



MINNESOTA  
**Brain Injury  
Alliance**

# MIND MATTERS

WINTER 2023



INSIDE—

- How Can I Help You Feel Successful at the End of the Day
- Citizen Advocates

... and More



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MINNESOTA  
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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.



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## Welcome *Mind Matters* readers,

As my radiator begins serenading my mornings with its clanking song of the winter season, I often find comfort in the gentle heat of a steaming cup of hot cocoa cradled in my hands. There's something about the soothing warmth and the rich, chocolatey aroma that makes it more than just a drink; it's a small, comforting ritual that brightens cold days. In fact, if I can end my day with a mug of cocoa, I consider it a small but sweet victory, not unlike the incremental victories one experiences on the journey of brain injury recovery.

In this edition of '*Mind Matters*,' we focus on cherishing these little yet profound moments in the recovery journey. Carla Berardi, a ten-year veteran of our Resource Facilitation program, shares her perspective on the importance of recognizing and celebrating each step in the healing process. Her insights offer a path to hope and resilience, highlighting the strength found in even the smallest achievements.

Resource Facilitator Jim Richardson contributes an insightful article on the theme of "hurry up and wait" within the context of navigating the traffic jam of the healthcare system. Regular contributors Amy Zellmer and Dr. Erwin Concepcion continue to bring their knowledge to bear on topics pertinent to families and professionals. Mike Strand offers his deeply personal and often humorous perspective on living a simpler life with brain injury.

This issue also celebrates the success of our recent Minnesota Statewide Stroke Conference, showcasing our ongoing commitment to enhancing understanding and support for those affected by stroke. The conference served as a valuable forum for learning, sharing, and fostering connections, underscoring the importance of community in our collective journey. MDH's Nicky Anderson presented a fascinating look at the state of Minnesota's stroke research which led brilliantly into Dr. Anjail Sharrief's incredible keynote on achieving equity in stroke care. We look forward to next year's Stroke Conference which promises to be even bigger.

As the year draws to a close, we encourage you to join us in our end-of-year fundraising effort. Your generous support enables us to sustain and expand our resources, education, and advocacy efforts for those impacted by brain injuries. Every contribution, no matter the size, weaves a tapestry of support and hope within our community. Please, visit [braininjurymn.org](http://braininjurymn.org) today and give generously. Each gift we receive is packed with potential.

So, as you savor your next cup of hot cocoa this winter, let it be a reminder of the warmth and comfort we aim to provide through our work.

Thank you for warming us with your unwavering support and readership.





# A simple life courtesy of **brain injury**

By Mike Strand

Like everyone says about themselves, prior to my brain injury I was above average. I was super smart, athletic, type A, and highly motivated. This also meant that I put a lot of pressure on myself. There was absolutely no reason I shouldn't be a captain of industry, spiritual advisor to the Dalai Lama, and the first president to be elected unanimously.

Of course, those things weren't happening, and as I eased into my mid-twenties I began a gradual descent into despair. I was living a life deferred. I was telling myself that somehow between now and forty, this would all happen. I was telling myself everybody would be so shocked when all this happened, even though I knew it would happen all along.

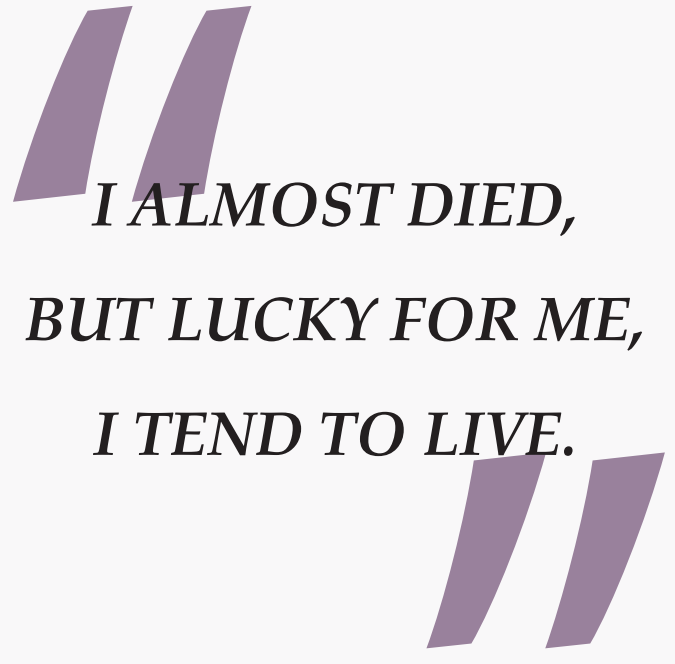
Except, that it wasn't happening, and deep down I knew it never would. I was going to be one of those guys from that Bruce Springsteen song reliving the glory days of my youth. And then something wonderful happened...

...I sustained a severe brain injury.

In one fell swoop, about as fell as swoops can get, all those hopes and dreams were off the table. It took a gravel hauling semi-truck to knock my dreams away. I almost died, but lucky for me, I tend to live.

Like everybody else who this happens to, I eventually became depressed. I didn't want to live half a life. I didn't want to be in a world with only half the possibilities (and they were the lower half of the range). I raged, I strove, and I willed it otherwise. I made a remarkable recovery, but the best I would ever be is "a very high functioning person with a brain injury."

My ideas and thoughts, achievements and surmounted peaks, would always have the brain injury qualifier; i.e., that was great... for a guy with a brain injury. I had attained some degree of agency, but without authority. Any argument I made was always suspect. Was I sure? How do you know? The most positive response I could get from any of my assertions was, "Well, I don't know about that..."



*I ALMOST DIED,  
BUT LUCKY FOR ME,  
I TEND TO LIVE.*

So, I wadded up all my ambition and tossed it away. I radically accepted that I was just me, same as everyone else. I wasn't better, smarter, or faster; nor did I have to be. When I did that, when I truly accepted that, a most wonderful thing happened. This huge onerous weight that I didn't even realize I was carrying, was gone.

That was the day I found that I had become a new person. I wasn't trying to be who I would have been if I hadn't had a brain injury. I may not be better, I certainly wasn't worse, but I was most definitely different.

I no longer lived a life complicated by my old ambitions. If I wanted a feeling of accomplishment, I could tie my shoes! There was a time that felt impossible, but that time was passed. I had done things, hard things. I didn't need to prove anything to the world, that was for other folks. Those poor people who didn't have brain injuries and had to do the Generally Accepted Tough Things (GATTs). I was simply me; I could care and feel, love and be loved, and be immensely happy all the while. I could be happy in the Here and Now.

The Hero awakens.

# How Can I Help You Feel Successful at the End of the Day?

*By Phil Gonzales, Public Awareness Associate*

In the journey of recovery, particularly from a brain injury, it's often the grand milestones that capture our attention. Society tends to measure success in bold, sweeping achievements, eagerly anticipating the moment when a particular goal is met and we're able, or even allowed, to say, "I did it!"

However, when these major milestones are slow to materialize, it's easy to slip into a narrative of failure or delayed accomplishment. Our self-talk can become overwhelmingly negative, focusing more on what we haven't achieved, than what we have. Yet, at the Minnesota Brain Injury Alliance, a deeper understanding has taken root: daily victories are just as crucial as the long-term ones.

One of the cornerstones of the Alliance's success in Minnesota, and as a national model in post-care treatment, is our Resource Facilitation program. This free, phone-based program is available for anyone in Minnesota living with the effects of a brain injury as well as family and caregivers. Many of the people profiled in the pages of *"Mind Matters"*, many of our readers in fact, have been or are currently a part of Resource Facilitation. We share their stories to

celebrate their successes as well as to demonstrate the value of the program to our community. However, often when looking at the big picture of recovery success, we can lose sight of what makes Resource Facilitation, and our Resource Facilitators, so special: the value of essential daily success.

Carla Berardi celebrated her tenth year at the Minnesota Brain Injury Alliance in June of 2023. Her experience speaks for itself but it's her insight into what makes for a successful recovery process that exemplifies the overriding philosophy of the entire program. Handling a caseload that typically ranges from 450 to 500 ongoing cases, she often works with the more intense, high-need situations, with a particular focus on Minneapolis. I sat down with Carla to learn how Resource Facilitation acts as a motivator for people as they face the often long wait times for services and supports.

"So you've got somebody who's struggling," Carla says. "We talk to them about how they are doing, what they are struggling with, what are some ideas or strategies to use for coping. We provide... I guess you could call it emotional support on their journey.

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How to change their inner self-talk so that they're not shaming themselves at the end of the day. How to be compassionate with themselves."

Resource Facilitators aren't therapists, a point Carla stresses repeatedly in our conversation, and they don't try to function as an alternative to therapy. What they do, however, is provide a listening ear and help guide the caller toward resources or options that they might not have known existed.

Carla's approach is not just about addressing the immediate needs of those with brain injuries, but also about fostering a long-term mindset of resilience and self-compassion. "It's about understanding the whole person, not just their injury," Carla explains. "We delve into their daily lives, asking about everything from family support to their daily routines. This helps us tailor our support to each individual's unique situation."

This personalized approach is evident in a story Carla shared with me about an elderly woman post-stroke. The woman was experiencing swelling in her feet, a symptom that was initially perplexing. Carla's observations led her to inquire about the woman's diet, revealing a high sodium intake from delivered meals and frozen foods. The woman hadn't received any education about managing her sodium intake and Carla wouldn't have thought to pursue that avenue of care if she hadn't spoken to the woman and gotten to know her day-to-day life.

The Alliance's commitment to individualized care, as opposed to having a standard conversation tree or a list of generic advice, allows our Resource Facilitators to dive deep into the intricacies of each person's life. This holistic approach is crucial, especially considering the diversity and complexity of the cases they handle.

"In my time here," Carla reflects, "I've seen just how varied the needs can be. From simple dietary adjustments to complex care coordination, each case is unique."

Carla's work also emphasizes the importance of building a rapport and trust with clients, especially when dealing with cognitive challenges post-injury.

"Follow-up calls are important," she says. "We go over what we discussed last time, which not only helps jog their memory but also reassures them that they're being listened to and are not alone in this journey."

Recovery is a multifaceted journey, where mental, emotional, and practical support is just as vital as medical treatment. "It's about helping people feel successful, day by day," Carla concludes. "Sometimes, that success might just be getting through the day without negative self-talk, or managing a small task independently. These victories might seem small, but they're monumental for the individuals we support."

These small victories have taken on a greater importance in recent months as the COVID-19 pandemic created a ripple effect in the healthcare system, significantly impacting those awaiting brain injury-related services. Carla explained how the pandemic caused a backlog in county services.

"During the emergency status of COVID-19, the government said anyone who applies for MA (Medical Assistance), [gets accepted] without the usual vetting," Carla notes. "Now, [as we emerge from that emergency phase] they have to go back and review all these cases, which has added to the delays."

These delays are particularly evident in the wait times for waiver approval, PCA (Personal Care Assistant) services, and screening appointments. "Before the pandemic, getting an appointment for screening might take about four weeks," Carla says. "Now, we're looking at six to eight months just for an appointment. Then when the appointment comes in, you're screened and then it's going to take probably four months or so to get approved by the county. And then you have to find a PCA agency that can staff you and the county doesn't find that. They leave that up to the person with the brain injury to find that."

This prolonged process places an immense burden on those with brain injuries and their families, underscoring the importance of the work done by Carla and her colleagues at the Minnesota Brain



Injury Alliance. In these extended waiting periods, the Resource Facilitation program steps in to provide not only emotional support but also practical guidance in navigating these complexities.

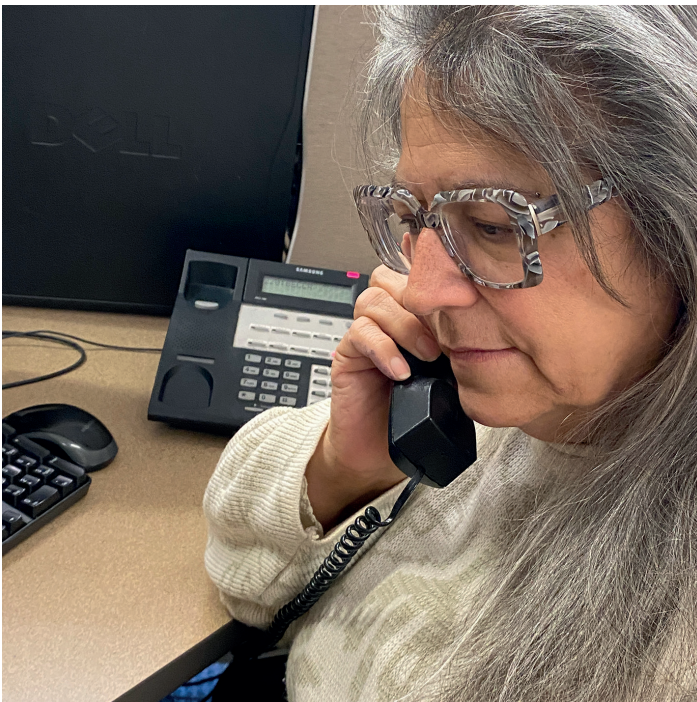
“It’s really difficult for people with brain injuries, especially when making phone calls or being on hold, particularly if there’s music playing,” she says. “They often can’t tolerate the music and end up hanging up. Many don’t know how to call personal care agencies and might not even have Internet access. We often assist them in making these calls; I can’t do it alone because I don’t have a release. We wait on the phone together, calling different agencies to find a provider. Only then can they receive services like help with showering or getting dressed.

It’s also challenging to get them into clinics. Many specialty clinics require a referral from their primary care doctor, which is another step because the primary care doctor needs to see them before giving a referral to a neurology or a stroke clinic. But primary care appointments can be booked six months out. We try to help people navigate all these processes because it’s too much for them to handle alone. They might also struggle with sequencing, so we assist them step by step.”

Carla’s approach during these times has been pivotal in maintaining clients’ morale and focus. She sees her role as going beyond just waiting for the appointment and into helping people with their day-to-day lives during these waits, educating them on what they can do in the meantime, and preparing them for when their turn finally comes.

“We try to find other resources that might be helpful in the meantime. We discuss whether family members can provide temporary assistance or if they’re connected to a church where volunteers might help until services are set up. We talk about their struggles and suggest coping strategies, making support calls to aid in their recovery journey. We do a lot of talking and supporting.”

This back and forth between the Minnesota Brain Injury Alliance and the individual is the heart of what makes the Alliance so effective across the state. From the organization’s beginnings in 1984, we started with a commitment to active listening. Because we were founded by families of people with brain injury, we knew





that a journey from point A to point B is rarely straightforward and that each distant milestone had to be punctuated with frequent smaller victories, particularly during the long waiting periods for services.

“How can I help you feel successful at the end of the day?” Carla asks. And this question forms the heart of Resource Facilitation’s philosophy. “What can we problem-solve around so that while we are waiting, we can live our lives? If I can help somebody change their inner self-talk so they’re not shaming themselves at the end of the day... that’s a success.”

This approach goes beyond mere problem-solving; it’s about instilling a sense of achievement in the everyday, no matter how mundane the task may seem.

“The cognitive change from the brain injury means they may no longer feel like themselves,” Carla adds, “it’s about helping people not just accept, but come to peace with the changes, so we can move forward.” It’s a gentle yet powerful reminder that acceptance is not resignation but a step towards rebuilding and redefining oneself. This approach to recovery functions not only in the walls on the Minnesota Brain Injury Alliance but out in our community as well. Consider this an invitation to engage with us in whichever way you can. Whether it’s through volunteering your time, advocating for brain injury awareness, or simply sharing information with others, every effort counts. Contact us today at 612-378-2742 or 800-669-6442 and learn how you can help. Visit [braininjurymn.org](http://braininjurymn.org) to learn more about upcoming events and classes. Make a donation to the Alliance to help us continue reaching out to others. Together, we can support the Alliance’s mission, aiding individuals in their recovery journey, one step at a time. **MM**



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The journey to finding a new normal after a brain injury is a profoundly personal, yet universally challenging, experience. We understand how hard it can be managing healthcare; advocating for necessary accommodations; and, for families, watching their loved ones grow into and out from their own disabilities. Our goal is to be a steadfast ally through these times.

Your support makes this all possible. It enables us to create spaces where individuals can use their voices to help others and where families can find guidance in an increasingly overwhelming healthcare system.

***Thank you for your commitment to the Minnesota Brain Injury Alliance and for your continued support!***

We invite you to join us in this crucial work by making a donation. Your gift can be made online at [braininjurymn.org](https://braininjurymn.org) or sent to our offices. Each contribution is a step towards empowering those navigating life after a brain injury

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# HURRY UP AND WAIT? WE'LL WAIT WITH YOU!

“LANES CLOSED...TRAFFIC MUST MERGE...DELAYS AHEAD...”

*By Jim Richardson, Resource Facilitator*

On Saturday mornings, I meet friends for coffee, fresh fritters, and – how shall I put it? – explaining current events to each other. We were classmates in a preceding geological era. We've been explaining things a long time.

Last week, I was later than usual. My excuse? A traffic jam. Unforeseen, without quickly-intelligible signage amidst the speeding and tailgating drivers to the left, right, and rear of me, and without enough warning to have taken an early exit ramp. The traffic jam didn't last long – about as long as the apple fritter with peach jam lasted.

Something akin to traffic jams developed within the “health-and-human-services” system over the past few years. During the flash flurry and the following frenetic fury of the pandemics viral spiral, many things got bottle-necked and backlogged. Clinics were closed. Appointments for many maladies other than COVID-19 got postponed or couldn't be made for months. Waiting-lists grew longer. Support groups were canceled. It took time for “virtual visits” and “remote sessions” to catch on. As the demand for services expanded, traffic jammed. But we've been here to help direct traffic.

The Big System, made up of many organizations with different missions – medical care, therapy and rehabilitation, human services, social services, governmental assistance – is vast and complex. Coordinating all the parts can be tricky. Occasional traffic delays seem inevitable. When, sooner or later, unjamming happens and traffic begins to move again, it can take a while for your vehicle to “get back up to speed.”

## RF to the Rescue!

The Resource Facilitation Program, which is funded by the Minnesota Department of Health, offers assistance, information and resources, to people under all road conditions. We're like a library in a firehouse, always prepared for a research project, ready for an emergency rescue, and anything in-between, whatever our clients' situations call for. Whether we have “smooth sailing” or jammed traffic, we want to help you get where you want to go, and we're at your side all the way. A team of eight covers the North Star State. Each of us keeps in touch with about 500 people, calling each client every few months over two years. Our clients – almost 4,000 annually – are welcome to call us any time.

Add many “cold callers,” and numerous Case Management clients, and other contacts – e.g., professionals and people who attended our trainings, conferences, and other events – and the Minnesota Brain Injury Alliance / Minnesota Stroke Association had contact with almost 12,000 people in 2023.

We Resource Facilitators work with many large and complex groups – hospitals, clinics, rehabilitation organizations, nonprofits, and governmental agencies – all with their own procedures and schedules. We work to coordinate their services with our clients' needs in the most efficient way possible. Recently, a client said to me, “Thanks for what you do, and for the Resource Facilitation Program. It's great just knowing that you're there. When things get delayed, or I've plateaued for a while and progress is less visible, it helps to keep me going, to keep working at it.”

Often, something in the system is dependent on something else in the system. To get therapies, one needs insurance. To get insurance, some clients must deal with time-consuming complexities of the counties in applying for governmental assistance. Applying for SSDI/SSI can be a challenge, and slow. Finally being declared eligible by the Social Security Administration can unlock or unfreeze progress toward other goals. The Resource Facilitation Program helps people navigate such frustrating traffic jams and roadblocks.

We work within the Big System to provide caring, understanding, and timely service. Now and then, delays happen somewhere within the system. If a delay does happen to you, we'll be like 9-1-1, dispatching traffic cops and food trucks if possible. We'll accompany you like a human GPS, searching for alternate routes and exit ramps, the best detours, and re-fueling stations along the way. We'll be like soothing music upon request. Another client said to me recently, “It's a long road. Thank you for being there, and for caring. I appreciate your calls.”

We try to be duly diligent about zipper-merging and observing “the rules of the road” as we work to keep the on-ramps, traffic circles, and off-ramps flowing smoothly. After all, we all want to reach our destinations as safely, soundly and as soon as possible. It can help to keep in mind the Twin Pillars of Recuperation: Patience and Perseverance. Your Resource Facilitator will be patient and persevering alongside you.

What about me next Saturday morning?

Maybe I'll try car-pooling.

***Resource Facilitation is a free, two-year telephone support program that provides education and connection to supports and services to assist people throughout Minnesota in navigating life after brain injury. Participants receive scheduled calls over a two-year period to help problem-solve issues and identify resources to help them transition back to family life, work, school, and the community while achieving the greatest level of independence as possible. Individuals can be referred by a professional or self-refer at any time. Call us at 612-378-2742 or 800-669-6442.***



## Medical Assistance in Minnesota: Significant Investments Were Made; Still a Ways to Go

The 2023 Minnesota Legislative Session will go down in history as one of the most, if not the most significant and monumental sessions in terms of investments in the Health and Human Services (HHS) Budget. More than a billion dollars in new funding was added to the two-year budget base for a total of \$6.2 billion in state general fund spending on HHS, much of it to be matched by the Federal Government. Regardless of your political perspective on this, no one can debate the fact that this was huge.

We saw expansion of eligibility for Minnesota Healthcare Programs, additional funding for mental health, childcare and homelessness services. Expanded funding for nursing homes, rate increases for service providers, higher pay-rates for direct service professionals, modernization of State computer systems and more staffing was all included in the final State Budget.

Specifically in disability services, there was significant investment in Personal Care Assistance (PCA) programs and services, employment services, homemaker services and a wide variety of customized living programs. Workforce incentive grants, technology grants, self advocacy grants, elimination of parental fees for families receiving services for their children with disabilities was all part of this vision of transformation. It was remarkable and historic.

At the risk of sounding like somebody who, when given a free lunch, demands to know why it didn't come with desert, I do think we need to be clear about something that didn't change during the 2023 Legislative Session. Efforts to raise the qualifying income and asset standards for those who need home and community based waivers, which we've been working on for many years, did not make any progress. We still expect, and in fact require those among us who need services and supports, to live in poverty before they can get help to live independently and successfully in the community. Those who are elderly or living with a disability and are low income continue to fall behind.

I do think we have to be careful when patting ourselves on the back for all the progress made during the last year. While significant, much of it is still based on the outdated model of a system that "takes care of people" as if they are needy, passive members of our society. Instead I believe we should be focused on creating a system that provides resources to people first and empowers them to seek out the services and supports they need in order to take care of themselves.

## Minnesota Legislative Session



This mindset shift is similar to the one that decades ago successfully transitioned Minnesotans who needed services from being warehoused in institutions to living in the community. The intention certainly wasn't to keep them home bound with severely limited income and savings. I'm sure being stuck in a room in an institution is worse than being stuck in your room in a four-bedroom group home or low income apartment, but is this really the solution we have in mind?

Let's solve the workforce shortage crises to ensure caregiving is a desirable and noble profession. Let's adequately support the organizations and businesses that provide these services with an economically sustainable service rate and long term business model. But let's also support and prioritize the actual individuals who need the help.

Of course, not everyone can do this themselves and some will need help managing their care; that is what empowerment is all about. Of course, we need accountability for the use of these funds and a way to fairly distribute resources, we can and already know how to set up a system for that. I do believe we are making progress, we just aren't there yet.

I look forward to the day these issues make up much of our political debate regarding healthcare and we truly put people first in the discussion of solutions. We can and must stop making being in poverty the first requirement for getting help from Minnesota's MA Home and Community Based Waiver System.

***If you would like to get involved in helping advocate for policy changes please contact Cynthia Callais at [cynthiac@braininjurymn.org](mailto:cynthiac@braininjurymn.org) or Jeff Nachbar at [jeffn@braininjurymn.org](mailto:jeffn@braininjurymn.org). There are many different ways for you to become involved and we are here to work with you!***

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*In Memory of Joseph Bieurance*  
Mr. & Mrs. Thomas R. McCune  
Ms. Robin Phillips  
Ms. Leah Rolley  
Ms. Judith Trempe

*In Memory of Melvin Hanson*  
Ms. Doborah Holmstrom

*In Memory of Roy Kirpatrick*  
Ms. Diane Boley



***Thank you for your commitment to  
the Minnesota Brain Injury Alliance  
and for your continued support!***



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One of the most challenging tasks in life is the search for meaning. This could not be truer than after having a life-altering brain injury. People with brain injury frequently struggle in this area because they are also questioning what they can do; managing their new emotions and frustrations; and living within smaller boundaries imposed on them by their new limitations.

A powerful way we can bring meaning into our life is by speaking up for those who can't, especially when it's for people who share our cause. Having a brain injury and advocating for the needs of people with brain injury can take many forms. Whether it's volunteering at the Brain Injury Alliance, speaking at a conference or classroom, helping someone trying to navigate a system that we have experience with, or educating legislators about the long-effects of brain injury, these acts of advocacy resonate within the community as well as within the advocate.

For example, becoming a Minnesota Brain Injury Alliance Citizen Advocate, through the training of Public Policy's Jeff Nachbar and Cynthia Callais, can not only make a big difference in the lives of others, but can help define a greater sense of purpose and satisfaction within ourselves. Pushing for legislation to improve the lives of those who can't advocate for themselves is an outlet that serves everyone by supporting people with brain injury, sharing their stories and bringing positive change to people's lives.

Advocacy can be both meaningful and therapeutic, providing an outlet for social interactions, engaging with lawmakers, raising public awareness, and supporting others facing similar challenges. In helping others we help ourselves find new meaning in who we are.

— by Dr. Erwin Concepcion, MD

I was first introduced to the MNBIA in the Spring of 2015, just a little over a year after my brain injury. I was immediately drawn to the Citizen's Advocates group that Jeff Nachbar was leading.

I had already gotten involved with the BIAA and had the opportunity to travel to Washington DC to lobby on behalf of TBI survivors, and was thrilled to be able to continue this advocacy work at a local level at the State Capitol in Saint Paul.

Working with Jeff and all of the Citizen Advocates has been empowering, and helped me feel less alone in my journey. It also has given me a sense of accomplishment, knowing that I was working with lawmakers and helping to make a change.

I was able to share my story with my state Senator and Congressman, and was impressed with how compassionately they listened and asked questions. At the national level, I was invited by Congresswoman Angie Craig to share my story at a press conference on healthcare (and then COVID ruined our plans).

Jeff spent many hours with me preparing me for my first big presentation in DC, as well as helping me understand exactly how our legislature works. If I was having trouble understanding, he would re-word it or draw a chart to help me visualize it.

At the state level, working alongside my fellow TBI survivors is satisfying work ... we all have such a sense of kinship and know we are all working towards a common cause.

Finally being back to in-person work at the Capitol this year felt SO good! I missed my people, and missed the connections that we have, as well as the satisfaction of meeting with my legislators and making change in the TBI community!

Change may be slow, but it is still progress! Awareness continues to grow with every effort!

—Amy Zellmer

# Attention Health Care Professionals!

# Mark Your Calendars



## April 25 & 26, 2024

Heritage Center of Brooklyn Center  
Brooklyn Center, Minnesota



[braininjurymn.org](http://braininjurymn.org) | 612-378-2742 | 800-669-6442



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