



Van H. Wanggaard

Wisconsin State Senator

March 1, 2023

Testimony on Senate Bill 27

Good Morning. Thank you Chairwoman Cabral-Guevara and committee members, for allowing me to testify on Senate Bill 27 (SB 27) 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.

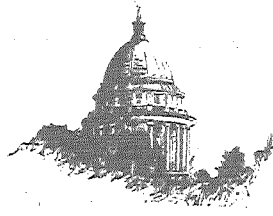
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As required in SB 27, every two years grant recipients would be required to participate in a symposium demonstrating their progress and provide collaborators an opportunity to share ideas in the effort to find a cure. In addition, in January of each 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 Senate Bill 27 today and helping to raise awareness about spinal cord injuries. Passing this bill is real substantive action that we can take to finally find a cure and I urge your support.



PAUL TITTL

STATE REPRESENTATIVE • 25TH ASSEMBLY DISTRICT

Senate Committee on Health

Senate Bill 27

March 1, 2023

First of all, I would like to thank you, Chair Cabral-Guevara and committee members, for allowing me to submit testimony concerning Senate Bill 27 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.

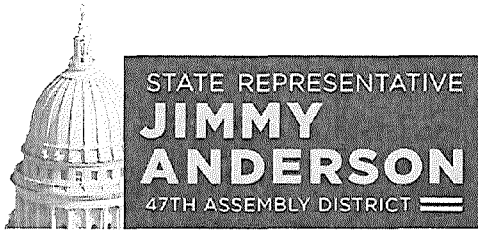
Every two years grant recipients would be required to participate in a symposium demonstrating their progress and providing collaborators an opportunity to share ideas in the effort to find a cure. In addition, in January of each year DHS would submit an annual report to the legislature identifying grant 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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*Testimony before the Senate Committee on Health
State Representative Jimmy Anderson
March 1, 2023*

Chair Cabral-Guevara and members of the Senate Health Committee,

Thank you for holding this public hearing to discuss Senate Bill 27 on spinal cord injury research grants and symposia.

SB 27 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. SB 27 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, SB 27 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 SB 27.

Jimmy Anderson
State Representative
47th Assembly District

DATE: March 1, 2023

TO: Senate Committee on Health

FROM: Mike Mohr

RE: Testimony in Support of Senate Bill 27

Chairperson Cabral-Guevara and Members of the Committee:

My name is Mike Mohr. I live in Madison. I grew up in Sheboygan. I've lived in Wisconsin pretty much all my life. I'm excited to be here today. And I thank you for your time and consideration of Senate Bill 27.

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 Senate Bill 27.

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.

**Senate Committee on Health
Wednesday, March 1, 2023
Testimony in Support of SB27
Provided by Dan Hellenbrand**

Chairperson Cabral-Guevara and Members of the Committee:

I am Dan Hellenbrand and I am here today to express support for Senate Bill 27 (SB27). 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 SB27 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. Senate Bill 27 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 Senate Bill 27 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. Sen. Wanggaard, Rep. Tittl, Rep. Wittke and Rep. Jimmy Anderson have developed a strong bill that I hope you give your full consideration. My sincere appreciation to those of you who have already indicated your support by signing onto the legislation including Chairperson Cabral-Guevara, Sen. Carpenter and Sen. Hesselbein.

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

DATE: March 1, 2023

TO: Senate Committee on Health

FROM: Dr. Murray Blackmore

RE: Testimony in Support of Senate Bill 27

Chairperson Cabral-Guevara 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.

DATE: March 1, 2023

TO: Members of the Senate Committee on Health

FROM: Mackenzie Wann

RE: Support for Senate Bill 27

Chairperson Cabral-Guevara and members of the Senate Committee on Health, My name is Mackenzie Wann and I am writing to you in support of SB27. 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!

SB27, 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 SB27.

DATE: March 1, 2023

TO: Members of the Senate Committee on Health

FROM: Douglas R. Rammer

RE: Support for Senate Bill 27

Chairperson Cabral-Guevara and members of the Senate Committee on Health. I am writing to support SB27 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 can not grasp paper with his hands, but there are researchable options that can give Max the ability to pinch his fingers and restore his tricep 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 SB27, 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 1st, 2023

TO: Members of the Senate Committee on Health

FROM: Samantha A. Troyer

RE: Testimony in Support of Senate Bill 27

Chairperson Cabral-Guevara and members of the Senate Committee on Health, my name is Samantha Troyer, and I am in support of SB27, 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 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. I truly wished I could have made my testimony in person, but I am still recovering from surgery. My SCI makes me feel pain more intensely than normal. Please give my community a lifeline to hope for a better quality of life.

DATE: March 1, 2023

TO: Members of the Senate Committee on Health

FROM: John Martinson

RE: Support for Senate Bill 27

Chairperson Cabral-Guevara and members of the Senate Committee on Health, 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 17th, 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 every day people and their families.

Please support SB-27 before more peoples LUCK runs out!

Thanks

DATE: March 1, 2023

TO: Members of the Senate Committee on Health

FROM: Robert Kozarek

RE: Support for Senate Bill 27

Chairperson Cabral-Guevara and members of the Senate Committee on Health, good morning, my name is Robert Kozarek, I am an Commercialization and Innovation Analyst at UW Health and I come before you in support of SB27.

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 SB27 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.

11/19/2021

11/19/2021

11/19/2021

11/19/2021

11/19/2021



TO: Honorable Members of the Senate Committee on Health

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 1, 2023

RE: Please Support Senate Bill 27, Related to Spinal Cord Injury Research Grants and Symposia

The Medical College of Wisconsin (MCW) strongly supports Senate Bill 27 (SB 27), 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 Cabral-Guevara and the Members of the Senate Committee on Health 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, if you have questions or need additional information regarding Senate Bill 27.



TO: Honorable Members of the Senate Committee on Health

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 1, 2023

RE: Please Support 2023 Wisconsin Senate Bill 27, 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 Senate Bill 27, 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, if you have additional questions or require additional information.

February 27, 2023

Re: Letter of Support for Senate Bill 27

To whom it may concern,

I'm writing to you today from multiple different positions and encouraging you to pass the Senate Bill 27 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.

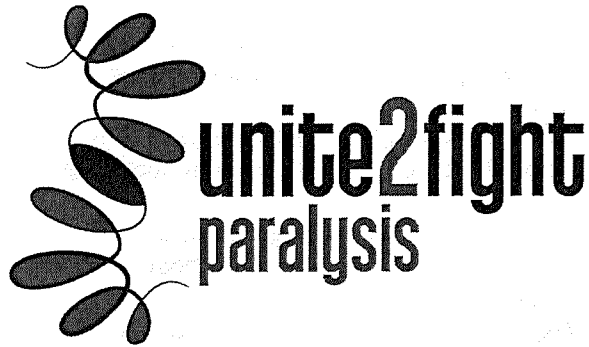
There truly is hope though! Being president of the Bryon Riesch Paralysis Foundation and supporting such institutions as the Medical College of Wisconsin and Marquette University I have seen progress being made. If we could simply continue to foster and encourage the research I truly believe we can make 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 Senate Bill 27 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



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 C(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: Schearer (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

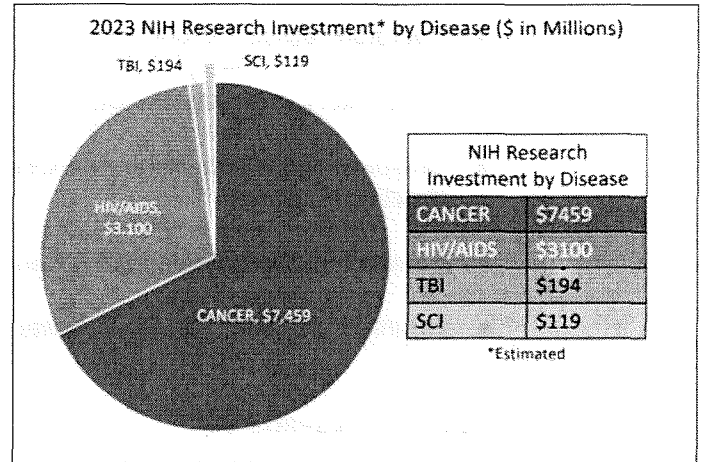
“The State of Ohio Third Frontier funding has helped accelerate the development of neurotechnology and assistive devices for those living with SCI in Central Ohio. Funding has led to several improvements in the NeuroLife technology platform and supported several researchers based at Ohio State and Battelle 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

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

DATE: March 1, 2023

TO: Senate Committee on Health

FROM: Matthew Rodreick

RE: Testimony in Support of Senate Bill 27

Chairperson Cabral-Guevara and Members of the Committee:

This July will mark 15 years since I received a nightmarish call on a beautiful warm summer Sunday evening. I was informed that my son, Gabriel, had been injured while swimming in the pacific ocean during a student exchange program in Costa Rica. This July will mark the halfway point of spending his life as a quadriplegic...all four limbs paralyzed along with a seemingly endless list of complications and secondary consequences from being paralyzed.

I spent the first few years after his injury as his full time caregiver, trainer, coach, travel companion (we traveled the globe seeking recovery), best friend, confidant and Dad. Then I became his advocate, and subsequently an advocate for everyone who has suffered this devastating injury.

I am not going to repeat the details and structure of this Bill all of which came from a great deal of research and thought. I simply want to ask you to consider two things:

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

Thank you for listening to us today and please vote yes to support this initiative.

Matthew Rodreick

Executive Director at Unite 2 Fight Paralysis



October 18, 2021

To whom it may concern,

On behalf of the Christopher & Dana Reeve Foundation, I am pleased to support Representative Tittl's proposed \$3 Million Spinal Cord Injury (SCI) Research Program for the 2021-23 budget. 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 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



knowledge changing life

Department of Neurosurgery

TO: Senate Committee on Health

FROM: Kajana Satkunendrarajah, PhD

DATE: March 1, 2023

RE: Testimony in support of Senate Bill 27 (SB 27)

Chairperson Cabral-Guevara 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 Senate bill 27 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.



State of Wisconsin
Department of Health Services

Tony Evers, Governor
Kirsten L. Johnson, Secretary

TO: Members of the Senate Committee on Health

FROM: HJ Waukau, Legislative Director

DATE: March 1, 2023

RE: SB 27 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 Senate Bill 27 (SB 27), 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, SB 27 appropriates \$3 million every fiscal biennium for the grants and symposia.

Governor Evers has included a provision similar to SB 27 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.

SB 27 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 SB 27 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 SB 27 and we offer ourselves as a resource for Committee members for any follow up or additional information that may be needed.



The Spinal Cord Injury Model Systems was created in 1970 as a prospective longitudinal multicenter study on demographics and the use of services by people with traumatic spinal cord injury in the United States.

This data sheet is a quick reference on demographic and condition status for 35,675 person with SCI collected through 2021 by federally funded SCI Model Systems and 5 Form II (follow up) centers and entered into the National SCI Database.

National SCI Statistical Center
515 Spain Rehabilitation Center
1717 6th Avenue South
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Incidence

The 2021 population size in the United States was estimated to be about 333 million people. The most recent estimate of the annual incidence of traumatic spinal cord injury (SCI) is approximately 54 cases per one million people in the United States, which equals about 18,000 new SCI cases each year. New SCI cases do not include those who die at the location of the incident that caused the SCI.

- **Data Source:** Jain NB, Ayers GD, Peterson EN, et al. Traumatic spinal cord injury in the United States, 1993-2012. JAMA. 2015;313(22):2236-2243.

Prevalence

The estimated number of people with SCI living in the United States is approximately 299,000 persons, with a range from 253,000 to 378,000 persons.

- **Data Source:** Lasfargues JE, Custis D, Morrone F, Carswell J, Nguyen T. A model for estimating spinal cord injury prevalence in the United States. Paraplegia. 1995;33(2):62-68.

Age at Injury

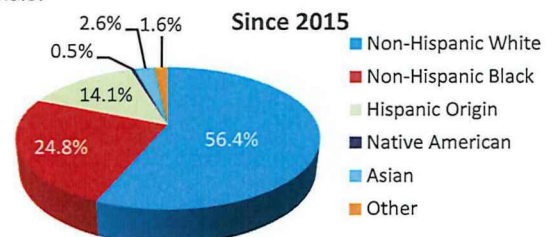
The average age at injury has increased from 29 years during the 1970s to 43 since 2015.

Sex

About 78% of new SCI cases since 2015 are male.

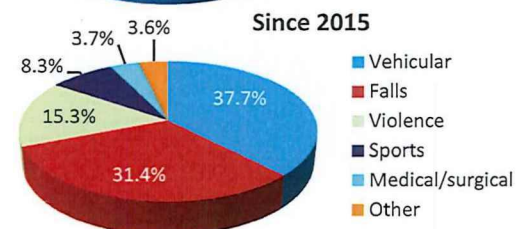
Race/Ethnicity

Recently, about 25% of injuries have occurred among non-Hispanic blacks, which is higher than the proportion of non-Hispanic blacks in the general population (13%).



Cause

Vehicle crashes are the most recent leading cause of injury, closely followed by falls. Acts of violence (primarily gunshot wounds) and sports/recreation activities are also relatively common causes. A customizable Leading Causes of SCI tool is at uab.edu/NSCISC.

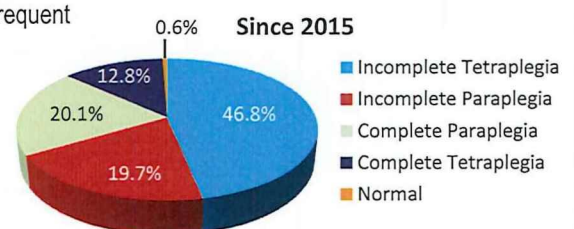


Lengths of Stay

Lengths of stay in the hospital acute care unit have declined from 24 days in the 1970s to 12 days since 2015. Rehabilitation lengths of stay have also declined from 98 days in the 1970s to 32 days since 2015.

Neurological Level and Extent of Lesion

Recently, incomplete tetraplegia is the most frequent neurological category. The frequency of incomplete and complete paraplegia is virtually the same. Less than 1% of persons experienced complete neurological recovery by the time of hospital discharge.



Education

Since 2015, about a quarter of persons with SCI have a college degree at the time of their injury, compared with 45% of people who survived 40 years of injury.

Education (%)	At Injury	Year 1	Year 10	Year 20	Year 30	Year 40
High School Only	51.8	52.3	49.3	47.4	41.8	34.8
College or Higher	23.5	25.8	28.4	26.9	34.5	45.4

Occupational Status

Since 2015, 18% of persons with SCI are employed at year 1 post-injury. The employment rate increases over time to 31% at 30 or more years post injury.

Status (%)	At Injury	Year 1	Year 10	Year 20	Year 30	Year 40
Employed	68.5	18.4	25.3	29.5	31.9	31.2
Student	7.8	6.4	2.7	0.7	0.3	0.1

Marital Status

Since 2015, the percentage of people who are married is relatively consistent up to year 30 post-injury, with single/never married status slowly decreasing and divorce status slowly increasing.

Status (%)	At Injury	Year 1	Year 10	Year 20	Year 30	Year 40
Single	44.9	42.5	37.9	35.9	33.6	24.7
Married	36.9	37.2	33.9	34.4	35.4	43.9
Divorced	8.4	10.2	18.7	20.2	22.3	21.7

Re-Hospitalization

Since 2015, about 30% of persons with SCI are re-hospitalized one or more times during any given year following injury. Among those re-hospitalized, the length of hospital stay averages about 18 days. Diseases of the genitourinary system are the leading cause of re-hospitalization, followed by disease of the skin. Respiratory, digestive, and musculoskeletal diseases are also common causes.

Historical Lifetime Costs

The average yearly expenses (health care costs and living expenses) and the estimated lifetime costs that are directly attributable to SCI vary greatly based on education, neurological impairment, and pre-injury employment history. The below estimates do not include any indirect costs such as losses in wages, fringe benefits, and productivity (indirect costs averaged \$82,329 per year in 2021 dollars).

Severity of Injury	Average Yearly Expenses (in 2021 dollars)		Estimated Lifetime Costs by Age at Injury (discounted at 2%)	
	First Year	Each Subsequent Year	25 years old	50 years old
High Tetraplegia (C1–C4) AIS ABC	\$1,218,106	\$211,528	\$5,404,774	\$2,970,372
Low Tetraplegia (C5–C8) AIS ABC	\$880,188	\$129,763	\$3,949,065	\$2,429,028
Paraplegia AIS ABC	\$593,660	\$78,642	\$2,642,911	\$1,734,463
Motor Functional at Any Level AIS D	\$397,544	\$48,287	\$1,805,650	\$1,274,478

Data Source: Economic Impact of SCI published in the journal *Topics in Spinal Cord Injury Rehabilitation*, Volume 16, Number 4, in 2011. ASIA Impairment Scale (AIS) is used to grade the severity of a person's neurological impairment following spinal cord injury.

Historical Life Expectancy

The average remaining years of life for persons with SCI have not improved since the 1980s and remain significantly below life expectancies of persons without SCI. Mortality rates are significantly higher during the first year after injury than during subsequent years, particularly for persons with the most severe neurological impairments. A customizable Life Expectancy Calculator tool is at uab.edu/NSCISC.

Age at Injury	Life Expectancy (years) for Post-Injury by Severity of Injury and Age at Injury										
	No SCI	For Persons Who Survive the First 24 Hours					For Persons Surviving at Least 1 Year Post-Injury				
		AIS D Motor Functional (Any Level)	AIS ABC Para	AIS ABC Low Tetra (C5–C8)	AIS ABC High Tetra (C1–C4)	Ventilator Dependent (Any Level)	AIS D Motor Functional (Any Level)	AIS ABC Para	AIS ABC Low Tetra (C5–C8)	AIS ABC High Tetra (C1–C4)	Ventilator Dependent (Any Level)
20	59.5	52.1	44.8	39.4	32.6	10.5	52.5	45.3	40.1	33.7	17.6
40	40.8	34.9	29.6	24.8	20.7	8.8	35.2	30.0	25.5	21.6	13.2
60	23.3	19.3	16.0	13.0	11.1	3.7	19.5	16.4	13.7	12.2	7.9

Historical Causes of Death

Persons enrolled in the National SCI Database have now been followed up to 48 years after injury. During that time, the causes of death that appear to have the greatest impact on reduced life expectancy for this population are pneumonia and septicemia. Mortality rates are declining for cancer, heart disease, stroke, arterial diseases, pulmonary embolus, urinary diseases, digestive diseases, and suicide. However, these gains are being offset by increasing mortality rates for endocrine, metabolic and nutritional diseases, accidents, nervous system diseases, musculoskeletal disorders, and mental disorders. There has been no change in the mortality rate for septicemia over the past 48 years, and there has only been a slight decrease in mortality due to respiratory diseases.

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