



MINNESOTA
Brain Injury
Alliance

MIND
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SPRING 2020



INSIDE —

- Aging With Brain Injury
- Katie Johnson- Walking With
- New Year, New Priorities
- Jackie Johnson-TBI Warrior
- ... And More

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MISSION

The mission of the Minnesota Brain Injury Alliance is to raise awareness and enhance the quality of life for all people affected by brain injury.



Editorial Policy

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Welcome *Mind Matters* readers,

It's been a cold winter and we're looking forward to a beautiful spring. We're also looking forward to several events as we head into the rest of the year.

First, our Annual Conference for Professionals in Brain Injury is rapidly approaching on April 16 and 17 at the Earle Brown Heritage Center in Brooklyn Center, Minnesota.

By David King

We've got some wonderful presenters lined up and endless opportunities for you professionals out there to connect with other people in your field, get to know each other and swap ideas. It's always a great couple of days and Pat Marciniak has the rundown of keynotes and plenary speakers later on in the issue. To register, visit www.braininjurymn.org/conference/ and join the Conference today.

Next, the Minnesota Stroke Association Strides for Stroke walk is coming up on May 16 in the Twin Cities, Duluth and Saint Cloud. This annual walk event is always a blast and brings together members of the stroke community from all over Minnesota. If you're a regular attendee of the Minnesota Brain Injury Alliance's Walk for Thought, and you've never been to Strides for Stroke, you should come check it out! Information about registration and locations is available at strokemn.org.

2020 is a very important year politically. As an election year, it's your chance to take to the polls and elect leaders who will represent your needs and lawmakers who will take your future into consideration. The Minnesota Brain Injury Alliance is here to help make sure you're ready on election day. If you have questions about voting or getting involved in the political process, visit braininjurymn.org/advocacy/ to get involved.

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 started in February of 2020. This brings the number of counties we contract with to four: Hennepin, Ramsey, Dakota and Anoka which 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.

Finally, March is Brain Injury Awareness month. This year, take the opportunity to raise brain injury awareness among your friends and loved ones. Tell them about your experiences; point them towards brain injury resources; and let them know about the Minnesota Brain Injury Alliance. If any of them need brain injury services in the future, they're already one step ahead simply by knowing about us.

Thank you so much for reading and for supporting the Minnesota Brain Injury Alliance. Enjoy the rest of the issue and I'll see you soon!

David King

AGING with Brain Injury

By Mike Strand

My brain injury occurred when I was twenty-five, now I'm fifty-six. For over thirty years I have struggled to get better. It was never fast enough; every gain did not seem commensurate to the effort. I always felt that if I didn't gain, at least I was holding my ground.

Recently, I have come to the realization that age-worn decline is upon me. For a few years now I have had to scale back some of my activities. I am having to acknowledge now that I can't drive when I'm tired. I really shouldn't be driving by late afternoon. I get too worn down. I am used to dealing with fatigue, and dealing with unprecedented age-related fatigue is nothing unique to brain injury, but having to deal with increasing limitations is something new.

When one is young there is the feeling that you're going to live forever. Life is nothing but a series of improvements. You get stronger, faster, and more worldly with each birthday. Based on past results, future predictions would tend to incline towards immortality.

Then there is a levelling off period where your gains slow, but you feel like you have what you have. Eventually, you start to realize that you've peaked somewhere, and you start trying to hang on to what you got. The day comes when you admit to yourself, "I'm old."

The brain injury development arc is different. In my case, I was at the top of my game when I was hit by a semi-truck. Overnight I became old. It was as if I was Merlin, the wizard of King Arthur's Camelot. Merlin could see the future because he lived his life backward through time, and every day he got younger and could not see into everyone's past, for he had not lived it yet. I felt like I was getting younger every day. Every day I was stronger, faster, and had a better grip on the here and now. Like Merlin, I lived without the same notion of the past that everyone else had.

Now I realize that I have lost my Camelot. I have come to realize that I am not getting better. In fact, I am beginning to lose that seemingly little bit that I was able to claw back all these past years.

Sometimes I feel like I have been cheated. Sure, I got better, but I was never "not brain injured." I have lived a life where I was always not quite all there. No one else can say that about me, but I can. I accepted it, but never really comprehended the loss until now.

"I was never "not brain injured." I have lived a life where I was always not quite all there."

-Mike Strand

Now, as my faculties begin to erode in a seemingly accelerated fashion, I find myself yelling, "Wait, I never got to be better!" I see now that I was always just "getting better." Drawing closer to an unreachable goal.

So, the Ferris Wheel has passed the top and I'm traveling down. I used to suck less at things, now I suck more. As always, I will learn to make peace with this. Long ago I mastered radical acceptance and epic grace. I will take what brain injury has given me. I will face my future with Strength, Resolve, and Dignity. I will be Sensitive, Open, and Strong.

"Mike Strand will be presenting at this year's Annual Conference for Professionals in Brain Injury. His presentation, "This Old Brain Injury" will touch on the topics in this article."

katie johnson - WALKING WITH

By Phil Gonzales, Public Awareness Associate

Katie Johnson was known in White Bear as “The Kid Who Did The Service Projects.” Even today, people on the street will hail her with “You’re that kid!” Her childhood of service led her to youth ministry and ultimately to Luther Seminary where she earned her Masters in Divinity. After grad school, Katie took a step back to figure out what she wanted to do with her life. She was working in an after school program in 2016 when she fell and hit her head.

“I fainted,” she says, “It was a long day at work, I came home and didn’t feel well, and I fainted in the bathroom. I hit my head on the tub and the floor.”



Katie had dizziness, headaches and head pressure. Doctors recommended brain rest and, eventually, therapy. So, Katie slept, stayed in a dark room and was told things would get better in a month or two.

“And then one month passed and two months passed and three months passed,” she says, “And I lost my job. And all of a sudden I wasn’t at work and there was no way to get back to the kids and the things I really loved doing. A lot of these kids were at-risk and this program gave them hope. And I really liked that. To see those kids who were leaders in their group go and do public speaking and I’d stand behind them at the galas and I loved supporting these kids.”

Not only was Katie now away from the work she loved, her social circle was growing smaller. Brain rest meant she wasn’t able to use her phone or computer and, although her mom attempted to reach out to people for her, Katie’s brain injury was causing her to become increasingly isolated.

“And I had this friend from work who came to pick up the

keys when they let me go,” Katie says, “and she’s now an art therapist and when she would come I would complain, ‘I want to go back! I want to do this and I feel really frustrated!’ And she helped me to re-frame it and look at it in a different way. She said, ‘What are things that speak to you?’ And I said, ‘Well, music but I can’t stand music right now because of my sound sensitivity.’ And she said, ‘Have you tried art?’ And my first impulse was, ‘I am terrible at art. It’s the one class I failed in high school!’ And she said ‘Well, it’s just about how you feel. Creatively.’ So we started painting. She’d bring over paints and we’d paint together, and that started to shape things for me. And then I started

painting on my own. And that’s when I started to feel like, ‘Okay this is what life looks like right now. I don’t know what the future is like, but I can sit in this.’ And that was the start.

“Then, I had to learn how to advocate for myself. My mom is hard of hearing and it’s nice that we both have disabilities because we can understand each other a little bit better so we start from that place. I have light and sound sensitivity, so when we’d go out to eat, I might need to sit in a darker spot or need to remove myself or wear a hat. And the first time I’d try these things I would end up in tears or in the bathroom.”

By 2017, Katie had started to feel better. She met with a pastor and took a temporary position as a Ministry Youth and Family Faith Formation Supply Minister. When that came to an end, she found a permanent job in a youth director position. Three days into the new job as she was getting into her car, she tripped and fell and hit her head on the door of the car.

"And I was like, 'I hope I didn't give myself a concussion' because it really hurt," she says, "and I started to get dizzy and confused and ended up going back to the brain injury specialist that day and not to work and I had to resign. And that was really really hard because I finally got to a place where I could serve again and that spawned what was to be a two year journey."

Perhaps as a result of her two falls, a disc in Katie's spine got moved resulting in terrible neck pain and the potential for paralysis. She ended up having spinal cord surgery in June of 2018 which left her learning to walk and use her arms again.

Throughout all of this, Katie was looking for people to connect with. People who might be able to relate to her situation.

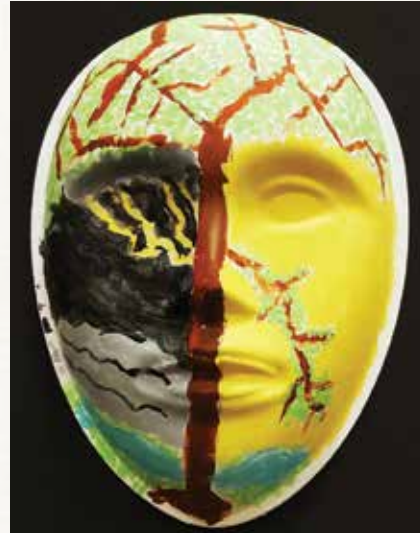
"I found out about the Minnesota Brain Injury Alliance through Courage Kenny," she says, "I interviewed with [Volunteer Program Manager] Debbi last spring and now I'm involved in advocacy. I initially typed up stories from the Unmaking event.

"It's been wonderful," she says of her experience as a Citizen Advocate, "I feel like I can just be myself. We all have this common shared experience. I don't need to explain myself. And everybody kind of lifts each other up. We all listen to each other's stories and we're all there for each other."

Today, light and sound are still vexing for Katie. She's learned to remove herself from overwhelming situations before they get to be too much. She still has brain fatigue and describes it as feeling like a dying computer that you can't turn back on to get your important papers or emails.

Katie struggles with the system at times. She's aware that if it weren't for her mom, she might very well be homeless. So she advocates for housing reform and transportation reform.

But outside of advocacy, she is a huge proponent of listening.



"I did a mask at the art fair. That was a very powerful experience. It expressed through art how I felt through this whole journey and how scary it was. It told my whole story. The imagery is of a tree that got hit by lightning. And then the clouds moved in and that was the brain fog that I was experiencing. And on the other side, there was light coming through the darkness. So there's hope at the end, but it's different. So the tree looks a little bit broken.

"And then Mollie [Clark, Public Policy Associate] met with me and said would you be interested in advocacy and I said sure! That's literally how it worked."

Katie received advocacy training through our Citizen Advocate Academy. There, she learned to shape her personal story to be used as a tool when talking with lawmakers. Through her work with the Public Policy department, she was selected to be the MC at the February 25 Disability Day at the Capitol.

Spring 2020

"In ministry, there's this concept of 'Walking With,'" Katie says, "which is not trying to change or fix a problem but just listening and being there. And that's different than advocacy because in advocacy you stand up and say, 'This is what needs to be fixed.' But when you're Walking With, you listen to peoples' stories. Stories have power. And so I think that's where the parallel is.

"I don't believe in platitudes. But, I think for me personally, it's like when a vase breaks - or when something breaks - and I know other people have said this but it's through the cracks that the light gets in. And even if you're sitting in the darkness there will be light that comes into your life. I guess another word for that would be hope. For me the light that came into my life was the church I'm now attending and the Brain Injury Alliance. There are people there that love you and support you. No matter what. Savour those moments. Like the friend that came to me and taught me about painting. Savour those moments. That's where the light starts breaking into the darkness. But also acknowledge the darkness because it's there."

Spreading Minnesota's Safety Net of Support

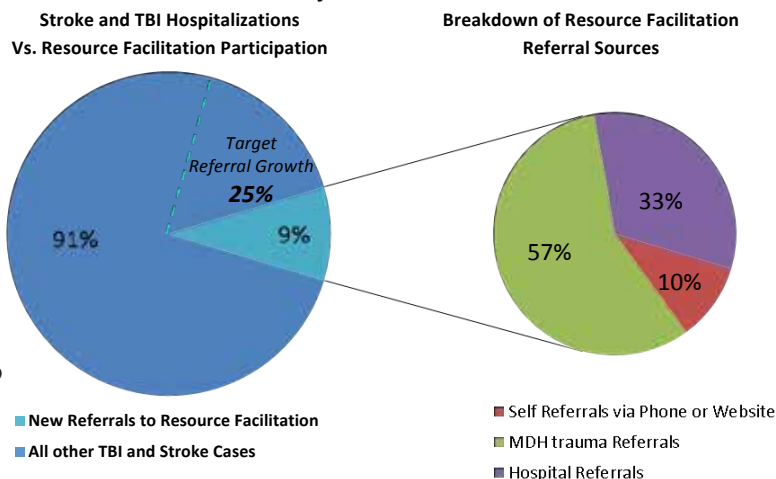
By Katrina Meyer,
Public Relations Associate

For the past six years, it has been my pleasure to connect with professionals around the state to share information about brain injury and the supports offered by the Minnesota Brain Injury Alliance. I have been able to meet a wide variety of individuals impacted by brain injury and the many professionals that serve them. These are incredibly wonderful and resilient people who know how difficult it can be to navigate complex systems serving people with brain injury. Thankfully, the Minnesota Brain Injury Alliance has a free, statewide phone support program called Resource Facilitation that can help those affected by brain injury find the resources, education, and advocacy support they need to keep from falling through the cracks.

When we look at the total number of TBIs and strokes that happen in Minnesota each year only nine percent of those individuals get connected to the Minnesota Brain Injury Alliance's Resource Facilitation program. We strongly believe that this number can grow. In 2020 we are putting out a challenge to increase that nine percent to twenty-five percent by connecting with hospitals and encouraging them to raise awareness of Resource Facilitation among their staff and patients.

How can you help? Well, if you are a professional working with individuals with brain injury, talk with them about Resource Facilitation and if they aren't already connected, offer to help them get connected to us. If you are not a professional supporting those with brain injuries you can still be a big help by spreading the word. Talk to the people who support those with brain injury or stroke at clinics, hospitals, and in the community about the Resource Facilitation program. Together we can spread Resource Facilitation's safety net of support to all who need it in Minnesota. If you would like help or guidance on how to help your clients or others get connected, contact the Public Relations team at 612-238-3241

Statewide Summary of Resource Facilitation Use



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NEW YEAR, NEW PRIORITIES

By Jeff Nachbar, Public Policy Director

After a very successful 2019, the Minnesota Brain Injury Alliance and its team of Citizen Advocates have turned their attention to the 2020 Legislative Session, which began February 11. The following priorities have been set and will guide the work until the expected adjournment in mid-May.

The Minnesota Legislature works in a two year cycle. The first year after an election is the budget year (last year) that sets the state budget for the next two years. The second year, the year we are in now, is the bonding and policy year. Policy bills are those that will not cost money to implement. Bonding is essentially the state's credit card, where we can borrow money to pay for projects now and then pay back that money over time out of future budgets.

We will be focused on both this year. Our agenda contains improvements in Medicaid policy, increasing investments in affordable housing, shelter, and housing services, preventing brain injuries, and changing the criminal justice system to work for people with brain injuries.

We know there are always more issues that people with brain injury face than the limited number we can work on at the State Capitol. We try to pick issues that we think impact the most people and ones that we can make a difference on. Let us know what you think.

2020 Public Policy Priorities:

1. Improve Medical Assistance (MA) in Minnesota

High quality and affordable healthcare through MA is critical for Minnesotans affected by brain injury. We will lead advocacy to improve the MA Spend-down bill passed last year, reduce the complexity of MA paperwork, and monitor changes to the Department of Human Services to protect key programs and supports.

2. Increase Investment in Housing

People with brain injuries disproportionately experience homelessness due to soaring health care costs and challenges with function following their injury. We will partner with Homes for All to pursue significant bonding for affordable housing and additional policy reforms protecting people with disabilities.

3. Prevent Brain Injuries

We strive to prevent brain injuries whenever possible. We will raise awareness about e-scooter safety and support legislation to reduce DWIs. We will partner with the Minnesota Coalition Against Sexual Assault (MNCASA) and the Minnesota Consortium for Citizens with Disabilities (MNCCD) to improve prevention and protection for individuals with disabilities experiencing gender-based violence by advocating for a package of policies that include prevention training for direct support staff, increased access to rape kits, and a caregiver misconduct registry.

4. Cassie's Law

Supporting a grassroots advocate, we will partner with him to pass legislation that promotes neuropsychological testing during criminal sentencing that improves outcomes for people with brain injuries involved in the criminal justice system.

The Minnesota Brain Injury Alliance works toward a Minnesota where everyone recognizes brain injury, its causes and effects, and where all individuals living with brain injury are encouraged to realize their full potential and their value to our community. If you would like to get involved please contact Mollie Clark at molliec@braininjurymn.org.

Jackie Johnson

TBI WARRIOR

By Phil Gonzales, Public Awareness Associate

Jackie Johnson lives in a liminal space familiar to many people with TBI; she is caught between what people expect a healthy young person to be able to do and what her body will allow her to accomplish. She has extreme limits on her energy, but also the knowledge and experience to handle a mentally stressful career. Jackie's learned a lot about balance; and she's taught a lot about it, too.

In May of 2019, Jackie was getting in her car to head to work at Eagle Ridge Academy, a K-12 charter school in Minnetonka, where she works as the School Psychologist. As she swung into the driver's seat, she hit her forehead just above her right eye. It was hard enough to make her swear out loud, but not hard enough to leave a mark. She shook it off and headed for school.

By the middle of the day, Jackie had an increasingly painful headache and was having trouble remembering students' names. A trip to the emergency room confirmed that she had a concussion, but doctors told her that the symptoms should only last about two weeks. It soon became clear, however, that

her symptoms - dizziness, fatigue, light and sound sensitivity - would not be gone in two weeks. Jackie was under a lot of pressure.

"In the special education world, there are a ton of legal deadlines," she says, "and so everything needs to be done within that time or the school gets in trouble or even you personally can get in trouble with your licensing. And being that it was May, we were trying to finish all these evaluations at the end of the year. I'd work for a few hours a day and come home and sleep then get up and do a couple more hours of work in the evening. But I'd have to take PTO for leaving early and not get paid for the work in the evening because they don't allow you to work from home."

Jackie's mom, Terri Rand, was at that time working as a registered nurse in the Neurology Clinic at Hennepin County Medical Center. She was able to get Jackie into the TBI Clinic where Jackie's issues, her dizziness in particular, were identified as stemming from her vision.

"There were three problems with my vision," she says, "my peripheral - which I hadn't noticed but I'd been bumping into things more than normal, things like that. And then excessive convergence - when I'd try to focus on something my eyes would focus several inches in front. It wasn't super noticeable for me, but reading was pretty much impossible and gave me a huge headache. And then my third thing was focus - my ability to have my lens in my eye focus."

Jackie began vision therapy, occupational therapy, and speech language pathology for cognitive issues and energy management. Although she says she "took the summer off," her father, Brett Johnson, notes, "When she said she didn't work that summer, she had at least three appointments a week."

Brett was taking Jackie to all of her appointments while Jackie was adjusting to life with a brain injury.

Jackie lost the ability to "feel" big emotions. "I didn't realize," she says, "I do now looking back - I ended up being apathetic." Although her body would still respond to stimulus by crying or getting angry. Jackie was incapable of describing what she felt. Even when her relationship with her boyfriend came to an end.

"I'd be sad or watching a sad movie and be crying but not actually feeling sad. Even going through the breakup, I'd be crying and he'd be crying and he'd say, 'I'm so sorry I'm making you sad' and I'd say, 'If it makes you feel any better I don't feel sad!'"

Eventually, Jackie's emotions began to return, but in July she realized that she herself might not be able



"I've learned I can't say I have a concussion, because people don't get it. After the first few weeks I'd get this vibe from people in my department of 'Why aren't you better yet? Shouldn't you be improving? Shouldn't this be gone?' So I switched to calling it a brain injury. But, when you use that phrase, people don't expect you to look normal and to act normal and to be able to have a conversation. People assume with a brain injury that there must be something physical that they can tell. And that's just not how it is."



to return to work, at least full-time. She called and suggested they hire a temporary substitute for her while she went on short-term disability, but her school told her coming back part-time would be fine.

In preparation for returning to work, Jackie contacted the Minnesota Brain Injury Alliance's Volunteer program. There, she was introduced to Debbi Erickson and Brittany Murnan, our Volunteer Manager and Volunteer Specialist. Debbi and Brittany helped Jackie to build up her cognitive endurance.

"I started two days a week in September for two hours a day," Jackie says, "Then we bumped up to three hours, then three hours three times a week. It got to the point where they would have to send me home because I'd get things done too quickly. I was doing data entry with billing and mailing. Helping with masks, organizing everything. And I'd get through things quicker and I'd spend less time there."

Jackie was eager to increase her stamina as her first day back at work proved frustrating. She worked her approved three hours, but was then informed by HR that they would either need her to return full-time or take short-term disability while they got a substitute for her position - the suggestion she'd made two months previous. Eventually, as it became apparent how valuable she was to the school, they allowed her to return on a part-time basis.

"The biggest difficulty is that they still wanted to know when I could come back full-time," she says, "'Well you can ask your doctor.' But, my doctor is going to have no idea. That was hard to get across for whatever reason. Why I couldn't give them a return date and why I still can't tell them when I'll be able to be full time."

But, Jackie's return to work has also been positive in many ways. She has developed a new understanding of the kids she works with, some of whom have TBI. And, her experience is helping her workplace learn to adapt for people with disabilities.

"I think it's been very interesting for everyone," she says, "Because I've been very very open about it with the majority of the people I meet or at work. At the end of the year I was really only focusing on the Special Education evaluations and any time a teacher would come to me with any concerns - if they were having a behavior problem or whatever with a student - I had to say, 'I do not have the ability to deal with that. You need to talk to the counselor or a Special Education teacher or somebody else.' Because I could not deal with it."

Now, Jackie is very strict about working only at work. Meaning, she doesn't answer work emails outside the office. She sets an alarm on her phone for when it's time to leave and will cut off a conversation to stick with it. Today, she is up to working five hours a day, and that means that if a meeting requires her to be in the office fifteen minutes early, then she leaves fifteen minutes early. If she stays late, she flexes those hours. She also has to keep her duties focused and sticks very strictly to her necessary tasks as school psychologist.

"My boss has been really great and flexible with things. There are times she'll come and ask me to do something and I'll say, 'I'm not going to get to that.' The school psych evaluations are the most important thing for a school psych to do because they are things that only a school psych can do. So I am there to do what only a school psych can do. As I increase my hours hopefully I'll get back to that other stuff. And she's like, 'Thank you for telling me.' If I'd been quiet about it she'd assume I could do it."

Today, Jackie enjoys her time with her friends, plays piano and stays involved in her community and family.

"The doctors told me you'll never get back to being 100 percent," she says, "but your brain will learn to compensate and figure that out eventually."

She has learned that life with a brain injury can be a life of fighting to show people that she is capable of doing her job, working with kids and contributing to her school. She's used to putting herself out there. She's good at putting in the work.

"I call myself a TBI Warrior," she says.

And, indeed she is.

BRAIN INJURY AND ISOLATION

By Sue McGuigan, Development Coordinator



One often neglected consequence of brain injury is isolation. Research shows that more than 70 percent of people who have sustained brain injuries have seen deterioration in their social life following brain injury, with a similar percentage feeling that people in their lives do not understand the effects of their condition. A 2015 Brigham Young University study has indicated that lack of social connection heightens health risks as much as smoking fifteen cigarettes a day or having an alcohol abuse disorder. This study also found that loneliness and social isolation are twice as harmful to physical and mental health as obesity.

"My co-workers as well as the general public had little understanding of brain injury. Few could relate to what I was going through." - Jon

Various factors produce relationship changes after brain injury. First, physical limitations, including sensitivity to light and sound, and pain may make it harder for people to do the things they used to do. Fatigue can also be a big factor. Having to take frequent naps and not having energy make it more difficult to join in social events. Kayla Meyer, a Minnesota Brain Injury Alliance volunteer, remarked that, "After my brain injury from concussions in hockey, my hockey team and other friends were not supportive. They stopped inviting me to things and wouldn't sit with me at lunch anymore. They didn't know why I was different and didn't want to try and understand. I had a lot of pain and missed school and hockey. This, in their eyes, made me boring and a problem to be around. So they all just decided not to be around me anymore."

Communication problems may also lead to isolation. Another Alliance volunteer, Ray Widstrand, says that although he had support from friends, family and his community, "I definitely felt intense isolation and depression. My ability to communicate was affected, as was how I was experiencing the world. I looked very much the same, but I was actually very different." Some people feel self-conscious about their injury and shy away from friends and family. Others avoid social interactions because they are afraid of being hurt or rejected.

"I feel very removed, like I'm an observer and commentator but no longer a participant in life." - Ray

After brain injury, many people may not be able to go back to their previous job or take part in their previous activities. Since they no longer have frequent contact with their work friends and acquaintances, the relationships may fall away. Finally, practical things like lack of income or difficulty finding appropriate transportation also limit people's ability to participate in social activities.

"Being excluded and left out made me very depressed and alone." - Kayla

So how do people cope with the loneliness they feel after brain injury?

Glen Hausfield, one of our Citizen Advocates, disclosed

that, "I went about my life the best I could. I learned to walk away from people who didn't treat me well."

Board member Jon Casey said, "I started to exercise again and went back to work three months later (way too soon). Getting back to my new 'normal' helped me be the person I was, even though that person was never the same after the assault."

"I did go to speech therapy twice per week, and we had several friends that drove me to appointments," said Terence Mistalski. "I also spent time on the phone speaking to friends, to minimize (and conquer) the aphasia that I had."

Mike Strand, a regular columnist for Mind Matters magazine, says "I made a consistent effort to be included. I did not take my friends for granted or adopt the attitude that they owed me anything. The thought of becoming isolated terrified me. I called my friends often and talked about them, not me. I had a couple friends who lived nearby and I would call them up and they would take me disc golfing."

"I contemplated running away or suicide at my lowest point." - Chad

The Minnesota Brain Injury Alliance also works to combat isolation by providing opportunities for people affected by brain injury to engage with their community. Our Resource Facilitation program connects people to supports and services, and lets them know that they are not alone. And our Public Policy Program's Citizen Advocate Academy teaches effective advocacy skills to encourage people affected by brain injury to become engaged in the political process. The group of Citizen Advocates regularly shares their stories with policymakers at the State Capitol to create positive change.

"I tried to keep up with everyone but couldn't. Some people tried to help me and include me but bigger kids bullied me because I was different." - Glen

Our Volunteer Program's Speakers Bureau provides opportunities for individuals who have sustained brain injuries and their loved ones to connect with their community by telling their brain injury stories in schools, churches, workplaces, and other venues. Also, through the Alliance's Unmasking Brain Injury in Minnesota project, thousands of people have viewed masks made by hundreds of people affected by brain injury, creating a statewide brain injury community. And our Education and Community Outreach Department brings together groups of people affected by brain injury to give them an opportunity to learn from each other about how to deal with brain injury in our Brain Injury

"After my stroke it was horrible, I had no family or kids and lived alone. My friends didn't really show up to help me. I felt really sad and lonely and scary." - Barb

Basics classes and Consumer and Family Conferences.

Ray says, "Volunteering with the Minnesota Brain Injury Alliance has been helpful for me. Sharing my story, using my experience to raise awareness, and doing advocacy work are so fulfilling and something I'm passionate about."

Kayla also commented, "To combat my isolation I attended my first Walk for Thought to be around other people with brain injuries. I wanted to be around other people who understood my experiences. I also joined the Speaker's Bureau to share my story and to start healing from my isolation."

Tim Nolan, a Citizen Advocate says, "I got the strongest support from the Brain Injury Alliance. It's amazing to be in communities of people with brain injuries. I sometimes look to my left and to my right surrounded by a room full of miracles. I love going to Tuesdays at the Capitol because I see people with all different types of disabilities. I see love

and compassion, we're all one and we're all a type of family. It resonates in my body when I'm in that community."

You can support Minnesota Brain Injury Alliance efforts to help those affected by brain injury re-engage with their community by donating during Brain Injury Awareness Month this March. You can give by mailing us a check or donating online at www.braininjurymn.org/donate. If you would like to contribute monthly through our Brain Trust program, please call our offices at 612-378-2742. Your generosity will make a difference in the lives of people like Ray and Kayla and Tim, to help them feel less isolated and more connected to their community. Thanks for all your support!

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LEADERS IN BRAIN INJURY AND STROKE CONVENE FOR 2020 ANNUAL CONFERENCE



April 16 and 17, 2020
Earle Brown Heritage Center,
Brooklyn Center, MN

*By Pat Marciniak,
Media Relations Coordinator*

2020 marks the 35th Anniversary of our Annual Conference for Professionals in Brain Injury to be held April 16 through 17 at the Earle Brown Heritage Center. According to Paula St. John, Education and Community Outreach Manager. The conference promises to deliver topics of interest for everyone in the brain injury field with engaging keynotes, outstanding breakout sessions and two powerful first person plenary sessions. Additionally you will have the opportunity to meet with vendors who can aid you in your profession.

Our 2020 conference opens with a keynote speaker whose topic is trending in the youth concussion arena. Dr. Katy O'Brien, PhD, CCC-SLP, will speak on "Postsecondary Settings, Concussions and Brain Injury: Understanding and Meeting the Range of Student Needs."

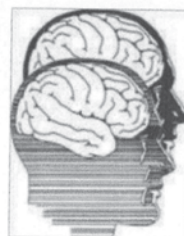
Our Friday keynote speaker is Emily Nalder, PhD, OT Reg (Ontario), Assistant Professor at the University of Toronto in the department of Occupational Science and Occupational Therapy. Dr. Nalder will present on "Resiliency in the Context of Traumatic Brain Injury: Conceptual Understandings and Implication for Rehabilitation." Both speakers will be presenting informative breakout sessions following their keynote each day.

As in previous years we will close each day with a first person, personal success story as our plenary. On Thursday we'll hear from Ray Widstrand, who stepped into a fight to save a stranger and became the victim of a brutal beating that almost cost him his life. Ray received the Police Chief's Award for Valor in 2016 and his story was featured on the news. He will speak on healing and recovery after a Traumatic Brain Injury.

Our Friday plenary is Joe Oppold, the author of "That's a Great Haircut." Joe will wrap the conference sharing how the determination he learned at West Point, along

with the strength of his family and friends, helped him through the challenges he faced to get back to leading a fulfilling life.

Information on the 2020 Annual Conference is available online at www.braininjurymn.org. If you are a professional who works with individuals in any area of brain injury, the conference is a great opportunity to network and bring back new information to help you in your work setting. You won't want to miss this event so register online now. It's also not too late to promote your business or service to a specialized audience in brain injury and stroke through sponsorship and vendor opportunities. We look forward to seeing you in April!



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- More than 35 years of helping persons with brain injury understand their injury and make improvements.
- Awards to Founder [1] "excellence in clinical practice and contributions to the field of rehabilitation psychology" and [2] "distinguished contributions to the field of brain injury."

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Taking Charge of Your Recovery

If being in charge of our own lives is important, then taking charge of our recovery is just as important.

For professionals working with individuals who have had a brain injury one of our most important roles is being their cheerleaders. We help them and their families understand the sometimes painful reality of changes in behavior, thinking and emotions that come with brain injury; but we also have an important part to play as the people who encourage them, help them see options to wellness and recovery, provide ideas when they are stuck, and generally cheer them on to better lives through their hard work.

We are sometimes at a loss for how to balance the reality of the problems the people we serve are faced with and holding out the hope we have for them as they struggle with changes in identity, relationships, school and work. For professionals working with individuals who have had a brain injury our approach needs to combine good customer service with a person centered approach that might be called recovery focused. It's

hard to describe a recovery focused approach given the expansive nature of what "recovery" is. A recovery focused approach is generally one that focuses on helping others be as active and independent as they are able and regaining connections to important people in their lives in order to have a meaningful life and positive sense of themselves.

Our most important job is to listen to where the person is in their recovery, what they want and ways to help them accomplish their goals. Without providing unwanted advice we can support people with brain injury to seek help when we see they are struggling. When they get stuck our job is to help them look at things from different directions, stay connected to the people they love and trust, and remember how to ask for help during their recovery process.

Listening has to be one of the most important things we do when we come to the realization that each person is their own expert in what recovery is for them.

— *by Erwin Concepcion*

When I first suffered my traumatic brain injury I remember going through a range of emotions, with questions constantly running through my head such as, "Why did this happen?" "Am I ever going to get better?" "When is this going to end?" "Why am I still struggling?"

Little did I know the journey was going to take me several years of living in a vicious cycle of chronic pain and coping mechanisms.

It wasn't until I finally said to myself, "Amy, it's time to put your big-girl panties on and take charge of your life again" that I finally had a turning point in my recovery.

Once I took acceptance of what had happened to me, my life started to change.

I began looking at life as "half full" instead of "half empty" and I celebrated all of the little things that were going right for me.

Yes, I was still struggling with the constant cycle of symptoms, but I had shifted my attitude from "poor
Spring 2020

me" to "I'm going to make the most of my life while living with this TBI" — and it was profound.

I eventually found The Functional Neurology Center and Dr. Schmoie. He was the first doctor to acknowledge the symptoms I had been struggling with, reaffirming that I wasn't exaggerating or making them up as other doctors had implied. He had a treatment plan that I followed, and over the next 10 or so months I had dramatic improvements.

If I hadn't shifted from a place of "victim" to a place of "survivor and thriver" I may have never found Dr. Schmoie nor received the proper care.

Taking charge of your recovery means you have to stop looking in the rearview mirror — that isn't your life anymore and you will never move forward if you're always looking backwards.

Embrace the new you, and empower your recovery journey!!

— *By Amy Zellmer*
www.braininjurymn.org



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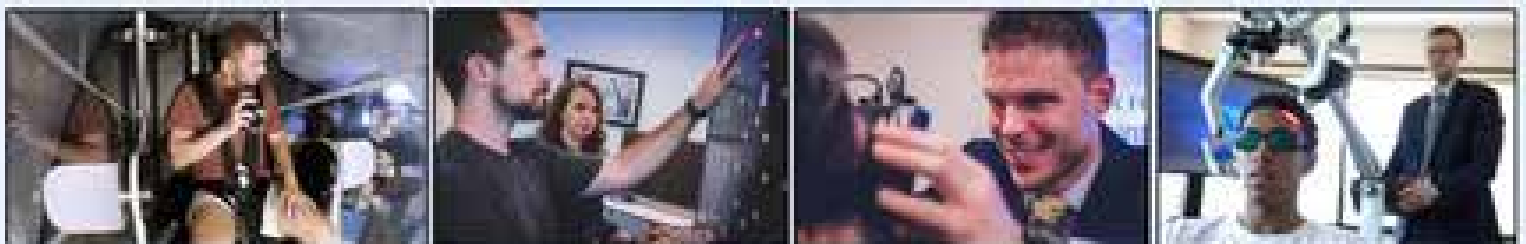
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