INSIDE—
• There is no background music
• ‘Normal’
• Public Policy
• No Obvious Symptoms
... And More
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Welcome *Mind Matters* readers,

By the time this edition of our magazine reaches your mailbox, the world will be different. The 2020 election is over and, hopefully, done with. All 67 seats in the Minnesota State Senate and all 134 seats in the Minnesota House of Representatives will have been filled.

We will have begun to adjust to a state and a nation under newly elected officials. And, regardless of whether or not your hoped-for candidates won, the work you and I and the staff of the Minnesota Brain Injury Alliance do to ensure the best quality of life for people living with brain injury will continue.

Because, no matter who sits in which seat, we have to continue making our voices heard. If a politician made promises before the election, we have to make sure those promises are kept. If our bill didn't get through, if our story didn't get heard, if our hard work didn't result in a win, then we have to take a deep breath, dust ourselves off and start again.

So, as you get to know our newly elected officials, know that there is work to do. And that you have the power to do it. Just call 612-378-2742 or 800-669-6442 to find out how you can get involved as an advocate.

Similar to our work in public policy, the challenges of fundraising never end. The entire nonprofit sector is facing a financial crisis, with nearly all nonprofits experiencing some level of disruption. The Minnesota Brain Injury Alliance is no exception.

COVID-19’s impact on our economy has left us vulnerable and operating at a loss. For us to continue to serve the brain injury community, we need your support more than ever.

For, while our normal routine has been disrupted, the needs of our community continue. Minnesota Brain Injury Alliance staff have found new ways to educate people about brain injury, get people access to the services they need, give people the chance to ask questions and talk to someone who understands brain injury, and offer people the opportunity to share their brain injury experiences. But, while these efforts have been keeping us afloat, and allowing us to continue providing our basic services, we are struggling. You can help us.

Donate at braininjurymn.org/donate or send your donation to our offices. Please, give what you can this year. I wouldn’t ask if we didn’t need it.

We live in a world very different to the one we lived in when I began this job. But, one thing has remained consistent: the passion our community has to support each other and make a difference. I count myself very lucky to be a part of the Minnesota brain injury community.

Thank you for everything, *David King*
I do not listen to the radio when I am driving. I cannot; I find it too distracting. It's like someone is sitting behind me, tapping on my shoulder and trying to get my attention. It is like they're saying, “Hey! Hey! Heeey!”

When I am driving, I do not talk to anyone else in the car. In fact, it is best if no one else is talking either. If I am going anywhere with any other people, I always let someone else drive, even if we are going to take my vehicle.

Usually, all that happens when I am distracted is, I start driving slower, which is annoying to other drivers, but not necessarily unsafe. It is probably an unconscious adjustment for my reduced reaction time. What can also happen, and this is not infrequent, is that I fail to observe intersections and other traffic in general. This is much more fraught. This inability to filter non-essential information also affects other areas of my life. I find myself greatly fatigued by large groups of people, from a few friends, to crowds at the State Fair. Even though I am not trying to hear what everyone is saying, I can not stop my brain from trying to hear what each and every one of them is saying. This is exhausting.

Those who work in an office environment know that it is important to get up and walk around for a while; to clear their minds so that they can come back refreshed. It is like that with brain injury, except the recovery period can be longer, and it is rare that one can conveniently walk away from ALL noise.

At home I have a quiet space. I have my den (where I am writing this right now) that I try to make my oasis, my haven. This works if I come home and I am alone. However, I do not live alone, and others in my house cannot be asked to shut off the stereo and TV all the time. I mean, I could ask them to turn things off, and there are some times when I do ask, but I try to be respectful of their needs as well.

And then there is light, in addition to sound, there is light that demands my attention. My wife and I travel quite often, and it is exceedingly difficult for me to sightsee for any length of time. I cannot just look at some scenery. Again, that is all I am trying to do, but my brain is trying to sort and define, measure and resolve all the imagery, and it is very taxing. I must take frequent breaks where I just watch where I am walking while my wife takes in all the sights. Fortunately, she is an avid and excellent photographer. This lets me see things later at a more relaxed pace, plus I am not bothered with depth perspective from a 2D image.

Back in my den, I draw the shades. I do not want absolute darkness, that is as bad as too much light and my eyes strain to see in the inky blackness. Soft light, and quiet gray noise, is best.
As an Urban Planner, Cole Hiniker is intimately connected to the streets of Minneapolis. He understands not only where the roads go, but why they go there. He also understands the inherent safety risks of being a pedestrian or a bicyclist. However, living in Minneapolis, getting around on a bike is frequently more convenient than driving.

However, with the convenience of biking comes the risk from the drivers with whom you’re sharing the road. As Cole discovered in August of 2016.

“They were drunk,” he says. “They were at a red light, and I was behind them. And there were about four cars at the red light. She was the back car. And the light turned green and all the three cars went. She didn’t move. She was looking at her cell phone. So I was like, well, I guess I’ll go around. I’ll just try to get in front of them to make it very obvious because I was turning left. And I got in front of them. And, I don’t know if they just didn’t see me, but they just hit me from behind.”

Cole wasn’t wearing a helmet and received a skull fracture and had internal bleeding. Doctors kept him in the hospital for five days for observation and he took the following month off of work to recover. And, recover he did.

“I have two issues that still stick with me,” he says. “Well, two obvious issues. My sense of smell is still damaged. That’s a pretty common thing, I guess. And I also get a lot of tension in my neck and shoulders; stress related tension. So that’s something that I think it’s just my body processing stress differently than what I did before the accident. And I think they know other things, like I’m probably just a little bit more irritable with a little bit shorter patience. And it’s been interesting to just realize when issues come up, I’m like, ‘Oh, God, that probably is just another trailing symptom of how my body’s reacting to like different triggers.’ I can’t drink caffeine, for example; it gives me an intense headache. I can drink like a can of Coke. But if I drink two cans of Coke, I probably will have problems.”

Cole’s mother lived with him during his recovery (“And, with all due respect to mothers out there, they over-worry. But, that aside, there was someone there if I needed something.”) and his job was incredibly accommodating.

“We have a very supportive system for people that have unexpected injuries. They filled out all the paperwork for me and kept me in the loop. I got to keep getting my salary for the whole month I was at home. So yeah, I had a lot of support for things that needed to get done.”

If Cole’s situation sounds ideal, compared to a lot of the stories we cover, it’s true. He even found our Resource Facilitation program to be redundant.

“I was generally able to find friends to kind of talk to just about how I was feeling and stuff. So I never really took advantage of your resources a whole lot.”

So, why share his story? Because Cole represents a huge percentage of people living with the effects of brain injury. People whose lives were altered just enough for them to notice but whose deficits would never be obvious to most other people.

“I know that I did well. But, I also know a lot of people that suffer from these injuries don’t come out of them the same person,” he says, “and my experience has been that nobody knows, when they first meet me, that I had a brain injury. You see a lot of people with disabilities and you can kind of be like, ‘Oh, we should help them.’ But you don’t really get that if you look ‘normal’ and you act ‘normal.’ And so there
has to be other ways for people to get help. And that’s what the Brain Injury Alliance is offering.

“I think for a lot of people these issues are sort of hard to talk about. They’re embarrassing if you feel like you can’t do something that sounds pretty simple just because of an injury. And particularly for people that don’t know that you had the injury, you must look like an inept person. And I think that’s really hard on people.”

Because of his loss of smell, Cole stopped eating for enjoyment. Everything tasted metallic and the only thing he could stomach for a long time was peanut butter and jelly. And this resulted in him developing a reputation as a picky eater. And, while this is small in the long run, it is indicative of the challenges people with invisible injuries face when their behavior changes with no perceptible cause.

“And, I’m sure it’s much worse for anyone that has bigger issues,” he says. “Like, it sounds pretty mundane. You know, your sense of smell. It’s not that big a deal; I can still do almost everything I want to do. But, I would get frustrated that people would judge an aspect of me that was out of my control.”

And, it was for this reason that Cole joined the 2020 Walk for Thought and started his team Wallets for Brains.

“So people don’t know that I have a brain injury, but it still affects me. And, I think that’s the story that is maybe under reported as the sort of subtle ways in which they can impact you longer term.”

As he says in his team write up, “It is truly an injury that is often below both the physical surface and the facade that someone puts up to appear normal. The resources from the Minnesota Brain Injury Alliance are helpful to those in need.”

Today, four years on from his injury, Cole’s life has changed in ways that may not be apparent to other people. His experience gave him insight into what it’s like to be one of the safety statistics he uses as an Urban Planner. It’s given him the unique perspective of a person with an invisible disability. And, it has taught him the importance of hope and sympathy in the face of a life-changing injury.

“Don’t feel ashamed to talk about issues that you’re having. The more you talk about them, the more people are going to be aware that it’s both an issue for you and also an issue with other people that have brain injuries. Find a group of people that you really trust that you can kind of talk to about it on a regular basis. If not a friend, a therapist. And hearing doctors say it was gonna get better was always like the silver lining for me. And luckily it did.”
2020 Elections

Every two years, Minnesotans flock to the polls to elect the next round of leaders to Saint Paul and Washington D.C. Shortly thereafter the public policy department takes stock of the results, sets new priorities and builds strategies to bring changes in public policy that improves the quality of people's lives and gives people a sense of their own power to bring about these necessary changes. To say the transition from 2020 to 2021 is unique would be the understatement of the year!

So where are we and what does this mean for people with brain injury? We'll have a new Democratic President in Joe Biden and likely a divided US Congress. The US House looks like it will remain in the majority hands of Democrats and the US Senate will continue to be controlled by Republicans. There are still outstanding races to be called, so this could change, but most political observers expect a split in party control in Washington.

Minnesota looks like it will also have split government and will continue to be the only state with divided party control of their state legislature. It seems a lot of Minnesota voters split their tickets, voting for both Democrats and Republicans to get us here. Democrats have lost only one statewide election in Minnesota out of 26 races since 2006. At the same time we have seen districts, both state and federal go back and forth between the parties over this same timeframe. In 2020 Republicans flipped a Congressional District, gained seats in the Minnesota House and maintained their Senate majority while losing widely in the US Senate and the US Presidential races. In six state senate districts where Joe Biden won more presidential votes people also gave the Republican State Senate candidate victory.

It looks like COVID-19 will continue to be a major challenge and the economy will be slow to turn around. We need to “stay above the political fray” and make sure lawmakers, both new and established, understand how people with brain injury and other disabilities will be impacted by their decisions. This is especially important as Minnesota gets ready to set its next two-year budget, which must be set by June 30, 2021. The only way anything productive is going to happen is if there is political will to compromise and the people demand the parties work together to solve problems.

Stay tuned and stay involved!

2021 Policy Priorities

The Minnesota Brain Injury Alliance Board of Directors will be meeting in December to officially set public policy priorities for the 2021 legislative session. The following four priorities will be considered for approval:

1) Protect Medical Assistance

Medicaid (Medical Assistance/MA) is a partnership between the Federal Government and the State of Minnesota that provides health care to low-income Minnesotans and is where home and community-based services funding comes from. In light of Covid-19 and the resulting economic crisis, MA is under serious threat for both state and federal budget cuts. This could be devastating to people with brain injury. Partnering with other organizations to protect this safety net funding will be our primary policy priority.

2) Promote Affordable Housing

Finding safe and affordable housing is a massive and growing problem for people with brain injury and is a critical foundation for building a strong quality of life. We will support the development and preservation of safe, affordable and accessible housing in partnership with the Homes for All Coalition through their public policy agenda. Development of new affordable and accessible housing, as well as funding and defending existing housing programs that help keep people in stable housing will drive this agenda.

3) Brain Injury Prevention

Commitment to public policy change that prevents brain injury by improving safety and reducing violence has long been part of our work. We will continue to partner with violence prevention organizations to support and improve programs that reduce the prevalence of gender-based violence and continue our partnerships to improve traffic safety.

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NEW TRADITIONS

In a year that has brought a disproportionate amount of exhaustion and fatigue to our community, and to the nation as a whole, expectations and planning will play a big role in whether our holidays become a burden or a time to reflect and decompress in preparation for 2021. While many of us look forward to this time of year, for others the holidays can trigger reminders of loss or sad events from the past. Even under the best of circumstances, the holidays can be taxing because of demands on your finances and the stress of organizing gatherings and travel. Either way, this year promises to be a very different experience for everyone.

However you decide to spend the season, there are some things you can do to make the upcoming holidays go better. Together or apart, start by focusing on the most meaningful parts of the holidays for yourself and your loved ones. Sharing family stories and laughing together are priceless. Older family members have the best and most embarrassing stories which are not to be missed. New traditions could include:

- Have family members record their favorite memories and stories on their phones. Put them together and share them over a Zoom call or as a “family podcast” to reflect on good times from the past and hopes for next year.
- Have everyone write special letters and messages to family members, like a Secret Santa but with letters. It will save everyone money and shopping time while giving everyone a cherished memory to keep.
- Put together a collection of pictures and family videos to share with family virtually.
- Swap favorite recipes for a 2020 Together/Apart edition of the family recipe book. Make each other’s favorite dishes and share the results!

This year, more than ever it will be important to find low stress and easy ways to share time and memories. Remember to take care of yourself and focus on the quality of the time you have together whether virtually or in person. Stay warm. Stay safe. And have a happy holiday.

— by Erwin Concepcion

STAYING CONNECTED

For many of us, the holidays will look a bit different this year. Because of the pandemic, we won’t be able to gather with our families, which for some of us may be a blessing in disguise, while others will struggle with the lack of physical contact.

I think most of us will agree that 2020 has been a crummy year for a variety of reasons, and we are hopeful that 2021 will bring new opportunities and change. But with that said, it’s still been a heck of an emotional roller coaster ride.

It’s important that we find creative ways to stay connected with those we love, those who are important to us this holiday season. Whether it’s a FaceTime call with a friend, or a Zoom meeting with your entire family, having that face-to-face contact is critical.

For a lot of us, we have difficulty understanding verbal cues for things like sarcasm and joking. We rely on facial and body movements to help us figure it out. If it’s a simple phone call, we can often struggle and get overwhelmed.

On the flip side, some of us have problems with too many people on a video call, and become overwhelmed and overstimulated. It’s important to understand what works best for you, and communicate that with your family and friends.

Human contact is so important to our mental health, and we’ve already been cut-off for the majority of this year. While you may not be able to give your family an in-person hug, take the time to give them a virtual hug over video or phone call. And, as always, make some time for your self-care — your mental health will thank you!

How do YOU plan to stay connected this holiday season?

— Amy Zellmer
Paul Deputy is a familiar face to many people in the Duluth area. The retired Professor of Speech-Language Pathology and former Dean of the University of Minnesota Duluth College of Education and Human Service Professions has always made it a point to be active in his community and to promote advocacy for people in need.

So, when Deputy fell on the ice and ended up with a brain injury, it was no surprise that he would reach out and see how his story could help others.

Paul’s initial fall occurred on January 10, 2019. But, he didn’t have any obvious symptoms until weeks later during his family’s trip to Europe.

“And I was on the Ski Patrol,” he says, “so I knew how to watch out for concussion.”

While the family was in Italy, Paul began to fall behind his group. He was suddenly tired and experiencing severe headaches. Finally, after their return to the States, Paul’s hand began going numb and he decided to ask his wife, Joyce, to take him to the hospital.

“And they determined from the MRI that I did have a bleed from the fall. And the hematoma had to be removed because it can cause damage if not. And during the operation it caused another bleed and they diagnosed me as having a small stroke.”

Paul spent five months in rehabilitation slowly, but surely, getting better at moving and speaking. He credits Joyce’s past experience with rehabilitation with fueling his drive to work harder.

“Joyce was in an accident in 2004,” he says. “Her legs were crushed. And she worked in the same rehabilitation unit I did and learned to walk. And she worked so hard. So I didn’t have anything in my mind but ‘work hard.’”

In an article he wrote for the Essentia Health-Polinsky Medical Rehabilitation Center newsletter, Paul notes that he worked on “language, cognitive rehabilitation, short term memory, sequencing tasks, and learning to more elegantly handle frustration and irritation.”

“My OT, PT, SLP, and Psychologist all worked on focus and attention over a period of four months during intense rehabilitation, and three months of outpatient therapy.

“Professionals tell me, ‘Yeah, but you worked hard.’ I always said, ‘Yeah, but look who I had to work with.’”

Paul’s experience as a speech pathologist helped him understand many of the issues he was experiencing.
“I probably can describe my symptoms better than the average person,” he says. “You know, the subtle ones that I have. And because I know what’s going on, I even know that there was posterior frontal lobe damage where it affects the associations you make. After you see and observe something, you make an association with it. And that’s what I do when I don’t make quick associations. So I think a little slower. And sometimes I have to ask my wife, you know, what happened in that movie? And so it’s the association.”

In addition to his recovery, Paul began focusing on his overall health, including getting more exercise and changing his eating habits. During a Zoom meeting with his doctor, he casually mentioned that he’d been experiencing tightness in his chest during his walk with the dog. His doctor scheduled a checkup and two weeks later Paul was getting a triple bypass.

“Several doctors have mentioned the link between brain health and heart health, and both cardiologists and neurologists have mentioned that. And so, a lot of people that get little strokes can get heart arrhythmia. And plus the extent to which you have to be put under anesthesia can give you a little arrhythmia. But, I had clear lungs. I didn’t have any valve issues. I had a strong heartbeat. And so it’s kind of like better than ever now. And in fact, I think my cognition might have improved. You know, it’s funny what happens when blood gets to your brain.

“So after the bypass I started feeling better, and the energy from that, from the recovery, I just said, ‘Okay, I’m gonna live, what’s my purpose? What do I want to do? I want to carry out some projects. And I got some things in mind.’

One of Paul’s goals is to raise more awareness of brain injury as an invisible injury. Despite his struggle with word associations and some damage to his short-term memory, he’s had people not believe he had a brain injury or assume his wandering thoughts are due to his age.

However, his good health has allowed him to participate in a brain injury study with the Mayo Clinic. The study is on follow-through with online therapy and Paul was selected to be in the control group of men not receiving online therapy. However, he’s made it his goal to, as he says, “Wreck their study by doing so good.”

He also wants to engage more with legislators and put his former oratory skills to work advocating for people with brain injury. The pandemic has slowed things down at the legislative level, but Paul is ready to jump in when the opportunity presents itself.

In a way, he sees his brain injury as a way to readjust how he wants to live his life.

“I think it’s helpful for me in thinking about things. It’s kind of like, I have a new life. I think I’m okay. I think I’m ready to get back to purpose and values and do something. And, my intention is to now start focusing on publishing something. I’ve always had the idea of publishing something that caregivers could get something out of, you know, because they might not have the knowledge about some of these brain injury situations. And I can tell them from personal experience, what I struggled with, and how it is best to help somebody you love. And also, you know, I’m not gonna pull the wool over anyone’s eyes, anybody’s eyes, you’ll have your worry moments. But there’s ways to get through your worrying moments.”
We all experience loss at one time or other in our lives. Loss comes in many different forms: personal, family, business, community. At the Minnesota Brain Injury Alliance, facing loss is part of what we do.

Brain injury is often explained through the lens of loss. We define types of traumatic brain injury by looking at loss of consciousness. We characterize brain injury symptoms through loss: memory loss, loss of inhibitions, vision loss, loss of taste or smell, loss of balance.

But people who have sustained brain injuries know that brain injury is more than the sum of all its effects. It often involves loss of self. Changes in the brain after brain injury can mean physical, cognitive, and personality changes, so much so that many people talk about life after brain injury as their second life. They work to rebuild a new life after such a profound loss.

Families of those who have sustained brain injuries also must deal with loss. They often experience what is known as ambiguous loss, where their loved one is not dead or physically gone, but is not the same as the person they knew prior to the brain injury. Families must learn to accept and grieve this loss.

Death is also a loss we face. Every year, traumatic brain injury contributes to over 50,000 deaths in the United States. Each year, MNBIA staff experience the death of our clients, donors, and volunteers. In the past year, Tim Rundall was one of those people. Tim, who passed away in November 2019, was an MNBIA board member and chair, volunteer, fundraiser, and Citizen Advocate. Jeff Nachbar, MNBIA Public Policy Director, remembers when he first met Tim. “Tim Rundall was one of twelve people in the room on my very first day with MNBIA. They all gave up their beautiful Saturday in May to come together to find ways to be more effective advocates for people affected by brain injury. For the next ten years, Tim and I worked together to build the organization’s public policy department into a powerful and effective agent for change. Tim’s non-stop energy and enthusiasm had an amazing impact on those around him.” Tim became involved with MNBIA after his son’s brain injury. He organized Brain-A-Palooza to raise money for MNBIA and was the 2011 Volunteer of the Year.

This year we also lost two members of the Petersen family: Lynda Petersen and her father Marshall. Jeff Nachbar also reflected on the contributions of the Petersens: Betty, Marshall, and Lynda. “The Peterson family is the embodiment of the term commitment. For decades after Lynda’s brain injury, her parents, Betty and Marshall, became Lynda’s lead advocates. For more than ten years, the three of them were fixtures of our Citizen Advocate Program and at the Capitol. Betty fought for better services and supports, not just for Lynda, but for all people impacted by brain injury, while also serving as the primary caretaker for both her husband and her daughter. Betty Peterson, who lost both Lynda and Marshall in 2020, is probably the most amazing woman I have ever known.” The Petersen family received the Social Change Volunteer Award in 2012 for their tireless advocacy work.

The coronavirus pandemic has brought with it a whole new set of losses. We have been
Unable to see our loved ones who are living in nursing facilities. Our children have been isolated from their friends and have had to adjust to distance learning. We have lost our jobs and our homes. We miss our families and friends. We feel as if we have lost seven months of our lives.

One loss the Minnesota Brain Injury Alliance cannot face is the loss of our ability to serve our clients, to provide a community for those who have been affected by brain injury to rely on. Minnesota has more than 9,000 nonprofits, with a record 385,000 workers who make up 13.3 percent of the state’s workforce. During the past seven months, the entire nonprofit sector is facing a financial crisis, with nearly all nonprofits facing some level of disruption. The cancellation of major events and fundraisers have left many nonprofits vulnerable and operating at a loss.

The Minnesota Brain Injury Alliance is adapting to these unprecedented times with remote services, technology, distance education, and virtual events, but we are struggling. We desperately need your help to continue our mission. You have supported us for over 35 years, and for us to continue to serve the brain injury community, we need your support now more than ever.

As John Steinbeck wrote in “The Winter of Our Discontent”: “It’s so much darker when a light goes out than it would have been if it had never shone.” Don’t let us loose our light. Please. Give what you can.

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### Tributes
- In Honor of Gwyneth Leder
- Mr. Rick Leder & Ms. Cherrill Spencer

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By Sue McGuigan, Development Manager
We will work to empower individuals with disabilities to actively educate lawmakers about the intersection of brain injury and gender-based violence.

4) Cassie's Law

Grass-root lead initiatives by advocates in the brain injury community bring meaningful change to peoples lives and builds political power and capacity for the long-term. We will continue to support passage of “Cassie’s Law.” This would allow judges to order neuropsychological evaluations of people with a history of stroke or brain injury to be used during pre-sentencing to find the best course of corrective action. This can improve outcomes for people with brain injuries caught up in the criminal justice system.

Public Relations staff can help you connect them to us.
Contact Katrina Meyer, katrinam@braininjurymn.org for more information.
Be safe, and stay connected!

Public Relations Update

The pandemic has disrupted our lives in many ways and at the same time has provided opportunities for progress, particularly at the intersection of medicine and technology. One exciting example of this is the development of better systems for tracking disease and injuries.

Epidemiologists have been tracking instances of Traumatic Brain Injury (TBI) for years but the collection method was lacking in the context of today’s modern technology. Now, thanks to advances made through tracking COVID, these health scientists will have the ability to access data that will be more readily available allowing them to track trends and provide for private and secure outreach. Brain injury survivors will be able to learn about supports like Resource Facilitation much more effectively. This exciting update to our system is already in place and will help provide more timely supports to TBI individuals when they need it most.

Contact Jeff Nachbar, Mollie Clark or Katrina Meyer for more information.
In 2020, our country faced unprecedented hardships that affected every sector including small nonprofits. The Minnesota Brain Injury Alliance was among those hit hard. Now, we need your help. Your financial support is vital in order for us to continue providing services and supports to the more than 100,000 Minnesotans living with brain injury.

Please, if you believe in our mission to enhance the quality of life for all people affected by brain injury, give today and give generously. Brain injury doesn’t stop and neither do we.

www.braininjurymn.org/donate/
www.strokemn.org/donate/
The FNC team works with patients from around the world. They are experts in Neuro-Recovery and experienced in working with:

- Complex Concussions
- Dysautonomia
- POTS
- Vertigo
- Dizziness
- Balance
- Migraines
- Whiplash
- Chronic Pain
- Brain Fog

Dr. Jeremy Schmoe, DC, DACNB
with Brock Nelson of the New York Islanders

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