



## Spring 2021 Newsletter

### South Carolina Spinal Cord Injury Outcomes Database Study

This newsletter is a product of the South Carolina Spinal Cord Injury Outcomes Database, which is a study of outcomes among people with spinal cord injury (SCI) in the state of South Carolina. The study was designed to help us better understand the needs of people with SCI in South Carolina and is supported by the South Carolina SCI Research Fund, grants 2017 SI-02 and 09-001. This newsletter is not meant to replace the advice of your physician or other healthcare provider. You should always consult your physician or healthcare provider before making changes to behavior, treatment, or use of medicine.

#### Special message

Our team is honored to continue our work on behalf of people with SCI. We know people are concerned about the impact of the coronavirus (COVID-19). As a person who has lived with SCI for 49 years, I understand that this is a serious situation and recommend everyone continues to take precautions. We all have faced adversity and we can use what we have learned to help us through this. Below are some resources that may be helpful. Together, we will get through this.

#### The South Carolina Spinal Cord Injury Association

(SCSCIA) is a chapter of United Spinal, and provides a variety of services, including information, education, referral, peer support, and support to families and SCI professionals. They are here for you.

For information and referrals, please call them at 803-252-2198 or email them at [info@scspinalcord.org](mailto:info@scspinalcord.org)



**SCSCIA Online Peer Support Groups**  
Occur every Wednesday at 1:30 PM EST  
Website: <https://zoom.us/j/340781916>  
Meeting ID: 340 781 916  
Phone number: 1-929-436-2866

#### Shepherd Center

SCI and COVID-19 information:

<https://news.shepherd.org/what-you-need-to-know-coronavirus-and-people-with-spinal-cord-injuries-brain-injuries-or-ms/>

Staying Prepared:

<https://news.shepherd.org/staying-prepared/>

#### Medical University of South Carolina (MUSC)

Find information about COVID-19 on the MUSC website: <https://web.musc.edu/coronavirus-updates>



## Data Collection Update

We continue to **collect new data** for the South Carolina SCI Outcomes Database. During the current data collection cycle, which began on January 1, 2019, we have enrolled 146 baseline participants with recent SCI (1.5 to 2 years post injury), identified through the state surveillance system. Another 46 people have been enrolled from the South Carolina Spinal Cord Injury Association. There have been 833 follow-up assessments (3, 4, 5, 10, 15, 20 and 25 years post-injury).

This is a chance for us to partner with you. We ask that you help us by completing the surveys when we send them. In turn, we will analyze the data and share our findings with you. We will also publish findings in journals so that others with SCI may benefit and we will share our findings with people who will hopefully be able to allocate needed funds to help those with SCI.

We post newsletters and materials on our website: <https://chp.musc.edu/research/help/tools>.

Thank you for your help!

## Research Update: The COVID-19 Pandemic and Spinal Cord Injury

### What are we studying?

We continue to collect data and are currently studying the effects of the COVID-19 on the lives of people with SCI who were identified through the South Carolina SCI Database, a project funded by the South Carolina Spinal Cord Injury Research Fund (SCIRF). Current results in this update are based 272 people who answered questions about how COVID-19 has affected their lives, whether they have been tested, and if they intend to take the vaccine.

Men made up 68.3% of the participants. The average age was 57.8 years and they averaged 12.9 years since the onset of their SCI. 72.3% were able to walk to some degree.

### Testing:

- 45% of the participants had been tested for COVID-19.
- Of these, 17 tested positive, which is 6.3% of the total cohort.
- 11% reported having at least one person in their household, other than themselves, who has tested positive for COVID-19.

### Impact of the pandemic:

- 28% of participants reporting delaying or cancelling medical care out of fear of catching COVID-19.
- 37% of participants use SCI supplies, such as gloves and catheters. Of these, one-third (33%) had difficulty maintaining their supplies.
- Around 41% of participants use SCI equipment, such as a wheelchair, walker, or hospital bed. 17% of these participants had difficulty maintaining equipment through the pandemic.

**Table 1. Self-reported effects of COVID-19 pandemic restrictions**

Variables	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
	%				
<b>Social/family/community participation</b>	21.2	10.8	16.7	30.9	20.4
<b>Employment</b>	35.5	15.8	28.6	9.8	10.3
<b>Physical health</b>	28.3	22.6	29.4	14.7	4.9
<b>Mental health</b>	25.1	16.7	30.0	20.5	7.6
<b>Financial well-being</b>	29.4	17.2	27.9	17.6	8.0

- Participants reported that the pandemic affected multiple areas of life, as displayed in the table above. The area that was impacted most greatly was social, family, and community participation, with 51% agreeing or strongly agreeing. Fortunately, the negative impact of the pandemic of people with SCI was far from universal. So, even for community participation, only 51% reporting a negative impact is encouraging.

### **Vaccination**

- At the time of data collection, nearly half of participants (49%) reported that they had the vaccine available to them.
- Of participants with access to the vaccine, 31% had been vaccinated.
- Of those not yet vaccinated, only 61% are planning on getting vaccinated.
- Half of all participants were concerned about the side effects. Of those not planning on taking the vaccine, a higher percentage (69%) were concerned about side effects.

### **What can I do to prevent getting COVID-19?**

To reduce your risk of getting or spreading COVID-19, practice social distancing, have good hygiene (particularly hand washing), use personal protective equipment, and take the vaccine once it is available to you. Some vaccines require two doses and taking both doses is important.

### **Should I be worried about side effects of the vaccine?**

We are not aware of any studies on side effects of COVID-19 vaccines specifically on SCI. In the general population, some side effects have been observed, including headache, tiredness, fever, chills, and a sore arm. There is agreement among health professionals that the benefits of getting vaccinated far outweigh the risks.

## Manuscript Spotlight

We highlight one published manuscript in each newsletter.

### Assistive devices and future fall related injuries among ambulatory adults with spinal cord injury: a prospective cohort study

Return to walking is often reported as one of the main goals after SCI, and a lot of emphasis has been placed on rehabilitation interventions to improve walking outcomes. However, while walking has many benefits, those with SCI who walk may also be at an increased risk of experiencing falls. Our purpose was to assess the relationship between the use of assistive devices for walking (at baseline) and the number of annual fall-related injuries (at follow-up) among a group of adults with SCI who were able to walk.

#### Key Findings

- The percentage of at least one fall-related injury decreased from 22% at baseline to 13% at follow-up.
- Participants using one walking device at baseline were associated with three times the fall-related injuries at follow-up comparing to those who used no device.
- Using multiple devices related to over eight times the amount fall-related injuries compared to those who used no devices.
- Among different walking devices, walkers and canes were significantly associated with higher numbers of fall-related injuries.

#### Conclusion

Although the chance of at least one fall-related injury decreased over time, the consequences of these injuries were severe, resulting in medical care in a clinic, emergency room, or hospital. Since using multiple walking devices was associated with very high risk of fall-related injuries, health professionals should be aware of the balance between promoting walking and taking more precautions about the risks of fall-related injury in those who walk and use devices.

To read more of this manuscript, **Assistive devices, and future fall-related injuries among ambulatory adults with spinal cord injury: a prospective cohort study**, please check out this link in the publication Spinal Cord: <https://www.nature.com/articles/s41393-020-00572-7>

## Research team gets new award for excellence

This coming Fall, Dr. Krause will accept the Excellence Award for Outstanding Leadership in SCI&D (spinal cord injury and disease) Healthcare Award from the American Paraplegia Society (APS) on behalf of the work of the research team and the commitment of people with SCI who participate in our focus groups and research. This award is given to a recipient who demonstrated outstanding leadership in the SCI&D healthcare. **We want everyone who has participated in any of our studies to know that the awards bestowed upon any member of the team also reflect the community of people who participated in our studies.** So, thank you.

#### Please feel free to contact us!

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