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President's Corner

"NASCIC operates by facilitating communication, sharing resources, and enhancing collaboration. People say our community is fractured and we can't work together. In reality, we all understand how complex it is to live with SCI and we need the diversity of organizations that exist in order to meet different needs at

Annual Meeting Update

The annual meeting held in Vancouver on October 21, 2018 was a success with 49 representatives from the North American SCI community, with representation from 9 U.S. states, 7 Canadian provinces, and the country of Curaçao.



The full version of the meeting summary report is available on our website as well as video archives of the full meeting.

<https://nasciconsortium.org/annual-meetings/>

Membership Value Proposition

Based on the table discussions with all attendees during the annual meeting, the following value proposition and benefits for each membership category have been created:

**Patron & Principal Member
(individuals living with SCI or their family members & non-profit organizations led by individuals living with SCI or their family members)**

Value Proposition:

Join the consortium in unifying the SCI community to cooperatively leverage resources and facilitate change to improve the lives of people living with SCI

Benefits:

- Promote an exchange of information, experience, and networking across the spinal cord injury community and help each other navigate resources
- Contribute to strengthening the voice of people living with spinal cord injury in North America.
- Drive change by sharing your lived experience with researchers, healthcare professionals, and policy makers – you are an expert

different times and in different locations.

NASCIC is not looking to take ownership of any organization. Rather, the goal of building membership in NASCIC is to work together across countries and organizations in situations when a single organization may not be as effective by itself to make change.” - President, Kim Anderson-Erisman

- Participate in innovative projects to move research results into care to impact the lives of persons with SCI.
- Participate in supporting efforts in shaping policy that responds to the needs of our community.

**Partner Member
(all other organizations or individuals interested in SCI)**

Value Proposition:

Engage with the SCI community to enhance effective partnerships between research, healthcare, and industry

Benefits:

- Engage and connect directly with the spinal cord injury community
- Learn about the priorities, needs, and opportunities of people living with spinal cord injury and the organizations that represent them in North America
- Gain access to people with lived experience and their family members as a critical component of the (patient) engagement movement
- Ability to present/co-design projects with NASCIC
- Earn exposure, recognition, and acknowledgment from the community living with SCI

Membership is free for all categories. To apply for membership all you have to do is fill out the appropriate form online <https://nasciconsortium.org/membership/>

Action Item!

The Executive Council of the North American Spinal Cord Injury Consortium (NASCIC) have been asked by the National Institutes of Health (NIH) to provide input from our spinal cord injured community to help chart the future of funding for spinal cord injury (SCI) research in the next decade. This is the first time that we as a community have been invited to provide meaningful input as to setting the priorities that may better represent our wishes when it comes to SCI research.

We respectfully ask that if you have an SCI or are a family member of caregiver of someone with an SCI that ***you take the time to fill out the attached survey*** and if possible, ***forward the survey*** to friends and family who have been impacted by SCI and to members of your organizations that represent people with spinal cord injuries. This is a great opportunity for all of us to have a voice!

Access the survey via this link:

<https://www.surveymonkey.com/r/SCI2020>

Please join us in providing guidance to both the NIH and the many SCI scientists in moving forward into the next decade of SCI research.

The survey will close January 18, 2019.

Meet newly elected Executive Council member Bill Fertig



Bill is Director of United Spinal Associations Spinal Cord Injury Resource Center. He lives with family in Virginia Beach, VA and telecommutes in his work with United Spinal. He served twenty-five years as a municipal police officer and training sergeant. An off-duty motorcycle accident resulted in T-7 paraplegia in 1999. Bill brings his past experiences and life with SCI to his Information Specialist team which helps support consumers who contact the Spinal Cord Injury Resource Center after injury or disease onset.

As an Executive Council member for 2019, Bill hopes to help build NASCIC membership through his SCI community contacts and assist as needed in the project-based initiatives of NASCIC.

Welcome Bill!

Exoskeleton Project Update

In 2018, NASCIC members approved a project request from IHMC and Myolyn to create an advisory team of diverse people living with SCI to partner with them in the design of a new robotic exoskeleton. The exoskeleton design project is part of the Toyota Mobility Foundation Mobility Unlimited Challenge. The Advisory Team helped identify and define the mobility goals of individuals with lower limb paralysis and provided a critical perspective for creating a road map that balances individuals' needs, concerns, preferences, and goals with available and emerging approaches to address them. It was just [announced](#) that IHMC and Myolyn are 1 of 5 [finalists](#) and have received \$500,000 grant to further develop their Quix exoskeleton concept. Prototypes of the 5 devices will be presented in Tokyo. The winner will showcase the device at the Tokyo Games in 2020 and

receive \$1 million to further manufacturing and commercializing the device. The Advisory Team will continue to work with IHMC and Myolyn throughout the competition to develop an exoskeleton that meets the needs of people living with paralysis. Congrats!!

SCI 2020: Launching a Decade for Disruption in Spinal Cord Injury Research, February 12-13, 2019, Bethesda, Maryland

The NIH is hosting a conference to bring together SCI researchers and stakeholders from across the injury spectrum (basic to clinical and acute to chronic), to critically address the current state of the science and to actively debate and define the most promising and meaningful research opportunities for the next decade. Specific goals are: to encourage breakthrough collaborative approaches that will disrupt existing silos, to engage SCI consumers in understanding and prioritizing key research questions, and to define the necessary resources and mechanisms to accelerate the trajectory of SCI research from discovery to implementation.

Information about the conference can be found here:

<https://meetings.ninds.nih.gov/Home/Index/21041>

The NASCIC Executive Council will be involved in communicating the needs of the community living with SCI. To provide your input to the Executive Council, please send an email to

info@nasciconsortium.org