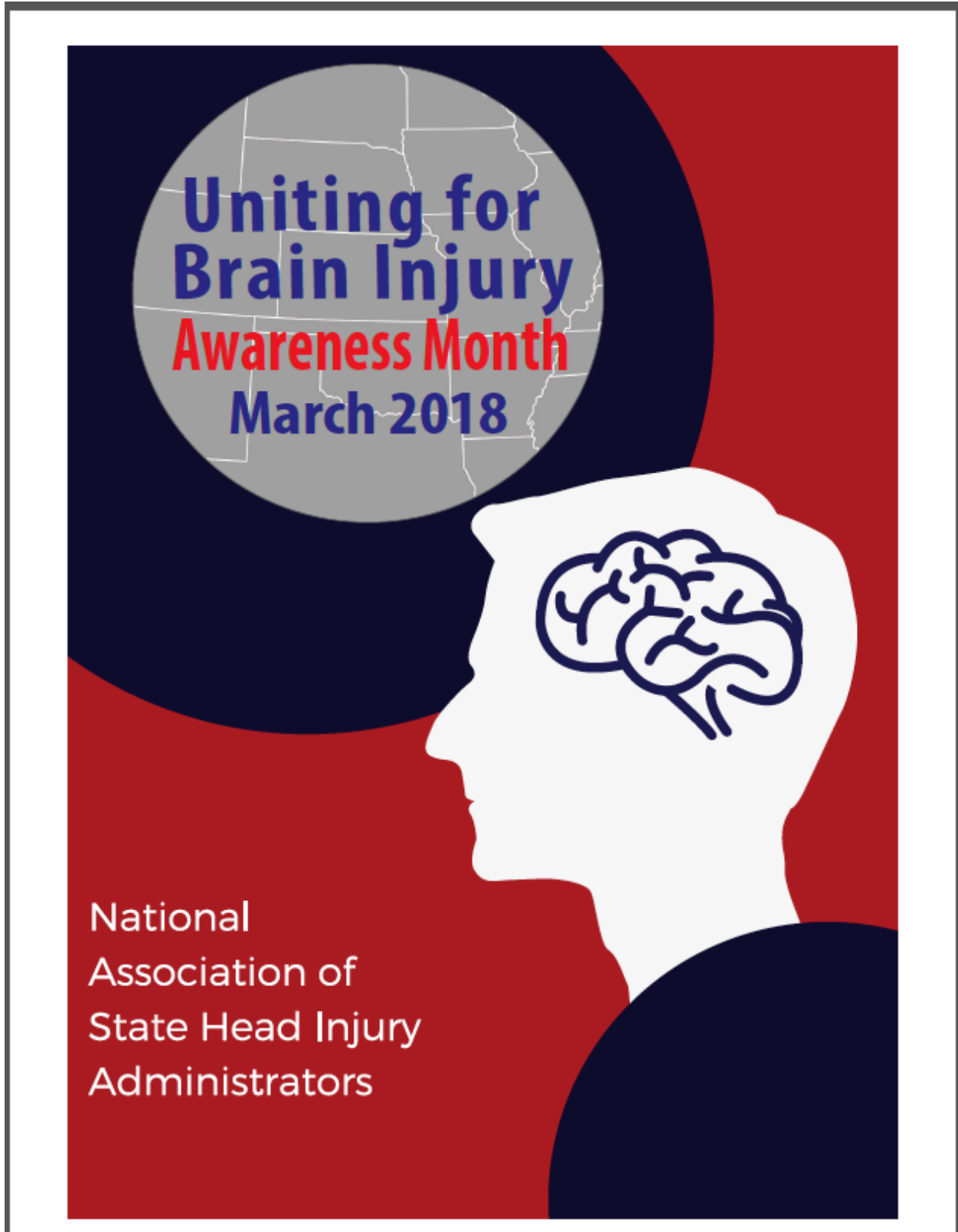


Table Tent:



It is envisioned that the table tent be printed on card stock and given to organizations, advisory board/council members, providers, policy makers and anyone interested in displaying the message on his or her desk.

Nancy Noha also has the capacity for tailoring to your state/organization by adding that name to the card. She can also add your name to the poster on the following page. You may contact her at: Nancy.Noha@nebraska.gov





A number of states and/or state brain injury associations or alliances promote March Brain Injury Awareness through these activities: sponsor conferences; obtain Governor proclamations; obtain resolutions from their legislative bodies; and work with their local media and social media to promote awareness. The following is a sample of activities shared with the National Association of State Head Injury Administrators (NASHIA).

Nebraska Brain Injury Advisory Council



In Nebraska, the TBI grant staff work closely with the Nebraska Brain Injury Advisory Council to increase awareness about brain injury and the work of the council. A council logo was designed in 2016 and is used to brand Council activities and print materials.

The logo is also an integral part of the redesigned web site launched last month, www.braininjury.nebraska.gov. The accessible and mobile responsive site includes a statewide calendar of events promoting awareness month, the annual brain injury conference, and webinars and workshops. State and national resources are included which benefit consumers and professionals.

The team in Nebraska includes Keri Bennett, Program Director, Tresa Christensen, Administrative Associate, Nebraska VR, and Nancy Noha, Coordinator for the Assistive Technology Partnership. The team is making plans for the Council's booth at the annual brain injury conference in March. Council members volunteer at the booth to answer questions and share materials. The team also sends periodic emails on policy/service updates, events, and training materials to stakeholders across the state.

Brain Injury Association of North Carolina: Conscious Brews 2018!

On March 4, the Brain Injury Association of North Carolina (BIANC) is sponsoring an afternoon of awesome music, great beer - all while helping to raise awareness. The theme is **Conscious Brews 2018!** The free event is held at the Highland Brewing Company. Local bands donate their time throughout the afternoon. There is also a silent auction for a variety of local goods and services, and Highland will donate \$1 from each pint sold during the event to BIANC, as well as collect tips over the course of the month.. There have been several media outlets that are also highlighting the event, well as on Facebook:

<https://www.facebook.com/events/303447606790482/> and
<https://mountainx.com/news/conscious-party-conscious-brews/>

North Dakota Brain Injury Network



In 2017, the North Dakota Brain Injury Network partnered with the state Department of Human Services to create and awareness media campaign with the tag line “Know Your Noggin” and the theme of “Brains Don’t Always Bounce Back. The campaign highlighted six North Dakotans who shared their survivor stories in TV commercials. The commercials can be found at this link: <https://www.ndbin.org/know-your-noggin>

San Diego Brain Injury Foundation

The San Diego Brain Injury Foundation will be hosting its 11th annual walk on **March 10, 2018** in Mission Bay Park de Anza Cove. The event, **surviveHEADSTRONG - Walk for Recovery**, is the largest annual gathering of the brain injury community in San Diego, with around 750-800 people in attendance. Professionals, hospitals, survivors, caregivers, friends, family and even local university students studying to be important members for the brain injury community, all in attendance walking, rolling or just cheering to celebrate all that has been accomplished. This is a tight-knit community that understands we achieve more together. This event is the embodiment of that spirit. Click here to link to the website page with all the information about our event:



<https://sdbif.org/index/events/2018-sdbif-surviveheadstrong-walk-brain-injury-recovery/>

Unmasking Brain Injury Project



A number of state government agencies, providers and state associations/alliances are participating in the **Unmasking Brain Injury Project** to promote awareness of the prevalence of brain injury; to give survivors a voice and the means to educate others of what it’s like to live with a brain injury. This traveling exhibition is a strong learning experience for everyone, students, parents and everyone in-between. The project was created by Hind’s Feet Farm, North Carolina, and is partnering with the Brain Injury Association of North Carolina, which is the point of contact.. Click here for more information. <http://unmaskingbraininjury.org/#home>

Sample March Brain Injury Awareness Month Press Release

[Cut and paste this press release onto your organization's letterhead and customize it as necessary. Send to your local media just before or at the start of March]

MEDIA CONTACT:

<NAME OF COMMUNICATIONS CONTACT AT ORGANIZATION>
<E-MAIL ADDRESS>
<PHONE NUMBER>

FOR IMMEDIATE RELEASE

<NAME OF ORGANIZATION> Joins Broad Effort to Observe National Disability Employment Awareness Month

Nationwide brain injury awareness campaign will take place in March

(City, State) — Date — <NAME OF ORGANIZATION> today announced its participation in "Uniting for Brain Injury," an annual March awareness campaign to educate the public about brain injury and resulting symptoms which may affect an individual's ability to return to home, community, school or work without adequate rehabilitative, community and family supports.

In 2013, 2.8 million Americans sought treatment for or died from a traumatic brain injury (TBI) as the result of a car crash, fall, sporting or recreational injury, an assault or other contributing factor, according to the Centers for Disease Control and Prevention (CDC). A TBI may cause problems with cognition, emotions, language, physical mobility and sensory affecting how a person is able to live, work and be a part of everyday life.

This year's theme, "Uniting for Brain Injury," recognizes that it takes federal and state policymakers, organizations, agencies, families and individuals with brain injury working together to advance rehabilitation and treatment and coordinating resources to enable individuals to return to living as independently as possible.

<NAME OF ORGANIZATION > is proud to be a part of this year's March Brain Injury Awareness Month said <NAME OF SPOKESPERSON>. Please contact us if you need further information or we can be of assistance.

Sample Brain Injury Awareness Month Social Media

Facebook and LinkedIn Posts

“Uniting for Brain Injury”

NAME OF ORGANIZATION is pleased to support March Brain Injury Awareness Month held each March to educate the public about the resulting disabilities relating to brain injury and the impact on individuals, family, friends, communities, employers and educators. Our organization offers resources and assistance_____

Tweets (examples)

Join the National Association of State Head Injury Administrators in celebrating March Brain Injury Awareness Month. #unitingforbraininjury

Join the Congressional Brain Injury Task Force for Awareness Day at Rayburn House Office Building, Washington, D.C. March 20. #unitingforbraininjury

Brain injury is a silent epidemic. Learn more @www.nashia.org. #unitingforbraininjury

Falls, sporting injuries, motor vehicle crashes means everyone is at risk for a TBI. #unitingforbraininjury

Brain injury does not discriminate. Anyone at any age can sustain a brain injury. #unitingforbraininjury

Know the symptoms of brain injury. Memory, thinking, personality changes, mood disorders can all result from a TBI. #unitingforbraininjury

Did you know a TBI is a leading cause of death and disability. #unitingforbraininjury

Writing a Blog

For those who blog, we encourage you to use your expertise and experiences to post your personal perspectives with regard to brain injury, whether you are an individual with brain injury, family member, professional or provide. A blog allows you to personally talk about brain injury from a personal viewpoint or a policy viewpoint on the needs of individuals with brain injury.

You may want to choose a blog name that is descriptive to your story. If the story is about you and your experience, write in first person. You may want to keep in mind the purpose of the blog. Is it to explain brain injury and how it happened or rehabilitation and services that followed or how it impacted the family or what you are looking for now – or all of this. Whatever the topic, keep in mind the reader may not know brain injury acronyms or jargon so make sure the blog and purpose are clear.