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NASCIC Newsletter - 'Speak Up' Vol. 1, Iss. 2

1 message

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Wed, Jul 11, 2018 at 9:14 AM

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North American
Spinal Cord Injury
— Consortium —

'Speak Up'

Volume 1, Issue 2

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Member Spotlight



[GUSU](#) is a Minnesota community driven nonprofit with the goals of advancing research, adaptive fitness, and community support for people living with spinal cord injury. Through GUSU's advocacy work they created a \$3 million/ year

state funded spinal and brain injury research grant program. GUSU continues to drive betterment of life for those with SCI by supporting research and educating the community.

Although GUSU is a relatively small organization, they became a member of NASCIC to join and promote the need for collective collaboration with the overall SCI community. As a principal member, GUSU's members and leadership have benefited by adding to the collective voice of SCI leaders, being aware of and contributing to impactful projects that affect the community, and keeping up to date on SCI related developments.

Rob Wudlick is GUSU's voting delegate. He was also voted on to the Executive Council of NASCIC and is serving a 2-year term (2018-2020).



Rob Wudlick - Chair, Treasurer and Co-founder, GUSU

Membership Update

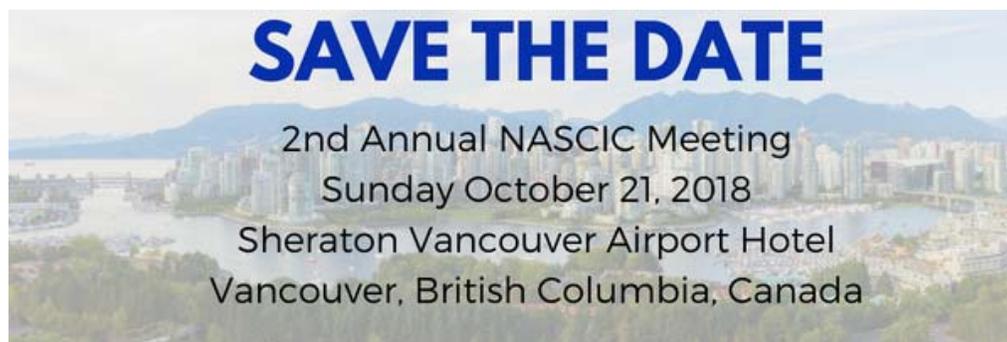
NASCIC is a grass roots effort to turn up the volume on the collective voice for spinal cord injury action in North America. By joining together on common topics, we can impact change on a larger level for a larger number of people living with SCI. Towards that goal, NASCIC serves as an umbrella for the diversity of people living with and organizations led by people with SCI. Everyone is welcome to join.

There are currently three types of membership:

- Patron (Individuals with SCI or caregivers) - currently 4 members
- Principal (Nonprofits led by people with SCI) - currently 12 members
- Advisory (Organizations not led by people with SCI) - currently 1 member

Join the movement, make a difference, and be part of the change!

www.nasciconsortium.org/membership



We will be discussing accomplishments and challenges, strategies for 2019, upcoming projects, and modifications to the charter. Membership engagement and SCI community inclusion are our overarching priorities. Stay tuned for event registration and an agenda.

Participation will be available in person as well as online.

For more information please visit our [website](#)

Action Item!

The advisory team working with the bladder and bowel neuromodulation working group has created a survey seeking the consumer perspective of nerve stimulation for neurogenic bladder and bowel dysfunction. Please see below.

If you could kindly distribute the survey to your networks, it will help obtain the collective input of people living with SCI.

We want to hear from individuals with spinal cord injury!



Who we are: We are a group of individuals from clinical, research, industry, and SCI advocacy organizations who have designed a survey that we believe is of high importance to the SCI community.

We need your help: We are conducting a survey and the purpose is to provide individuals with spinal cord injury (SCI) with a voice to help the research community understand your needs and priorities for managing your bladder and bowel functions.

Why this survey matters: Your feedback will be used to directly affect research and development priorities for improving bladder and bowel care for people living with SCI.

As a person living with SCI, your input is critical to finding real solutions to bladder and bowel management issues that you face on a daily basis. We want to understand your needs and priorities for improving your bladder and bowel functions, and understand your opinions about using nerve stimulation technologies to achieve these goals.

This survey will take approximately 20 minutes to complete. Please follow the link below to complete the survey and enter for a chance to win a \$50 Amazon gift card!

President's Corner



**NASCIC President,
Kim Anderson-
Erisman**

“To have started from nothing, NASCIC has come a long way in a short period of time. From talking about people living with SCI needing a greater voice at the research table in 2016, to having a full-fledged organization with a charter, membership, leadership, and initial projects in 2018 – a small number of people have accomplished a lot. Now we want to grow our organization, respond to our member’s needs, and develop a mechanism by which the community of people living with SCI at large is comprehensively represented. People living with SCI are valuable, smart, and have the true insight of the depth of SCI. We will be equal partners in the research enterprise and we will do so by using our diversity as our strength.”

Project Updates

Spinal Cord Injury Trial Toolkit (SCITT)

The SCI clinical trials participant-to-research matcher is currently being developed! A Beta release is targeted for this fall and official launch by the end of the year.

NASCIC member, Rob Wudlick (GUSU2Cure Paralysis), has been helping add the consumer perspective for development of the portal. Nial El-Assaad (Fuel Service), a paraplegic from the United Kingdom, has been developing the website and adding additional consumer perspective with professional development and user interface experience. By utilizing professional and community input on this project, a more meaningful and user friendly clinical trials matcher will be created which will help those with SCI and researchers looking for trial participants connect. SCITT will be sending out a survey for consumers and researchers during the beta release, to aid further development of the portal.



Community Advisory Team for Robotic Exoskeleton Working Group for Increased Mobility

In May, the NASCIC membership voted on and approved a new project. This project aims to create an Advisory Team comprising 4-6 people living with SCI with diverse perspectives to collaborate with the Robotic Exoskeleton for Increased Mobility Working Group. This project will be led by representatives from the Florida Institute for Human & Machine Cognition (IHMC) and Myolyn as part of their Discovery Award for the Toyota Mobility Unlimited Challenge. The high-level vision for this exoskeleton is a self-balancing, semi-autonomous, hands-free, highly mobile device that will increase mobility for people with lower limb paralysis. The initial advisory team, of five diverse individuals living with SCI, met with the working group on June 21 at IHMC. The focus was to gain an understanding of consumer needs and potential design needs. As a follow up to the initial meeting, there is continuous dialogue between the advisory team and the working group using Slack in preparations for their full proposal submission due in August 2018.

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.

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



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