



## Online Risk Calculator is now available!

We are truly thrilled that our first individualized tool for determining risk of outcomes will be coming online any day. As part of our Knowledge Translation grant, we are developing online risk calculators, where a person will enter personal demographic information/risk factors and receive immediate results. Our first calculator will be on **life expectancy** and will emphasize socioeconomic factors that include education, work, and employment.

Life expectancy estimates help people to get an idea of the average number of years of life left for people with SCI have characteristics similar to them. Taking into account socioeconomic factors, the calculator shows how, in general, life expectancy relates to educational accomplishments, working, and having different levels of income. Life expectancy estimates are only general and no one lives to their exact life expectancy – some people will outlive the estimate, even substantially, while none of us is guaranteed tomorrow.

We are also very excited that to announce that we have two other calculators near completion, **unintentional injuries due to falls** and **unintentional injuries due to events other than falls**.

## Community Advocates Remembered



Minnesotans with disabilities are paying tribute to two of our community members who dedicated themselves to advocacy and improving the lives of others. John Schatzlein and Jennifer Mundl died in June and will be greatly missed by many.

Read the article on Access Press:

<https://nonprofitcharity.org/schatzlein-mundl-remembered-for-contributing-to-community/>

# Research Updates

**South Carolina SCI Outcomes Study:** This is *an opportunity for us to continue to identify important outcomes for people with SCI in South Carolina and to do research that will hopefully lead to effective changes to improve outcomes.* We are in the process of obtaining the MUSC Institutional review board approval, which is necessary to obtain before we can start the study. We are following newly injured participants for the first five years after injury with annual surveys, and we are following up every five years thereafter.

**Department of Defense - SCI Negative Health Spirals Study:** This study recently wrapped up data collection. Participants included military veterans and civilians with SCI as well as family members. We completed 69 individual interviews and focus group meetings in Minneapolis MN and Atlanta GA. We also hosted multiple virtual focus group and conference call meetings to accommodate participants who had severe health issues, were too far from the meeting locations or had no access to online services.

We have just started to analyze the data and it is helping us understand how negative health patterns or spirals emerge. Many people are caught off guard by something that happens, particularly a pressure ulcer, and then simply cannot stop the spiral. Some people have lived with conditions for a very long time. Others have had complications that led to life changes, such as amputation. As we learn from the data we analyze and the openness and sharing of our participants of their life experiences. We will continue to share our findings in newsletters and on the website where we summarize our findings.

**A few words of wisdom.** Do not get complacent because you have avoided health problems successfully so far. Keep a watchful eye. To the best of your ability, surround yourself with people who care and people who know of

your situation. Many participants have not shared their situation with family and friends, so they have not had the support necessary when problems have occurred. If you have something that starts to develop, do not take it lightly. Many of the things we have seen are truly preventable at the beginning. However, once they have reached a certain point, it has been difficult for some folks to recover. The old expression that an ounce of prevention is worth a pound of cure is something that we see every day in our research.

**Aging MN45 Longitudinal Study:** This study is wrapping up the 45th year of data collection. We have received 556 self-report assessments. The adjusted response rate after taking into account the deceased participants is 86.5%. We have started data analysis. This study is the most long-standing study of SCI anywhere in the world. How amazing that we have 29 individuals who have been in this study for 45 years and over 500 others who have joined the study since that time who are still actively participating.



**Knowledge Translation Study:** We are finalizing two online risk calculators. We have hosted multiple community Focus Groups in Charleston SC, Columbia SC and Minneapolis MN to evaluate the online tools for content as well as our evaluation materials.

# Research Brief

## Changes in Alcohol Use after the Onset of Spinal Cord Injury

Davis JF, Cao Y, Krause JS. (2017), the Journal of Spinal Cord Medicine, 1-8.

### WHAT IS THE STUDY ABOUT?

Alcohol sometimes leads to spinal cord injury (SCI). If people continue to drink heavily after their SCI, they are at greater risk for poor health outcomes, even accidental death. Our purpose was to identify how often people drink alcohol after their SCI and how often they did heavy drinking, as defined by five or more drinks on occasion. We compared these rates with data from the general population. We also identified how alcohol usage and heavy drinking rates changed by about 1 ½ years after SCI onset.

### WHO PARTICIPATED AND HOW WAS THE STUDY CONDUCTED?

524 participants were enrolled between January 2002 and September 2006 from a large specialty hospital in the Southeastern United States. The SCI peer support coordinator met with all new patients and described the study. Participants completed the self-report assessment, which included basic information about themselves. It also included questions regarding alcohol use before their SCI and their current alcohol use pattern. The participants averaged 33.5 years of age at the time of self-report assessment.

### WHAT DID WE FIND?

At the time of their SCI, the portion of people with SCI who used alcohol, particularly five or more drinks upon occasion (i.e., heavy drinking), was substantially higher than the general population (SCI = 44.9%; general

population = 13%). The portion of people who drank alcohol at all and those who were doing heavy drinking decreased by 17 months post-injury. However, even with the decrease in alcohol use, the drinking rates remain somewhat elevated compared with the general population.

### IMPLICATIONS AND OR RECOMMENDATIONS?

The decrease in the portion of people were doing heavy drinking is important. Yet, there continues to be many people with SCI were doing heavy drinking who are at risk for health problems related to unintentional injuries and even unintentional death. We recommend that people with SCI who are heavy drinkers talk to a healthcare professional about their drinking to see if they may need to change their pattern and where to get help. For rehabilitation and public health professionals, we recommend the routine assessment of alcohol use in emergency departments and other healthcare settings where people have had an unintentional injury or another health problem that may be related to heavy alcohol use.

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# Krause's Corner

On July 21, I passed the 48<sup>th</sup> anniversary of my spinal cord injury. For those of you who have had long-standing SCI, you know the feeling of passing these landmarks. For those who are younger, being 48, much less having 48 years after SCI onset seems almost unthinkable. But, time marches on for all of us and those of us who were young and wide-eyed with our futures ahead of us what seemed like yesterday now are looking back over the years and asking what we done with our lives. The more important question is, for all of us – what can we do moving forward?



As I look back on my own life, I have followed my own narrow path in research to help clarify the issues facing people over the years and decades after SCI onset and point others in the direction of what needs to be done in terms of research, policy and care. However, I have personally not given enough time to being in an advocate in my own community. It is something that I have simply left to others. With the recent death of my friend John Schatzlein, one of the greatest people that I have ever been privileged know and a great friend to people with SCI and disability, there is an incredible void for advocacy. I personally have benefited from John's efforts. I would urge everyone to be an advocate in your own way in your community. Sometimes it is as simple as speaking up on little things.

In my own community here now which is South Carolina, I have (finally) begun to work to change the way our institution chooses places to hold events. I have been surprised by the favorable response, even though there have been problems in choice of venues previously, even some that are clearly without even basic accessibility. Sometimes even those who perhaps should be thinking about accessibility do not. We all need to do our part. I can say this as someone who has worked in the field of disability, but not really done my share with even basic advocacy. John's death has changed that. I know we all need to do our part. I have always known it. But now, I am finally doing it. Thank you John for your lifelong contributions. Thank you to all who have participated in our studies and who have done advocacy and other things to help others with SCI and disability. For all that you have done and will do moving forward, I am personally grateful.

## Save the Date, September 19, 2019

**During next Grand Rounds, September 19, 2019,** Dr. James Krause presented on our ongoing Knowledge Translation grant. He will take you through the process to develop online risk calculator, an online tool, where a person will enter personal demographic information/risk factors and receive immediate results.

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