

*Testimony before the Assembly Committee on Colleges & Universities
State Representative Jimmy Anderson
April 6, 2022*

Chair Murphy and members of the Committee,

Thank you for holding a public hearing on Assembly Bill 873. I appreciate the opportunity to speak about this bill.

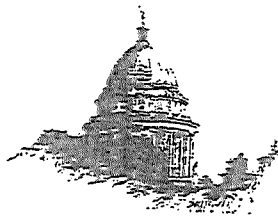
Each year, there are about 17,000 new spinal cord injuries across the country, including more than 200 here in Wisconsin. Spinal cord injuries place an incredible toll on the injured and their families, physically, emotionally and financially. High-level injuries cost over \$1 million in the first year and \$100,000 every year after that.

Despite advances in most areas of medical research, spinal cord and traumatic brain injuries are understudied and the research that does exist is vastly underfunded. AB 873 would establish a \$3 million grant program for research 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, providing hope for people far beyond their state lines.

In addition to providing research funding, AB 873 will create a Spinal Cord Injury Council to bring researchers and people with spinal cord injuries together to help direct the program. Having people with spinal cord injuries as part of the council will ensure that real life experience is 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 legislation has incredible potential to change the lives of thousands of people across the country, as you will hear from those here to testify today. Rarely do we get such an opportunity to have such a positive impact on so many lives but this can only happen with your support.

Thank you for your consideration of AB 873.



PAUL TITTL

STATE REPRESENTATIVE • 25TH ASSEMBLY DISTRICT

Assembly Committee on Colleges and Universities

Assembly Bill 873

April 6, 2022

First of all, I would like to thank you, Chairman Murphy and committee members, for allowing me to submit testimony concerning Assembly Bill 873 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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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: April 6, 2022

RE: Please Support AB 873, Related to Spinal Cord Injury Research Grants and Symposia

The Medical College of Wisconsin (MCW) strongly supports Assembly Bill 873 (AB 873), 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 Paul Tittl and Senator Tim Carpenter for authoring and advancing this legislation, as well as Chairperson David 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 Director of Government Relations, at 414.955.8217, or nberken@mcw.edu, if you have questions or need additional information regarding AB 873.



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Be The Difference.

TO: Chairman Dave Murphy and Members of the Wisconsin State Assembly Committee on Colleges and Universities

FROM: Dr. Jeanne Hossenlopp, Vice President for Research and Innovation and Dr. William Cullinan, Dean of Health Sciences

Jeanne M Hossenlopp *William Cullinan*

DATE: April 5, 2022

RE: Assembly Bill 873 Relating to: spinal cord injury research grants and symposia and making an appropriation

On behalf of Marquette University, we are writing to thank Representative Tittl and Senator Carpenter for authoring the bipartisan supported Assembly Bill 873 related to spinal cord injury research grants and symposium up to \$3 million every biennium. We are unable to attend the Committee's public hearing on April 6, 2022 but wanted to weigh in on this matter.

Assembly Bill 873 requires Wisconsin's Department of Health Services to appoint a Spinal Cord Injury Council with one member representing the University of Wisconsin School of Medicine and Public Health, one member representing the Medical College of Wisconsin, and the following members: 1) a person with a spinal cord injury; 2) a family member of a person with a spinal cord injury; 3) a veteran with a spinal cord injury; 4) a physician specializing in the treatment of spinal cord injuries; 5) a neurosurgery researcher; and 6) a researcher employed by the federal Veterans Health Administration of the U.S. Department of Veterans Affairs.

Marquette University is respectfully requesting an amendment to Assembly bill 873 to include "One member representing Marquette University" to the Spinal Cord Injury Council.

We are aware that on behalf of Unite 2 Fight Paralysis, Dr. Murray Blackmore, plans to testify at the public hearing. Dr. Blackwell is one of the nation's leading spinal cord researchers and we will allow his story and body of work to speak for itself at the hearing.

Again, thank you for your consideration of this amendment and Marquette University looks forward to working with the State of Wisconsin on spinal cord research in the future.



Assembly Committee on Colleges and Universities
April 6, 2022
Testimony submitted in support of AB873

I write today to express our support for Assembly Bill 873 which seeks to establish a \$3 million biennial grant program and advisory council for spinal cord research within the Wisconsin Department of Health Services. We appreciate the leadership Representatives Tittel, Wittke and Anderson have demonstrated through introduction of this bill. 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. We also applaud the authors' recognition of the value having a representative from the UW School of Medicine and Public Health would bring to the advisory council and we would be happy to serve.

Thank you for your efforts to advance spinal cord research. Please let me know if you have any questions.

DATE: April 6, 2022

Welcome: Members of the Assembly Committee on Colleges and Universities to my WORLD.

FROM: John Martinson

RE: Testimony on Assembly Bill 873

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 iron worker 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 expensiver than air-Jorden shoes which can cost around \$200 - \$400, mine runs around \$3000 unlike my colleges Mike Mohr's shoes which cost \$25,000! I call Mike's power wheelchair, air-Mohr shoes.

I wouldn't wish a spinal cord injury or disease on my worst enemy, I see and experience all the mental and physical pain that it inflicts on every day people and their families.

Please support AB-873 before more peoples LUCK runs out!

Thanks



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To whom it may concern:

I am writing this letter of support for Representative Tittl's proposal of a \$3 Million Spinal Cord Injury (SCI) Research Program for the 2021-23 budget. I am a neuroscientist at Marquette University who leads a research lab that is devoted to the problem of spinal cord injury. I am also a family member of someone who suffered a spinal cord injury; my mother was paralyzed from the neck down by a car accident. As both a professional who grapples with this devastating problem in the lab, and as someone who witnessed first-hand what it looks like to piece a life back together after this injury, I would like to vouch for both the importance of this initiative and for the exceptional intelligence and effectiveness of its design.

To state it plainly, this is not a proposal for money that will simply melt into the fabric of higher education. Instead, the program is designed to keep the funds focused on the core problem and to deliver maximal impact.

- 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.
- Research grants target innovation in the translation of deliverable therapies to those who live with the injury.
- Research grants remain in the state and are competitive among researchers, institutions, and businesses.

Besides the obvious value in terms of providing hope and advancing toward a cure for spinal injury, I can also attest to the economic impact that comes with smart investment in research. Several years ago, my own lab received seed funding from a local foundation for pilot projects, which we then leveraged into multi-million dollar grants from the federal government. These federal funds now support multiple employees and students. It is also notable that over the last ten years at least six undergraduate students have come through the lab and then proceeded to medical school in Wisconsin, followed by practice in the state. The point is that targeted investment in research has tremendous ripple effects.

We don't need to wonder if this program works. It already has a track record of success and effectiveness, modeled on the programs instituted in Minnesota, Ohio, Pennsylvania, and Washington. There exists a community of researchers in Wisconsin that are poised to make real progress on this difficult problem. With this targeted investment, with dollars that are sheltered from administrative burden and which flow through a board that keeps



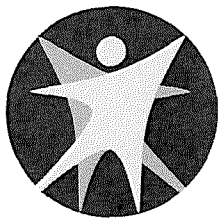
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the focus on the real needs of individuals with SCI, there is an opportunity to put Wisconsin on the map as a hub for medical advances in spinal injury.

Sincerely,

A handwritten signature in black ink, which appears to read "Murray Blackmore".

Murray Blackmore
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414-288-4532
murray.blackmore@marquette.edu



State of Wisconsin
Department of Health Services

Tony Evers, Governor
Karen E. Timberlake, Secretary-Designee

TO: Members of the Assembly Committee on Colleges and Universities

FROM: HJ Waukau, Legislative Director

DATE: April 6, 2022

RE: AB 873 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 873 (AB 873) 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 873 appropriates \$3 million every fiscal biennium for the grants and symposia.

Governor Evers included a provision similar to AB 873 for spinal cord injury grants and symposia for \$3 million in his 2021-23 biennial budget. 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' 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.

While AB 873 does not change the current injury prevention law 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 for these efforts. Dedicated funding would ensure that DHS is able to meet the legislative intent of the funding of the grants for spinal cord injury research.

We thank the Committee for the opportunity to provide written testimony in support of AB 873 and we offer ourselves as a resource for Committee members for any follow up or additional information that may be needed.

U2FP CAN Economic Impact Synopsis

*Prepared Jan 5, 2022 and updated with new responses.

This document is composed of returned data from about 20% of the researchers funded through the Cure Advocacy Network (CAN) initiatives in four states, MN, WA, PA and OH. MN is the oldest legislation (Began in 2015) and has produced the most work.

Purpose: to inform legislators of the value of proposed SCI grant research program.

Private Business Startups Since CAN Funding:

Anatomic (MN-Dutton) <https://www.anatomic.tech/>

StimSherpa (MN-Darrow et al) <https://stimsherpa.com/>

NervGen Pharma (OH-Silver) <https://www.nervgen.com/>

Additional Federal Grants Since CAN Funding:

1.9 Million DOD (WA-Moritz)

3.7 Million NIH (MN-Ebner)

7 Million NIH (pending Fed. Cont. Res.) (OH-Kilgore)

2.3 Million NIH (MN-Dougherty)

2.5 Million NIH and DOD (MN-Parr)

Additional Private and Matching Grants Since CAN Funding:

\$740K (WA- Moritz)

\$600K in device investment (OH-Kilgore)

\$300K (MN-Dougherty)

Industry Partnerships:

Onward sponsored, multi-site clinical trial (WA-Moritz) <https://www.onwd.com/>

Abbott device donations approximately \$4.2 million (in kind donation of 100 estim devices committed...24 utilized to date = a little over \$1 million) <https://www.abbott.com/>

Public/Private Partnerships:

NervGen (Silver OH)

Abilitech (Conley MN)

Positions Created:

21 person/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/years (MN-Dougherty)

2 positions per year (MN-Parr)

Careers Propelled: individuals whose career progressed to the next stage
le, Megan Gill,

Translation to human trials:

One WASCIC grant supported, animal study, now in first human trials (WA-Moritz)

Outcomes for Unmet Human Need:

12 participants now and 10 more enrolled, functional recovery of grasp (WA-Moritz)

https://youtu.be/z9abb_N8JKY <https://www.youtube.com/watch?v=iuqv3Tu5CpY>

30 participants enrolled for clinical trial, significant recovery of hand function (feeding themselves) and standing

24 patients implanted for e-stand (MN-Parr/Darrow/Samadani)

3 patients implanted (Mayo Clinic- Zhao/Grahn)

10 patients treated with autologous (from the patient) MSC's (mesenchymal stem cells)

***important to note that all of the above are in chronic injury**

Areas of SCI Research Supported:

Transcutaneous Epidural Stimulation: (WA-Moritz) and Samadani/Darrow/Parr C(U of MN)
Grahn/Zhao (Mayo Clinic)

Stem Cells (MN-Dutton) Mohamad Bydon (Mayo Clinic)

Neuroprosthesis (OH-Kilgore)

Sex Hormones and Nueroplasticity (MN-Dougherty)

Stem Cell/Scaffold (MN-Parr)

Quotes:

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.

From Kevin Kilgore, PhD, Case Western Reserve University and MetroHealth System
Recipient of State of Ohio SCI Program Funding for June, 2020.

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

DATE: April 6, 2022

TO: Members of the Assembly Committee on Colleges and Universities

FROM: Douglas R. Rammer

RE: Testimony on Assembly Bill 873

Chairperson Murphy and members of the Committee on Colleges and Universities. I come before you in support of AB873. The previous testimony was presented by my son but I have also been a work colleague to a man with a C5 injury for nearly 20 years, but unfortunately, I did not truly know the impacts of the injury on the day to day lives of this community. For those 20 year working with this person, 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 quadrapelgic is more than just the loss of the use of their legs or hands – it is the unseen complications and loss of time 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, and the general loss of time in his day.

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 one 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 risker 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.

Moving forward, my son is scheduled to graduate from the UW- Madison School of Business in the Spring of 2023. I would like to say he will graduate with a 3.5 or greater average. For all he has to encounter during this time I am very proud. For example, last semester 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, Max was experiencing the beginning 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.

This semester, Max is experiencing 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.

Looking beyond the spring of 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. Max has highlighted that he was discouraged to pursue a degree in political science but he was further discouraged to pursue his interest in information management systems during a discussion in an Human Resources class. It was made clear to him that he would need full use of his hands to pursue this interest, and no company would hire him due to that limitation. 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. For example this semester, one of Max's class's professors only allows 4 missed classes without a consequence, no excuses are acceptable. He has called me twice in a panic that his paratransit ride has missed his pick up schedule by more than the allotted 20 minutes. There is research and surgical options that can give Max the ability to pinch his fingers and restore his tricep strength that would greatly improve his employment potential that this bill could fund.

Note, 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.

Finally, I am a researcher for the US government so I have both written and evaluated research proposals for over 30 years. I have many experiences on how research is conducted and developed. I have found that a researcher that engages with the community their work will help typically have their ideas implemented.

Well meaning researchers think that they have the solution to a perceived problem. For example, one SCI researcher has proposed a sensor to determine if the feet of a person in a wheelchair touch something. I can tell you Max is aware of where his feet are most of the time. For Max and a large number of members of the SCI community this would be a low priority idea or redirected to use this idea to develop a better bed or cushion that can reduce pressure sores.

For the research to have the greatest impact, the bill before you requires active participation of the SCI community during both the evaluation research proposals and subsequent reporting process. 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. While not specifically spelled out in the bill, we advocate the overhead rate of this research by ideal 8%. Consider overhead a tax that a university accesses on research funding. This tax results in less funding going to research but to other priorities of the university. At some universities overhead rates on some proposals can be as high as 50%. As a researcher in the USDA, when sending funding to

university for research activities, I strongly consider land-grant colleges, since I impose a 0% overhead rate.

Finally, I strongly support AB873, 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 the State of Wisconsin of this community. Thanks for your time and support of this effort.

DATE: April 6, 2022

TO: Members of the Assembly Committee on Colleges and Universities

FROM: Maxwell Rammer

RE: Testimony on Assembly Bill 873

Chairperson Murphy and members of the Committee on Colleges and Universities. I come before you in support of AB873. In 2017, I had the world to look forward to. I had just graduated high school and got accepted into my dream school UW-Madison. I was excited, nervous, and ready for what the future has in store for me. It was the end of summer before going off to college and I was having the time of my life with my friends. That's when everything changed. A week before I left for Madison, I was meeting up with my friends for one last get together before we headed off to school when a diving accident ruined my life forever. I became a C6 quadriplegic which means that I'm paralyzed from my chest down and can't use my fingers or half of my arms.

When you look at me you might see a wheelchair and someone that will never walk again, but I'm here to tell you that walking is the least of my worries. While I don't speak for everyone with this injury, I personally don't care that I will never walk again. As someone who lives the day-to-day life of being paralyzed I am more concerned with the many other aspects of this injury that affect my life in much more severe ways than being able to stand or walk again. For example, I experience bedsores and urinary infections that interrupt and threaten my life or leave me bedridden for extended periods of time. Just last semester, I was hospitalized twice for a week each time due to urinary tract infections that threatened my life. I had to be put on IV antibiotics of last resort because the bacteria was resistant to all the others antibiotics. My treating doctor tell me that I was lucky as f*** to be alive after the second one. It is incredibly hard to go to college and try to live a normal life in this society when I have to constantly worry about life or death scenarios. While this injury makes my daily life hard, the hardest fact I have had to face is the strong possibility that my parents will have to bury their son instead of me burying them. My level of injury and the associated unseen medical issues have cut my life expectancy. I don't expect to live beyond the age of 60 with the current treatments .

Like I stated previously, this injury is so much more than not walking. It is a fight every single day between the mental, physical and societal pressures just to stay sane. Through my work with the UFP, I was excited to pursue a major in political science at UW Madison. I thought that I could use my experiences, get into politics, and help change things for the better for people like me. When I arrived on campus I was heartbroken to discover that the political science building is located halfway up Bascom and doesn't have any elevators or adapted bathrooms for me. I had to completely change career paths not because I didn't have the grades or the heart. But simply because the University didn't want to accommodate the building and it would be difficult to accommodate in my pursuit of this degree . Since my injury, I have found peace in

music and dreamed of joining a student radio club and was unable to because the communications building is inaccessible. The lack of accommodations and understanding from professors is also a common experience. Last semester, I dropped out of a class because my professor was giving me a very hard time about rescheduling quizzes and exams while I was in the hospital. This was too much for me to handle at the moment, I with the disability center made several attempts to find a path forward. Unfortunately this is a commonplace experience for people like me and is just the tip of the iceberg of the daily societal challenges that we face.

To continue, There are other aspects of my injury that physically impact my life significantly on a daily basis. I mentioned previously that I cannot use my fingers or my triceps. This means that I cannot cook or acts of daily living which includes getting dressed, showering, cooking, cleaning Etc. I can't even go to the bathroom fully by myself. Additionally, tasks that I can do are time consuming. It impacts literally everything and if I were just able to pinch my fingers together I would be able to do a majority of these tasks - turn a key to get my mail, start a car, open a door, hold a pencil or turn a knob on my music synthesizer. This would also mean that I would improve my independence, make myself more attractive to the business community, and finally it would reduce daily hours of caregiving I require. Services that are paid for by the state in order to complete these simple tasks.

My injury impacts every single waking moment of my life. From social encounters, all the way down to simple physical things like how much air I can breathe into my lungs, Yet it unfortunately seems like a majority of the research currently being done is solely focused on getting me walking again. While this would be nice it is not on my top priority of things that could greatly improve my life and lifespan . I just want real tangible improvements to help me live my life again and that is why I support this bill. Thank you for your time and your continued support to enact this legislation.

DATE: April 6, 2022

TO: Members of the Assembly Committee on Colleges and Universities

FROM: Michael Mohr

RE: Testimony on Assembly Bill 873

Thank you, Chairperson Murphy and members of the committee. My name is Mike Mohr. I'm excited to be here and excited about AB 873. I hope you'll join me in my excitement as we move forward with this proposal. I am also including with my testimony numerous letters from people living with SCI and researchers from around the country who support AB 873. We are also submitting a letter in support from a Minnesota legislator.

I live in Madison. I grew up in Sheboygan. I have a spinal cord injury. I was paralyzed in a diving accident when I was 15. I was a swimmer for Sheboygan North High School. Our starting blocks were in the shallow end of the pool at that time, roughly 3 1/2 feet deep. I did a racing start / dive at practice and hit my head on the bottom of the pool. I was instantly paralyzed. I am a quadriplegic. I can't feel or move anything from the chest down. I have limited arm and hand movement, and no finger dexterity.

Like Max, I rely on many hours of personal care workers helping me in order to complete my activities of daily living every day. Going to bed, getting undressed, going to the bathroom, showering, meal preparation, transfer to and from wheelchair, so on and so forth. I deal with very long morning and night routines, urinary tract infections, skin breakdown and pressure sores, chronic lymphedema in my feet, and many other frequent health issues that go with having a high level spinal cord injury. It can be a very difficult life. It's still a good life. But it's a difficult one.

As I said though, I'm excited. I'm excited about the potential for this legislation and the effects it could have. I'm excited because it's already working in other states and we can make it work here. You see, we aren't just requesting money, but we are requesting money to be allocated in a really smart way. These funds will be allocated in the form of competitive grants. These grants will be decided upon by an advisory committee made up of researchers who know the state of the art, clinicians who treat people with spinal cord injuries, and most importantly – individuals with injuries or their family members. We have a unique understanding of what to prioritize when evaluating potential function outcomes.

Furthermore, the competitive grants carry smart conditions. The stipulations include no more than 8% of the funding go to overhead and that 92% of the funds actually go to the research. Also, researchers need to return every other year and present their results at a symposium. Money is used efficiently and the symposia will gather people together who otherwise wouldn't be connecting.

Similar legislation has been successful in other states. We have seen success in Minnesota, Ohio, Pennsylvania, and Washington. Minnesota is a great example. They're seeing additional funds and grants from other sources showing up as a result of these studies. They are

experiencing growth in the local research economy. Minnesota is a main spot on the global map of spinal cord injury research now. They are seeing business start-ups as a result of these grants. Minnesota has seen a 10 to 1 return on its investments. But most importantly, they are conducting human clinical research trials.

Finally, I'd like to note that Wisconsin stands to benefit financially if we improve spinal cord injury research. Wisconsin spends \$500 million a year providing care for those of us with SCI. It's a lot of personal care hours. It's the health issues we experience that land us in the hospital. Improving functionality would result in us relying less on state assistance, thereby saving the taxpayers money.

I'm excited because there is interesting research going on in Wisconsin. I'm excited to see that research be accelerated to human clinical trials. AB 873 is a great way to make that happen. Thank you for your time and consideration.

DATE: April 6, 2022

TO: Members of the Assembly Committee on Colleges and Universities

FROM: Robert Kozarek

RE: Testimony on Assembly Bill 873

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 AB873.

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 AB873 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.

DATE: April 6th, 2022

TO: Members of the Assembly Committee on Colleges and Universities

FROM: Samantha A. Troyer

RE: Testimony on Assembly Bill 873

Not one person ever imagines a future where they suffer a physical and emotionally life changing traumatic event. At the age of 19, on my way to college with my best friend in the passenger seat, a person ran a red light as my car crossed an intersection since I had the green light. Upon impact my door was ripped off and I was thrown 50ft. Nearly dying I had to be airlifted to Froedtert hospital with little hope from paramedics that I would survive. Fortunately I did due to their heroic efforts by not giving up on resuscitating me.

From there my existence and how I knew how to get around in this world changed forever. Life became a series of obstacles, pain, and sadness burdened by being physically less capable because I had become a C1 quadriplegic. Investing my time and energy into recovery of physical function became my life which started with learning to breathe again.

All these years later I have achieved more functional recovery then what the doctors initially predicted. However, that all came at a financial cost. Two of those times due to needing to find research programs and get treatment in other States. Once was just in 2019 in Florida because they strongly invest in SCI research as a state. Why couldn't my own state which has a science community and institutions ripe with the fruits for potential SCI cures available for picking invest in research? All that money put towards rehab and research I spent could have been spent here.

This is why I support AB 873. I believe a state and country that invests in reducing the long-term damage and suffering of an injury that anyone at any age may get can give more hope to the future. Might even open more doors for treating many other central nervous system disorders. Not only will cures or advanced treatments help a person with a SCI recover function in their own life, but also get back to work and contribute more easily to the community.

Dear Members of the Committee of Colleges and Universities,

I am writing this letter in support of passage of the Assembly Bill 873. 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: April 4, 2022

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

From: David L. Messling

Re: Letter of Support for Assembly Bill 873

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 wheel-in 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.

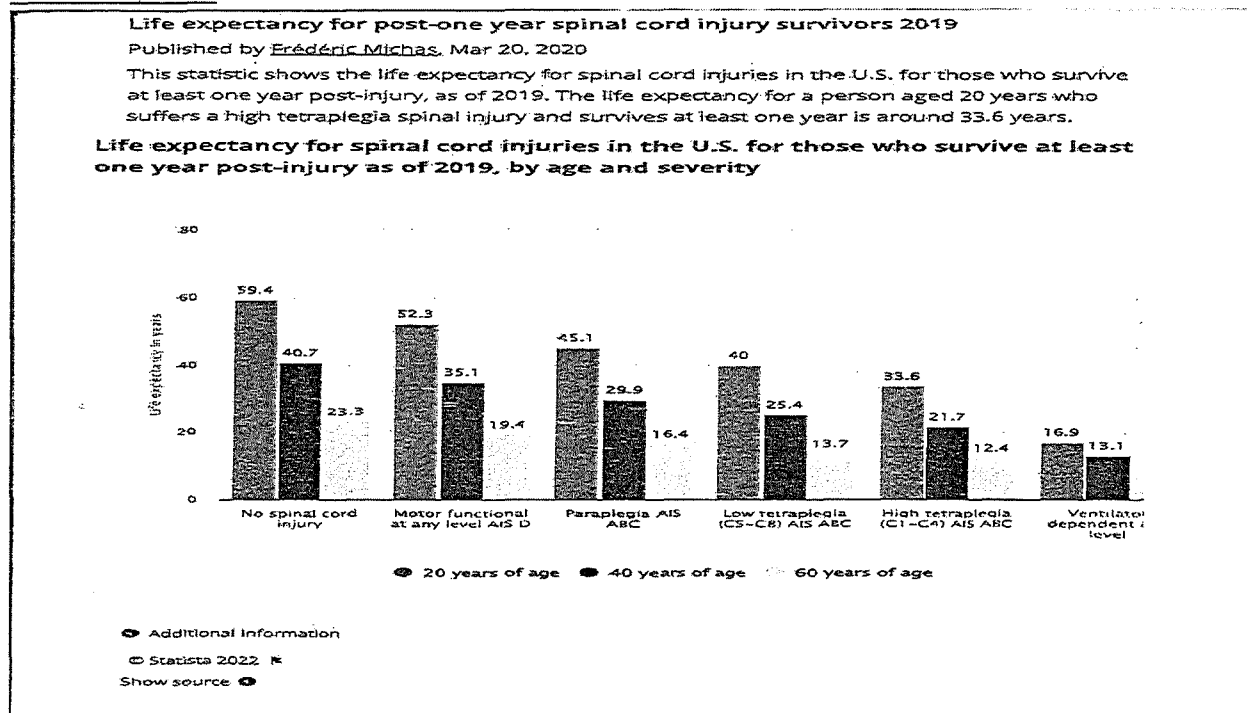
Here are the numerous surgeries and infections I have had since being injured 5 years ago:

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



I would like to thank the Assembly of the Colleges and University for your time and your consideration of Bill 873.

Sincerely,
 David L. Messling



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 style with a large, prominent "K" and "B".

Kimberly Beer
Director, Public Policy

DATE: March 21, 2022

TO: Members of the Assembly Committee on Colleges and Universities

FROM: Michael Uppenkamp

RE: Letter of Support for Assembly Bill 873

Chair Murphy,

Thank you for pulling for the WI SCI Research Grant Bill AB 873. 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 19, 2022

TO: Members of the Assembly Committee on Colleges and Universities

FROM: Sharon Drennan

RE: Letter of Support for Assembly Bill 873

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 873 as we continue to move toward a cure.

Sincerely,
Sharon Drennan

Marshall Begel
WI Cure Advocacy Network

Representative David Murphy
Assembly Committee on
Colleges and Universities

Re: AB 873

March 21, 2022

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.

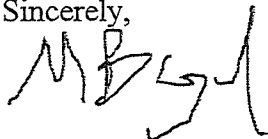
I'm 51 now, and have spent 25 years as a C5 quadriplegic. Though much is lost, much is left. I enjoy my job, love my wife, and spend personal time playing video games, working on small inventions, and reading science fiction. Still, I hold precious the memories of backcountry hikes, hand-kneading bread 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



MARQUETTE
UNIVERSITY

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

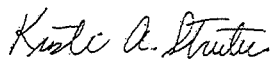
I'm writing this letter in support of Representative Tittl's proposed \$3 Million Spinal Cord Injury (SCI) Research Program for the 2021-23 budget. This initiative builds on the success of similar programs adopted by multiple other states including Minnesota, Ohio, Pennsylvania, and Washington and strives 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



Shekar N. Kurpad, MD, PhD
Sanford J. Larson Professor and Chairman
Co-Director, Center for Neurotrauma Research
Medical Director, Neuroscience Service Line, Froedtert Health and the Medical College of Wisconsin

Department of Neurosurgery

May 11, 2021

To Whom It May Concern:

I am writing this letter of support for Governor Evers proposal of a \$3 Million Spinal Cord Injury (SCI) Research Program for the 2021-23 budget. I am a neurosurgeon and neuroscientist that has been involved in the care of patients with paralyzing injury to the spinal cord from motor vehicle and other accidents, and also a researcher interested in the discovery of novel treatments to cure paralysis and bring these treatments to patients suffering from spinal cord injuries.

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; and 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 Governor Evers 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:

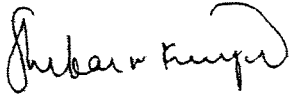
- Research grants remain in the state and are competitive among researchers, institutions, and businesses.
- Research grants target innovation in the translation of deliverable therapies to those who live with the injury.
- The program mandates a low indirect cost rate of 8% so that taxpayer dollars 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.

As a neurosurgeon and scientist that has been closely involved in the care of Spinal Cord Injury patients over the last 20 years, I am fully in support of this program. The program will use public funds judiciously 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

Medical College of Wisconsin
8701 Watertown Plank Road
Milwaukee, WI 53226
414-955-0950

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.

Sincerely,

A handwritten signature in black ink, appearing to read "Shekar N. Kurpad". The signature is fluid and cursive, with a large loop at the end.

Shekar N. Kurpad, MD, PhD
Sanford J. Larson Professor and Chairman
Department of Neurological Surgery
Co-Director, Center for Neurotrauma Research
Medical College of Wisconsin
Medical Director, Neuroscience Service Line
Froedtert Health and The Medical College of Wisconsin



knowledge changing life

Marle R. Orr, MD
Assistant Professor

Department of Physical
Medicine and Rehabilitation

November 2, 2021

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 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. 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.

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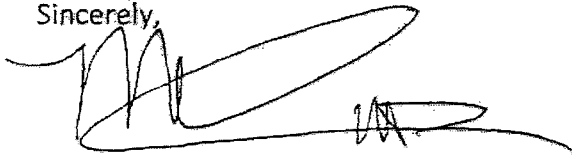
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- The program implements a state advisory council composed of researchers, clinicians and most importantly, those living with spinal cord injury, to recommend which research projects should be funded.

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

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,

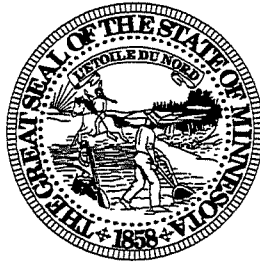


Merle R. Orr, MD
Assistant Professor
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Rod Hamilton
State Representative

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", written over a white background.

State Representative Rod Hamilton
House District 22B

U2FP CAN Economic Impact Synopsis

*Prepared Jan 5, 2022 and updated with new responses.

This document is composed of returned data from about 20% of the researchers funded through the Cure Advocacy Network (CAN) initiatives in four states, MN, WA, PA and OH. MN is the oldest legislation (Began in 2015) and has produced the most work.

Purpose: to inform legislators of the value of proposed SCI grant research program.

Private Business Startups Since CAN Funding:

Anatomic (MN-Dutton) <https://www.anatomic.tech/>

StimSherpa (MN-Darrow et al) <https://stimsherpa.com/>

NervGen Pharma (OH-Silver) <https://www.nervgen.com/>

Additional Federal Grants Since CAN Funding:

1.9 Million DOD (WA-Moritz)

3.7 Million NIH (MN-Ebner)

7 Million NIH (pending Fed. Cont. Res.) (OH-Kilgore)

2.3 Million NIH (MN-Dougherty)

2.5 Million NIH and DOD (MN-Parr)

Additional Private and Matching Grants Since CAN Funding:

\$740K (WA- Moritz)

\$600K in device investment (OH-Kilgore)

\$300K (MN-Dougherty)

Industry Partnerships:

Onward sponsored, multi-site clinical trial (WA-Moritz) <https://www.onwd.com/>

Abbott device donations approximately \$4.2 million (in kind donation of 100 estim devices committed...24 utilized to date = a little over \$1 million) <https://www.abbott.com/>

Public/Private Partnerships:

NervGen (Silver OH)

Abilitech (Conley MN)

Positions Created:

21 person/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/years (MN-Dougherty)

2 positions per year (MN-Parr)

Careers Propelled: individuals whose career progressed to the next stage
le, Megan Gill,

Translation to human trials:

One WASCIC grant supported, animal study, now in first human trials (WA-Moritz)

Outcomes for Unmet Human Need:

12 participants now and 10 more enrolled, functional recovery of grasp (WA-Moritz)

https://youtu.be/z9abb_N8JKY <https://www.youtube.com/watch?v=iuqv3Tu5CpY>

30 participants enrolled for clinical trial, significant recovery of hand function (feeding themselves) and standing

24 patients implanted for e-stand (MN-Parr/Darrow/Samadani)

3 patients implanted (Mayo Clinic- Zhao/Grahn)

10 patients treated with autologous (from the patient) MSC's (mesenchymal stem cells)

***important to note that all of the above are in chronic injury**

Areas of SCI Research Supported:

Transcutaneous Epidural Stimulation: (WA-Moritz) and Samadani/Darrow/Parr C(U of MN)
Grahn/Zhao (Mayo Clinic)

Stem Cells (MN-Dutton) Mohamad Bydon (Mayo Clinic)

Neuroprosthesis (OH-Kilgore)

Sex Hormones and Nueroplasticity (MN-Dougherty)

Stem Cell/Scaffold (MN-Parr)

Quotes:

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.

From Kevin Kilgore, PhD, Case Western Reserve University and MetroHealth System
Recipient of State of Ohio SCI Program Funding for June, 2020.

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



International Collaboration on Repair Discoveries: a research centre in the UBC Faculty of Medicine and VCH Research Institute
3rd April 2022

To: Members of the Assembly Committee on Colleges and Universities

RE: Letter of Support for Assembly Bill 873

Chair Murphy and members of the Colleges and Universities Committee,

I am writing in strong support of Bill 873 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 873 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 | www.icord.org

Making spinal cord injury preventable, livable, and curable

Blusson Spinal Cord Centre, 818 West 10th Avenue, Vancouver, BC, Canada V5Z1M9 | 604-675-8810 | www.icord.org

DATE: 4 April, 2022

TO: Members of the Assembly Committee on Colleges and Universities

FROM: M. Claudia Garofalo

RE: Letter of Support for Assembly Bill 873

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 873.

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 873 as we continue to move toward a cure.

Sincerely,
M. Claudia Garofalo

8008 Inistork Dive
Dublin, OH 43017

Peter Nowell
pnowell264@gmail.com

Home: 614-408-0085
Cell: 614-570-7870

March 17, 2022

Dear Representative Murphy

Thank you for scheduling a hearing for AB 873 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.

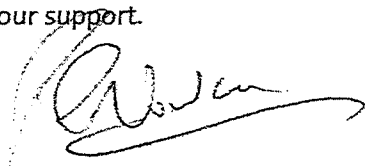
The structure we have put in place for selection of projects to fund, requires the researchers to provide regular progress reports to the SCI community, and this has been educational all around. Not only have we as "users" had the privilege of learning about what's going on at the cutting edge of research,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

Nancy Nicholas
19704 192nd Ave. NE.
Woodinville, WA 98077

March 18, 2022

RE: AB 873

Dear Representative Murphy,

Thank you so much for giving AB 873 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



Boston Children's Hospital

Where the world comes for answers



**HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL**

4 Austin Street
Burlington, MA 01803

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 873 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



Boston Children's Hospital

Where the world comes for answers



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March 22nd, 2022

Dear Representative Murphy,

Thank you for getting a hearing scheduled for the AB 873 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