

U2FP's Wisconsin Cure Advocacy Network

Testimony on Assembly Bill 873
Assembly Committee on Colleges and Universities
April 6, 2022

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 riskier and longer process. On bathroom and showering days, at least an additional three hours are required. These days are different for each person. As a result, Max does not schedule his classes before 11 am to assure he is completed with this task.

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 to the State of Wisconsin of this community. Thanks for your time and support of this effort.

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 Harly 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

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.

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.



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 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, appearing to read 'Murray Blackmore', written in a cursive style.

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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.

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.

