

INSIDE: Gerhard and Renee – In a Split Second
Grey Matters • Amy Zellmer • It's the Holiday's...Again • More

Mind Matters

Winter 2018



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**Brain Injury
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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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Letters to the Editor should be limited to 300 words. Letters may be edited for spelling, grammar and length. In order for letters to be considered, please include your name, address and the daytime phone number of the author. The Minnesota Brain Injury Alliance reserves the right to refuse letters for publication, and submission of material does not guarantee publication. Opinions expressed in Letters to the Editor are solely those of the author and do not represent the opinions or positions of the Minnesota Brain Injury Alliance.



Dear *Mind Matters* readers,

When I was a kid, I looked forward to the holiday season. But, I always had a tough time with one part of it: asking for gifts. I enjoyed giving gifts to people, but would freeze up when I had to make out a list of things I wanted. Then, one year, a relative told me, "Don't think about what you want; think about what you need."

By David King

Well, it's been about sixty years since I last made out a wish list, but when it comes to asking for gifts I still follow that advice. And, this year the Minnesota Brain Injury Alliance needs your gift.

The Alliance uses the money sent to us to power our programs and explore new opportunities to raise and spread brain injury awareness across the state. For example, this fall our Public Policy department made it their goal to ensure that people with brain injury understood their options when it came time to exercise their right to vote. Voting is a major part of shaping policy to benefit Minnesotans with disabilities (thank you, by the way, to everyone who made it to the polls) and Public Policy efforts are funded, in part, with your donations.

Your gifts also help fund our Education and Community Outreach (ECO) program which offers free or low-cost educational opportunities to all people affected by brain injury, including family members and friends. ECO also provides Traveling Workshops around the state on subjects such as pediatrics, falls prevention and support group facilitator training. And, it's your donations that help us continue to grow these opportunities.

So, please, when considering your gift giving this year, visit braininjurymn.org/donate and include us on your gift list. Each and every dollar is appreciated and put to good use.

Speaking of opportunities, this year we were the beneficiaries of a major opportunity to work with veterans, thanks to a grant from the Arts

and Cultural Heritage Fund that was created with the vote of the people of Minnesota on November 4, 2008. This grant allowed us to partner with the Eagle's Healing Nest in Anoka and Sauk Center for "Veterans Unmasking Brain Injury" an extension of our ongoing "Unmasking Brain Injury In Minnesota" project. The collaboration was a huge and satisfying success.

Finally, please take the rest of the year to give yourself whatever rest and time you need. Life can get pretty hectic, and we all deserve to think about ourselves and put our health and wellbeing front and center. Ask for help from loved ones; use the resources you have at hand; if you feel a bit lost, call our Resource Facilitators at 612-378-2742 or 800-669-6442 for free one-on-one advice. You're not alone out there and we're here to help.

Happy Holidays!

David King

Does your household receive more than one copy of *Mind Matters*?

Mind Matters currently is sent to over 23,000 individuals. Some of those people live in the same house. If your household receives multiple copies of *Mind Matters* and you'd like to get that down to one, we can help you with that.

To reduce the number of copies you receive or to stop receiving *Mind Matters* altogether, please call us at 612-378-2742, 800-669-6442 or e-mail us at info@braininjurymn.org. Have the label nearby to help our staff find your name in our database!

TWILIGHT ZONE

Fatigue

By Mike Strand

It was a dark cloudy day as I stood at the storefront. In the gloom I could see a large carpeted room, but no details. The lettering on the door said, "Tai Chi" and gave a number below. This was apparently the place I had been looking for, after a frustrating search. I could find it on GPS, but when I got to the location marked by the dot, I was in an empty lot. I had sighed and looked around. I had found a few landmarks and determined that I was right on the dot, but there was nothing here! Eventually, I discovered that the dot I was seeing was the dot that told me my location, not where I wanted to be. I had zoomed in to find the exact location when I got close, and I didn't make the distinction that the only dot on the map at that range was me.

I stared at the door for a few moments and then entered the number on the door into my phone. I gave myself credit for at least getting that information secured. I turned around to get back into my red van. I like owning a cherry red van, it is so much easier to find!

Except it wasn't where I had left it. There were eight parking spots in front of the building, they were all full, and none of the cars were mine. "Who took my van?" was my first thought. I panicked, then I calmed down. I must have parked somewhere else. The last place I remembered was the empty parking lot. Nope, it wasn't there. Now panic gave way to resignation. Here I go again, something simple has turned into a huge deal. I paced up and down the closest blocks. Nothing, no big cherry red van. Aha, I remembered I have a button on my key fob, just push it and my van's horn starts honking. Technology is so awesome, even if I don't remember to use it right away.

I reach in my pocket and pulled out a strange key. "What?" I furrow my brow. Then I see the name of the dealership on the key tag and I remember that I had brought my van in for maintenance right before I went to look for the Tai Chi class. I had gotten a loaner. That's why I didn't see my van.

I stuffed the key in my pocket and started walking back to the store. Then it occurred to me that I had no memory of what car they had loaned me. Forlorn and baleful, I looked at the cars, all strange. I began looking up and down the street, hoping something would flash in my memory. Nothing. I walked up to the first car and looked inside. Nothing. Same with the next car. Finally, the third

"I stared at the door for a few moments and then entered the number on the door into my phone. I gave myself credit for at least getting that information secured. I turned around to get back into my Red van. I like owning a cherry red van, it is so much easier to find!"

-Mike Strand

car had the dealer's decal emblazoned on its door. I got out the key and remotely unlocked the doors, at the same instant realizing that I could have just pushed the button and set the car honking. Doh!

I drove straight home. I had planned on doing a few more things that day, but now I was just too worn out. How many episodes of the Twilight Zone can one be expected to live through? First, I had to find a place that didn't seem to be; next, I found a closed store where I had expected to be welcomed in; then, my car had disappeared; finally, I remembered I had a different vehicle, but I couldn't remember what it was. It is so jarring to have your whole world suddenly not make sense. Panicked and on edge wears a body down. I get so tired of having all the boundaries, what folks call the "real world" suddenly disappear and then reappear in nonsensical ways.

I retreated to my study, turned off the lights, and sat in my recliner. I lay back and stared at the grey ceiling. I took a moment to be thankful that I had created this oasis of nothing. From here I began the slow process of recharging my warp drive.

Gerhard and Renee

In a split second

By Phil Gonzales, Public Awareness Associate



Gerhard Wehr and his daughter, Kate recently appeared in the Minnesota Stroke Association's magazine "Stroke Matters."

Brain injury doesn't care about how things are going for you. It doesn't care if you've spent the last year putting your health back together; it doesn't care if you recently had a stroke; it doesn't care if you're days away from getting a clean bill of health. Brain injury is dispassionate. It can, as we say, happen to anyone.

Gerhard and Renee Wehr certainly weren't expecting anything unusual to happen as they waited at a red light in June of 2018. Their lives had been filled with the unusual, or at least the unexpected, recently; but every health issue the family had faced could be traced back to very specific anomalies and causalities.

For example, Gerhard and his daughter Kate had each experienced strokes as a result of small holes in their hearts known as PFOs. Gerhard's PFO had been

growing, which was unusual, but could be traced to his acromegaly – a disorder where the pituitary gland produces too much growth hormone. His acromegaly had been detected after needing hip replacement surgery in his forties and, later, being misdiagnosed with arthritis. Gerhard had received surgery to remove the offending tumor on his pituitary gland and was mere days away from receiving the go-ahead from his doctor to finally continue life as normal. While these medical events were numerous and life-changing, they all fit together. They made sense and, once their sources were figured out, they presented an ordered view of medicine and health.

But, brain injury isn't ordered. It doesn't fit into the puzzle of a person's health.

"We were waiting at a stop sign" says Gerhard, "we were talking and the next thing we knew, the car just explodes."

Gerhard and Renee had been hit at full speed by a drunk driver. Their car was thrown into the intersection where it spun several times, thankfully avoiding being hit by the cars crossing at the intersection.

"We looked at each other," Renee says, "and Gerhard was like, 'Are you okay?' and I'm looking at myself and I say, 'Are you okay?' And then I said, 'Are we in Heaven?' I thought we had died."

The Wehr's car had been hit with such force that Gerhard's seat was broken and Renee's shoes had flown off. Because they were hit from behind, their airbags didn't deploy and Gerhard hit the steering wheel. The car spun several times and the combined forces of the impact and the spinning motion meant that Renee and Gerhard's brains were jostled about within their skulls from multiple angles

Because of Gerhard's stroke, he was on Xarelto, a powerful blood thinner. While this medication was important for preventing a future blood clot, it did mean that any brain bleed Gerhard experienced would have been fatally unstoppable.

"I probably should be dead," Gerhard says. "If my brain had started bleeding, there's no reversal for Xarelto."

The symptoms of concussion can take a while to manifest. Gerhard was experiencing headaches and dizziness, sensitivity to light, concentration issues and

nausea. Renee felt dizzy but over the next few days her symptoms got worse. Within five days she was having trouble talking and feeling very dizzy. As it worsened, Renee, a nurse, began worrying she was having a stroke or a slow brain bleed. But, a CT scan revealed no bleeding, just the overwhelming effects of a severe concussion.

To make matters more complicated, the Wehrs had a graduation party for their daughter Maggie the following week. The idea of cancelling it seemed more daunting than letting it go on, so Renee and Gerhard let their children, Kate, Maggie and Jackson, friends and neighbors do the heavy lifting.

"I was so dizzy," Renee says, "and it was loud and people were inside and outside and in the garage. I came inside and laid down for a half hour three times. But Jackson was in the kitchen refilling and restocking. Maggie was herding people."

"And I didn't do much at all," Gerhard adds.

Despite all of the support, Gerhard and Renee still had to manage getting to and from doctors appointments on their own. Plus, they had piles of paperwork to track as well as lawyers, doctors, insurance companies. All this can be overwhelming for a person in the best of health. But, when both partners are dealing with their own symptoms, the challenges seem to increase exponentially.

Gerhard had nerve damage and a misaligned jaw from the impact. The couple both had to have chiropractic care, massage therapy and went to the National Dizzy and Balance Center for occupational and physical therapy.

"I was off work for eight weeks," says Renee, "and I went back for two to four hours and then three to six. And then we backed off because I'd get more symptoms. I'd get super dizzy. At about 12 weeks it was like a fog lifted. Now, I work for three days but I still get headaches by the end of the day. And there's a long hallway at work where the lights bother me and I always get a little dizzy. It feels like that's getting better but this morning I was dizzy for a

little bit. For now it just feels like a new normal. And there are certain things that will trigger. Like if I go shopping the lights or stimulation is too much."

"Yeah, crowds or too many people," Gerhard adds. "I mean even seven or eight people in a conversation. My brain can't pick anything out. I can't concentrate. But the therapy has helped. I'm way over the hump."

"I mean I feel like I'm a whole lot better," says Renee, "but then I get frustrated with 'Why can't I do that?' Or 'Why did that happen?' I'm working and he's not working, though, so there's a big difference there. He can rest more."

"And she went back to work after eight weeks," Gerhard says, "I didn't. I slept, napped. I didn't go play golf. I didn't go outside. I wasn't interested. My head hurt. The brain is just not interested in doing anything.

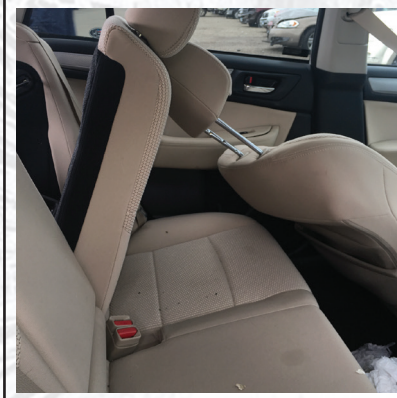
Nothing sounds fun or exciting. And I hadn't been doing anything because of the pituitary surgery. I went through twelve weeks where I couldn't exert myself so I didn't put pressure on my brain. So the therapists had to encourage me to do things. Because you have to retrain your brain into doing things. You have to ease your way back into it."

"If I had been off work twelve weeks and tried to go back to a full day, I would have suffered," Renee says. "Even now I've

been back several weeks but I still get really fatigued. But it's getting a lot better."

"I went and saw the ENT who did my surgery two days after the accident," Gerhard says, "because I was afraid that something could have happened with the surgical site, that it could be leaking. I was like 'Dang it! I was so close to feeling good.' And he looked at it and said things were inflamed but the site was okay. But he said 'Don't do it again!'"

After so many months and years of medical issues, Gerhard and Renee are looking forward to a life where they can settle in and relax. And maybe, just maybe, they can finally take things easy.



By Dr. Erwin Concepcion

Making Changes for the New Year



Are you thinking about making some changes in the coming New Year? Here are some ways to help meet those challenges:

Do it for yourself and pick something that is really important to you. Changes that we make for ourselves are more likely to succeed than the ones we do because we think we should or because someone else wants us to do it.

Pick a pace you can handle. Sometimes picking something too big or complicated can set us up for disappointment and even sour us on the idea that we can change. Which you most certainly can!

Be specific and think about what you want to change and how. Instead of thinking about “feeling better” focus on what you are going to do to accomplish that: sleep two hours more each night; walk at least 5,000 steps each day; listen to an eBook chapter on the bus, etc.

Tips to help stay motivated:

- Share your goals with others
- Take a few minutes at the end of each day to review how you did and what you can improve
- Get help from the people that cheer you on
- Agree to make the change with one or more other people
- Stay in touch with others about how you’re doing and ask them for help when you need it
- Reward yourself with small things on the way to your final goal

Finally, and most important, is to remember to be nice to yourself and give yourself a break even when old habits return. Sometimes our own pressures undermine our ability to succeed. Part of adapting to change is finding where new limits in thinking and energy are, but also where new possibilities and opportunities are waiting!

By Kris Nozal

The Dance of Change

Brain injuries force you to change your habits and routine. You can no longer just go with the flow and do things the old way. Changing habits is harder when trauma like a brain injury has been forced upon you. It creates resentment for the bad luck you have had, life isn’t fair sometimes! Working through this resistance is worth it, you need to take care of your brain since it runs your whole body!

The biggest changes for me with my brain injuries are my limitations on how much I can process. Conversation, stimulation, noise and learning are challenging. When I hit my stimulation ceiling, I need it to stop. I may need to flee a situation for quiet. Now!

The old me was very busy, active and lived a full life. My parents nicknamed me the Energizer Bunny as a child and temperaments usually don’t change as adults. Nowadays this bunny operates at half throttle. If I pack my schedule too full I suffer consequences like brain fog and anxiety. The worst part is that I’m not ‘fully there’ because my brain can’t keep up with the stimulation. I don’t contribute to or follow conversations as well as I would like. I may miss the main parts of something I’m watching because my brain is wiped out. There is this tension of wanting to do things the old way yet knowing my limitations prevent me from doing so. If I push myself and suffer consequences then I feel ashamed for what I put my body through.

Nowadays, I’m very conscientious to accommodate my brain but still live a full life. I do as many errands as I can in one day so I leave the house less. I do one social event a day because the organization and conversation of social plans can be exhausting. I used to say yes to anything fun or educational. Now my brain energy takes priority and I say No to things. Shocker!

Changing habits is a process, a progression of one step forward and then maybe two steps back. Research says it takes 21 days to change a habit. You’re rewiring your brain and creating new neural pathways for behavior. Knowing that it’s unreasonable to expect perfection on Day 1 allows me to forgive myself and return to my good habits as soon as I can.

2019 Legislative Priorities

With the 2019 legislative session approaching, the Minnesota Brain Injury Alliance has been engaging with a broad range of people invested in improving supports and services for people with brain injury. Through these conversations with case managers, citizen advocates, other disability organizations and coalitions, five policy areas have been identified as priorities for the upcoming session.

Working with coalition partners we intend to promote the following policy changes:

1. **Medicaid:** We will be working to reduce the Medical Assistance spend down and increase income and asset limits. These incredibly low limits make living on MA difficult, and force people with disabilities to live in poverty just to get the care they need.
2. **Housing:** The affordable housing crisis in Minnesota limits the well-being of thousands of Minnesotans. People with brain injuries disproportionately experience homelessness due to expensive health care costs and challenges with executive function following their injury. We will be advocating for more affordable housing options across the state.
3. **Transportation:** For people both in the metropolitan area and greater Minnesota, we know transit options are limited. For people with disabilities that rely on transit options to get around, this can be a significant impairment to a healthy life. We will be working to increase transit options across the state.
4. **Prevention:** Preventing brain injuries is a top priority for MNBIA. This is why we will be supporting hands-free cell phone legislation to reduce the distraction of cell phone use while driving. Cell phone use while driving can lead to car crashes that cause brain injuries. Reducing distracted driving is one of our primary goals to decrease and prevent brain injuries.
5. **Mitchell's Law:** After his accident, one of our citizen advocates came up with an idea to add emergency contact information into the driver's license database to more quickly reach loved ones following a crisis. Mitchell and the MNBIA policy team will continue to advocate for this policy change that will provide comfort and support to individuals in emergency situations.

Collaborating in Rural Minnesota

The Public Relations team here at Minnesota Brain Injury Alliance has the rewarding job of connecting with health care professionals in hospitals and other healthcare facilities all across the state. We work to raise awareness and utilization of our programs and services that are available to those who have experienced brain injury or stroke. Through our journeys across Minnesota, the PR team has gotten the pleasure of connecting with one of those Healthcare Professionals, Bonnie Franklin from the Fergus Falls, MN area.

After a fall caused a major brain bleed in February of 2017, Franklin who had worked as a Mental Health Therapist was now herself a TBI survivor. Faced with the biggest hardship of her life, Bonnie embarked on her own healing journey.

It did not take long for her to realize that the resources for brain injury survivors in her region were extremely scarce. With Franklin's characteristic innate optimism she decided to turn her hardship into something positive. Her mission led her to start the Brain Injury Collaborative of West Central Minnesota. Franklin believes that by working collaboratively, providers, partners, teachers, coaches and parents in the region can develop an area-wide brain injury network for survivors and their family members.

Franklin is now the director of the Collaborative. Along with a group of leaders from the local community, they do everything from having monthly meetings and generating a monthly newsletter, to holding resource education seminars for both professionals and consumers, to helping high school kids in their community connect with colleges or jobs post-graduation.

We are honored to partner with Bonnie Franklin and her Collaborative who have taken their personal adversities and modeled a self-starter attitude for advocacy for all affected by brain injury in their community.

If you have any questions about our legislative priorities or our public relations program, reach out to the public policy team at 612-378-2742 or 800-669-6442.

FACES of TBI

You may not know Amy Zellmer, but you've most likely read her words

By Phil Gonzales, Public Awareness Associate

You may not know Amy Zellmer, but you've most likely read her words in the Huffington Post or heard her voice on her podcast "Faces of TBI." The published author of two books and an anthology, a YouTuber and a much requested speaker at brain injury events around the globe, Amy didn't plan on living the life of a brain injury expert. She had no idea that brain injury was even going to be a part of her life. But, as we've said before, brain injury doesn't take our plans into account. It is sudden, unexpected and can happen to anyone and at any time.

"I'd had a photography studio in Shakopee for eight or nine years," Amy says. "But, I'd gotten divorced and was downsizing. I moved into the Schimdt Artist Lofts in Saint Paul, it was a live/work space. It was perfect. And I'd literally lived there two months when I fell on the ice."

Amy had landed on her head, and life suddenly became incredibly difficult for the self-employed photographer. Dates and appointments slipped from her memory. Her body was wrecked with whiplash, a dislocated sternum and torn muscles, making it impossible for her to lug her equipment to and from photo shoots. In the weeks immediately following her fall, Amy had trouble finding words, remembering names and even operating her camera. Fortunately, the photography community rallied to help her keep up with her business, but medically things were looking grim.

"I honestly can't tell you how I made it through that first year," She says. "It's fuzzy. Like, I remember, but I don't remember."

Amy's doctor had informed her that her symptoms were typical for a concussion and to come back in six weeks if they hadn't cleared up. When they didn't clear up, she went to a neurologist.

"She said to give it more time. After six



months I'm not feeling better, I'm actually worse; my short term memory is gone, I'm dizzy all the time, there's something wrong with my eyes. I literally asked should I be doing PT, OT, cognitive? What should I be doing? 'Let's just give it more time.' So, I went back again at 15 months, May of the following year. And I was not better. But the doctor said 'Well, it might be the best you'll get.'"

This whole time, Amy had been living with extreme dizziness and fatigue. She had also been insisting that there was something wrong with her eyes. Her doctors, meanwhile, had failed to heed any of her observations with a neuropsychologist telling her she "didn't try hard enough on my neuropsych test. Which you can't fake!"

After some success with craniosacral therapy, Amy felt her brain fog starting to lift.

Meanwhile, she had started blogging about her experiences with brain injury and the runaround she received from the medical world. A friend of hers suggested she submit her writing to HuffPost, a popular news website and blog. She did and within hours received a response.

"They wanted to run it," she says, "and it went ridiculously viral."

Amy's first piece "Life With A Traumatic Brain Injury" began her relationship with HuffPost, a relationship that has spawned dozens upon dozens of articles and think-pieces. This new direction in her life brought her to the attention



on Minnesota chiropractor Dr. Jeremy Schmoie, who wanted to run a full evaluation on Amy to address some of the issues she'd been writing about.

After a number of basic tests, Dr. Schmoie was able to determine that Amy's eyes weren't working together. "This is what I'd been telling doctors for two years!" she says. "Were they just not taking me seriously? So, you wear these goggles and it records your eyeballs and I'm watching stripes go by and whatever; or, I have to hold my gaze on a dot or follow a dot and they're able to show you what your eyes are doing. And a normal person, if you're staring at a dot, your eyes should not move, and mine were doing this little movement. And my pupils were going up and down. And how did no one

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#NotInvisible

This February, Amy Zellmer is launching a new awareness campaign. #NotInvisible: Putting a Face On Brain Injury is the natural extension of Amy's own "Faces of TBI" website and podcast.

Amy, herself a professional photographer, is going to travel the country speaking at brain injury events and photographing people living with brain injury in order to demonstrate that brain injury truly does not discriminate. She will highlight people of all ages, races, gender and



incomes in order to personalize this invisible injury. Using the hashtag #NotInvisible, Amy is planning a complete media blitz, over the next three years, spreading awareness to providers, survivors and the general public about options in therapies and opportunities for advocacy.

In March of 2021, Amy plans to hold an exhibit at the Congressional Brain Injury Awareness Day in Washington D.C. before taking her photographs on a traveling tour around the country.

Details on the campaign are still being worked out, more information will be released on Facebook and Twitter, but if you have any questions or wish to become involved in #NotInvisible, please email info@braininjurymn.org.

Recognition – Connection – Contribution

By Sue McGuigan, Development Coordinator

As a supporter of the Minnesota Brain Injury Alliance, you certainly have a significant interest in understanding the impact of your support. Probably you are familiar with the many things Alliance staff members and volunteers are doing to raise awareness about brain injury:

- Educating the general public about the causes of brain injury
- Guiding family members and caregivers as they adjust to the effects of brain injury
- Training professionals about how to best serve their clients living with brain injury
- Discussing bicycle safety with families and giving away bicycle helmets.

And you may be acquainted with our work in helping folks affected by brain injury get access to resources and services:

- Resource Facilitators offering telephone support to assist people in navigating life after brain injury
- Case Managers assessing the needs of their clients who have sustained a brain injury; overseeing their services; and monitoring their clients' changing needs
- Care Coordinators assisting individuals with disabilities in finding health care supports and services.

You may not, however, be aware of our efforts to help those affected by brain injury make a contribution to society. As our vision statement says: we work toward a Minnesota where all individuals living with brain injury are encouraged to realize their full potential and their value to our community. In many ways, across many Alliance programs, your support gives people with brain injuries the opportunity to find ways to reintegrate into their community and work toward making a meaningful contribution to society. For example:

A group of Alliance volunteers met with St. Catherine University's Master of Physician Assistant Studies Program students who are in their first year of study. This valuable partnership allows brain injury survivors to share their journey with future medical professionals, while the professionals learn how best to communicate with and understand those living with brain injury. Jerry, one participant, said that partaking in this project gave him purpose.

Michael was recovering from a brain injury due to a fall. Because he was not yet able to drive, he

was unable to do the things he used to do before his injury. An Alliance Resource Facilitator gave Michael and his wife a variety of options near his area to go for driving re-evaluation. From the resources given by the Resource Facilitator, Michael has now successfully returned to driving. He was able to get evaluated and deemed safe to return to the road, becoming more independent again.

A new client was issued an incorrect bus card through her waiver services and the error would have taken more than a month for the county to correct. Within that time, she had a number of appointments, errands, and social gatherings to attend. Her lack of transportation limited her access to food and her gym. Through the Alliance's Emergency Resource Fund, her Alliance Case Manager was able to get her a temporary Metro Mobility card so she could continue to participate in the community activities that were important to her.

The Public Policy Department's Citizen Advocate Academy gave Kris the tools to achieve the things she needed to work toward a full and integrated life. After her brain injury, she joined other Advocates at the Capitol and successfully fought for changes in disability insurance law. She wanted to do more, so other people with disabilities did not have to go through what she went through. The Academy gave Kris and other advocates an opportunity to both change public policy and change lives.

"Joy, feeling one's own value, being appreciated and loved by others, feeling useful and capable of production are all factors of enormous value for the human soul," said Maria Montessori. Through your end-of-the-year gift or your monthly donation through Brain Trust, our monthly giving program, you can know that your donation will be used to achieve our vision to encourage those affected by brain injury to realize their full potential and their value to our community. Donate online at www.braininjurymn.org/donate, mail us a check, or contact Sue McGuigan at suem@braininjurymn.org. May this giving season bring you joy.



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It's the Holiday Season... Again!

By Nancy Christensen, Administrative Specialist

The holidays are quickly approaching and, with them, the difficulties a person with a brain injury may encounter when embracing the season. Holiday celebrations can bring a host of conflicting emotions for anyone. While these occasions are meant to be filled with joy and happiness with family and friends, sometimes they become a bit stressful and can cause anxiety. Often there is a lot of pressure to have the perfect holiday, and for the person affected by brain injury, feelings of stress, worry, sadness, and even anger are normal.

Caregivers too, can feel overwhelmed and at a loss as to what to do to help support their loved one through this time of year. But rest assured there are ways to manage this time of year with minimal difficulty, disruption and ease.

Let's take a look at some tips that can lessen the stress for the survivor.

Say "yes" to offers of help: Often times, people really want to help so let them.

Do only what you feel like doing: Decline invitations to avoid fatigue. Family and friends will understand your need to rest and relax.

Talk to your loved ones and tell them how you feel: They will understand if you're feeling overwhelmed or stressed.

Avoid isolation: Surround yourself with those that know and understand your situation. Let those who love you encourage you and give you comfort.

Always look for the positives: Try to not focus on "what was" but rather on "what is."

Stick to as normal a routine as possible: Eat regular meals, exercise and go about your usual activities; think of the holiday season as "temporary." This too will soon pass.

Set realistic expectations: Don't put unnecessary pressure on yourself to be or act a certain way.

Be kind to yourself and treat yourself with respect. Know that you are not alone!

The caregiver also has a difficult and sometimes even more complicated road to travel during the holidays.

Be there and listen: This is one of the best gifts you can offer a brain injury survivor. Many times brain injury survivors feel isolated and by merely offering some time for listening, you are providing an opportunity for them to be heard.

When in doubt, ask! No one can read another person's mind and finding out what their needs are typically will help in the caregiving process. Communication is the key to understanding.

Be accepting and compassionate: Put yourself in their shoes. Accept that they have limitations and be empathetic to their needs. Provide love; isn't that what the season is all about?

Take care of yourself: This might be this most important tip. Get outside, get some sunlight, exercise, pay attention to your diet, think positive and have some fun!

From its humble beginnings, the Minnesota Brain Injury Alliance has been a vital organization in helping people living with brain injury with their needs. The Alliance understands what is necessary to provide help, encouragement and resources to the brain injury population. The holiday season is never without challenges but having had a brain injury does not need to steal the joy, the love and the warmth that the season brings.



For the Caregiver

Tips for Surviving the Holiday Season

Continued from page 11

see any of this?"

Amy did a week-long intensive with Dr. Schmoie and in two to three days her eyes were working better. Once her eyes were starting to function properly, her balance issues, dizziness and fatigue began to lessen. Amy's mind became clearer as her brain was no longer having to work to simply keep her upright and focused. After years of searching, Amy had discovered a therapy that worked for her.

She also realized the importance of having someone who could advocate for you.

"I wish I'd brought someone with me who could have said 'this is not Amy.' That could have helped."

Amy's desire to help people feel less alone with their brain injuries, as well as the audience she was reaching with her HuffPost articles, inspired her to start a Facebook group which now boasts thousands of followers from around the globe. Amy was invited to Washington D.C. for Brain Injury Awareness Day at the Capitol in 2015 where she was able to meet with elected officials, medical professionals and many people living with brain injury.

"I'd felt very alone," she recalls. "So now I meet all these people and Holy cow! There's tons of us! And that opened the door to advocacy. So I continued writing to HuffPost, and then I met a woman who runs a writing group and she encouraged me to turn my pieces into a book."

Amy's book "Life With a Traumatic Brain Injury: Finding the Road Back to Normal" was an instant success and her 2018 follow-up "Embracing the Journey: Moving Forward After Brain Injury" has reached many people as well.

Amy first discovered the Minnesota Brain Injury Alliance in D.C. and started volunteering at the Annual Conference in 2015. Since then, she has become an active participant in our Public Policy's Citizen Advocacy group. For three years, Amy has spoken thoughtfully and passionately at "Tuesdays At The Capitol," learned about the inner working of the political world and fought to preserve Medicare for people with disabilities. This past February,

she was the closing speaker at "Disability Day at the Capitol" in Saint Paul and, in August, was awarded the "Social Change" award at our annual Volunteer Appreciation Picnic, for all the work she does advocating for people living with brain injury.

Around the time her first book came out, Amy started her podcast, "Faces of TBI" which now reaches thousands of listeners each month and has included such guests as Dr. Bennet Omalu, doctors from the Boston University CTE research center, numerous providers, survivors and caregivers. Each March, she co-hosts a free Brain Health Online Summit with interviews with providers and survivors in order to provide people with information about available therapies.

In 2019, Amy is kicking off her #NotInvisible campaign (see sidebar) which she hopes will help raise awareness about, not only brain injury, but the importance of being heard and taken seriously as a patient and a brain injury survivor.

"I want to specifically reach providers," she says, "because, change has to happen at the provider level. I didn't even know what to ask for. After about a year and a half I was ready to give up."

After the campaign launch, Amy will begin a three-state tour, in Florida, Georgia and North Carolina, talking at events and raising awareness for people living with brain injury.

Amy Zellmer didn't plan on becoming the voice of TBI. She didn't know that her life as a photographer was about to be interrupted and taken in a very different direction. But, she has grown with the experience into a fierce advocate for brain injury awareness and we are proud to have her on our team.



MINNESOTA
**Brain Injury
Alliance**



UPCOMING EVENTS



34th Annual Conference

for Professionals
in Brain Injury

April 25 & 26, 2019

Earle Brown Heritage Center,
Brooklyn Center, Minnesota



STRIDES FOR STROKE

SATURDAY, MAY 18, 2019 • 10 A.M.

DULUTH: CANAL PARK

SAINT CLOUD: CENTRACARE HEALTH PLAZA

TWIN CITIES/NEW BRIGHTON: LONG LAKE REGIONAL PARK



Consumer & Family Conference

"Journey to Wellness: Body. Balance. Being."

Saturday, June 1, 2019

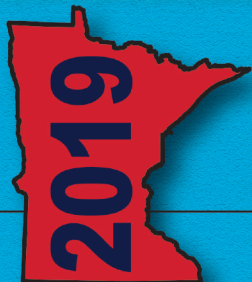
Saturday, October 19, 2019

New Life Presbyterian Church, Roseville, MN

WALK FOR THOUGHT

Saturday, September 21, 2019
Walk begins at 10 a.m.

Duluth • Saint Cloud • Twin Cities



Minnesota Statewide Stroke Conference

Thursday & Friday, November 14 & 15, 2019
Earle Brown Heritage Center • Brooklyn Center