Van H. Wanggaard
Wisconsin State Senator

Testimony on Senate Bill 99

Thank you Chairwoman Cabral-Guevara and committee members, for allowing me to testify on Senate Bill 99 (SB 99) 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 SB 99, 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.

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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 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 Senate Bill 99 today 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.

PAUL TITTL
STATE REPRESENTATIVE • 25TH ASSEMBLY DISTRICT

Testimony before the Senate Committee on Health

Representative Paul Tittl

June 4, 2025

Thank you Chairwoman Cabral-Guevara and members of the committee for allowing me to testify before you today concerning Senate Bill 99.

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.

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State of Wisconsin
Department of Health Services
Tony Evers, Governor
Kirsten L. Johnson, Secretary

TO: Members of the Senate Committee on Health

FROM: Arielle Exner, Legislative Director

DATE: June 4, 2025

RE: Senate Bill 99 and Senate Bill 145

The Department of Health Services (DHS) appreciates the opportunity to submit written testimony in support of SB 99, which requires DHS to establish a program to award grants for spinal cord injury research, host symposia, and appoint a Spinal Cord Injury Council; and for information only regarding SB 145, which adds federally recommended conditions to the state's newborn screening panel, grants rulemaking authority, and exempts the process from emergency rule procedures.

SB 99

SB 99 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 SB 27. 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.

SB 99 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 SB 99, 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. The Department appreciates the Committee's consideration of this position and the associated funding.

SB 145

Wisconsin's Newborn Screening Program is an essential health program that identifies infants with conditions that can impact a child's long-term development, health, and/or survival. DHS operates this program in great partnership with the Wisconsin State Lab of Hygiene (WSLH) and screens babies for hearing loss, congenital heart disease, and currently 48 blood disorders. As the Committee is aware, two additional conditions, X-ALD and MPS1, are undergoing the rulemaking process to be added to the program.

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Under current law, conditions are added to the screening panel based on the recommendation of the DHS Secretary's Advisory Committee on Newborn Screening (SACNBS). Individuals can nominate conditions to the committee for review. Each nomination is subject to subcommittee evaluation, committee evaluation, and ultimately, recommendation by the DHS Secretary. In addition to the current process for nominating conditions, SB 145 requires review of all conditions listed on the federal Recommended Uniform Newborn Screening panel (RUSP) for potential addition to the screening panel

Since last session's version of this proposal 2023 SB 962 was considered, it has been reported that the U.S. Advisory Committee on Heritable Disorders in Newborns and Children, which had managed the RUSP, has dissolved.[1] The Advisory Committee has not met since November of last year and does not have future meetings scheduled to date.[2] In the Advisory Committee's absence, it is unknown if and how the RUSP will be updated to reflect the latest evidence regarding the benefits of screening for new conditions. The Department appreciates the Committee's careful consideration of the reliability of this resource moving forward as it reviews this proposal.

DHS thanks the Committee for the opportunity to provide testimony. The Department remains available as a resource to the Committee regarding these two proposals or any other matters.

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[1] Henderson, Jennifer. "HHS Scraps Advisory Committee on Newborn Screening." Medical News, MedpageToday, 10 Apr. 2025, www.medpagetoday.com/special-reports/features/115070.

[2] "Meetings." HRSA, www.hrsa.gov/advisory-committees/heritable-disorders/meetings. Accessed 3 June 2025.

MEDICAL
COLLEGE
OF WISCONSIN

Chair Cabral-Guevara and Members of the Senate Committee on Health,

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 Senate Bill 99. 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 Senate Bill 99 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.

In conclusion, Senate Bill 99 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,

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

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UNIVERSITY OF WISCONSIN-MADISON

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

Senate Committee on Health
Written Testimony in Support of Senate Bill 99
Submitted by Daniel Hellenbrand, PhD
June 3, 2025

Chairperson Cabral-Guevara and members of the committee,

I am submitting this written testimony to express support for Senate Bill 99 as a representative of the UW School of Medicine and Public Health and UW Health. I am sorry my schedule does not permit me to appear at the public hearing tomorrow to endorse this legislation in person because it 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. Below are the three primary reasons I believe Senate Bill 99 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 University, the Medical College of Wisconsin, and more with many incredible researchers working on several distinct aspects of 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, and 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 Senate Bill 99, 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. In addition, the current proposed cuts to research at the federal level will make SCI research funding far more competitive. This program will help Wisconsin researchers to remain competitive during this changing landscape.

In closing, I'd like to thank the primary authors of this legislation for their commitment to spinal cord injury research. Senator Wanggaard and Representative Tittl have developed a strong bill that I hope you will give your full consideration.

Thank you for your interest and attention. Please reach out to me via Connie Schulze, Director of Government Affairs at cschulze@uwhealth.org if you have any questions about this testimony.

DATE: June 4, 2025

TO: Senate Committee on Health

FROM: Christina R. Baurichter

RE: Testimony in Support of SB99

Chairwoman Cabral-Guevara and Members of the Committee:

I submit this as a supplement to the many powerful testimonies you have received regarding Senate Bill 99.

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 SB99 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.

If 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 Senate Bill 99.

Sincerely,

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

DATE: June 4, 2025

TO: Senate Committee on Health

FROM: William Crowley

RE: Testimony in Support of SB99

Chairwoman Cabral-Guevara and Members of the Committee:

I submit this testimony in support of Senate Bill 99. When I was two years old, my life drastically changed forever. I was traveling in a car with my stepdad and mother, who was 8 months pregnant at the time, when we were struck head on by a drunk driver. The crash killed both my stepdad and mom, along with the baby she was carrying, and I was left a quadriplegic with a C6/7 incomplete spinal cord injury, paralyzing me below the chest and fighting for my life.

Since that dark day, I have come a long way. Growing up I sought to lead as normal a life as possible, making lots of friends, doing well in school, and eventually going on to graduate both college and law school. It has by no means been an easy road. I required both physical and occupational therapy to build strength and maintain the limited function that I retained. There are also ever-present health risks, including bladder infections, pressure wounds, and decreased ability to fight off respiratory illnesses. To this day, I still require an average of 12 hours per day of caregiving support to support me as I live independently in the community, not to mention the power wheelchair I need to get around and the other durable medical equipment that I require to help complete basic activities like getting out of bed and taking a shower.

I support SB99, as the curative research that it supports has great potential to not only greatly improve the lives of Wisconsin residents living with spinal cord injuries, but also reduce the level of support that I and many others need in order to lead full and active lives.

Sincerely,
William Crowley

DATE: June 4, 2025

TO: Senate Committee on Health

FROM: Scott Griffith

RE: Testimony in Support of SB99

Chairwoman Cabral-Guevara and Members of the Committee:

Thank you for the opportunity to submit testimony on behalf of the Paralyzed Veterans of America – Wisconsin Chapter (PVA-WI) regarding Senate Bill 99. I am Mr. Scott E. Griffith, and I am submitting written testimony in favor of SB99.

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 rescissions, 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 Lejeune 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 chair 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 Winckel 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.

Sincerely,
Scott E. Griffith
Vice President/Government Relations Director
Paralyzed Veterans of America - Wisconsin

UWHealth | School of Medicine and Public Health
UNIVERSITY OF WISCONSIN-MADISON

Contact: Connie Schulze
Director, Government Affairs
608/516-2552 mobile
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Senate Committee on Health
Testimony in Support of Senate Bill 99
Written by Daniel Hellenbrand, PhD
June 4, 2025

Chairwoman Cabral-Guevara and Members of the Committee:

Thank you for holding this public hearing today. I am Dan Hellenbrand and I am writing to express support for Senate Bill 99 as a representative of the UW School of Medicine and Public Health and UW Health. I am also writing 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 Senate Bill 99 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 Senate Bill 99, 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 SB99 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.

Sincerely,

Daniel Hellenbrand, PhD
Department of Neurological Surgery
University Of Wisconsin School of Medicine and Public Health

DATE: June 4, 2025

TO: Senate Committee on Health

FROM: Mike Mohr

RE: Testimony in Support of SB99

Chairwoman Cabral-Guevara 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. And I thank you for your time and consideration of Senate Bill 99.

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 Senate Bill 99.

Sincerely,
Mike Mohr

DATE: June 4, 2025

TO: Senate Committee on Health

FROM: Bryon Riesch

RE: Testimony in Support of SB99

Chairwoman Cabral-Guevara 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: June 4, 2025

TO: Senate Committee on Health

FROM: Samantha A. Troyer

RE: Testimony in Support of SB99

Chairwoman Cabral-Guevara and Members of the Committee:

Thank you for allowing Senate Bill 99 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 am writing in support of SB99; 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 of the most efficient and effective SCI research funding in the world was eliminated from the Department of Defense.

I am writing to 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 SB99. 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 SB99 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.

Sincerely,
Samantha Troyer