

Testimony before the Assembly Committee on Colleges and Universities

Representative Paul Tittl

May 15th, 2025

Thank you Chairman Murphy and members of the committee for allowing me to testify before you today concerning Assembly Bill 92.

This bill requires the Department of Health Services (DHS) to establish a grant program for research into spinal cord injuries and appoint a spinal cord injury council to administer that program.

It has been said the question is no longer *whether* a cure for paralysis is possible, but *when* it will be found. The council established by this bill would bring together doctors, scientists, veterans, and individuals with spinal cord injuries to work toward that goal. That council would develop criteria for DHS to evaluate and award grants, and would review and make recommendations on grant applications.

A key aspect of the council is that it would not be formed solely of professionals in the field. It would include a member who has a spinal cord injury, as well as a member who has a family member with a spinal cord injury, and a member who is a veteran with a spinal cord injury. Their inclusion is designed to give attention to research leading to actionable results rather than findings which are mostly academic in nature.

The bill allows DHS, with the permission of the council, to hold symposia, not more than once every two years, for grant recipients to present findings of research supported by the grants. In addition, in January of each year DHS would submit an annual report to the legislature identifying grant recipients and the purposes for which the grants were used. The bill specifies that no more than eight percent of any grant award may be used for administrative or indirect costs and expenses.

The bill is an important one for so many people throughout the state who are waiting for a cure either for themselves or for a family member. We have made wonderful progress regarding a wide-range of other medical conditions, and there is no reason we cannot find a cure for spinal cord injuries as well. This bill would help to move us in that direction.

Thanks for hearing this proposed legislation today and helping to raise awareness about spinal cord injuries and legislative action we can take.



Van H. Wanggaard Wisconsin State Senator

May 15, 2025

Testimony on Assembly Bill 92

Good Morning. Thank you Chairman Murphy and committee members, for allowing me to testify on Assembly Bill 92 (AB 92) relating to spinal cord injury research grant funding.

In short, this important legislation would require the Department of Health Services (DHS) to establish a grant program for research into spinal cord injuries and appoint a spinal cord injury council to administer that program.

Please know that this legislation is not just simply the right thing to do from a legislative policy perspective, but also very personal to me as I, former members of my staff, and others I know, have suffered neck and spinal cord injuries. In fact, it was a spinal injury that I suffered while on duty as a police officer that inadvertently and ultimately led me to become a state senator.

As you may have heard before and will likely hear repeatedly today during testimony on this bill - The question is no longer *whether* a cure for paralysis will be found, but *when* it will be found. The Council established by this bill would bring together doctors, scientists, veterans, and other individuals with spinal cord injuries to work toward that goal. The bill also tasks the council in developing criteria for DHS to evaluate and award grants, and would review and make recommendations on grant applications.

A key aspect of the council is that it does not consist solely of scientific professionals; it also includes individuals with a spinal cord injury, have family members with a spinal cord injury, and veterans with a spinal cord injury. Their inclusion is designed to give attention to research leading to actionable results rather than findings which are mostly academic in nature.

As required in AB 92, every two years grant recipients would be required to participate in a symposium demonstrating their progress and provide collaborators an opportunity to share ideas in the effort to find a cure. In addition, in January of each year, DHS would submit an annual report to the Legislature identifying grant recipients and the purposes for which the grants were used.

This bill is absolutely vital for so many people throughout Wisconsin and beyond who are waiting for a cure either for themselves or a loved one. We have made substantial progress regarding a

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wide-range of other medical conditions and illnesses, including: Alzheimer's, cancer, HIV/AIDS, countless infectious diseases, among many other things, and I know we can do the same for spinal cord injuries as well. This bill would help to move us in that direction.

Thank you again for hearing Assembly Bill 92 oday and helping to raise awareness about spinal cord injuries. Passing this bill is real substantive action that we can take to finally find a cure and I urge your support.

DATE: May 15, 2025 TO: Assembly Committee on Colleges and Universities FROM: Mike Mohr RE: Testimony in support of Assembly Bill 92

Chairman Murphy and Members of the Committee:

My name is Mike Mohr. I live in Madison. I grew up in Sheboygan. I've lived in Wisconsin pretty much all my life. I'm excited to be here today. And I thank you for your time and consideration of Assembly Bill 92.

I have a spinal cord injury. Twenty-eight years ago, when I was 15, I was a member of the swim team at Sheboygan North High School. At the time, our starting blocks were at the shallow end of the pool, where it is 3 ½ feet deep. At practice one day, I did a racing start off the blocks and hit my head on the bottom of the pool. I broke the fifth vertebra in my neck and was paralyzed instantly. I'm paralyzed from the shoulders down with a complete injury. I have no feeling or movement below my shoulders, and I have limited arm movement with no finger dexterity. I also don't have much feeling in my hands or arms.

What is a spinal cord injury? The spinal cord is part of the central nervous system along with our brain. It is the communication pathway between our brain and the rest of our body. Injury occurs through trauma or illness and disrupts this communication. The result is a lack of function and sensation throughout the body.

Spinal cord injuries are permanent. There are no curative therapies available to regenerate the damaged tissue. And no amount of physical therapy, well wishing, or other natural interventions can fix what's been damaged. It's not a matter of will, determination, or working hard enough. That's just how our physiology works.

The result of my injury has been a tremendous life change. You see, my paralysis affects all areas of my life. When you look at me, it's obvious that I can't walk as I use a wheelchair. My spinal cord injury impacts so much more than that. Nearly all my activities of daily living are impacted. You see, I require assistance with my morning routine—getting up, getting dressed, washed up, transferred to my wheelchair, and getting going for the day. That alone takes a couple of hours, and a personal care worker to assist.

Throughout the day, I require help with a variety of activities, including meal preparation, laundry assistance, housekeeping, grocery shopping and so on. Finally, at night I require help with a lengthy night routine, which can include a bowel routine that takes a couple of hours on its own, as well as assistance with showering and getting positioned in bed. All these things take tremendous amounts of time and require assistance from others to complete them.

Additionally, life with a spinal cord injury often results in other secondary health issues.

These can include urinary tract infections, skin breakdown/pressure sores, severe lymphedema in the lower extremities, and chronic pain. I have had a couple of severe pressure sores that required lengthy hospital stays after surgery—hospital stays of two or three months. Also, it is not unusual for people with spinal cord injury to have co-occurring mental health impacts such as depression. Indeed, the suicide rate among folks with spinal cord injuries is higher than the general population.

Life with a spinal cord injury is a hard life. It's still a good life. I work, I travel, go to concerts, have relationships, and do lots of other interesting things. But it's a hard life. Spinal cord injuries result in significant financial cost to both the individual and the state. We use expensive medical equipment, take prescription medications, have frequent medical appointments, and have occasional hospitalizations. The costs from all the hours of personal care assistance are high, as well.

There are roughly 10,000 people in Wisconsin living with paralysis, and we estimate the cost of care paid by the state of Wisconsin to be about \$250 million each year. Most of us with spinal cord injuries rely on state funding sources such as Medicaid. Also, the postinjury unemployment rate is close to 70%, so the state is incurring additional costs by not receiving income tax and by paying out supplemental income.

The state of Wisconsin has a financial interest here. Curative therapies could reduce the cost of care significantly. Even incremental therapies that might improve my function a little bit would reduce my reliance on personal care workers and improve overall health. Unfortunately, there is a dearth of funding for spinal cord injury research. We don't see private investment from pharmaceutical companies because there's not a strong profit motive here. There's not a lot of money to be made by pursuing a cure for spinal cord injury. We also don't see it prioritized by state or federal grants.

The bill we are proposing here fills this gap. And it does so in an intelligent way. We are asking for the state to fund grants for research. Grants that will target curative therapies. Grants that will have smart conditions that command efficient use. What are those conditions?

- 1. Grants will target innovative curative therapies
- 2. Grants will be competitive, not just a block grant
- 3. Indirect costs for grants are capped at 8%
- 4. People living with SCI will be part of the committee awarding grants

This bill is modeled after programs that are already working well in other states. Those programs have proven track records that are moving the ball forward. I'm excited to see it happen now here in Wisconsin.

Spinal cord injuries result in a huge impact to the individual, a huge impact to our friends and families, a huge impact to the communities in which we live, and, frankly, a huge impact to the state. I'd really like to see the state of Wisconsin do something about it. I encourage you to support Assembly Bill 92. You're going to hear from some other advocates: Christina Baurichter will discuss how this bill supports veterans; Mackenzie Wann will tell you about SCI impacts on health costs, and Dan Hellenbrand will tell you about how this bill supports SCI science in Wisconsin. But if you have questions for me before that, I'd be happy to answer them.

-RE: Oral Testimony on Assembly Bill 92 (7-10 minutes) Written by: Christina Baurichter

Members of the Committee, **THE PROBLEM:**

We're here today because spinal cord injury is a permanent condition with no cure. It doesn't go away—it changes lives forever.

Four years ago, my life was turned upside down when a tumor was removed from my C2 spinal cord. The surgery left me paralyzed. At the time, I was serving on COVID orders with the Wisconsin Army National Guard. I was lucky to be stationed in Madison with access to one of the top spinal surgeons in the country.

Since then, I've worked hard to recover and rebuild my life—as a single mother, a military veteran, and an advocate for others in this "club" no one chooses to join. Spinal cord injury impacts every part of life—mobility, independence, employment, relationships. And it comes with an enormous financial cost. Roughly 70% of SCI patients rely on social services. Insurance often doesn't cover critical supplies or equipment. The burden on individuals and families is heavy—but the cost to the state is massive.

Healthcare is the number one expenditure in Wisconsin. SCI survivors—though we may be few—leave a huge financial footprint in the system. What this bill proposes is a cost-effective way to reduce that footprint while improving lives. Seed money for SCI research has worked in other states—and it's time for Wisconsin to act.

THE VETERANS' PROBLEM:

Let's talk about veterans. Over 42,000 veterans live with SCI in the U.S., and warfighters are 8 to 10 times more likely to suffer SCI during combat. The VA is the largest single provider of SCI care in the nation. That makes veterans a unique and urgent population when it comes to spinal cord research.

My own journey took me to the Minneapolis VA, where Minnesota's investment in SCI research exposed me to innovation I never imagined possible. I saw a fellow veteran—wheelchair-bound for 21 years—walk again after six months of exoskeleton therapy. Twenty years ago, that was impossible. Now, it's real.

I joined Paralyzed Veterans of America, connected with Get Up Stand Up, and discovered Unite 2 Fight Paralysis—all because Minnesota's seed money created a robust, collaborative ecosystem. We can build that here in Wisconsin. In fact, we already have the building blocks: the Milwaukee VA's state-of-the-art SCI clinic, top universities, and motivated private partners. Just last year, a 20-year-old Marine was transferred to Milwaukee's SCI center after a traumatic injury. He's already regained enough function to use a manual wheelchair instead of a motorized one—thanks to nerve transplant surgery made possible through SCI research. That's not just a savings of tens of thousands of dollars. That's quality of life.

We've also seen research from Minnesota—like Dr. Ann Van de Winckel's study on brain network changes—reduce neuropathic pain without the use of costly medications like Gabapentin or Baclofen. This is research that works, and it's time to bring it home to Wisconsin.

THE SOLUTION:

Assembly Bill 92 presents a smart, proven model. It does four key things:

- 1. Caps Indirect Costs at 8% ensuring dollars go to research, not overhead.
- 2. Uses a Competitive Grant Process so the best ideas rise to the top.
- 3. Focuses on Innovative Research with priority for projects that develop and deliver treatments.
- 4. Establishes a Wisconsin SCI Advisory Board with seats for those of us living with SCI. We finally get a say in what matters and where the money goes. Importantly, the board includes a Veteran representative—someone who can truly empathize with and understand the unique challenges faced by our military population.

This model is not theoretical—it's working in other states.

FISCAL ARGUMENT:

Let me give you a personal example. Since receiving an epidural stimulator, MacKenzie Wahn been able to stop taking two medications that cost the state over \$24,000 annually. Her autonomic function has improved, and—most critically—she gone from five UTIs a year to zero.

Each UTI can cost anywhere from \$2,000 to over \$70,000 depending on the severity. Multiply that by 5 per year. That's up to \$350,000 in potential savings. And that's just *one person*. One person, out of 10,000 in Wisconsin living with SCI.

So yes, \$5 million in state seed funding might sound like a big ask. But Wisconsin spends over \$250 million *every single year* on SCI care. Our request? Pennies on the dollar.

WHY WISCONSIN:

Let me close with a perspective from the research side. Dan Hellenbrand—a Wisconsinite with SCI, now a PhD biomedical engineer—is part of UW's Department of Neurological Surgery. He's a living example of what happens when you mix personal passion with scientific purpose.

Dan emphasizes that:

- Wisconsin has the talent.
- State-level funding helps us retain and grow it.
- Grants in this bill are designed to deliver real treatments.
- Every dollar the state invests could return eightfold in federal and private funding.

The ten states receiving the most federal SCI funding? All have seed funding programs like the one AB 92 proposes. It works. Let's not fall behind.

IN CLOSING:

This legislation is thoughtful. It's strategic. And it's personal—for me, for Dan, for the 10,000 Wisconsinites with SCI, for the veterans, for the caregivers, and for every taxpayer footing the healthcare bill.

I challenge you to consider two things:

- If this terribly unfortunate injury happened to someone you love, what would you do?
- Will you help us to lead Wisconsin to change this "sentence of permanence" for the thousands of people living with paralysis here and the millions around the world?

Please vote **yes** on Assembly Bill 92. Help us invest in real solutions—and in the future we deserve.

Thank you for your time. I'd be happy to take any questions.

Christina Baurichter Advocate Unite 2 Fight Paralysis Owner of More Than a Veteran Home LLC Representative of Paralyzed Veterans of America

Date: May 15, 2025

TO: Assembly Committee on Colleges and UniversitiesFROM: Christina R. BaurichterRE: Testimony on Assembly Bill 92

Members of the Committee,

I submit this as a supplement to the many powerful testimonies you have received regarding Assembly Bill 92.

Four years ago, my life changed dramatically after surgery to remove a tumor from my C2 spinal cord left me paralyzed. At the time, I was serving with the Wisconsin Army National Guard on COVID orders. I was fortunate to be stationed in Madison, WI, where I had access to one of the best spinal surgeons in the country.

Since joining the community of individuals with Spinal Cord Injuries (SCI)—a "club" no one intends to join—I have committed myself to improving my function and quality of life as a single mother, military veteran, and advocate.

I was introduced to Unite 2 Fight Paralysis through legislation similar to AB 92 that was enacted in Minnesota. My journey took me to the Minneapolis VA, which—looking back—was a blessing. Minnesota's investment in SCI research has created a robust support network for people like me. Even the VA physical therapy department collaborated with a company developing exoskeletons. This is the kind of innovation and partnership I want to see here in Wisconsin.

The Milwaukee VA already houses a SCI/Disorders specialty clinic. We have the population, the universities, and the private sector interest to be a leader in this field. What we need is the seed funding to plant the roots of progress.

I personally witnessed a fellow veteran, wheelchair-bound for 21 years, walk again after six months of exoskeleton therapy. Twenty years ago, SCI was considered a permanently debilitating condition. Now, we're beginning to see what some might call miracles. I highly recommend the book *Don't Call It a Miracle* (2014), which highlights how early-stage SCI research once was—and how far we've come. If we were infants in this field then, we are toddlers now. But science still needs support to grow.

My time at the Minneapolis VA led me to the Paralyzed Veterans of America – Minnesota Chapter, which advertised a research opportunity at the University of Minnesota. There, I connected with an exercise physiologist with over 15 years of experience in SCI. He introduced me to *Get Up Stand Up* and *Unite 2 Fight Paralysis*—a testament to the rich community formed with just a small amount of funding.

This journey also introduced me to Wisconsin's own history with this legislation. *Unite 2 Fight Paralysis* first proposed similar legislation here in 2018 after hearing from Wisconsin advocates like John Martinson. If you've seen someone rolling through the Capitol year after year for this cause, you've seen him. I'm forever grateful for his dedication and for paving the way for others like me.

SCI patients are loud—if not in voice, then certainly in the financial footprint we leave in the healthcare system. Healthcare is Wisconsin's #1 state expenditure. Seed money for SCI research can help reduce these costs by promoting effective treatments and reducing long-term care needs. This funding also acts as a magnet, attracting additional federal and private research dollars to the state—an outcome we've seen in top-performing states with similar programs.

Let me speak briefly on neuropathic pain. The primary drug prescribed to me was Gabapentin, a medication developed in the 1970s for epilepsy and later repurposed for pain and depression. It was given to me in the ICU before I had even reported pain. I remained on it for over a year. Weaning off it took three attempts due to severe withdrawal symptoms: irritability, headaches, and overwhelming discomfort. Even when it no longer addressed my pain, I had to take it daily or suffer.

Another option offered to me was Botox injections to block nerve signals—an uncertain treatment requiring a 3-month commitment. Neither treatment was developed specifically for SCI. This reflects how little research has historically been dedicated to spinal cord injuries. I haven't even touched on the complexities of bowel, bladder, and sexual dysfunction—areas also in dire need of dedicated clinical trials.

Today, I am enrolled in my second research study for neuropathic pain—both based in Minnesota. Not everyone has the means to travel out of state to participate in studies like these. Over 10,000 Wisconsin residents live with SCI. They deserve the chance to be part of the research—and the solutions—that directly affect them.

This bill is not just about funding research. It's about shifting the paradigm. It ensures that people with lived experience—including veterans like myself—have a voice in shaping the research that affects us.

Thank you for your time, your attention, and your service. Thank you to the authors and supporters of this bill. I respectfully urge you to vote **yes** on Assembly Bill 92.

Sincerely,

Christina R. Baurichter

Advocate Unite 2 Fight Paralysis Owner of More Than a Veteran Home LLC Representative of Paralyzed Veterans of America Date: May 15th, 2025 To: Members of the Assembly Committee on Colleges and Universities From: Mackenzie Wann Re: Testimony on Assembly Bill 92

Chairman Murphy:

Thank you Chairman Murphy and Members of the Committee for your time today.

Let me tell you a little bit about myself. My name is Mackenzie Wann. I am from Walworth, WI. I sustained a cervical spinal cord injury (SCI) in June 2014 after a fall, rendering me quadriplegic. This past decade of being wheelchair bound has opened my eyes to the variety of issues that face individuals with a SCI, many of which go far above & beyond the inability to walk.

I learned about the WI Spinal Cord Injury Grant Program from the work I do with Unite 2 Fight Paralysis and the very similar piece of legislation that was passed in Minnesota. I was able to be a direct beneficiary of research that was funded by this MN legislation and was implanted with a device called an epidural stimulator 2 years ago. In addition to the quality of life gains this has given me, it allows me to make a clear fiscal argument for WI: I am just one example of how clinically applied research from this bill has paid for itself many times over in the reduction of the states cost for my care.

Since being implanted, I have had some significant gains in recovery of function. For example, I've been able to eliminate two extremely expensive medications that cost the state upwards of \$24,000 annually! I've also had improvements in my autonomic functions, such as better thermoregulation, which is a priceless improvement in my quality of life in a climate such as Wisconsin's. And perhaps the most impressive advancements of them all? I went from experiencing 5+ UTIs per year to not a single incident of a UTI since my epidural stimulator surgery. On the milder side, this saves my state insurance from paying for an office visit to the doctor, laboratory tests and urinalysis, prescription antibiotics, and increased caregiver hours to help me manage the symptoms. However, they can be as extreme as to provoke a visit to the emergency room or even potentially warrant several days long hospital stays with IV fluids and round the clock treatment and prevention of the infection from going up to my kidneys... so every single UTI that I contracted would cost the state anywhere from \$2000 on the low end up to \$70,000 or more! And this could occur anywhere up to five times in one year and is reflective of just myself as one individual; one of the 10,000 Wisconsinites living with SCI.

I know that I have just put a lot of different facts and figures in front of you, but let me encapsulate it into a nutshell. On the surface a \$5 million appropriation may seem like a large number. However, *the largest expenditure to the states budget is in healthcare*. When you consider the fact that the state of Wisconsin alone spends (conservatively) over \$250 million ANNUALLY in the care of its residents with spinal cord injury, our ask for a curative research appropriation becomes pennies in the bucket. We may not be the largest group that comes knocking on your door, but we are certainly a costly one!

And I've seen the success of this program in other states, such as Minnesota. The reason I think it's successful? The design of the Program itself. It's focused on the innovative, the curative, not the palliative. Fiscal accountability is built in. It's competitive. There's an 8% cap on indirect cost so that 92% of the research dollars goes to exactly what it was intended for. There's a review panel, comprised of healthcare professionals, researchers and those of us living with the injury, those of us with "skin in the game" have a voice in what the priorities are. *All of this* allows the best research to rise to the top. My stimulator is testimony to that.

For all of these reasons, I ask you to support me in advocating for those who don't have the energy or ability to show up for themselves, for my 10,000 fellow residents with this injury...

For all of those coming along behind me, who will also one day wake up in a hospital room being told by a surgeon they'll likely never walk again, joining a club that we never desired ourselves to be a part of. A club that we never BELIEVED, we would be a part of because that's something that "only happens to other people"... Until it suddenly, unexpectedly, and heartbreakingly does. And your entire world changes in that one instant.

Thank you for all of your time and your consideration of this legislation. Thank you on behalf of my disabled community. Let's get Wisconsin on the map, not only for our incredible level of research, but to demonstrate how we take care of our own, our fellow Wisconsinites.





Contact: Connie Schulze Director, Government Affairs 608/516-2552 mobile cschulze@uwhealth.org

Assembly Committee on Colleges and Universities Testimony in Support of Assembly Bill 92 Presented by Daniel Hellenbrand, PhD May 15, 2025

Chairperson Murphy and members of the committee,

Thank you for holding this public hearing today. I am Dan Hellenbrand and I am here today to express support for Assembly Bill 92 as a representative of the UW School of Medicine and Public Health and UW Health. I am also here to endorse the bill because this legislation is particularly meaningful to me. Allow me to explain.

In 2003, I was working as a carpenter and suffered a C5 spinal cord injury after a fall from a house we were building in Middleton. This basically changed everything in my life. After my accident, I went back to school and earned a PhD in Biomedical Engineering from UW-Madison. Since 2010, I have been working at the UW as a researcher in the Department of Neurological Surgery. The reason I pursued a degree in Biomedical Engineering is because I firmly believe research will lead to better treatments for spinal cord injury.

Since I'm living with a spinal cord injury and researching treatments for the injury, I offer a unique perspective. Today, I would like to outline three primary reasons I believe Assembly Bill 92 makes sense for Wisconsin.

- 1. State funding supports excellent scientists right here in Wisconsin:
 - a. A comprehensive return of function after chronic spinal cord injury will come from a combination of factors. Wisconsin has several excellent research institutions including University of Wisconsin campuses, Marquette, Medical College of Wisconsin and more with many incredible researchers working on several distinct aspects needed for developing treatments for spinal cord injury.
 - b. State funding will help train and keep these great scientists in Wisconsin working directly on treatments for spinal cord injury. In our lab, we have had some excellent PhD students and I want to see them continue in the field of developing treatments for spinal cord injury.
- 2. The program is designed to directly develop treatments for chronic spinal cord injury:
 - a. These research grants target the development of deliverable therapies designed to greatly enhance the quality of life for patients living with the injury.
 - b. The research grants are programmatically tiered with larger grants designed to push current science toward clinical trials and smaller grants designed to test new exploratory findings.

- c. The program implements a state advisory council composed of researchers, clinicians, and, most importantly, those living with spinal cord injury like me, to recommend which research projects should be funded.
- 3. State funding will bring money back to Wisconsin:
 - a. The current states with seed funding had an 8:1 return on investment bringing funds back to Wisconsin including large federal grants, and from private foundations such as Wings for Life grants, Craig H. Nielson. This has also led to several private business startups and industry partnerships.
 - b. Most of the funding for spinal cord injury has come from federal NIH and DOD grants that generally require preliminary data, which is difficult to obtain without proper funding. State level funding, as proposed in Assembly Bill 92, helps to address this discord.
 - c. The benefits of seed funding are clearly illustrated by the fact that the five states that received the most federal funding for spinal cord injury research have state seed funding mechanisms.
 - i. As a researcher, this clearly demonstrates that state funding works to move research forward and brings money back to the state.
 - ii. Several good federal grant applications likely weren't funded in states *without* seed money.
 - d. Proposed reductions in grant funding at the federal level will make spinal cord injury research funding far more competitive. The grant program established by AB92 will help bolster Wisconsin researchers seeking grant funds in a highly competitive environment.

In closing, I'd like to thank the authors of this legislation for their commitment to spinal cord injury research. Representative Tittl and Senator Wanggaard, have developed a strong bill that I hope you give your full consideration. My sincere appreciation to those of you who have already indicated your support by signing onto the legislation.

Thank you for your interest and attention today. I'd be happy to take questions from committee members at this time.



Wisconsin Institute of NeuroScience

A partnership of Froedtert, the Medical College of Wisconsin, Children's Wisconsin and the Clement J. Zablocki VA Medical Center

Shekar N. Kurpad, MD, PhD Professor of Neurosurgery Senior Associate Dean, Neuroscience Founding Director, Wisconsin Institute of NeuroScience (WINS) Froedtert Health, Children's Wisconsin, Zablocki VA, and The Medical College of Wisconsin

April 21, 2025

Chairman Murphy and Members of the Committee on Colleges and Universities,

My name is Shekar Kurpad. I work at the Medical College of Wisconsin. My official designation is Senior Associate Dean of Neuroscience at the Medical College of Wisconsin (MCW) and the Founding Director of the Wisconsin Institute of NeuroScience (WINS). As such I oversee all of Neuroscience, both research and clinical work that happens at MCW, FTCH and CW.

What is the Wisconsin Institute of NeuroScience (WINS)?

The Wisconsin Institute of NeuroScience (WINS) is a pioneering collaboration launched in 2023 between Children's Wisconsin, the Froedtert & the Medical College of Wisconsin health network, the Clement J. Zablocki VA Medical Center, and the Medical College of Wisconsin. WINS combines cutting-edge clinical treatment, world-class academic faculty, and leading international research to provide comprehensive care for adult and pediatric neurological patients. Our goal is to advance neurosciences through innovative clinical trials, groundbreaking research, and exceptional education. By integrating the extraordinary expertise and resources of our partners, WINS is dedicated to delivering leading-edge care for all disorders of the brain and spine.

My Professional Background:

My day job is as a neurosurgeon. I specialize in caring for people with spine problems and other neurological issues, and especially those with spinal cord injury (SCI). SCI care focused on trying to restore lost function is my passion. I have had the terrible task of having to be the first person to share, over the last 25 years, with hundreds of patients and their families with a new spinal cord injury that they (or their child or other loved one) will likely never recover lost function in paralyzed limbs from the injury they have suffered.

I have about two and a half decades of experience in research into spinal cord injury, have treated patients with SCI both surgically and in intensive care, have facilitated the development of new medicines and stem cells to treat SCI, run about 12 clinical trials for SCI (of the 14 that have ever been conducted in the world since about 2005). I am also part of national and worldwide groups of physicians and scientists that write and publish recommendations on how to care for patients with acute SCI.

I am honored to present this testimony on behalf of MCW in strong support of Assembly Bill 92. This bill represents a crucial step forward in advancing research and treatment for spinal cord injury (SCI), a

condition that profoundly impacts the lives of many individuals in our state.

Overview of the Medical College of Wisconsin

MCW is a distinguished leader and innovator in the education and development of the next generation of physicians, scientists, pharmacists, and health professionals. Our mission is to discover and translate new knowledge in the biomedical and health sciences, provide cutting-edge, collaborative patient care of the highest quality, and improve the health of the communities we serve.

MCW brings together the most inquisitive minds in science, medicine, education, and community engagement to solve the toughest challenges in health and society today. As the largest private research center in Wisconsin and one of the top 100 research universities in the nation, MCW is at the forefront of medical research and education.

Why Support SCI Research by creating an SCI Council and Support Research?

1. Far-Reaching Implications of SCI Research: Impact on Many "Incurable" Neurological Problems

Research into spinal cord injury (SCI) has far-reaching implications beyond the immediate scope of SCI itself. Laboratory model systems developed for SCI research provide invaluable insights into the basis of numerous neurological diseases. These models help us understand the fundamental mechanisms underlying conditions such as stroke, Lou Gehrig's disease (ALS), multiple sclerosis, and Parkinson's disease. By investing in SCI research, we are not only addressing the needs of SCI sufferers but also paving the way for breakthroughs in a wide array of neurological disorders.

2. Economic Impact of Restoring Function in Young SCI Sufferers for all Constituents of our State

SCI sufferers are typically young individuals who face a lifetime of challenges due to their injuries. Restoring any lost function for these individuals has enormous economic implications for the state of Wisconsin. Enabling SCI sufferers to regain independence and participate fully in society reduces the long-term healthcare costs and increases their potential to contribute economically. The investment in SCI research through Assembly Bill 92 is not only a compassionate choice but also a fiscally responsible one.

3. Understanding the Nervous System: What can we do in the future to reverse paralysis?

SCI research provides a fundamental understanding of how the nervous system operates in human beings. It explores how nerves communicate with each other and investigates strategies to restore lost connections. This knowledge is essential for developing effective treatments and interventions for SCI and other neurological conditions. By supporting SCI research, we are fostering a deeper comprehension of the nervous system, which is critical for advancing medical science and improving patient outcomes.

4. Implications for Other Neurological Diseases

The knowledge gained from SCI research has far-reaching implications for other diseases of the nervous system that lead to paralysis of language and limbs. Conditions such as stroke, Lou Gehrig's disease (ALS), multiple sclerosis, and Parkinson's disease can benefit from the advancements made in SCI research. The ability to rewire, rescue, and regenerate nerve cells holds promise for treating these debilitating conditions and improving the quality of life for countless individuals.

Medical College of Wisconsin 8701 Watertown Plank Road Milwaukee, WI 53226 414-955-3180 In conclusion, Assembly Bill 92 is a vital piece of legislation that will significantly advance SCI research and its broader implications for neurological diseases. The Medical College of Wisconsin strongly supports this bill and urges its passage to ensure continued progress in understanding and treating spinal cord injuries and related neurological conditions.

Thank you for your attention and consideration.

Sincerely,

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Shekar N. Kurpad, MD, PhD Professor of Neurosurgery Senior Associate Dean, Neuroscience Founding Director, Wisconsin Institute of NeuroScience (WINS) Froedtert Health, Children's Wisconsin, Zablocki VA, and The Medical College of Wisconsin

> Medical College of Wisconsin 8701 Watertown Plank Road Milwaukee, WI 53226 414-955-3180

DATE: May 15, 2025 TO: Members of the Assembly Committee on Colleges and Universities FROM: Samantha A. Troyer RE: Testimony on Assembly Bill 92

Thank you Chairman Murphy and committee members for allowing AB92 to be heard. There is no doubt that existing in this world comes at great risk of acquiring severe injury. A routine as simple as driving can potentially entirely alter the trajectory of one's life due to another driver's rash choice. This was the circumstance over 18 Years ago that happened to me after another driver chose to run a red light. Becoming a quadriplegic at 19 years of age was definitely not in my life plans. Which brings me to why I present testimony in support of AB92; spinal cord injury can happen to anyone, at any point in life no matter their status. Improving upon care/cure provides opportunities to reduce the suffering and financial costs to individuals with SCI and the communities that help them.

Proof of the benefits of such legislation having meaningful results has occurred in other states. Minnesota was one of those states. As an outcome of providing a mechanism of effective and efficient competitive SCI research funding Minnesota opened the door to getting further proof of the benefits of epidural stimulator implants in those with an SCI. Over 2 years ago I traveled to Minnesota to receive an implant. I was hoping to have my neuropathic pain reduced by the device, but what happened was much more. Not only was my daily pain reduced from an average of seven to four 24/7, but I ended up with more physical function returning to my left side, the ability to completely eliminate one medication and reduce one medication down to the lowest dose with intention to also eliminate this year. The cost savings to the state of Wisconsin comes to over \$20,000 yearly due to removing the necessity of the medications with epidural stimulation.

Not many with an SCI can go a great distance from home to receive advanced care. It is in the state's best interest fiscally to fund research that reduces the cost of care the state funds for the over 10,000 SCI survivors of at conservatively estimated \$250 million a year. The World Health Organization ranks quadriplegia as the second most expensive acquired condition to live with. It's important we address such a costly & severe injury that anyone at any point in their life could receive. Unfortunately, this year has seen a massive setback at the federal level for funding SCI research. One the most efficient and effective SCI research funding in the world was eliminated from the Department of Defense.

I sit before you today as proof of the benefits created by funding competitive, effective and efficient research. I have been able to improve my quality of life by returning bodily function & reducing costly medical needs.

This is why I support AB92. I believe a state and country that invests in reducing the long-term damage and suffering of a permanent injury that has open enrollment, due to the existence of illness & physics, gives more hope to the future. An investment into SCI research may even

open more doors for treating many other central nervous system disorders. Wisconsin has an opportunity to be an additional light on an overlooked path that leads to historical medical advancements. Please support AB92 for those in front of you today and those who are yet to receive involuntarily enrollment to my community. This is no life we would wish on anyone, but we do wish to have people who can create us the means to provide opportunities for us to have a better life. Thank you for your time and attention to an important initiative.

Please help us set Wisconsin up to be a beacon of hope for the SCI community. We have such an intelligent group of individuals here intent on giving people who have lost everything a better quality of life.

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DATE: May 1, 2025

TO: Assembly Committee on Colleges and Universities

FROM: Bryon Riesch

RE: Testimony in Support of AB19

Chairman Murphy and Members of the Committee:

On April 25, 1998, I dove on a slip and slide as a 19-year-old where I hit my chin wrong resulting in me becoming a C5 quadriplegic. I obviously know firsthand the devastating effects that this has had not only myself, but my family and community. I'm lucky enough to come from a family where they have the means to able to help me with a lot of the exceptional expenses that come along with an injury such as this. So many others are not so lucky.

Today, I am part owner and Executive Vice President at R&R Insurance Services in Waukesha Wisconsin. I am also president of the Bryon Riesch Paralysis Foundation where our goal is to find a cure for paralysis and help others with the expenses that come along with it. Since 2002 we've raised well over \$8 million in the fight against paralysis, which I am extremely proud of, but it is just a drop in the bucket in what is needed to help individuals today dealing with the injury.

Over my 27 years of being a quadriplegic I have seen how research has led to new inventions and cures that have made me more productive and successful. Even the smallest advancements can lead to a drastic difference in the amount of care and costs needed to take care of an individual suffering from paralysis like myself.

That is why this bill is so important. It can help lead to thousands if not millions of dollars in direct savings to the state and give hope to thousands of individuals suffering from paralysis. I do not need to repeat the details and structure of this Bill of which came from a great deal of research and thought, but I think it's important you understand the difference it can make in so many people's lives and the savings that it can lead to for the state.

I appreciate you listening to us today and please vote yes to support this initiative.

Sincerely,

Bryon Riesch

President of the Bryon Riesch Paralysis Foundation

Executive Vice President of R&R Insurance Services

DATE: May 15, 2025

TO: Assembly Committee on Colleges and Universities

FROM: Scott Griffith

RE: Testimony in Support of AB92

Chairman Murphy and Members of the Committee:

Thank you for the opportunity to testify on behalf of the Paralyzed Veterans of America – Wisconsin Chapter (PVA-WI) regarding Assembly Bill 92. I am Mr. Scott E. Griffith, and I'm testifying in favor of AB92.

I'm an incomplete spinal cord-injured (SCI) veteran. I have a tumor inside my spinal cord at the C2-C3 level. I've lived with this tumor for over 26 years, and I'm blessed to be alive and speak with you today. I come from a long line of military lineage as I'm the 8th generation to be a combat veteran and the 2nd generation to retire with over 20 years of service.

Over the past 26 years living with this ticking time bomb inside my spinal cord, I've undergone multiple surgeries, cord recissions, radiation, and chemotherapies. I've gone from wheelchair to half marathon, twice during this journey.

Today, I'm providing a voice to the vast population of Veterans, their caregivers, and family members living with spinal cord injury/disease. The war-fighter is 8-10 times more susceptible during combat to incur a spinal cord injury. The Veterans Health Administration (VHA) is the largest single provider of SCI care. Our SCI facility in Milwaukee is truly state-of-the-art, and the SCI Chief has partnered with many researchers to bring advanced modernization and specialized medicine to care for these war fighters.

To that point, recently, a young Marine, only 20 years old, was transferred from a trauma center near Camp Lejune directly to the SCI center in Milwaukee after suffering a complete cervical spinal cord injury and being paralyzed from the neck down. Since his injury, he has undergone two nerve transplant surgeries and has already gained some function back in his arms, which allows him to use a manual wheelchair versus a power wheelchair. This nerve transplant surgery was developed through SCI research. Without this research, the veteran would be confined to a motorized wheelchair costing tens of thousands of dollars as opposed to the cost of a manual wheelchair. You cannot put a price tag on the quality of life that has been achieved by this successful example.

Other states that have passed similar legislation have documented success in VHA partnering with local researchers. Dr. Ann Van de Wickel in Minnesota had a successful clinical trial involving Identifying Body Awareness-Related Brain Network Changes after Cognitive Multisensory Rehabilitation for Neuropathic Pain Relief in Adults with Spinal Cord Injury, which resulted in a significant reduction in neuropathic pain, which minimized the costly medications like gabapentin, Lyrica, and baclofen.

According to research by the University of Alabama, I only have 16 years to live. Help me prove their science wrong by passing this important legislation and promoting curative SCI research in Wisconsin.

Scott E. Griffith

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Vice President/Government Relations Director

Paralyzed Veterans of America - Wisconsin



State of Wisconsin Department of Health Services

Tony Evers, Governor Kirsten L. Johnson, Secretary

TO: Members of the Assembly Committee on Colleges and Universities

FROM: Arielle Exner, Legislative Director

DATE: May 15, 2025

RE: Assembly Bill 92, relating to: spinal cord injury research grants and symposia and making an appropriation.

The Department of Health Services (DHS) would like to submit written testimony in support of AB 92, regarding the requirement of DHS to establish a program to award grants for research into spinal cord injuries, hold symposia, and appoint a Spinal Cord Injury Council. Additionally, AB 92 appropriates \$5 million every fiscal biennium for the grants and symposia. Governor Evers has consistently recognized the importance of advancing research in spinal cord injuries, and the Department expressed support for last session's version of this proposal, 2023 AB 19. This underscores the administration's commitment to enhancing the understanding and treatment of spinal cord injuries.

The information that would be generated by the research grants could help DHS identify future areas of need, action, and research for spinal cord injuries. Such information could be particularly beneficial for the Department's broader injury prevention and treatment efforts. Current law, Wis. Stat. § 255.20, requires DHS to: 1) maintain an injury prevention program that includes data collection, surveillance, education, and the promotion of intervention; 2) assist local health departments and community agencies by serving as a focal point for injury prevention expertise and guidance and by providing the leadership for effective local program development and evaluation; and 3) enter into memoranda of understanding with other state agencies to reduce intentional and unintentional injuries.

AB 92 does not change existing injury prevention laws but mandates DHS to establish a dedicated Spinal Cord Injury Council and allocate grant funding for related research. It is worth noting that DHS currently has an injury prevention program mandated in statute but does not have any additional funding or staff capacity for these important efforts. To effectively administer the initiatives outlined in AB 92, including grant oversight, symposia coordination, and Council management; DHS requires the creation of at least one full-time equivalent (FTE) position within the Department's Division of Public Health. The estimated annual cost for this position is approximately \$91,300 in General Purpose Revenue (GPR). This staffing is essential to ensure the program's success and to fulfill the legislative intent of the proposed bill.

We at DHS thank the Committee for the opportunity to provide written testimony in support of AB 92 and the Department remains available as a resource to the Committee for any additional information.

1 West Wilson Street • Post Office Box 7850 • Madison, WI 53707-7850 • Telephone 608-266-9622 • www.dhs.wisconsin.gov Protecting and promoting the health and safety of the people of Wisconsin DATE: May 15, 2025 TO: Assembly Committee FROM: Bethany Sullivan RE: Testimony in Support of AB92

Chairman Murphy and Members of the Committee:

My name is Bethany Sullivan. I come before you in support of AB92. I am a C4/C5 quadriplegic. On an early morning in June of 2017, I awoke unable to feel my feet. In the next four and one half years, I went to over one hundred fifty doctor appointments in Wisconsin seeking answers to symptoms that progressively got worse until I was bedridden with debilitating neurological symptoms and pain leaving me unable to walk or stand in place. I left Wisconsin unable to get a diagnosis and in December 2021, after a four month work up at Mayo in Rochester, Minnesota, I received a diagnosis of Transverse Myelitis, a rare neuro-immunological illness that causes inflammation of the spinal cord and leaves people with a spinal cord injury.

The biggest challenge for me living with spinal cord injury was supporting my family through employment as I was unable to work due to my symptoms. My husband passed away nine months after the onset of my injury which meant I was the sole provider for my two young children, ages 12 and 15. At the time, I was a stay-at-home mom and helped care for my husband during his illness. My immediate family lives out of state so I unfortunately did not have the family support that I needed to help my family. During this timeframe, I was living solely on the income provided by the federal government through Social Security Survivors Benefits, a federal assistance program that provides monthly income for the children and spouse of a deceased parent who paid Social Security taxes. The monies were temporary and the payment ended when each of my children turned age 18 and graduated from high school.

Spinal Cord Injury/Disease affects the entire community. The injury creates a huge loss of opportunity and productivity for both the spinal cord injury community and the public. Research is critical! Research lowers health care costs, increases productivity and opportunity.

A new neurologist that I see, who closely follows spinal cord injury research, has learned of very new research out of a California lab that discovered that low Vitamin B12 levels (also called cobalamin) causes spinal cord injuries in the dorsal C4/5 section of the spinal cord. Based on evidence, he believes that my injury may have been caused by low Vitamin B12 levels. Without further research by multiple labs on the effect of Vitamin B12 levels and spinal cord injury, this information does not help clinicians and the spinal cord injury community. My injury may have been preventable if research like this was in place and available to clinicians and consumers. I now take a monthly Vitamin B12 shot in order to prevent another spinal cord injury. Vitamin B12 levels are simple, cheap and cost me less than \$5/month to administer by shot.

I am fortunate enough to have received implantation of epidural spinal cord stimulation at Mayo, a newer therapy that has helped me improve my neurological function. For me, spinal cord

stimulation gave me enough functional recovery to eventually return to work and take care of my family. It significantly decreased my pain enough to allow me to sleep at night and give me increased mobility allowing me to have a better quality of life. The research behind spinal cord stimulation has benefited me, my family and the State of Wisconsin. With this therapy I have been able to seek employment opportunities that support my family.

I am self-employed as a Medicare broker and I now run a Medicare agency that helps Medicare beneficiaries find Medicare health insurance. I am able to support my family and I am supporting both my children through their higher education goals. On May 10, my son earned a double major in Data Science and Economics at UW-Madison. My daughter just completed her sophomore year at Marquette University studying mechanical engineering. She will continue her engineering studies this summer in Vienna, Austria by working as an engineer for the Austrian Institute of Technology, a technology organization and employer within the international scientific community.

Without the epidural therapy, I would be unable to work and would need support from the State of Wisconsin and my health care expenses would be significantly more.

Spinal cord stimulation was considered impossible just a few years ago, but with the advancement of this research and research across the United States, the promise of medical innovation to address spinal cord injury and the issues associated with it has never been stronger.

Finally, what you will hear from some living with spinal cord injury testifying to support AB92 are inspirational stories and how much people have overcome. But I'd like to point out the elephant in the room. What my community understates is the magnitude of human suffering that spinal cord injury causes. The handful of people and faces that you see living with and advocating for this bill represent just a small number of the 10,500 people in Wisconsin living with this injury. The remaining thousands of people who are not here to advocate for AB92 are those who are bedridden, unable to work or reliant on the help of personal care workers for the activities of daily living. This is because spinal cord injury causes permanent, irreversible damage which can affect every system in the human body and has a tremendous amount of human suffering.

I am unfortunately unable to attend the meeting today due to traveling out-of-country for a trip I earned through my work as a Medicare broker. I am the recipient of the 2024, 2023 and 2022 state sales excellence award, an honor given to only five Medicare brokers in Wisconsin.

It is for these reasons why this bill is so very important to me and to my community. Please support AB92.

Respectfully,

Bethany Sullivan