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# PAUL TITTL

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STATE REPRESENTATIVE • 25<sup>TH</sup> ASSEMBLY DISTRICT

## Assembly Committee on Colleges and Universities

Assembly Bill 19

March 16, 2023

First of all, I would like to thank you, Chairman Murphy and committee members, for allowing me to submit testimony concerning Assembly Bill 19 relating to spinal cord injury research grants and symposia.

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.

Every two years grant recipients would be required to participate in a symposium demonstrating their progress and providing 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.

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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# Van H. Wanggaard

Wisconsin State Senator

March 16, 2023

## Testimony on Assembly Bill 19

Good Morning. Thank you Chairman Murphy and committee members, for allowing me to testify on Assembly Bill 19 (AB 19) 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.

It is important to note that, after our attempts last session as well as this current Legislative session to have this bill to become law, Gov. Evers has also recognized how important it is as well and has included the legislation in his current biennial budget bill.

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, 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.

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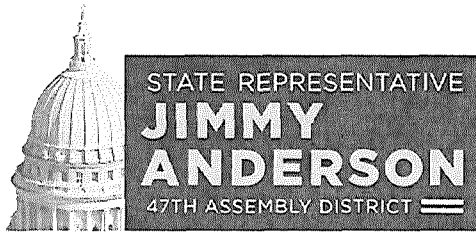
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As required in AB 19, every two years grant recipients would be required to participate in a symposium demonstrating their progress and provide collaborators an opportunity to share ideas in the effort to find a cure. In addition, in January of each 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 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 19 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.



*Testimony before the Assembly Committee on Colleges and Universities  
State Representative Jimmy Anderson  
March 16, 2023*

Chair Murphy and members of the Assembly Committee on Colleges and Universities,

Thank you for holding this public hearing to discuss Assembly Bill 19 on spinal cord injury research grants and symposia.

AB 19 provides a rare opportunity to change thousands of lives, not only in Wisconsin but across the country. This bill would facilitate cutting-edge research that has the potential to help people with spinal cord injuries live with greater independence, health, and dignity.

About 300,000 people in the United States are currently living with spinal cord injuries, and every year, almost 18,000 new spinal cord injuries occur, including about 200 in Wisconsin. These injuries often result in some degree of paralysis, taking a devastating physical, emotional, and financial toll on those injured and their families. For instance, high-level SCI injuries typically cost \$1 million in the first year and \$180,000 every year after. They have grave effects on health outcomes and life expectancy, and can make day-to-day living extremely challenging.

Despite advances in most areas of medical research, spinal cord injuries are understudied, and the research that does exist is vastly underfunded. AB 19 would establish a \$3 million grant program for research here in Wisconsin on new and innovative treatments for these injuries. Minnesota has already passed \$8 million in state funding for a similar program, and as a direct result, the Mayo Clinic has made great progress in developing new treatments.

In addition to providing research funding, AB 19 will create a Spinal Cord Injury Council, bringing medical researchers and people with spinal cord injuries together to help direct the program. Including the perspectives of people with spinal cord injuries as part of this council will ensure that real-life experience is a vital part of the decision-making process. This bill also provides funding for a symposium where researchers across the state can come together, share ideas, and build on each other's success.

This bill is an incredible chance to invest in promising research and provide hope to thousands of individuals both within and beyond our state lines. Thank you for your consideration of AB 19.

Jimmy Anderson  
State Representative  
47th Assembly District



**TO:** Honorable Members of the Assembly Committee on Colleges and Universities

**FROM:** Shekar N Kurpad MD PhD  
*Sanford J Larson Professor*  
*Chairman, Department of Neurological Surgery*  
*Founding Director, The Neuroscience Institute*  
*Froedtert Health, Children's Wisconsin, Zablocki VA and The Medical College of Wisconsin*

**DATE:** March 16, 2023

**RE:** Please Support Assembly Bill 19, Related to Spinal Cord Injury Research Grants and Symposia

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The Medical College of Wisconsin (MCW) strongly supports Assembly Bill 19 (AB 19), legislation creating spinal cord injury research grants and symposia, as well as a Spinal Cord Injury Council, for the State of Wisconsin. MCW appreciates Representative Tittl's leadership for authoring and advancing this initiative, as well as Chairperson Murphy and the Members of the Assembly Committee on Colleges and Universities for holding a public hearing on this important legislation.

The creation of a Spinal Cord Injury Council for our state, as well as enumerating state funds for spinal cord injury research grants and symposia, will be critical to the future health and well-being of Wisconsin's patients suffering from spinal cord injuries. Summarized below is a brief overview of the financial impact as a result of spinal cord injury to patients and our community & State as well as research that is being actively undertaken at MCW.

Spinal cord injury is a devastating neurological condition. Well over 60% of new spinal cord injuries occur as a result of motor vehicle accidents and, thus, can affect any age group and particularly healthy individuals. Stated differently, "driving to work and back home" is a risk factor for a person to suffer from a devastating spinal cord injury. The annual incidence in the United States is now well over 12,000 new spinal cord injuries per year. Since these injuries occur in younger individuals, both men and women, of all backgrounds and races, the overall healthcare burden and cost to the economy significantly exceeds \$6 billion per year.

In addition to the significant financial impact on both patients with a spinal cord injury (lost wages, disability, inability to work, etc.), as well as on the economy for health care for spinal cord injury patients, there is a significant psychological toll on these patients that requires a significant amount of mental health investment for their care. There are personal trials of a significant degree that these patients undergo, including difficulty with establishing and maintaining relationships with friends, family, and co-workers. The mental health burden represents a cost that is unaccounted for in the "physical care" dollars required to care for these patients. The overall negative economic impact per individual with a new spinal cord injury each year (healthcare costs plus lost wages) is estimated to be about \$500,000 per year.

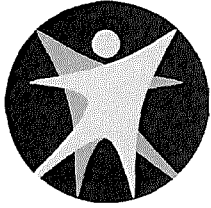


Significant research strides have been taken to treat patients with spinal cord injury with the eventual goal of restoring neurological function. MCW is a key center in the world for spinal cord injury research and clinical trials. Immediate research technologies related to device development include the development of engineering and robotic devices that might assist in the functionality for spinal cord injury patients, to help these individuals accomplish the minimal tasks associated with day to day life. In addition, more significant research includes various methodologies that are geared toward restoration of function. Significant progress has been made in clinical trials in regenerating nerve tissue to help the spinal cord function in normal ways. These include medications that can be administered immediately after injury, research in antibodies that can reduce inflammation in the spinal cord and limit the extent of injury, as well as molecular and cellular therapies designed to regenerate nerves and restore function. Regenerative technologies are complemented by conventional care advances in emergency care to optimize the early medical and surgical care and support for newly injured patients with spinal cord injury. These include training of the emergency medical service providers, therapists, interventions to optimize critical care in the ICUs for newly injured patients, as well as early surgical intervention to decompress an injured spinal cord to try to preserve function.

There are currently more than a dozen clinical trials being performed worldwide, all of which are also being conducted in Wisconsin. The infrastructure at MCW permits advanced clinical care for spinal cord injury patients and is a preferred site internationally for clinical trials.

It is anticipated that with the current pace of research and the involvement of MCW in these clinical trials that within the next decade we would be able to offer meaningful functional restoration for paralyzed patients who are injured in Wisconsin. With the financial and personal impact that spinal cord injuries cause to our patients and community, the effort by the State of Wisconsin to encourage research into spinal cord injury represents a welcome investment that can have a lasting effect on improving the prognosis for these unfortunate individuals.

Thank you for your time and consideration. Please contact Nathan Berken, MCW's Interim Vice President of Government & Community Relations, at 414.955.8217, or [nberken@mcw.edu](mailto:nberken@mcw.edu), if you have questions or need additional information regarding Assembly Bill 19.



State of Wisconsin  
Department of Health Services

Tony Evers, Governor  
Kirsten L. Johnson, Secretary

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**TO:** Members of the Assembly Committee on Colleges and Universities

**FROM:** HJ Waukau, Legislative Director

**DATE:** March 16, 2023

**RE:** AB 19 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 Assembly Bill 19 (AB 19), as drafted, 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 19 appropriates \$3 million every fiscal biennium for the grants and symposia.

Governor Evers has included a provision similar to AB 19 for spinal cord injury grants and symposia for \$3 million in both his 2023-25 and 2021-23 biennial budgets; underscoring the commitment and need for funding this initiative to better understand 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 DHS'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.

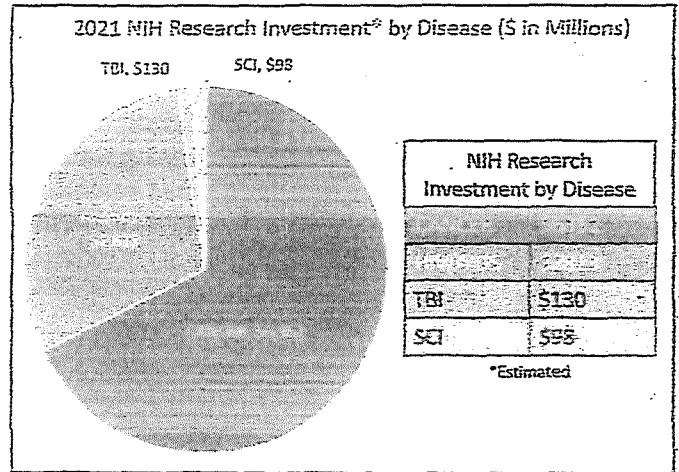
AB 19 does not change the current injury prevention law but it does require DHS to create a council specific to spinal cord injuries and provides grant funding for spinal cord injury research. DHS currently has an injury prevention program mandated in statute but does not have any additional funding or staff capacity for these important efforts. While AB 19 allows for the coverage of the costs associated with 1.0 FTE, DHS may consider pursuing a permanent position to administer this grant in the future. Dedicated funding and position authority would ensure that DHS is able to meet the intent of the funding of the grants for spinal cord injury research both now and in the future.

We thank the Committee for the opportunity to provide written testimony in support of AB 19 and we offer ourselves as a resource for Committee members for any follow up or additional information that may be needed.

# Wisconsin Spinal Cord Injury Research Grant Act

## Problem:

- 10,500 residents of Wisconsin live with spinal cord injuries (SCI).
- Research spending in this field has primarily been for continuing care and rehab, not for strategies to deliver functional improvement. Considering the enormous costs of care for those living with SCI, these priorities are out of alignment.



## Context:

- Lifetime costs of care for an individual with SCI range from \$1.5 to \$4.6 million.
- Total annual cost of caring for people with SCI in Wisconsin is approx. \$550 million.
- The National Institutes of Health fund only approximately 10-15% of all applications in this field, leaving many promising inquiries unfunded or underfunded.

## Goal:

- Accelerate and Deliver therapies that enable functional improvement of breathing, bowel, bladder, sexual, and sensorimotor functions of Wisconsin residents living with SCI.
- Establish a collaborative advisory board consisting of WI residents living with SCI, family members of those living with SCI, researchers, and clinicians with expertise in the field to prioritize and recommend funding for research projects.

## Request:

- \$3 million appropriation from the state budget. Funds would go to two categories of expenditures:
  - Seed money for innovative research available to any Wisconsin institutions conducting research into device, pharmacologic, biologic, and rehabilitation strategies and techniques.
  - Push innovation forward—from lab to clinical trial to industry.

## Projected benefits:

- By moving the research to the clinic, WI would see an enormous reduction in the costs of care. Any improvement to the consequences of these injuries such as recovery of breathing/bowel/bladder/sexual function and mobility would additionally have a significant impact upon quality-of-life and employability.
- Attract neuroscientists and researchers to Wisconsin's biomedical engineering industry.
- Catalyze biotech spin-offs.

For more information, please contact Matthew Rodreck at 617-334-5472 or [matthewrodreck@unite2fightparalysis.org](mailto:matthewrodreck@unite2fightparalysis.org)

Led by: Unite 2 Fight Paralysis

Supported by: Quest For Cures, Get Up Stand Up 2 Cure Paralysis Foundation, Canadian and American Spinal Research Organization, Spinal Cord Society

Citations for information at [u2fp.org/get-involved/resources.html](http://u2fp.org/get-involved/resources.html)





**TO:** Honorable Members of the Assembly Committee on Colleges and Universities

**FROM:** Benjamin Wagner  
*Chair, Neuroscience Research Center Board  
Medical College of Wisconsin Neuroscience Research Center*

Cecilia J. Hillard, PhD  
*G. Frederick Kasten, Jr Chair in Parkinson's Research  
Professor of Pharmacology and Toxicology  
Director of the Neuroscience Research Center  
Associate Dean for Research  
Medical College of Wisconsin*

**DATE:** March 16, 2023

**RE:** Please Support 2023 Wisconsin Assembly Bill 19, Related to Spinal Cord Injury Research Grants and Symposia

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The Neuroscience Research Center Board is a community, faculty and staff-led advisory board whose mission is to support the Medical College of Wisconsin's (MCW) Neuroscience Research Center (NRC), as well as the newly founded MCW Neuroscience Institute (NSI). The Board's purpose also includes advancing the NRC and NSI, serving as ambassadors in the community to educate and advocate for the NRC and NSI's respective missions.

The MCWNRC's goals are to enhance basic and translational neuroscience at MCW through the development of an MCW-wide programmatic plan for neuroscience research. MCW's NSI was formed to further research and advance treating neurological disorders. Many neuro-related disciplines, including spinal cord injury research and treatment, are housed within the NRC and NSI.

The membership of the Neuroscience Research Center Board support 2023 Wisconsin Assembly Bill 19, which will create spinal cord injury (SCI) research grants and symposia. The design of this initiative has a track record of success and effectiveness, modeled on the programs instituted in Minnesota, Ohio, Pennsylvania, and Washington. Simply put, the SCI Research Program acknowledges the severe quality of life burden carried by those living with SCI, acknowledges the disproportionate funding to this area of research compared to its prevalence in the population and is designed to address specific funding gaps towards the translation of discoveries to human relevance.

No one chooses spinal cord injury. Approximately 10,500 Wisconsinites are affected by SCI and, unfortunately, that number continues to grow. What SCI looks like under the surface is severe neuropathic pain, the loss of bowel, bladder and sexual function, the loss of temperature

and blood pressure regulation, breathing, and voluntary movement. In many cases it brings with it severe depression, a shortened lifespan and an impaired ability to fully engage with family, friends, and employment opportunities.

Fortunately, programs such as the one Senator Wanggaard and Representative Tittl are proposing to fund, are helping to alleviate the burden of SCI. Technology and innovative research are on the cusp of major breakthroughs, catalyzed by public investment. This program's effectiveness relies on a few key features:

- Research grants remain in the state and are competitive among researchers, institutions, and businesses.
- Research grants target innovation in the translation of deliverable therapies to those who live with the injury
- The program mandates a low indirect cost rate of 8% so that taxpayer dollars go directly to the work and not general administrative funds.
- The program implements a state advisory council composed of researchers, clinicians and most importantly, those living with spinal cord injury, to recommend which research projects should be funded.

The Board is fully in support of this program. It is a judicious use of public funds to help alleviate the quality of life burden born by those currently living with SCI and acts as an insurance policy for those yet to experience SCI. It is an opportunity to stimulate the biotechnology markets in Wisconsin. It is an opportunity to alleviate the taxpayer burden of support for the 65% of the SCI community that cannot work because of the condition. It will offer educational opportunities for students who choose SCI research as a career path. Lastly and importantly, this program is non-partisan and offers an opportunity to reach across the political aisle to affect the public good.

Thank you for your consideration of this impactful legislation, which will benefit Wisconsin's residents for generations to come. Please feel free to contact Nathan Berken, Interim Vice President of Government and Community Relations, at 414.955.8217, or [nberken@mcw.edu](mailto:nberken@mcw.edu), if you have additional questions or require additional information.

TO: Members of the Assembly Committee on Colleges and Universities  
FR: Dan Hellenbrand, Researcher – Dept of Neurological Surgery  
CC: Connie Schulze, Director of Government Affairs  
DT: February 21, 2023  
RE: Support for AB19/SB27

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I write today as a spinal cord injury survivor to express our support for Assembly Bill 19 (AB19) and Senate Bill 27 (SB27), establishing a \$3 million biennial grant program and advisory council for spinal cord injury research within the Wisconsin Department of Health Services. The UW School of Medicine and Public Health's Department of Neurological Surgery is home to several research projects intended to improve the health and well-being of patients with spinal cord injuries and we would welcome an opportunity to seek new grant support to advance our work.

Spinal cord injury is a devastating trauma that leaves approximately 10,000 to 20,000 people paralyzed every year in the U.S. After spinal cord injury, there is a loss of both sensory and motor function below the level of injury. Due to this loss of function, patients with spinal cord injuries are often unable to care for themselves and rely on family and friends to serve as their primary caregivers. Our Department of Neurological Surgery treats several patients with spinal cord injuries and observes firsthand the enormous burden it poses for both the patient and their families. Patient care is of the utmost importance to the Department of Neurological Surgery, and we contend research is the most promising way to develop treatments that lead to better outcomes for these patients.

To that end, the primary reasons we strongly support AB19/SB27 include:

- These research grants target the development of deliverable therapies designed to greatly enhance the quality of life for patients living with spinal cord injury.
- The research grants remain in the state and support local researchers, institutions, and businesses.
- The research grants are tiered with larger grants designed to push current science toward clinical trials and smaller grants designed to test new exploratory findings.
- The program implements a state advisory council composed of researchers, clinicians, and, most importantly, those living with spinal cord injury, to recommend which research projects should be funded.
- The program is designed to promote collaboration among researchers in the state of Wisconsin.
- The program mandates a low indirect cost rate of 8% so that taxpayer dollars go directly to the work and not general administrative funds.

We also applaud the authors' recognition of the value in having a representative from the UW School of Medicine and Public Health on the advisory council and we would be happy to serve.

A special thank you to Rep. Tittl, Rep. Wittke, Rep. J. Anderson and Sen. Wanggaard for your leadership. We sincerely appreciate your efforts to advance research into treatments for spinal cord injury.

Please let us know if you have any questions.

451 West Wilson Street  
Apartment 410  
Madison, WI 53703-4669

March 16, 2023

Members of the Wisconsin Assembly Committee on Colleges & Universities  
Wisconsin State Capitol  
2 East Main Street  
Madison, WI 53702

Dear Representatives Murphy, Nedweski, Goeben, Johnson, Krug, Michalski, Moses, Schutt, Summerfield, Wittke, Emerson, Shankland, Anderson, Stubbs, and Joers,

As a Wisconsin resident, **I am testifying in support of Assembly Bill 19**, which would establish a program to fund spinal cord injury research grants and symposia.

Before I was born, one of my parents' friends suffered a serious spinal injury and became fully paralyzed from the neck down. Growing up, I got to know this friend and learned first-hand how challenging life as a quadriplegic is on a day-to-day basis.

As important as it is to care for those in our community living with spinal cord injuries using the best treatments currently available, it is equally important to find a cure. Finding a cure to spinal cord injuries would mean (1) transformational improvements to current patients' quality of life, (2) an improved prognosis for future sufferers of spinal cord injuries, and (3) reduced healthcare costs due to the elimination of long-term intensive care.

Assembly Bill 19 provides a potent tool to advance the cause of finding a cure to spinal cord injuries. It leverages state resources and public oversight to direct research toward impactful—as opposed to theoretical—research.

Please support Assembly Bill 19. Thank you for your attention to this important matter.

Sincerely,



Andrew W. Stevens

**DATE: March 16, 2023**

**TO: Assembly Committee on Colleges and Universities**

**FROM: Mike Mohr**

**RE: Testimony in support of Assembly Bill 19**

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 19.

I have a spinal cord injury. Twenty-six 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. I require help with a variety of activities throughout the day, 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 to be about \$300 million each year. The bulk of that money comes from the state, as 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. 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 19.

You're going to hear a little more from Dan Hellenbrand about how our program will work and why it is efficient. Then you're going to hear from Dr. Murray Blackmore, a highly regarded researcher in this field. But if you have questions for me before that, I'd be happy to answer them.



**Assembly Committee on Colleges and Universities**  
**Thursday, March 16, 2023**  
**Testimony in Support of AB19**  
**Provided by Dan Hellenbrand**

*Chairperson Murphy and Members of the Committee:*

I am Dan Hellenbrand and I am here today to express support for Assembly Bill 19 (AB19). In 2003, I had been working for eight years as a carpenter. One morning in April, there was some freezing rain and I suffered a C5 spinal cord injury when I fell from a house we were building in Middleton. Fortunately, I had access to great healthcare almost from the moment the injury happened. I underwent successful spinal cord surgery stabilization at University Hospital within days of my fall. Then I began the lengthy rehabilitation process and today, I have use of my arms but I lack control of my triceps and fingers. It has taken a long time to relearn how to do normal daily tasks and I still rely on the support of my wife, Amy.

After my accident, I went back to school and earned a bachelor's degree from University of Miami, Ohio and a master's degree 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 my master's in Biomedical Engineering and the reason I am currently working on my PhD, is because I firmly believe research will lead to better treatments for spinal cord injury.

To date, there have been extensive improvements in terms of spinal stabilization and surgery after spinal cord injury. However, no substantial improvements have been made in terms of functional recovery after spinal cord injury. Functional losses place enormous physical, mental, and financial burdens on someone with the injury, significantly reducing their quality of life. This is observed first-hand by clinicians at the Department of Neurological Surgery at UW-Madison who treat patients with spinal cord injuries.

Most funding to support spinal cord injury research comes from federal agencies, primarily the National Institutes of Health (NIH) and Department of Defense (DOD). In order to successfully compete for those grants, a researcher must have preliminary findings, which requires pilot funding. State funding as proposed in AB19 could play a critical role in early exploratory research needed to gain the preliminary data necessary to bring more federal funding to Wisconsin. State-level medical research programs, such as in Kentucky, have already proven to be successful. Through state funding, Dr. Susan Harkema's lab at the University of Louisville discovered that a patient with a motor-complete injury was able to control leg movements with the aid of epidural electrical stimulation. Her work created a paradigm shift, where instead of thinking we need to develop compensation strategies for spinal cord injured patients to achieve functional goals, we

should rather be thinking of the injured nervous system as having enormous potential for adaptation and modification to facilitate recovery for patients. Assembly Bill 19 is specifically designed with this bold paradigm shift in mind, to develop therapies that promote functional recovery for patients with chronic spinal cord injuries.

Furthermore, I'm excited about Assembly Bill 19 both as someone dealing with a spinal cord injury and as a researcher working to develop treatments for the injury, because I believe this bill is designed efficiently, directing financial support to solving the problem. For example:

- These research grants target the development of deliverable therapies designed to greatly enhance the quality of life for patients living with the injury.
- The research grants remain in the state and support local researchers, institutions, and businesses.
- 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.
- 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.
- The program requires a symposium to present results, which promotes collaboration among researchers.
- The program mandates a low indirect cost rate of 8% so that taxpayer dollars go directly to the work and not general administrative funds.

In closing, I'd like to thank the authors of this legislation for their commitment to spinal cord injury research. Representatives Tittl, Wittke, Jimmy Anderson and Sen. Wanggaard have developed a strong bill that I hope you give your full consideration. Special thanks to Rep. Summerfield, a member of this committee who has already indicated his support by signing on as a co-sponsor of the bill.

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

**DATE: March 16, 2023**

**TO: Assembly Committee on Colleges and Universities**

**FROM: Dr. Murray Blackmore**

**RE: Testimony in support of Assembly Bill 19**

Chairman Murphy and Members of the Committee:

My name is Murray Blackmore. I am a Professor at Marquette University and I lead a research lab devoted to the problem of spinal cord injury. I serve on a federal grant review panel, I help organize national and international meetings on the topic of spinal cord injury, and my lab is funded by research grants.

So I'm here to give a scientist's perspective on this initiative. But I'm also here as a family member. When I was thirteen my mother suffered a spinal cord injury and was paralyzed from the shoulders down. I watched her live for 27 years with the injury. And ten years ago, I watched her die from it as her lungs slowly gave out, which is a common complication.

The reason I became a scientist is to help solve this problem. And the reason I'm here today is because I believe this bill is a very smart and very effective way to do that. You have heard how this initiative works, so let's take a look at what similar initiatives have accomplished in other states. The key idea is to provide seed money to researchers so that they can launch initiatives. So, what exactly have researchers done with it in other states? I would say two main things.

The first is commercialization, funding projects that then attract venture capital and allow startups. There are now three startup companies, two in Minnesota and one in Ohio, that are addressing different aspects of the injury. Or in a variation on this, researchers have used these projects to attract partnerships with large corporations as a way to launch clinical trials. There are great examples from Washington and Minnesota.

The second outcome has been successful competition for large federal grants. And again, as you have heard, this is essential because federal grants require pilot studies. This is the outcome that is easiest to measure, and it turns out to be about an 8-to-1 return on investment. That's an unusual number, and it means that state funds have been used very effectively to attract the larger federal support.



It is a remarkable track record, and it raises the question – what explains the success? I think there are several factors. It is fast acting, it is accountable, it is competitive. But if I had to pick just one, I would say it is the judging panel. It is outside of universities, outside of academic politics, and includes not just scientists but also clinicians and people living with the injury. I believe it is that mix of scientists with clinicians and community members that allows these panels to identify the ideas with real impact and bring them to the surface.

I will close with one final point: Wisconsin is ready for this initiative. We already have a strength in nervous system repair, especially in the areas of tissue regeneration and advanced genetic techniques. I think that is important, because I see those approaches as the future of SCI research. I count at least fourteen labs, at four institutions, that are already working directly on the problem of nerve regeneration and spinal injury. More labs are working on related topics and could be pulled in.

I am certain that if these funds are established there will be a flood of strong applications. Certainly, my lab will compete for these funds, but there is no guarantee we will succeed; it will be a strong field. But I trust that this judging system to identify the ideas with real-world potential, and I think it will be very exciting to see the private and federal initiatives that we can attract.

There is an opportunity here for Wisconsin to take a step out front in finding solutions for this problem. I want to thank you again for your consideration and I am happy to take any questions.



**TO:** Honorable Members of the Assembly Committee on Colleges and Universities

**FROM:** Shekar N Kurpad MD PhD  
*Sanford J Larson Professor*  
*Chairman, Department of Neurological Surgery*  
*Founding Director, The Neuroscience Institute*  
*Froedtert Health, Children's Wisconsin, Zablocki VA and The Medical College of Wisconsin*

**DATE:** March 16, 2023

**RE:** Please Support Assembly Bill 19, Related to Spinal Cord Injury Research Grants and Symposia

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The Medical College of Wisconsin (MCW) strongly supports Assembly Bill 19 (AB 19), legislation creating spinal cord injury research grants and symposia, as well as a Spinal Cord Injury Council, for the State of Wisconsin. MCW appreciates Senator Wanggaard and Representative Tittl's leadership for authoring and advancing this legislation, as well as Chairperson Murphy and the Members of the Assembly Committee on Colleges and Universities for holding a public hearing on this important legislation.

The creation of a Spinal Cord Injury Council for our state, as well as enumerating state funds for spinal cord injury research grants and symposia, will be critical to the future health and well-being of Wisconsin's patients suffering from spinal cord injuries. Summarized below is a brief overview of the financial impact as a result of spinal cord injury to patients and our community & State as well as research that is being actively undertaken at MCW.

Spinal cord injury is a devastating neurological condition. Well over 60% of new spinal cord injuries occur as a result of motor vehicle accidents and, thus, can affect any age group and particularly healthy individuals. Stated differently, "driving to work and back home" is a risk factor for a person to suffer from a devastating spinal cord injury. The annual incidence in the United States is now well over 12,000 new spinal cord injuries per year. Since these injuries occur in younger individuals, both men and women, of all backgrounds and races, the overall healthcare burden and cost to the economy significantly exceeds \$6 billion per year.

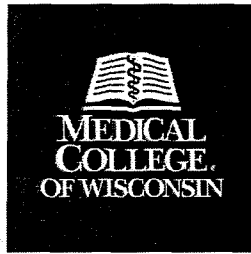
In addition to the significant financial impact on both patients with a spinal cord injury (lost wages, disability, inability to work, etc.), as well as on the economy for health care for spinal cord injury patients, there is a significant psychological toll on these patients that requires a significant amount of mental health investment for their care. There are personal trials of a significant degree that these patients undergo, including difficulty with establishing and maintaining relationships with friends, family, and co-workers. The mental health burden represents a cost that is unaccounted for in the "physical care" dollars required to care for these patients. The overall negative economic impact per individual with a new spinal cord injury each year (healthcare costs plus lost wages) is estimated to be about \$500,000 per year.

Significant research strides have been taken to treat patients with spinal cord injury with the eventual goal of restoring neurological function. MCW is a key center in the world for spinal cord injury research and clinical trials. Immediate research technologies related to device development include the development of engineering and robotic devices that might assist in the functionality for spinal cord injury patients, to help these individuals accomplish the minimal tasks associated with day to day life. In addition, more significant research includes various methodologies that are geared toward restoration of function. Significant progress has been made in clinical trials in regenerating nerve tissue to help the spinal cord function in normal ways. These include medications that can be administered immediately after injury, research in antibodies that can reduce inflammation in the spinal cord and limit the extent of injury, as well as molecular and cellular therapies designed to regenerate nerves and restore function. Regenerative technologies are complemented by conventional care advances in emergency care to optimize the early medical and surgical care and support for newly injured patients with spinal cord injury. These include training of the emergency medical service providers, therapists, interventions to optimize critical care in the ICUs for newly injured patients, as well as early surgical intervention to decompress an injured spinal cord to try to preserve function.

There are currently more than a dozen clinical trials being performed worldwide, all of which are also being conducted in Wisconsin. The infrastructure at MCW permits advanced clinical care for spinal cord injury patients and is a preferred site internationally for clinical trials.

It is anticipated that with the current pace of research and the involvement of MCW in these clinical trials that within the next decade we would be able to offer meaningful functional restoration for paralyzed patients who are injured in Wisconsin. With the financial and personal impact that spinal cord injuries cause to our patients and community, the effort by the State of Wisconsin to encourage research into spinal cord injury represents a welcome investment that can have a lasting effect on improving the prognosis for these unfortunate individuals.

Thank you for your time and consideration. Please contact Nathan Berken, MCW's Interim Vice President of Government & Community Relations, at 414.955.8217, or [nberken@mcw.edu](mailto:nberken@mcw.edu), if you have questions or need additional information regarding Senate Bill 27.



knowledge changing life

Department of Neurosurgery

TO: Assembly Committee on Colleges and Universities

FROM: Kajana Satkunendrarajah, PhD

DATE: March 16, 2023

RE: Testimony in support of Assembly Bill 19 (AB 19)

Chairperson Murphy and Members of the Committee:

My name is Kajana Satkunendrarajah, and I am a Professor in the Department of Neurosurgery at the Medical College of Wisconsin. I moved here from the University of Toronto in Canada to establish my neuroscience research program focused on spinal cord injury at the Clement J. Zablocki VAMC.

Just like that, spinal cord injury resulting from any number of events can lead to devastating functional deficits. As a neuroscientist, I am very aware of how many tasks, such as breathing and getting out of bed, that we all take for granted can become extremely difficult or impossible after sustaining a spinal cord injury. As others like Samantha have expressed, individuals with spinal cord injury don't just want wider sidewalks but a cure for spinal cord injury. Despite many significant medical advances, we are yet to find a cure for spinal cord injury.

I moved from Toronto to start my lab here in Wisconsin at the MCW because of the talented and dedicated clinicians and scientists who strongly desire to make a difference in the lives of people with spinal cord injuries. I wanted to be part of a team that could make a difference by taking discoveries made in the lab to the bedside to improve the patient's quality of life. Despite the talent and dedication of researchers and clinicians at MCW and other institutes in Wisconsin, there are still many roadblocks to our path to a cure. The impactful Assembly Bill 19 proposed by Senator Wanggaard and Representative Tittl could be the key to removing some of these roadblocks and finding treatments to restore function after spinal cord injury.

The program proposed in this bill has a high likelihood of success based on the success of similar programs in Minnesota, Ohio, Pennsylvania, and Washington. Wisconsin, through MCW, is already part of many, if not all, spinal cord injury-related clinical trials. The proposed bill will further facilitate innovative discoveries and new clinical trials, leading to meaningful functional recovery for SCI patients in Wisconsin and globally.

In summary, the proposed bill has the potential to make a difference in the quality of life of SCI patients and reduce the financial and emotional burden of patients and caregivers. I appreciate your consideration, and I am happy to take any questions.

**DATE: March 16, 2023**

**TO: Members of the Assembly Committee on Colleges and Universities**

**FROM: Mackenzie Wann**

**RE: Support for Assembly Bill 19**

Chairman Murphy and Members of the Committee on Colleges and Universities, my name is Mackenzie Wann and I am writing to you in support of AB 19. In June 2014, I woke up in a hospital bed, surrounded by a team of doctors. They broke me the heart shattering news that I had a spinal cord injury (SCI) and was now quadriplegic. I felt both helpless and frightened. On top of that, I was unable to even verbally respond or ask any questions due to being on life-support. I didn't realize at that point in time that my new inability to walk was only one in quite literally hundreds of ways that my life would be permanently altered.

After my three month stay at UW Madison's hospital, I was then transferred to a skilled nursing facility in the Lake Geneva area. I was only 26 years old and didn't think my morale could take any further blows. But then I developed a stage four pressure sore, an unbearably painful and life-threatening condition that is common to SCI. Because of the pressure ulcer, I was mandated to bedrest for almost one full year, broken up only by several weeks long stays in the hospital and ultimately required multiple surgeries to heal it.

Prior to my SCI, I had worked as a special education teacher and behavior therapist for children with autism. At the time of my injury, I had been living in Madison as a candidate for their Master's in occupational therapy program. How ironic that only a handful of months later, I would instead be the one needing occupational therapy! Sustaining a SCI has not only significantly affected my career path, but quite honestly, has a tremendous impact on every waking moment. What used to seem like the smallest of tasks which have become tremendous obstacles to continually overcome. An example of this would be something as "simple" as unlocking my front door, but the manipulation of a key is an extreme challenge when you no longer have finger dexterity. My day to day is now filled with pressure relief breaks to avoid these sores, management of personal caregivers, trying to avoid UTIs because my bladder can't drain correctly, or days where I struggle to get out of bed because my nerve pain is intolerable. It has affected my social life in fear that I will have a urine accident while out in public and these are all just the tip of the iceberg!



AB 19, if passed, has the potential to alleviate some of these impacts that I alluded to. In 2015, a very similar piece of legislature was passed in Minnesota. The amount of success that has come from this bill demonstrates what could be done in our very own state. For example, the Minnesota bill funded research that allowed for a study to be done using epidural stimulators in people with SCI. This has attracted people from all around the country, including myself, to travel to MN and spend significant amounts of money between the surgery and travel costs. It ends up being a win-win, where MN has opened new business revenues and those with SCI are able to regain some function.

Following MN's example, not only would we be improving the daily life of Wisconsin's SCI community, but we could both attract new revenue and alleviate some of the financial burden. Hundreds of thousands of dollars are spent annually not just in the cost of personal caregivers, but also with nursing facilities, hospital stays, and surgeries such as those in my past. In funding research that is curative in nature rather than palliative, Wisconsin has a tremendous opportunity to do all of these things. In short, this is why I am in full support of AB 19.

**DATE: March 16, 2023**

**TO: Members of the Assembly Committee on College and Universities**

**FROM: Douglas R. Rammer**

**RE: Support for Assembly Bill 19**

Chairperson Murphy and Members of the Committee on Colleges and Universities.

I am writing to support AB19 to improve the lives of my son, my work colleague, and the over 10,000 other residents of Wisconsin living with a spinal cord injury.

For over 20 years, I have worked with a colleague with a C5 injury, but unfortunately, I did not truly know the impacts of his injury on his life. I knew that he could not walk or use his hands but I was ignorant to that unseen day to day issues. I would find myself asking, "Why can't we have a meeting earlier? Why can't he be here at the 8:30 work time? Where is he today? He is sick again?" Answers to these questions were given to me on August 13, 2017 at 11:05 pm. Being a quadriplegic is more than just the loss of the use of their legs or hands – it is the unseen complications, loss of time, and accessibility that most worry me and my son for his future. Max has accepted the fact that he will never walk but what truly agonizes him is pressure sores, urinary tract infections (UTI), and the general loss of time in his day. As I write this, Max is experiencing yet another UTI, his 4th since the beginning of December.

As I alluded to with my colleague and have observed with my son, it is the amount of time that is lost each day for personal care for someone with an SCI. This time loss has tremendous personal, emotional, social, and professional consequences for those in the community as well as those who know and care for them. Why didn't my colleague arrive till after 9 am each day? I will tell you it is time needed to start his day. Each morning that does not involve going to the bathroom and showering, it takes Max about an hour to get from waking to his chair. While time consuming, we are fortunate, Max is only 150lbs and is able to assist in the transfer from the bed to chair. For most quads, this will involve a lift and sling, a significantly riskier and longer process. On bathroom and showering days, at least an additional three hours are required. These days are different for each person. As a result, Max does not schedule his classes before 11 am to assure he is completed with this task.

Prior to this last rash of UTI's, my son was scheduled to graduate from the UW- Madison School of Business in the Spring of 2023, but this has been postponed to December to

restore his physical and mental health. While seeing him graduate will be a great accomplishment academically, I am more proud of all the health and mental obstacles he had to overcome during this pursuit of a degree. For example, in the fall of 2021, Max had two 5 plus days in the hospital and several days at our home for IV treatment for a Urinary Tract Infection. Urinary tract infections are significant and demoralizing. For example, in 2019, when we first visited this capital in support of this spinal cord research effort, Max was in the beginning stages of a UTI. The need to urinate is frequent and unpredictable, and I convinced him to attend because I assured him that a government building would have accessible bathrooms. While this building does, they are not easy to get to or well-marked. A couple of times, staffers directed us to traditional bathrooms because they thought all bathrooms would be accessible. By the end of our visit, Max was sitting in a cushion full of urine with a ride to Janesville before he could clean him. We believe this only added to the severity of his UTI condition and led to some skin related issues.

Additionally, during this time in school, Max experiences stomach pains related to bowel issues that are affecting his ability to attend and focus on class. To alleviate the pain, he needs to bend over in his chair or reach out to see if a caregiver or I can come over to do a 3-hour bowel program. These bowel and bladder issues are significant and the research that this bill would fund would greatly improve Max's life and also improve his employment prospects.

As I stated in the beginning, even though I worked with a colleague that has a SCI injury for more than 20 years, I was unaware of the effects of the injury on his day-to-day life. The bill before you requires active participation of the SCI community during both the evaluation research proposals and subsequent reporting process. For the research to have the greatest impact, the funding is reviewed by a panel that consists of a person with a lived SCI experience, a family member of a SCI person, noted researchers in the SCI area, a Veterans Affairs representation and others that have knowledge of the day to day needs of the SCI community.

Looking beyond 2023 is very stressful and depressing for Max. Who will employ him while accommodating his disability and the associated personal care needs. Even while being at a school that has a staff designated to help him with accommodations, it has been difficult. This leads me to question if any company will accommodate his basic disability needs and this personal care need requirements. The need to have a flexible work schedule and unforeseen days he misses due to UTI's if a viable solution is not found. During his time at UW-Madison, professors or teaching assistants have required assignments to be handed in on paper instead of electronically. Max cannot grasp paper with his hands, but there are researchable options that can give Max the ability to pinch his fingers and restore his

triceps strength. This bill could fund these research options that would greatly improve his employment potential and independence.

Approximately 80% of the disabled community is unemployed and the state of Wisconsin spends approximately \$500 million dollars for the care of the SCI community in each biennium budget. Max wants to be a member of the Wisconsin workforce and reduce his burden to Wisconsin.

I strongly support AB19, because it is structured to formulate research to address the unseen, daily concerns of the SCI community. As a result of this research, I believe it will improve Max ability to be employed and reduce the overall cost to the State of Wisconsin of this community. Thanks for your time and support of this effort.

**DATE: March 16, 2023**

**TO: Members of the Assembly Committee on Colleges and Universities**

**FROM: Samantha A. Troyer**

**RE: Testimony in Support of Assembly Bill 19**

Chairman Murphy and Members of the Committee on Colleges and Universities, my name is Samantha Troyer, and I am in support of AB 19, because last April I testified in support for similar legislation AB873. I described how I received a C1 spinal cord injury (SCI), how it has impacted my existence, having to seek treatments to improve my quality of life outside of WI, and why the SCI research legislation is important for our state. I am not the type of person to be content with allowing my now to be my forever if it means a life of struggle and suffering. Which is why over the past year I turned my attention to what Minnesota had to offer as a result of the SCI research legislation passed in 2015.

Resulting from that funding was a study on an epidural stimulator spinal implant being used to return function and reduce pain in SCIs. The results were encouraging and motivated a neurosurgeon to implant SCIs beyond the study. Long approved by the FDA for pain management in the general populace, the epidural stimulator was able to be repurposed for recovering function in SCIs, because MN made available more robust and competitive funding.

February 16th of this year I received the implant. The procedure was difficult to undergo and even more so because I had to stay at a hotel in an unfamiliar place for a week. Between the medical procedure and my stay in MN the cost was well over \$65,000. I am not the only one either having had to travel far and spend money. The implant has been placed in 45 people from all over the country and a few international SCIs have made the trip. Between Abbott providing the stimulators, a surgeon branching off to open her own clinic, and a 5 or more day stay for the procedure, profit was drawn to MN and the business industry. No offense to MN, but I would have preferred to spend my money and stay in my own state.

The other two aspects in all of this that should be considered is by making recovery happen faster, and/or finding a cure, the cost to the state of WI for long-term care will decrease. The state spends over half a billion per year on SCI residents, because SCIs are costly to have since it affects both the autonomic & peripheral nervous system. The second aspect is the translation of developing SCI treatments and cures to other



**DATE: March 16, 2023**

**TO: Members of the Assembly Committee on Colleges and Universities**

**FROM: John Martinson**

**RE: Support for Assembly Bill 19**

Chairman Murphy and Members of the Committee on Colleges and Universities, Welcome to my WORLD.

LUCK; I'd like to tell you about how my spinal cord injury came about. Growing up on a farm in Wisconsin my family grew tobacco which involves a lot of manual labor and risk, especially hanging the tobacco in drying sheds. Being the oldest boy, my job was being up in the air straddling two poles beneath my feet while hanging laths of tobacco.

Another risky job that I did was being an ironworker all over this great state of Wisconsin. I worked on the Green Bay Packers practice facility which is sixty-five feet to the peak, the bonus was that I had a bird's eye view of the Packers practicing in the field next to me.

Being an avid deer hunter, I was always climbing trees for a better view and advantage point while hunting and never got hurt, unlike five of my new friends who fell while being up in a tree stand.

Don't get me started on my Harley riding experiences.

My luck ran out on June 17<sup>th</sup>, 2002 while working in my shop at home. I was spray painting the ceiling when I had to close the overhead door to spray the peak. It was really hot that day, I was in a hurry, I had a mask on but, it wasn't a respirator, I was really susceptible to the solvent in the paint and passed out and fell twelve feet injuring my spinal cord at the thoracic eight level (just below my nipples).

Now a wheelchair is my expensive shoes. More expensive than Air-Jordan shoes which can cost around \$200 - \$400, mine runs around \$3000 unlike my colleague Mike Mohr's shoes which cost \$25,000 or more! I call Mike's power wheelchair, Air-Mohr shoes.

I wouldn't wish a spinal cord injury or disease on my worst enemy, I've seen and experienced all the mental and physical pain that it inflicts on everyday people and their families.

Please support AB 19 before more peoples LUCK runs out!

Thanks

neurologic conditions like multiple sclerosis, Parkinson's disease, and stroke. Solving the most complex issue like an SCI has the potential to make long-term existence and aging better.

I am eager to see what my epidural stimulator will bring me over the next year, but what I am seeing even without precise programming being done yet has encouraged my expectation. My hope is that WI can be a contributor to bettering the future with its promising research, as MN, and maybe even more so. I thank the committee for taking time to hear and read support for this legislation. Please give my community a lifeline to hope for a better quality of life.

**DATE: March 16, 2023**

**TO: Members of the Assembly Committee on Colleges and Universities**

**FROM: Robert Kozarek**

**RE: Testimony on Assembly Bill 19**

Chairman Murphy and Members of the Committee:

Good morning, my name is Robert Kozarek, I am a Commercialization and Innovation Analyst at UW Health and I come before you in support of AB 19.

I am fortunate enough to have participated in the eStand trial based in Minneapolis, Minnesota. eStand, as you have heard today, is a research project centered around the implantation of epidural stimulators in spinal cord injury patients with the goal of improving function. Here, 'function' can mean many things just as 'success' can mean many things to this population. In my case, both 'function' and 'success' were intertwined in my goal of improving autonomic function – bowel, bladder, blood pressure, etc. For others, however, this research has given them the ability to be more independent in their care, the ability to mitigate health issues before they take root, or even the possibility to restore function. All of these things were considered impossible just a few years ago, but with the advancement of this research and research like it across the United States, the promise of medical innovation to address spinal cord injury and the issues associated with it has never been stronger.

My work with UW and the University Hospital puts me in direct contact with cutting-edge medical technology that has the ability to change the face of healthcare today. These institutions and the many research institutions in Wisconsin have earned the state its reputation as a leader in healthcare innovation and advancement. The bill you see before you today aligns directly with this reputation and has the ability to affect countless lives of those living with a disability as well as those who may be affected in the future.

Empowering Wisconsin with the tools to drive medical innovation opens the door to the possibility to drive positive economic change in the state. States that have approved similar funding have seen upticks in both businesses that have spun out of that research and jobs that further drive that innovation to commerciality. Sponsorships from larger medical device manufacturers result from the successes derived from this funding. And most importantly, Wisconsin residents would benefit from this in a

meaningful way. No longer would Wisconsinites need to look beyond state lines to find a way to take part in these life-changing studies. This funding creates an ecosystem that sustains, promotes, and drives an economy that is currently missing in Wisconsin.

Interest for AB 19 extends well beyond that of patients as the potential economic benefit from the work bill will generate is extensive. Improving health in the population will reduce the economic burden for patients, increase efficient hospital resource allocation, and reduce government cost expenditure that is often necessary with treatment within this population.

The benefits of approving this bill far outweigh the costs. For every dollar invested in research toward improving the health and wellbeing of this population, the cost relief for downstream effects increases exponentially. I would once again like to reiterate my support for this bill and encourage you all to approve this as an investment in a population of underrepresented people, medical advancement, and the State of Wisconsin.



## Economic Impact Summary

U2FP's Cure Advocacy Network

The Cure Advocacy Network (CAN) has directly supported SCI research by establishing state-level, competitive medical research grant programs. Since 2015, four programs have been established. In order of passing, they are Minnesota, Washington, Ohio and Pennsylvania. By the end 2022, it will have invested \$25 million supporting 45 research projects, a third of which are in or moving to human clinical studies.

This document is composed of responses from about 30% of the researchers funded through the CAN initiatives. These initiatives support the local research economy by leveraging moderate state funding to secure more significant federal funding. It creates jobs and research positions and spurs business startups, but the most significant impact is that it is bringing recovery of function to the SCI community.

### Private Business Startups:

Anatomic (MN-Dutton) <https://www.anatomic.tech/>  
StimSherpa (MN-Darrow et al) <https://stimsherpa.com/>  
NervGen Pharma (OH-Silver) <https://www.nervgen.com/>

### Examples of Additional Federal Grants Since CAN Funding:

2.2 Million in State to 17.4 Million in Fed (1:8 leverage among researchers responding to survey...pending more respondents)

\$800,000 state to 1.9 Million DOD (WA-Moritz)  
\$250,000 state to 3.7 Million NIH (MN-Ebner 2018)  
\$996,000 state to 7 Million NIH (pending Fed. Cont. Res.) (OH-Kilgore)  
\$45,000 state to 2.3 Million NIH (MN-Dougherty)  
\$151,000 state to 2.5 Million NIH and DOD (MN-Parr) over 5 years

### Additional Private and Matching Grants:

\$740K (WA- Moritz)  
\$600K in device investment (OH-Kilgore)  
\$300K (MN-Dougherty)  
\$375K (MN-Ann Parr) Spinal Cord Society (private foundation) Matched the state funds for Ann Parr.

### **Industry Partnerships:**

- Onward sponsored, single-site clinical trial (WA-Moritz) provided the proof of concept for large multi center clinical trial testing transcutaneous stimulation for upper extremity function in chronic SCI
- Abbott provided device donations to the EStand Trial (MN-Darrow) approximately \$4.2 million (in kind donation of 100 estim devices committed...20 utilized to date = a little over \$840,000).
- NervGen preclinical work (OH-Silver) using the Intracellular Sigma Peptide (NVG291) now being tested in Phase 1 human study and Phase 2 (2023) in humans with chronic SCI, MS and Alzheimers
- Abilitech (Conley MN) funded human study in the development of upper extremity device to improve hand function in chronic SCI

### **Positions Created:**

- 21 person per years from initial bill and subsequent funding (WA-Moritz)
- 3 Full time positions created (MN-Dutton)
- 8 Full time positions, 5 more pending (OH-Kilgore)
- 2 person per years (MN-Dougherty)
- 2 positions per year (MN-Parr)

### **Outcomes for Unmet Human Need:**

- 12 current participants and 10 more enrolled, functional recovery of grasp (WA-Moritz)  
<https://www.youtube.com/watch?v=iuqv3Tu5CpY>
- 20 patients implanted for e-stand (MN-Parr/Darrow/Samadani)  
<https://www.frontiersin.org/articles/10.3389/fnsys.2020.00035/full>  
Media:<https://www.ctvnews.ca/mobile/health/paralyzed-canadian-says-experimental-spinal-stimulator-improves-quality-of-life-1.4741128>
- 24 patients implanted clinically (Samadani in clinic...20 covered by insurance)  
Media:<https://www.kare11.com/article/news/local/kare11-sunrise/suni-lee-father-veterans-affairs-clinical-trial-minneapolis/89-75815a03-75f5-49ae-9191-ff4e62c66dc8>
- 3 patients implanted (Mayo Clinic- Zhao/Grahn)  
Media:<https://www.webmd.com/brain/news/20180924/spinal-implant-could-be-breakthrough-in-paralysis>
- 10 patients treated with autologous (from the patient) MSC's (mesenchymal stem cells)  
Media:<https://www.goodmorningamerica.com/wellness/story/man-paralyzed-neck-walks-medical-innovation-67335606>

**\*important to note that all of the above are in individuals with a chronic injury**

### **Some Areas of SCI Research Supported:**

- Neuromodulation: Transcutaneous / Epidural Stimulation: (WA-Moritz), Samadani/Darrow/Parr (U of MN), and Grahn/Zhao (Mayo Clinic) Lavrov (Mayo Clinic)
- Stem Cells: (MN-Dutton) Mohamad Bydon (Mayo Clinic) Michael Lane (PA-Drexel) Ying (PA-Drexel)
- Stem Cell/Scaffold: Parr (U of MN) Windebank (Mayo Clinic)
- Neuroprosthesis: (OH-Kilgore) Ying (PA-Drexel)

- Sex Hormones and Neuroplasticity: (U of MN-Dougherty)
- Genetic Reprogramming: Low (U of MN) Qiang (PA-Drexel)
- Gut Biome: and relationship to neuroinflammation post injury(OH-McTigue/Popovich)
- Factors/Proteins: Silver (OH-Case Western Reserve) Lee (OH-Cleveland Clinic)
- Respiratory Function: Bezdudnaya (PA- Drexel)
- Engineering/Device: Scheerer (OH-Case Western Reserve) Bourbeau (OH- Case Western Reserve)
- Sexual Function: Coolen (OH- Kent State)
- Neuropathic Pain: Van De Winckel (U of MN)

### Quotes from Researchers:

*"The research pathway is a single chain of events that requires funding at each stage. If funding is not available, research stops and, in some cases, never recovers. In our particular case, the funding from the State of Ohio SCI program filled a key gap at a critical time in our research pathway. It was an absolutely critical link in the chain, without which our research would have stopped. Specifically, in our case, the funding was used to directly demonstrate to our commercial manufacturer that we had the resources to purchase devices for our clinical study. This convinced them to make their own investment in the project and allowed us to continue. This turned out to be absolutely necessary in the midst of the pandemic and our research pathway would have come to a halt without the funding"*

**Kevin Kilgore, PhD,**

Case Western Reserve University and MetroHealth System

*"Though the funding amount was modest, the timing of the award was CRITICAL in establishing our laboratory research program and it allowed me the freedom to support a graduate student to assist with the collection of preliminary data. These data were utilized to obtain our lab's first major research funding from the Craig H. Neilsen Foundation."*

**Brendan Dougherty, PT, PhD**

University of Minnesota Medical School

Department of Rehabilitation Medicine

Divisions of Physical Therapy and Rehabilitation Science

*"The State of Ohio Third Frontier funding has helped accelerate the development of neurotechnology and assistive devices for those living with SCI in Central Ohio. Funding has led to several improvements in the NeuroLife technology platform and supported several researchers based at Ohio State and Battelle to pursue solutions for the SCI community. This research will be a springboard for bringing in both federal and private funding to continue the development and commercialization of technology to improve hand function in the SCI community."*

**David Friedenber, PhD**

Battelle Memorial Institute · Division of Health and Analytics

Statistics Ph.D. Carnegie Mellon University

# Wisconsin Spinal Cord Injury Research Grant Act

## Problem:

- 10,500 residents of Wisconsin live with spinal cord injuries (SCI).
- Research spending in this field has primarily been for continuing care and rehab, not for strategies to deliver functional improvement. Considering the enormous costs of care for those living with SCI, these priorities are out of alignment.

## Context:

- Lifetime costs of care for an individual with SCI range from \$1.5 to \$4.6 million.
- Total annual cost of caring for people with SCI in Wisconsin is approx. \$350 million.
- The National Institutes of Health fund only approximately 15% of all applications in this field, leaving many promising inquiries unfunded or underfunded.

## Goal:

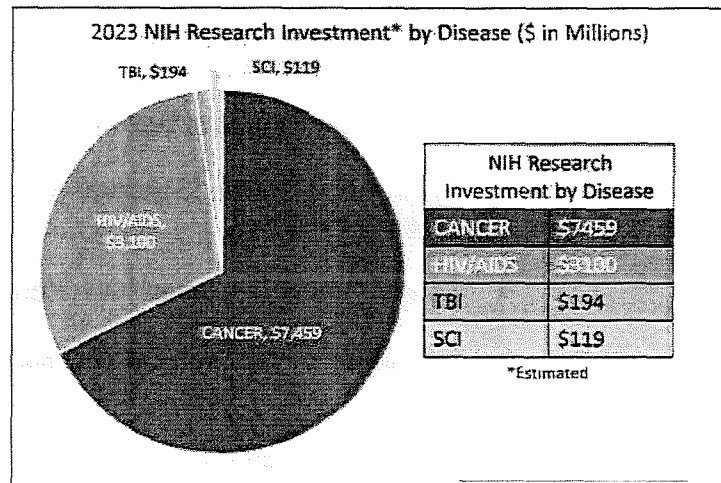
- Accelerate and Deliver therapies that enable functional improvement of breathing, bowel, bladder, sexual, and sensorimotor functions of Wisconsin residents living with SCI.
- Establish a collaborative advisory board consisting of WI residents living with SCI, family members of those living with SCI, researchers, and clinicians with expertise in the field to prioritize and recommend funding for research projects.

## Request:

- **\$3 million appropriation** from the state budget. Funds would go to two categories of expenditures:
  - **Seed money for innovative research** available to any Wisconsin institutions conducting research into device, pharmacologic, biologic, and rehabilitation strategies and techniques.
  - **Push innovation forward**—from lab to clinical trial to industry.

## Projected benefits:

- By moving the research to the clinic, WI would see an enormous **reduction in the costs of care**. Any improvement to the consequences of these injuries such as recovery of breathing/bowel/bladder/sexual function and mobility would additionally have a significant impact upon quality-of-life and employability.
- Attract neuroscientists and researchers to Wisconsin's biomedical engineering industry.
- Catalyze biotech spin-offs.



For more information, please contact Matthew Rodreick at 612-834-5472 or [matthewrodreick@unite2fightparalysis.org](mailto:matthewrodreick@unite2fightparalysis.org)

Led by: Unite 2 Fight Paralysis

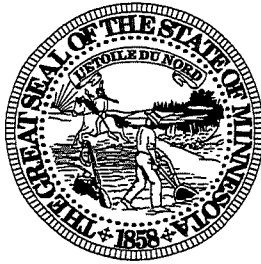
Supported by: Quest For Cures, Get Up Stand Up 2 Cure Paralysis Foundation, Canadian and American Spinal Research Organization, Spinal Cord Society

Citations for information at [u2fp.org/get-involved/resources.html](http://u2fp.org/get-involved/resources.html)



Rod Hamilton  
State Representative

District 22/B



# Minnesota House of Representatives

May, 2021

Dear Colleagues,

I'm writing to share my enthusiastic support for the Unite 2 Fight Paralysis' led initiative to locally fund Spinal Cord Injury research and treatment innovations. I was the House author/sponsor of the \$1 million appropriation that established the Minnesota SCI/TBI Research Grant Program in 2015. And due to its initial successes I supported the subsequent increase to \$6 million in 2017, recommended by the Committees on Higher Education in both the House and Senate.

As a person living with a neurodegenerative disease I am empathetic to both the profound impact injuries such as these have on the lives of our citizens as well as the complexities inherent to the research enterprise. The programmatic elements that these community advocates have crafted to address these complexities are why the program has been so successful in Minnesota, such as:

- Establishing an advisory board consisting of both clinical and research experts **as well as individuals who live with the injury**
- A competitive fund that seeks to invest in the best research as well as research that is **moving towards clinical implementation**
- Giving preference to research seeking to **change the nature and course of the injury** above conventional adaptations

The program here in Minnesota has led to groundbreaking projects that are now leading the nation. We have funded a number of human clinical trials that have involved collaborations across institutions and partnerships with industry.

I am excited for the days ahead when we will see not just breakthroughs in the research but treatments that begin to ameliorate the profound and debilitating effects of paralysis.

I hope you will consider supporting this initiative in your state and bring momentum to the catalyzing effect that has already begun.

If you have any questions or would like to discuss, please contact me.

Respectfully,

A handwritten signature in black ink, appearing to read "Rod Hamilton".

State Representative Rod Hamilton  
House District 22B

Nancy Nicholas  
19704 192<sup>nd</sup> Ave. NE.  
Woodinville, WA 98077

March 16, 2023

RE: AB 19

Dear Representative Murphy,

Thank you so much for giving AB 19 a hearing!

I'm a mother of 3 active boys and in 2013 while mountain biking with them, I sustained a spinal cord injury (SCI) in a crash. I suddenly went from career woman, busy mom, and wife who took care of everyone to needing to ask others for help from morning until night. I had to learn how to navigate the world in a wheelchair and adapt to a whole new world of challenges.

I serve as the SCI Community Liaison in the Blackmore lab at Marquette University. In that role, I represent the lived experience of individuals with spinal cord injuries in the research process. Dr. Murray Blackmore and his team are searching for gene therapies that could allow regrowth of the injured spinal cord. This exciting work in combination with physical rehabilitation could allow those of us living with this debilitating condition to regain function and live longer, healthier, happier, and more productive lives.

There is no current treatment for spinal cord injury. This bill provides a mechanism to fund promising research and provide hope of a better life for those of us with the condition. It also includes the ability to have our voices heard in the direction of research to assure that we are meeting the needs of the community. The symposia aspect of the bill encourages information sharing and collaboration as researchers investigate different approaches to finding treatments for this complex condition.

Thanks again for giving us a chance to be heard and for keeping Wisconsin at the forefront of research and hope.

Best regards,  
Nancy Nicholas

March 16, 2023

Re: Letter of Support for Assembly Bill 19

To whom it may concern,

I'm writing to you today from multiple different positions and encouraging you to pass the Assembly Bill 19 for Spinal Cord Injury Research in the state of Wisconsin. First, I am a C5 quadriplegic and obviously a member of the spinal cord injured community here in Wisconsin. Second, I am part owner of R&R Insurance which employs over 200 individuals and is one of the largest independently owned insurance agencies in the state. Third, I am also president of the Bryon Riesch Paralysis Foundation where I have helped raise over \$7 million to date to fund the latest in medical research and to provide assistance to those that suffer from neurological disorders.

In 1998 as a freshman at Marquette University I dove on a slip and slide where I hit my chin. It threw my head back, causing immediate paralysis from my chest down. In a matter of an instant, I went from an independent student with a bright future to a scared 19-year-old kid dependent on individuals to help with the simplest of tasks. No matter how determined I was or how much therapy I did from that point in my life I would be spending it in a wheelchair.

Through my course of 25 years of being in a chair I have definitely had my ups and downs. The injury itself goes far beyond just the lack of mobility. I at times suffer from debilitating nerve pain where my skin feels like it's burning. I have frequent urinary tract infections and have had multiple pressure sores and other related health issues that I've had to battle with. Unequivocally though, the toughest part of being injured is the mental burden it places on the individual day in and day out. The truth of the matter is that it doesn't only affect the individual that is injured either, it greatly impacts their family, friends and community as well.

The costs associated with taking care of individuals such as myself can also be astronomical. This includes not only frequent doctors visits, but aids to help take care of them and the equipment necessary to make them as independent as possible. Most individuals have no choice but to be on Medicaid and other state assistance. It obviously places a heavy burden on the taxpayer.

There truly is hope though! Being president of the Bryon Riesch Paralysis Foundation and supporting such institutions as the Medical College of Wisconsin and Marquette University I have seen progress being made. If we could simply continue to foster and encourage the research I truly believe we can make huge strides in overcoming many of the burdens that paralysis currently provides. Even the slightest cure or increase in movement can have a profound effect on the individual suffering from paralysis and the community as a whole.

The solution being put forward in Assembly Bill 19 has a proven track record in other states and can have a significant impact in Wisconsin with the resources we have already in place. It's not just the money that is important, but the bill provides a structure to direct the money to the best translational research for functional recovery through a competitive grant process. It has the ability to make Wisconsin one of the leaders in spinal cord injury research leading to increased innovation, possible business startups and hopefully an eventual cure.

Sincerely,



Bryon Riesch  
President  
Bryon Riesch Paralysis Foundation

Dear Members of the Committee of Colleges and Universities,

I am writing this letter in support of passage of the Assembly Bill 19. As a member of the spinal cord injury community, I feel strongly that funds need to be allocated for more research into this devastating injury that has major effects on so many people.

I myself was injured in a skiing accident in 2001 which caused damage to my spinal cord in the region of C4-6. While I did recover from the initial paralysis and functioned well for many years, I find myself now at age 75 with inability to walk without assistance and have difficulties with the activities of daily living and will soon need a power chair.

Research funds are valuable tools to encourage and support SCI research. Having DHS create a council to oversee the evaluation and award grants gives weight to the process and allows for a transparent process. In addition, we feel that having a symposia would be a terrific idea. Families and individuals involved with SCI are keenly interested in current research.

This should be a bipartisan effort as individuals across the state are aware of the damage of a spinal cord injury. We look forward to the passage of the bill in the near future,

Sincerely,

Craig Wehrle  
4886 Spinach Dr  
Fitchburg, WI 53711

**Date: March 16, 2023**

**To: The Members of the Assembly Committee on Colleges and Universities**

**From: David L. Messling**

**Re: Letter of Support for Assembly Bill 19**

Friday, November 4th, 2016, the day I started living a nightmare, the one where I can no longer control over three fourths of my body, the one where I put my family through a nightmare of their own, the one where I became a C5 quadriplegic. A 4-wheeler accident left me waiting to be rescued in the ravine for two hours. I was laying face down in the leaves and knew I was paralyzed. I could not move and all I could feel was extreme pain in my shoulders. My brother was there telling me "Everything will be okay because you can wiggle your toes". But I knew it was not okay, I could not feel anything and I could not move anything.

While I was laying there waiting to be airlifted to Gunderson Hospital in LaCrosse, I called my wife while she was working and told her I was really hurt. She picked up our daughters aged 12 and 18 to meet me at the Neuro ICU.

The following two hours I had my whole life flashing through my mind, all of the things I wish I could have done or changed and all the things I would no longer be able to do, but I did not know the half of it yet. When the rescue team finally arrived, I was crammed into a medflight helicopter with two paramedics. I remember arriving at the hospital, but the next few days were just a blur.

I spent 11 days at Gundersen Hospital with extraordinary and compassionate care by the nursing staff and the doctors. Next, I spent roughly five weeks at UW Rehab hospital in Madison. The focus of rehab was to build up my strength, learn a new life routine, and get strong enough to go home. It wasn't as easy as it sounds. Each day I needed to be lifted by a sling and a hoist lift, but many days the doctors had me on too many laxatives and that combined with no bowel control, I crapped my pants and missed my therapy time and would have to wait for the next day and hope it would not happen again. You could say I was discouraged; I'd say that's an understatement.

Six weeks after my accident I went home to my renovated house with widened doorways to fit my power wheelchair, a hospital-esque room where my wife and I's bedroom used to be, and a completely revamped bathroom to fit a commode and wheelchair shower. I had a nurse stopping by our house two times per week. I wish someone

would have suggested more rehab or a rehab facility better suited for newly paralyzed individuals where I could have learned more skills or received more help for recovery. I tried physical therapy at our local hospital but they are not equipped or knowledgeable about paralyzed individuals.

In the days following my accident I didn't know if I was going to live, or if I would die. But I did wish that I would die because of all the problems I would be causing my family. Just knowing how much it was going to change everyone else's life and worrying about my wife and two daughters and how it would affect them as well. It is still changing our lives every day. There is the personal pain of seeing your daughters and wife crying all the time and having to go to counseling. Myself, my wife, and my daughters have started taking some sort of medication to help us deal with depression and anxiety. I should be caring for my children, not having them care for me at this time in my life. I truly miss playing basketball with my daughter, rebounding for her, walking with her and just spending that special sport/bonding time with her. One of my special joys was coaching basketball and playing ball with them. This has been very difficult for me. I have not been able to teach her how to drive either. There is just so much that is different.

Some of my personal losses include: not being able to control my bowel and bladder, no movement or feeling of my body below the breast line, loss of use of my hands, loss use of triceps, no feeling on the back of my hands, not being able to travel and stay anywhere (hotels/motels are not accommodating to hooyer lifts and other accessibility issues), I had to stop working at the age of 56 (no income for the family from work), and my wife retired 3 years early to be my primary caregiver. Additionally, it is extremely difficult to find and retain caregivers, even through agencies. Not to mention, caregivers are very expensive, especially through agencies.

Here are the numerous surgeries and infections I have had since being injured 5 years ago:

1. Cervical fusion just a few days after injury
2. Baclofen pump implant due to the spasticity one has from being paralyzed. This allows medication to be directly delivered to the spinal column to stop spasms.
3. Permanent suprapubic catheter placed below the belly button directly into my bladder. This allows one to have an indwelling catheter in the bladder that is changed once a month instead of inserting a catheter into my urethra every 4 hour.
4. Colostomy surgery due to a perforation in my colon. This was a reversible loop

colostomy hoping for healing.

5. More colostomy surgery. This was a permanent colostomy to remove the descending colon due to a complicated infection and no healing

6. Colorectal fistula infection / tailbone removed right after permanent colostomy leading to a surgical opening of my backside. Osteomyelitis was detected in my tailbone at this time and multiple antibiotics were needed as well as infectious disease doctor required to help with this type of infection

7. Rectum removed and flap surgery required to completely heal the previous surgery after the infection cleared. Once this surgery was complete, I had to stay in bed for 12 weeks, gradually increasing the elevation of the head of the bed over 12 weeks so there was little to no pressure on my bottom.

8. Multiple UTIs treated with various antibiotics

9. Hospitalized with Cellulitis which caused me to become septic

10. Pressure sores on heels that required vacuum pump to heal

11. I now require bilevel positive air pressure ventilation (BiPap) to assist my breathing as well as a machine that allows me to cough because about half of the muscles in my lungs and my diaphragm no longer work.

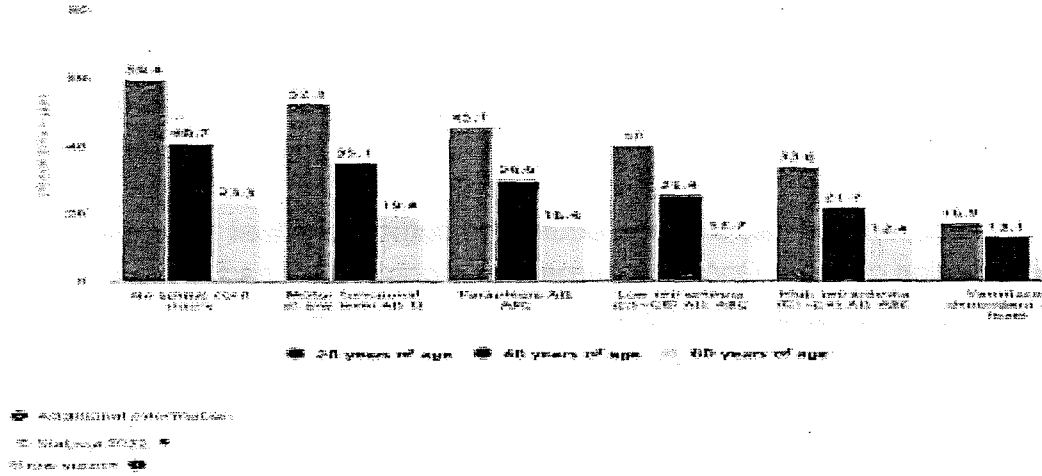
The lifespan of an individual with a spinal cord injury is shortened according to Frederic Michas March 20, 2020

**Life expectancy for post-one year spinal cord injury survivors 2019**

Published by [www.spinalcord.com](http://www.spinalcord.com), Mar 20, 2020

This statistic shows the life expectancy for spinal cord injuries in the U.S. for those who survived at least one year post-injury, as of 2019. The life expectancy for a person aged 20 years who suffers a high tetraplegia spinal injury and survives at least one year is around 34.6 years.

**Life expectancy for spinal cord injuries in the U.S. for those who survive at least one year post-injury as of 2019, by age and severity**



I would like to thank the Assembly of the Colleges and University for your time and your consideration of Bill 19.

Sincerely,  
David L. Messling



**DATE: March 16, 2023**

**TO: Members of the Assembly Committee on College and Universities**

**FROM: Marshall Begel**

**RE: Support for Assembly Bill 19**

Chairman Murphy,

It's true that most people's lives do not turn out as they planned. But almost nothing will take a shredder to your plans like a cervical spinal cord injury, and then, for decades, make you watch. Losing the ability to drive a car, to visit friends in their homes, be financially independent, experience intimacy, to have children, to create art with your hands – losing any one of these is life-changing. Losing all of them in an instant is devastating.

I'm 51 now, and have spent 25 years as a C5 quadriplegic. Though much is lost, much is left. I enjoy my job, love my wife, and spend personal time playing video games, working on small inventions, and reading science fiction. Still, I hold precious the memories of backcountry hikes, hand-kneading bread dough, and playing horn in a not-very-good klezmer band.

I see recently injured people, and I feel for them – and for those who will end up in a wheelchair and can't know it yet. I know what they will have lost, and what they face. But I also see better times ahead.

I have seen technology improvements that improved accessibility. Speech-to-Text is now mainstream, and the voice-activated smart home is no longer cost prohibitive. Expanded communication tech gives greater social access to those who have to spend so many hours a day stuck in bed. While small, each bit of adaptation means more time to be productive, more independence, more dignity, better mental health.

And these are just incidental benefits to mainstream tech advances. Now imagine the effect of technology development targeted to the needs of those with SCI. Seating improvements to allow more up-time with lower skin breakdown risk? Devices to shorten our long care routines? Biomedical advances that limit infections, heal wounds, or allow a regain of function? Even the small steps are worthwhile to us. Does it mean a problem of adjusting to increased time, better health, and more physical capabilities? Now that's a good problem to have!

Sincerely,

Marshall Begel

489 Togstad Glenn

Madison, WI 53711

608-338-1825, mbegel@lycos.com



**TO:** Honorable Members of the Assembly Committee on Colleges and Universities

**FROM:** Benjamin Wagner  
*Chair, Neuroscience Research Center Board  
Medical College of Wisconsin Neuroscience Research Center*

Cecilia J. Hillard, PhD  
*G. Frederick Kasten, Jr Chair in Parkinson's Research  
Professor of Pharmacology and Toxicology  
Director of the Neuroscience Research Center  
Associate Dean for Research  
Medical College of Wisconsin*

**DATE:** March 16, 2023

**RE:** Please Support 2023 Wisconsin Assembly Bill 19, Related to Spinal Cord Injury Research Grants and Symposia

---

The Neuroscience Research Center Board is a community, faculty and staff-led advisory board whose mission is to support the Medical College of Wisconsin's (MCW) Neuroscience Research Center (NRC), as well as the newly founded MCW Neuroscience Institute (NSI). The Board's purpose also includes advancing the NRC and NSI, serving as ambassadors in the community to educate and advocate for the NRC and NSI's respective missions.

The MCW NRC's goals are to enhance basic and translational neuroscience at MCW through the development of an MCW-wide programmatic plan for neuroscience research. MCW's NSI was formed to further research and advance treating neurological disorders. Many neuro-related disciplines, including spinal cord injury research and treatment, are housed within the NRC and NSI.

The membership of the Neuroscience Research Center Board support 2023 Wisconsin Assembly Bill 19, which will create spinal cord injury (SCI) research grants and symposia. The design of this initiative has a track record of success and effectiveness, modeled on the programs instituted in Minnesota, Ohio, Pennsylvania, and Washington. Simply put, the SCI Research Program acknowledges the severe quality of life burden carried by those living with SCI, acknowledges the disproportionate funding to this area of research compared to its prevalence in the population and is designed to address specific funding gaps towards the translation of discoveries to human relevance.

No one chooses spinal cord injury. Approximately 10,500 Wisconsinites are affected by SCI and, unfortunately, that number continues to grow. What SCI looks like under the surface is severe neuropathic pain, the loss of bowel, bladder and sexual function, the loss of temperature

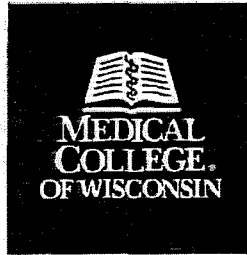
and blood pressure regulation, breathing, and voluntary movement. In many cases it brings with it severe depression, a shortened lifespan and an impaired ability to fully engage with family, friends, and employment opportunities.

Fortunately, programs such as the one Senator Wanggaard and Representative Tittl are proposing to fund, are helping to alleviate the burden of SCI. Technology and innovative research are on the cusp of major breakthroughs, catalyzed by public investment. This program's effectiveness relies on a few key features:

- Research grants remain in the state and are competitive among researchers, institutions, and businesses.
- Research grants target innovation in the translation of deliverable therapies to those who live with the injury
- The program mandates a low indirect cost rate of 8% so that taxpayer dollars go directly to the work and not general administrative funds.
- The program implements a state advisory council composed of researchers, clinicians and most importantly, those living with spinal cord injury, to recommend which research projects should be funded.

The Board is fully in support of this program. It is a judicious use of public funds to help alleviate the quality of life burden born by those currently living with SCI and acts as an insurance policy for those yet to experience SCI. It is an opportunity to stimulate the biotechnology markets in Wisconsin. It is an opportunity to alleviate the taxpayer burden of support for the 65% of the SCI community that cannot work because of the condition. It will offer educational opportunities for students who choose SCI research as a career path. Lastly and importantly, this program is non-partisan and offers an opportunity to reach across the political aisle to affect the public good.

Thank you for your consideration of this impactful legislation, which will benefit Wisconsin's residents for generations to come. Please feel free to contact Nathan Berken, Interim Vice President of Government and Community Relations, at 414.955.8217, or [nberken@mcw.edu](mailto:nberken@mcw.edu), if you have additional questions or require additional information.



knowledge changing life

Merle R. Orr, MD  
Assistant Professor

Department of Physical  
Medicine and Rehabilitation

March 16, 2023

To Whom It May Concern,

I am writing this letter in support of Representative Tittl's proposed \$3 Million Spinal Cord Injury (SCI) Research Program. The design of this initiative has a track record of success and effectiveness, modeled on the programs instituted in Minnesota, Ohio, Pennsylvania, and Washington. Simply put, the SCI Research Program acknowledges the severe quality of life burden carried by those living with SCI, acknowledges the disproportionate funding to this area of research compared to its prevalence in the population and is designed to address specific funding gaps towards the translation of discoveries to human relevance.

No one chooses spinal cord injury. Approximately 10,500 Wisconsinites are affected by SCI and, unfortunately, that number continues to grow. What SCI looks like under the surface is severe neuropathic pain, the loss of bowel, bladder and sexual function, the loss of temperature and blood pressure regulation, breathing, and voluntary movement. In many cases it brings with it, severe depression, a shortened lifespan, and an impaired ability to fully engage with family, friends, and employment opportunities.

Fortunately, programs such as the one Representative Tittl is proposing to fund, are helping to alleviate the burden of SCI. Technology and innovative research are on the cusp of major breakthroughs, catalyzed by public investment. This program's effectiveness relies on a few key features:

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- The program implements a state advisory council composed of researchers, clinicians and most importantly, those living with spinal cord injury, to recommend which research projects should be funded.

HUB for Collaborative Medicine  
8701 Watertown Plank Road  
Milwaukee, Wisconsin 53226-0509  
Phone: (414) 955-1908  
Fax: (414) 955-0104  
Email: morr@mcw.edu



**MARQUETTE**  
UNIVERSITY

Re: Wisconsin Spinal injury Initiative  
To whom it may concern,

I'm writing this letter in support of Representative Tittl's proposed \$3 Million Spinal Cord Injury (SCI) Research Program. This initiative builds on the success of similar programs adopted by multiple other states including Minnesota, Ohio, Pennsylvania, and Washington and strives to make progress in developing novel strategies to improve life for individuals with SCI.

Roughly 10,500 Wisconsinites are affected by SCI. As a college student at UW-Whitewater I took care of disabled students and saw firsthand the devastating consequences of SCI. In addition to the lack of voluntary movement visible to bystanders, individuals with SCI often suffer other losses. A loss of independence. A loss of friends. A loss of a lifestyle. A loss of privacy. **It is through our research efforts that we can offer hope to these individuals.** The development and translation of innovative technology and therapies to improve motor output will lessen these losses and can have dramatic improvement on their quality of life. By restoring something as seemingly small as hand function, an individual may be able to live more independently. By restoring independent breathing individuals may be freed from a lifetime of mechanical ventilation.

As a researcher, these individuals motivate me to develop therapeutic strategies to improve their lives. Over half of all SCIs occur in the upper portion of the spinal cord and respiratory related deficits and complications are the leading cause of morbidity and mortality. Imagine the stress that comes with relying on a machine to breathe for you and the isolation of not being able to communicate like you once could. Our research is focused on designing strategies to strengthen the pathways to respiratory muscles and improve independent breathing. In addition, our lab contributes to developing young scientists and educating students. We currently have undergraduate, masters, and doctoral students learning how to develop scientific rationale and design and test experimental questions. These efforts rely on grant dollars and initiative like this one to continue to make strides towards our goals of improving the lives of individuals with SCI.

I offer my full support of this program.

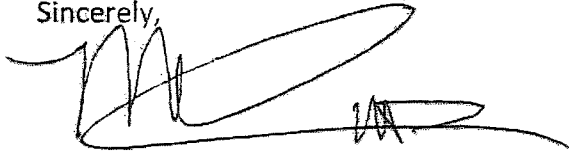
Sincerely,

Kristi A. Streeter, PhD  
Assistant Professor  
Department of Physical Therapy  
Marquette University  
[Kristi.streeter@marquette.edu](mailto:Kristi.streeter@marquette.edu)

I fully support this program. It is a judicious use of public funds to help alleviate the quality-of-life burden born by those currently living with SCI and acts as an insurance policy for those yet to experience SCI. It is an opportunity to stimulate the biotechnology markets in Wisconsin. It is an opportunity to alleviate the taxpayer burden of support for the 65% of the SCI community that cannot work because of the condition. It will offer educational opportunities for students who choose SCI research as a career path. Lastly and importantly, this program is non-partisan and offers an opportunity to reach across the political aisle to affect the public good.

Thank you in advance for your consideration.

Sincerely,

A handwritten signature in black ink, appearing to be 'M. Orr', written over a horizontal line.

Merle R. Orr, MD  
Assistant Professor  
Spinal Cord Injury Service Medical Director  
Department of Physical Medicine and Rehabilitation

Merle R. Orr, MD  
Assistant Professor  
Department of Physical Medicine and Rehabilitation  
8701 Watertown Plank Road  
Milwaukee, Wisconsin 53226-0509  
Phone: (414) 955-1908  
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**Boston Children's Hospital**

Where the world comes for answers



**HARVARD MEDICAL SCHOOL  
TEACHING HOSPITAL**

4 Austin Street  
Burlington, MA 01803

**Jason Biundo**

[jason.biundo@childrens.harvard.edu](mailto:jason.biundo@childrens.harvard.edu)

Cell: 781 – 915 – 9950

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March 16th, 2023

Dear Representative Murphy,

Thank you for getting a hearing scheduled for the AB 19 SCI Research Grant Bill in Wisconsin. I am writing as a representative of the SCI community and SCI research community, and I want to emphasize the importance of this Bill and the potential impact it could have.

Three years ago, I was a regular college student studying neuroscience and biology at the University of Massachusetts Amherst. I had just finished a summer research fellowship at Carnegie Mellon studying the disrupted movement after Parkinson's Disease.

On October 21st, 2019 my life was changed forever. I had a terrible accident while rock climbing and ended up falling over 30 feet directly onto my back. The fall shattered a section of my lower spine and left me initially completely paralyzed below the waist. I consider myself extremely lucky that the injury wasn't worse and will forever be thankful that I didn't injure my head and retained full control of my arms/hands.

Luckily, I had access to Spaulding Rehabilitation Hospital in Boston, one of the top rehabilitation hospitals in the country. Spaulding is partially funded by the SCI Model Systems program, which provides federal funding for hospitals specializing in SCI to do innovative research and provide top medical care for people living with spinal cord injury. With amazing support from friends and family, and lots of intense physical therapy at Spaulding, I have begun to regain movement in my legs and hope to walk again someday.

After leaving the hospital and completing many months of outpatient rehab, I was able to transition back to my life and college and still graduate on time with honors and two degrees. Given my neuroscience background, it was easy to transition my research focus from Parkinson's to spinal cord injury. I got a job working with Dr. Zhigang He, one of the top researchers in the SCI field, at Harvard Medical School/Boston Children's Hospital.

The research in the lab focuses on both finding ways to increase regeneration of the spinal cord after injury to promote functional recovery, and on understanding the structure and function of the spinal cord to find new targets for translatable therapies. My personal experience with SCI has already been a great help in both my own research and the lab in general. I am regularly able to provide personal anecdotes to give insights to my colleagues and can provide feedback to guide the direction of many projects in the labs towards more relevant outcomes. As I learn more about the SCI research field, I am becoming



**Boston Children's Hospital**

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**HARVARD MEDICAL SCHOOL  
TEACHING HOSPITAL**

4 Austin Street  
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**Jason Biundo**

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increasingly excited with the promising research being done and I am confident that with enough resources we will be able to move towards a promising treatment for paralysis.

In my spare time, I volunteer on several consumer advisory boards where people in the SCI community can provide feedback on research projects and commercial products designed for SCI. Structured much like the SCI Council outlined in the AB 19 Bill, these consumer advisory boards assemble a diverse group of representatives. I've personally seen these groups to be essential to making sure that the research and products will actually benefit the SCI community by using their collective personal experiences to provide recommendations to avoid hurdles that would otherwise limit progress.

While I have managed to become successful despite my injury, there are still so many invisible challenges that people with spinal cord injury have to face every day. Besides not being able to walk, there are many secondary complications that come with paralysis. A research study done by Dr. Kim Anderson at Case Western showed that the highest priority of recovery of people in the SCI community was bowel/bladder function, but very little research is focused in that area. Having a panel with a diverse group of people from the SCI field/community will help direct research funds to areas that will have the greatest impact.

Thank you for your time and support,

Jason Biundo

SCI Researcher at Boston Children's Hospital / Harvard Medical School





International Collaboration on Repair Discoveries, a research centre in the UBC Faculty of Medicine and VCH Research Institute  
March 16, 2023

To: Members of the Assembly Committee on Colleges and Universities

RE: Letter of Support for Assembly Bill 19

Chair Murphy and Members of the Colleges and Universities Committee,

I am writing in strong support of Bill 19 in my role as Professor and Director of one of the globally leading research centres in spinal cord injury at the University of British Columbia, Canada: ICORD. This centre has over 45 investigators (professors), >80 research staff and >160 graduate trainees spanning from engineering and neuroscience to acute surgical care and rehabilitation research.

A spinal cord injury is one of the most devastating traumas a person can sustain leading not only to paralysis which is visible to all, but also to loss of bowel, bladder and sexual function, pain, spasticity, blood pressure problems, infections, pneumonia, diabetes, depression, ulcers and many other health challenges. The personal sufferings are immense and the losses of opportunities in life immeasurable. Often, life expectancy is reduced by 1-2 decades. Unemployment and family break ups are common. It can't be overlooked that with 1.5 to 5 million dollars lifetime healthcare costs per person (depending on the level of injury) spinal cord injury is among the most expensive conditions burdening the healthcare system.

Supporting research towards finding better treatments and ultimately a cure for spinal cord injury is not only an imperative from a humanitarian point of view but it also strengthens the research infrastructure in your State of Wisconsin and makes the scientists more competitive to bring in further federal research dollars which create more jobs. We calculated that in our province British Columbia such provincial program (lead by Rick Hansen) lead to a 12-fold return on investment in the form of national and international grants. I cannot imagine that it will be much different in your State. Ultimately, these research dollars will greatly contribute to the search for cures that are bound to reduce the sufferings of this population. This in turn will result in a major health care savings for your State down the road, let alone the improved quality of life for these individuals.

Therefore, I urge you to give Assembly Bill 19 your support and make spinal cord injury "livable and curable" by making an appropriation for "spinal cord research grants and symposia".

Yours sincerely,

Wolfram Tetzlaff, MD, PhD  
Professor and Director ICORD  
(International Collaboration on Repair Discoveries)  
John and Penny Ryan British Columbia  
Leadership Chair in Spinal Cord Research  
University of British Columbia Departments  
of Zoology and Surgery  
phone 6046758848 | email: [tetzlaff@icord.org](mailto:tetzlaff@icord.org) | [www.icord.org](http://www.icord.org)

Making spinal cord injury preventable, livable, and curable

Blusson Spinal Cord Centre, 818 West 10<sup>th</sup> Avenue, Vancouver, BC Canada V6Z 1M9 | 604-675-8810 | [www.icord.org](http://www.icord.org)



**March 16, 2023**

To whom it may concern,

On behalf of the Christopher & Dana Reeve Foundation, I am pleased to support Representative Tittl's \$3 Million Spinal Cord Injury (SCI) Research Program. The design of this initiative has a track record of success and effectiveness, modeled on the programs instituted in Minnesota, Ohio, Pennsylvania, and Washington.

The SCI Research Program acknowledges the severe quality of life burden carried by those living with SCI, acknowledges the disproportionate funding to this area of research compared to its prevalence in the population and is designed to address specific funding gaps towards the translation of discoveries to human relevance.

No one chooses spinal cord injury. Approximately 10,500 Wisconsinites are affected by SCI and, unfortunately, that number continues to grow. Individuals living with SCI experience severe neuropathic pain, the loss of bowel, bladder and sexual function, the loss of temperature and blood pressure regulation, breathing, and voluntary movement. In many cases it brings with it severe depression, a shortened lifespan, and an impaired ability to fully engage with family, friends, and employment opportunities.

Fortunately, programs such as the one Representative Tittl is proposing to fund, will help alleviate the burden of SCI. Technology and innovative research are on the cusp of major breakthroughs, catalyzed by public investment. This program's effectiveness relies on a few key features:

- Research grants remain in the state and are competitive among researchers, institutions, and businesses.
- Research grants target innovation in the translation of deliverable therapies to those who live with the injury
- The program mandates a low indirect cost rate of 8% so that taxpayer dollars go directly to the work and not general administrative funds.
- The program implements a state advisory council composed of researchers, clinicians and most importantly, those living with spinal cord injury, to recommend which research projects should be funded.

The Reeve Foundation believe this is a judicious use of public funds to help alleviate the quality of life burden born by those currently living with SCI and acts as an insurance policy for those yet to experience SCI. It is an opportunity to stimulate the biotechnology markets in Wisconsin. It is an opportunity to alleviate the taxpayer burden of support for the 65% of the SCI community that cannot work because of the condition. It will also offer educational opportunities for students who choose SCI research as a

career path. Lastly and importantly, this program is non-partisan and offers an opportunity to reach across the political aisle to affect the public good.

Thank you for the opportunity to submit this letter of support. Please do not hesitate to reach out to me at 202-557-9146 or [kbeer@christopherreeve.org](mailto:kbeer@christopherreeve.org) with any questions or if you require additional information.

Sincerely,

A handwritten signature in black ink that reads "Kimberly Beer". The signature is written in a cursive, flowing style.

Kimberly Beer  
Director, Public Policy

Peter Nowell  
8008 Inistork Dive  
Dublin, OH 43017  
pnowell264@gmail.com  
Home: 614-408-0085  
Cell: 614-570-7870

March 16, 2023

Dear Representative Murphy

Thank you for scheduling a hearing for AB 19 for Spinal Cord Injury Research Grants in Wisconsin.

I am writing to share a little of our experience in Ohio with a similar bill.

In a nutshell the results of Ohio state funding for SCI Research have been a win for all concerned; the SCI Community, the academic community and near-term prospects for new high-tech jobs in the state.

I was injured in 2005 in Ohio and have been very involved with the group who lobbied to get funding here a few years ago. Our first round of funding of \$3 million supported 5 projects and the feedback and results were so positive another award of \$3 million was included in last year's state budget; this enabled a further six projects to be funded, one of which is a collaborative effort with the University of Wisconsin.

We love to support collaborative efforts; so much research in the past was done in silo's which slowed down the progress towards benefit for the SCI community.

The funding mechanism in Ohio is via the Third Frontier within the Department of Higher Education; this funding structure was implemented to support and encourage entrepreneurial businesses and the commercialization of new technology. The vision was never about charity, but a long-term goal to encourage new business which would improve the quality of life of the SCI community and lower the costs to the state **social** care budget.

The structure we have put in place for selection of projects to fund, requires the researchers to provide regular progress reports to the SCI community, and this has been educational all around. Not only have we as "users" had the privilege of learning about what's going on at the cutting edge of research, but the scientists have universally

thanked us for the real time feedback and occasional redirection we have been able to provide for their efforts. When it's our tax dollars in play it does no harm to hold their feet to the fire! The 8% cap on indirect costs ensures that funds are efficiently used for research rather than padding some university general fund (many universities have a standard indirect cost loading in excess of 50%).

You may have heard that an Ohio company NervGen announced in a press release recently that intends to test its spinal cord nerve regeneration drug NVG-291 in human clinical trials late last year. This is the culmination of 40 years research in Case Western Reserve University; the last couple years funded by an Ohio State grant. This a terrific example of how state funding can move the needle towards improved quality of those living with Spinal Cord Injuries, AND bring high paying tech jobs to the state.

The more states we can get on board the more we all benefit. The Mid-West is leading the charge on this initiative.

Thanks again for your support.

Peter Nowell  
Co-chair Ohio SCI Research Funding Review Committee

**DATE: March 16, 2023**

**TO: Members of the Assembly Committee on Colleges and Universities**

**FROM: M. Claudia Garofalo**

**RE: Letter of Support for Assembly Bill 19**

Chair Murphy and Members of the Colleges and Universities Committee,

I'm writing today as a person living with paralysis.

We need your help.

We need you to support Assembly Bill 19.

We need you to be a part of the change.

We need you to see a world where people with paralysis can once again live a quality life. We need you to be part of our world where every person has equal access to treatments restoring health and independence after SCI.

We need you to lead our community on a path toward responsible self-determination, self-care and independent living.

We cannot reach these goals without your help.

Thank you for your time and consideration. I ask for the committee to support AB 19 as we continue to move toward a cure.

Sincerely,

M. Claudia Garofalo

**DATE: March 16, 2023**

**TO: Members of the Assembly Committee on Colleges and Universities**

**FROM: Michael Uppenkamp**

**RE: Letter of Support for Assembly Bill 19**

Chair Murphy,

Thank you for pulling for the WI SCI Research Grant Bill AB 19. Although I am not a resident of Wisconsin, I am grateful that you have supported the bold move to get funding for research to help support SCI persons.

I am passionate in this movement since my son was injured in a mountain bike accident on Aug 5, 2019, that put him in a wheelchair at age 19. Although this was a "Hard Right Turn" for my family, we have all been giving this gift to help others. Here is Alex's story (donations have been closed) <https://www.gofundme.com/alex-uppenkamp-recovery-fund>.

Thank you, Chair Murphy, for helping others.

Sincerely,  
Michael Uppenkamp

**DATE: March 16, 2023**

**TO: Members of the Assembly Committee on Colleges and Universities**

**FROM: Sharon Drennan**

**RE: Letter of Support for Assembly Bill 19**

Chair Murphy and members of the Colleges and Universities Committee,

On behalf of myself, my son, Rob, and the entire SCI community, we thank you for your time and commitment to this hearing. Twelve years ago, my son was an active 14-year-old middle school student playing sports and running through our neighborhood with his group of friends. We knew he was born with a vascular condition, but it went under diagnosed until we realized it was eroding his spinal cord. Surgery to correct what was happening to his spine left him a paraplegic. I can't begin to tell you the nightmare our family endured when this unexpected tragedy rocked our lives. Our world was turned upside down and has never returned to those simpler days.

My son is now 26 years old and lives as independently as he possibly can. Although we have support from family and friends, the last 12 years have been more than difficult. Enduring a spinal cord injury and the immediate rehab that comes with that is only the tip of the iceberg. The setbacks over the years have included numerous hospitalizations due to infections and pressure wounds, bone atrophy, the humiliation that comes with random bowel and bladder accidents, and most importantly to Rob, the loss of sexual function. No man or woman should have to live with this cruelty.

Over the years we have seen so much hope and promise in scientific and medical research that could potentially restore function for hundreds of thousands of individuals. We are so close to finding a cure, but we are a community that has historically been underfunded and that needs to change. Those living with spinal cord injuries not only deserve this funding but also a seat at the table where they can share their lived experiences and weigh in on the prioritization of ongoing research.

I dream of the day my son will have a return of function bringing him the dignity and daily pleasures of a lifestyle so many of us take for granted.

Thank you for your time and consideration. I ask for the committee to support AB 19 as we continue to move toward a cure.

Sincerely,  
Sharon Drennan