

North American Spinal Cord Injury — Consortium —

# 'Speak Up'

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## In This Issue

• Annual Meeting Highlight

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## Annual Meeting Held October 6<sup>th</sup>!

The face-to-face NASCIC annual meeting was held in Cleveland, Ohio on Sunday October 6, 2019.

The theme was 'COLLABORATING FOR CHANGE'. We have collectively been making great progress over the last year on our initial activities. We welcomed members and nonmembers to come together and continue building our ability to collaborate across our community and across various stakeholders.

The day started with a description of the current results of the Needs Assessment Survey of our community.



Cure, research, and care are all important to our community. Two areas the community wants us to direct our efforts to are improving access to SCI-specialized care and to available research studies and clinical trials. Bladder, bowel, pain, and care are the top challenges people face on a daily basis. Members of our community want to be actively engaged in the research process.

The next session was about building capacity within our community. One of our primary goals over the next two years is to build capacity within the community living with SCI to become more engaged and active partners in research and care activities. This is a large undertaking, but it will ultimately allow our community's voice to have a larger impact across North America.



This was followed by a description of tools currently available for researchers to engage people living with SCI.

These resources will soon be on the NASCIC website. Two NASCIC resources that were highlighted were the newly formed Project Engagement Database and the www.SciTrials.org platform.

After lunch a lively discussion was had with our Partner Panel. Partner representatives Dennis Bourbeau (FES Center), John Gensel (SCoBIRC), Lisa Lombardo (APT Center), and Michelle Towle (DP Clinical) answered discussion questions about challenges engaging the community as well as the great value the community adds. People living with SCI don't need to be scientists to bring value to research, they just need to bring their lived experience.



The day ended with a discussion of the full scope of translational research: from basic research to clinical trials to clinical practice in the communities. What is each of us going to do to ensure that all the time and money invested in SCI research results in tangible impacts to all of us living out in the community? It's a complex problem requiring complex solutions, but one thing is for sure – all of us living with SCI have to become part of the team working towards resolutions.

The slides and videos of the meeting will be made available shortly.