



North American Spinal Cord Injury — Consortium —

2 nd NASCIC ANNUAL MEETING - FINAL AGENDA	
DATE	Sunday, 21 October, 2018
TIME	9:00AM - 4:00PM PST
LOCATION	Sheraton Vancouver Airport Hotel, Richmond, BC, Canada All activities will be in the Minoru A+B meeting space

MEETING AGENDA

PURPOSE:

To bring together members for collaboration, interaction, and planning for the next year and near future.

OBJECTIVES:

1. Develop NASCIC strategic goals for 2019
2. Update charter and project selection process
3. Discuss current and future projects
4. Network across membership

AGENDA AND TIMELINE:

TIME	DESCRIPTION	SPEAKER
8:00	Registration and Breakfast	
9:00	Opening/Welcome	Kim Anderson-Erisman
9:10-9:30	Accomplishments and Challenges <ul style="list-style-type: none"> • History, accomplishments, governance, current projects, current membership, financial status 	
9:30-10:30	Strategic plan discussion <ul style="list-style-type: none"> • Year 1 action items • Membership value proposition 	Jen French
10:30	BREAK	
10:45-11:30	Amendments to NASCIC documents <ul style="list-style-type: none"> • Charter Amendments <ul style="list-style-type: none"> ○ Review all text sent pre-meeting ○ Vote on revisions 	Barry Munro



North American Spinal Cord Injury — Consortium —

	<ul style="list-style-type: none"> • Project selection process <ul style="list-style-type: none"> ○ Review all text sent pre-meeting ○ Vote on revised process • Open nominations for elections <ul style="list-style-type: none"> ○ Treasurer ○ Delegate for 1-year term ○ Project Review Committee, 4 members 	<p>John Chernesky</p> <p>Sasha Rabchevsky</p>
11:30-12:30	LUNCH	
12:30-2:00	<p>On-going Project Status and Update (5 min each)</p> <p>New Project Discussions:</p> <ul style="list-style-type: none"> ○ Engagement tools – 20 min ○ SCI registry – 20 min ○ Preference study – 20 min 	Matthew Rodreick
2:00	BREAK	
2:15-4:00	<p>Finish any unfinished topics discussed earlier in the day</p> <p>Open discussion and idea formulation from current events</p>	All
4:00	Adjourn	
4:00-6:00	Networking Cocktail Reception	

OUTPUTS/OUTCOMES

1. Revised charter
2. Revised project selection process
3. Consortium Goals and Direction for 2019
4. Nominees for election

STRATEGIC PLAN

July 17, 2018

NORTH AMERICAN SPINAL CORD INJURY CONSORTIUM INFRASTRUCTURE PROPOSAL

PURPOSE OF THIS PROPOSAL

Until about 15 years ago, the opinions of people living with spinal cord injury (SCI) were rarely considered in terms of research or clinical care. In the recent past, the term “consumer engagement” has begun to be a topic in many areas that serve people living with SCI. The discussions have been important toward encouraging change, but the execution has not been strong. There have been successful efforts in other conditions, such as Parkinson’s disease and ALS, where the people living with the condition have become equally valued partners with stakeholders including research/clinical entities, industry, funders, and regulatory agencies. These partnerships have developed collaborations that have had a meaningful impact in terms of research, care, and policy. The time is now for the community of people living with SCI to develop a mechanism by which meaningful consumer engagement can occur on multiple fronts.

The North American Spinal Cord Injury Consortium (NASCI) has been designed to identify gaps, communicate resources, and be a conduit for collaboration between the community of people living with SCI and the many stakeholders. With this in mind, NASCI submits this business plan and infrastructure building proposal to the Craig H. Neilsen Foundation for consideration of supporting **\$45,000** over 3 years (split \$20,000 Year 1, \$15,000 Year 2, \$10,000 Year 3) with a matching fund challenge. This infrastructure proposal will yield a strong foundation for the mission of NASCI as a sustainable and impactful organization to harness the collective voice of those living with spinal cord injury and their families and caregivers. The strategic plan focuses first on membership development and operational framework, then toward project outcomes, and engaging the stakeholder community. This proposal will provide an overview of the organization, NASCI’s current status, a three-year plan for the organization, and outstanding needs for further developing the organization.

INTRODUCTION TO NASCI

NASCI was launched in January 2018 following 18 months of discussions, research, and communications among members of the spinal cord injury community (**For the full history of NASCI refer to Appendix A**). As a recently established organization, NASCI is in the process of building the infrastructure for a sustainable and impactful entity.

BACKGROUND OF NASCI

Mission

(NASCI) has the mission to bring about unified achievements in research, care, and policy by advocating for collaborative efforts across the spinal cord injury community.

Purpose

NASCI is an organized and intentional response to the growing recognition of the need for strong and trusting partnerships between those living with SCI and the SCI stakeholder community. Through NASCI we seek to improve research, care, and policies that impact people living with spinal cord injury, their families, and their community. Working

collaboratively, the organization is structured to effectively bring about collective change through approved projects. This is achieved through:

- A) Formation of relationships and active engagement between the individuals and organizations representing spinal cord injury;
- B) Exchange of valid, trustworthy, and useful information, experience, and knowledge;
- C) Promotion of and involvement with 'best practices of consumer engagement' in research, care, and policy;
- D) Creation of a unified platform for SCI advocacy in North America;
- E) Collaboration between the SCI community and experts in the fields of research, care, and policy.

As a new organization, NASCIC's initial focus is to create a framework for thoughtful decision making, membership engagement, and prioritization of community interests. While there are many potential issues to address with SCI such as rehabilitation, independent living, secondary conditions, and employment, NASCIC's initial focus is on research, and in particular, strengthening the connections between the research and SCI communities across the full continuum of research, from T0 to T4.



SCI research is quickly progressing in North America, and SCI consumers need to be equitable partners to ensure the end results are oriented toward consumer needs, are clinically relevant, and are transparent in order to increase engagement from consumers.

Prior to forming the Consortium, a team of founding members conducted a search to seek similar organizations and determine the factors of their success. They researched a field of similar groups to NASCIC in order to better understand key success factors. Successful examples presented of collaborative consortia were the Health Charities Coalition of Canada and the European SCI Federation. Based on their analysis, seven recommendations were made for the formation and operation of NASCIC:

1. Dedicate resources to a secretariat/administration;
2. Be project focused, not committee driven;
3. Have projects driven by members that best fit the project description;
4. Structure the consortium so that all members are recognized equally;
5. Start by identifying a common project as a test case (i.e., cure) and then develop a guidance as the project comes to fruition;
6. Create a memorandum of understanding;
7. Create a realistic budget to drive the chosen project.

The framework for NASCIC was established from this basis.

Guiding Principles of NASCIC

The defining interest of NASCIC is to bring about positive change for persons living with spinal cord injury, their care, and their quality of life.

1. NASCIC achieves its mission through the conduct of projects, rather than through the establishment of committees.
2. The members of NASCIC are treated equally regardless of size, financial means, and breadth of reach.
3. NASCIC builds collaborative partnerships and connections to the SCI community.
4. The organization will operate in an ethical and financially responsible manner.
5. NASCIC is structured as a learning organization, with periodic internal reviews, including annual/semi-annual reviews of the NASCIC Charter.

The success of NASCIC hinges on its ability to harness the commonalities of a diverse and fragmented SCI community.

The next step to move NASCIC forward is two-fold: membership development with outreach and infrastructure development.

MEMBERSHIP BASE

The strength of NASCIC is in its members. As noted in the creation of the organization, there are many organizations representing people living with spinal cord injury. NASCIC will work towards bringing them together, finding commonalities, and collaborating on those commonalities to make a larger impact.

NASCIC was formed with 15 founding members who worked toward an inaugural meeting that included 40 organizations. The attendees were tasked with creating a governance and framework from which NASCIC could be created in order to achieve its mission. Attendees also had to determine the definition of a member, who those members would be, and how to democratically designate leadership.

They decided on three membership categories:

1. **Principal:** A consumer-based organization. The organization must be a registered 501c3(USA), Registered Charity, not-for-profit organization, or the equivalent that directly serves, represents, or advocates for the SCI community whether nationally, regionally, or locally. A principal member that represents the disability community in general, must have some direct interaction or related focus on the SCI community.
2. **Patron:** Any individual living with a spinal cord injury or directly representing a person living with a spinal cord injury, such as a caregiver or family member, with the main objective of representing themselves and not an organization.
3. **Advisory:** Any organization or individual with an interest or activities related to people living with SCI, but not a consumer-based registered 501c3 (USA), Registered Charity not-for-profit organization, or the equivalent in its jurisdiction that directly serves, represents or advocates for the SCI community. Examples may be clinical care facilities, professional associations, funding agencies, for-profit entities, government agencies, research institutions, etc. As members, NASCIC is the conduit to disburse and receive information, guide decision making and gain greater participation among the SCI Community.

In keeping with NASCIC being a consumer-led and consumer-focused advocacy consortium, only Principal and Patron members have voting rights within the organization. There are no voting rights for Advisory members. This decision was made because of the importance of establishing an autonomous SCI consumer voice and is a critical guiding factor for the consortium.

As of the date of this proposal, there are currently 17 members of NASCIC. Membership recruitment is a key element to the success of the consortium.

- **Principal members = 12**
- **Patron members = 4**
- **Advisory members = 1**

PROJECT BASIS

The focus on projects allows the consortium members to engage in activities with tangible outcomes. Projects may be proposed to the consortium by members as well as non-members.

NASCIC members provided feedback on the proposed projects using the following criteria:

1. The potential to form relationships between the individuals and organizations representing spinal cord injury;
2. The potential for the exchange of valid, trustworthy, and useful information, experience, and knowledge;
3. The potential for promotion of and involvement with 'best practices' in research, treatment, and care;
4. The potential to create and/or strengthen a unified voice for SCI in North America;
5. The potential to promote collaboration among experts in the fields of research, clinical care, and advocacy of participating members;
6. The resources required of NASCIC, and
7. The potential impact (considering both breadth and depth) of the proposed project.

Members then vote as to whether or not NASCIC will be involved in the project. If adopted, the project is assigned a lead for the execution and oversight of the project. The inaugural projects are:

- Consumer Advisory Team for Neuromodulation Working Group for Bladder & Bowel
- Spinal Cord Injury Trials Toolkit (SCITT)
- Enhancing Partnerships: Guiding Principles for Conducting and Disseminating Research in Partnership with the SCI Community
- Consumer Advisory Team for Robotic Exoskeleton Working Group for Increased Mobility

(See Appendix B for further breakdown of current projects)

GOALS, OBJECTIVES, & MILESTONES THREE YEAR OUTLOOK

The goals, objectives, and milestones are presented below. Membership and sustainability are the hallmarks of the initial efforts followed by measuring outcomes and building collaborations.

- **Goal 1: Grow the membership of the North American SCI Consortium.**

Current Status: The Charter designates how people and organizations become members of NASCIC. There is now an online application, a means of processing payments and donations, and conflict of interest form. NASCIC has a website, has created an e-newsletter, and scheduled the next annual meeting; all to improve communication with members.

- Objective A: Establish a consistent communication message for member recruitment.
- Objective B: Outreach to Founding members and organizations who were in attendance at the Inaugural meeting to become members. Result = 40 members.
- Objective C: Launch and execute a recruitment assignment for members to grow the total member-base. Result = 75 members.
- Objective D: Develop and execute an awareness/marketing campaign to grow membership. Result = 100 members.

Key Milestones

	Action	Complete
Objective A	Define the organization, member benefits, and the value proposition.	Q4 2018
Objective A	Build a shared engagement resource for the SCI community	Q1 2019
Objective B	Connect with founding and inaugural attendees through personal meetings, email, phone calls for recruitment. Reach membership goal of 40 total.	Q4 2018
Objective C	Challenge NASCIC members to recruit at least one additional member for viral growth of the membership base. Reach membership goal of 75 total.	Q1 2019
Objective D	Launch outreach through social media channels, traditional media, meeting presentations, etc. to build awareness. To also include interactive communication channels with current members. Reach membership goal of 100 total.	Q3 2019

● **Goal 2: Build operational support and a sustainable funding platform.**

Current Status: NASCIC is currently affiliated with the Canadian/American Spinal Research Organization (CSRO/ASRO). This allows the organization to operate as a registered charity and 501(c)(3) status. A part-time secretariat has also been contributed in-kind by CSRO/ASRO to NASCIC. The organization has an address for donations and a means of processing donations. NASCIC also has some operational funds (\$13,000) drawn from the surplus from the inaugural meeting. There is also a 3-year budget.

- Objective A: Secure continuation of In-kind donations from CSRO/ASRO.
- Objective B: Develop financial review process as stated in the Charter.
- Objective C: Solicit sponsors and financial support for the annual meeting.

- Objective D: Identify strategic sources of revenue and an approach for each.

Key Milestones

	Action	Complete
Objective A	Draft and sign a formal MOU for NASCIC continued in-kind support from CSRO/ASRO to house the consortium with a defined scope, formalizing job description and timeframe.	Q4 2018
Objective B	Establishment and completion of an annual financial and structure review to be reported at the annual meeting along with a quarterly financial review for the Executive Council.	Q4 2018
Objective C:	From the targeted list, approach potential donors for sponsorship support of the annual meeting to gather the members both in-person and streaming online to address the business of the organization and adopt and/or review new projects.	Q4 2018 Q2 2019 Q2 2020
Objective D:	Conduct a landscape search and identify strategic funding sources to support the NASCIC budget.	Q1 2019
Objective D:	Develop the “pitch” for support.	Q2 2019

- **Goal 3: Adopt and measure impactful projects outcomes that have importance to the spinal cord injury community.**

Current Status: NASCIC has an initial project proposal and feedback mechanism. This was tested at the inaugural meeting after the realization that a project-driven mission is required to show the consortium has value to the community.

- Objective A: Finalize the project process and evaluation mechanisms.
- Objective B: Develop a mechanism to refine the efficacy of the project process to manage as the number of requests increases.
- Objective C: Create a measurement of and communication for projects

Key Milestones

	Action	Complete
Objective A	Present the revised project evaluation at the annual meeting; test and gain feedback	Q4 2019
Objective B:	Develop a mechanism for measuring outcomes of the project completion and a means of communicating the outcomes	Q1 2020
Objective B:	Implement a project and external request management system	Q2 2020

Objective C:	Create evaluation criteria and metrics for projects	Q3 2020
Objective C	Build a comprehensive communication plan for projects	Q1 2021

• **Goal 4: Build a communication network between the SCI and the stakeholder communities in North America.**

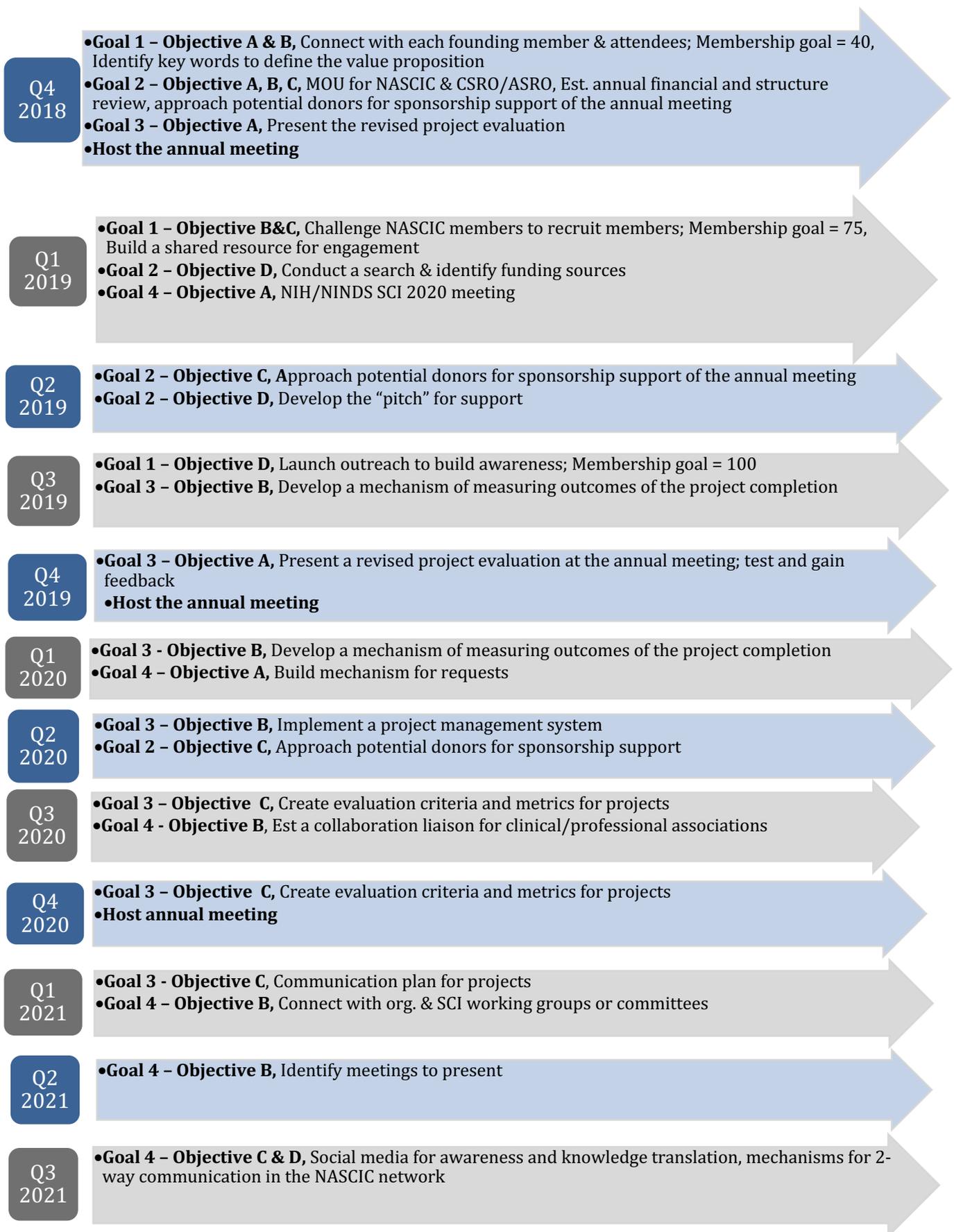
Current Status: This is an area that is important for the impact of NASCIC. To date, any actions on this front have been sporadic and we seek to develop this area as NASCIC evolves.

- Objective A: Build an infrastructure to manage outside requests and needs from organizational partners.
- Objective B: Develop collaborations with research & professional associations.
- Objective C: Build awareness among SCI stakeholder organizations.
- Objective D: Develop a mechanism for the translation of knowledge to the SCI and stakeholder communities.

Key Milestones

	Action	Complete
Objective A	Build internal mechanisms to manage requests to NASCIC from external stakeholders.	Q1 2020
Objective B	Establish a collaboration liaison between NASCIC and the clinical/professional associations, such as ASIA, ASCIP, ACRM, NNS.	Q3 2020
Objective B	Involvement in the NIH/NINDS SCI 2020 meeting and planning.	Q1 2019
Objective B	Connect/partner with aforementioned organizations along with their affiliated SCI working groups or committees.	Q1 2021
Objective C	Identify SCI research/clinical meetings and submit proposals for abstracts and/or presentation by NASCIC to them.	Q2 2021
Objective C/D	Develop social media channels to increase awareness of NASCIC and knowledge translation.	Q3 2021
Objective D	Develop protocols and mechanisms to engage a two-way communication within the NASCIC network	Q3 2021

Timeline of Objectives/Milestones



BUDGET - NASCIC 3-YEAR BUDGET

REVENUE	2018	2019	2020
Cash	\$ 13,010.73	\$ 283.38	\$ 1,051.03
Estimated Yearly Membership Fees	\$ 10,000.00	\$ 15,000.00	\$ 20,000.00
Grants	\$ 10,000.00	\$ 15,000.00	\$ 15,000.00
Sponsorship	\$ 20,000.00	\$ 25,000.00	\$ 30,000.00
TOTAL	\$ 53,010.73	\$ 55,283.38	\$ 66,051.03

EXPENSES	2018	2019	2020
Administrative Salary (no benefits - currently in-kind)	\$21,353.75	\$21,353.75	\$21,353.75
Annual Audit and Accounting/Legal Services	\$1,000.00	\$1,000.00	\$1,000.00
Bank Fees	\$50.00	\$50.00	\$50.00
Computer Software	In-Kind	In-Kind	In-Kind
Conference Line (Zoom and Bell)	\$749.00	\$749.00	\$749.00
Conferences	\$0.00	\$5,000.00	\$10,000.00
Courier Costs and Postage	\$350.00	\$350.00	\$350.00
CRM Management Account	\$120.00	\$120.00	\$120.00
General Office Supplies	\$1,000.00	\$1,000.00	\$1,000.00
Insurance	\$310.60	\$310.60	\$310.60
Meeting Expenses - Annual Meeting	\$10,000.00	\$10,000.00	\$10,000.00
Office Equipment/Furniture	In-Kind	In-Kind	In-Kind
Phone/Internet	In-Kind	In-Kind	In-Kind
Promotion/Marketing	\$9,000.00	\$7,000.00	\$5,000.00
Rent	In-Kind	In-Kind	In-Kind
Signage & Promotional Materials	\$750.00	\$750.00	\$750.00
Stripe Fees	\$200.00	\$200.00	\$200.00
Travel Expenses	\$5,000.00	\$5,000.00	\$5,000.00
Quickbooks Online	In-Kind	In-Kind	In-Kind
Website Design & Hosting	\$2,495.00	\$1,000.00	\$1,000.00
WuFoo Account	\$349.00	\$349.00	\$349.00
TOTAL	\$52,727.35	\$54,232.35	\$57,232.35

TOTAL NET REVENUE	\$283.38	\$ 1,051.03	\$ 8,818.68
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REQUEST FOR SUPPORT AND ALLOCATION

The Craig H. Nielsen Foundation's support to NASCIC will kick-start the implementation of the above Goals, Objectives, and Milestones to be achieved by the end of 2020. Much has been done toward crafting our mission, purpose and principles, adopting the organizational charter by the founding members, and listening to the current needs that are unfulfilled. The next step is executing the plan for valuable consumer engagement. The focus of NASCIC initially will be toward membership development and communication and building a sustainable operational framework, and then shift toward project outcome for the SCI community and building communication with the stakeholder communities.

We are proposing an initial investment of \$20,000 (Year 1). In the following two years funds provided by the Nielsen Foundation will be contingent upon NASCIC's own fundraising capability. In Year 2, \$15,000 of financial support will be provided only if NASCIC is able to raise matching funds of \$5,000. Year 3 will be reduced to \$10,000 and only provided if NASCIC is able to raise matching funds of \$10,000. The proposed three-year commitment will draw down as the Consortium grows. The initial investment in seed-funding for Year 1 will focus on membership development and operational infrastructure, to include but not limited to waiving of Patron and Principal members' dues, establishing communication channels within the community, and improving the operations of the organization. The second year will focus on building funding resources and outreach mechanisms. Year 3 will move toward stakeholder partnerships and project implementation.

IMPACT OF NASCIC & CRAIG H. NEILSEN FOUNDATION

By accepting this proposal, the Craig H. Nielsen Foundation will be supporting the advancement of collaborative efforts within the community of people living with SCI, enabling them to become equitable partners in the enterprise encompassing SCI. Through our aggregation and activation of individuals and organizations affected by SCI, NASCIC can bring the voice of the community of people living with SCI into every state of the discovery pipeline and become a conduit to increase the potential for unified achievements in research, care, and policy. Meaningful consumer engagement has become a growing need for all facets servicing people living with medical conditions. SCI research is rapidly progressing in North America, and it is through collaboration and communication that we will be able to achieve results that are oriented toward the needs of people living with SCI, are clinically relevant, and are transparent with the shared goals of NASCIC and the larger community of stakeholders.

APPENDIX A

HISTORY

The formation of the North American SCI Consortium is a direct result of a centralized theme from the 2016 Praxis meeting hosted by the Rick Hansen Institute. The theme is to have a greater voice of consumers living with SCI with action items of setting up a centralized consumer body and enabling effective communication between consumers and researchers. With the listing of pledging founding members below, the creation of an operational framework is essential for the sustainability of this effort.

Founding members:

- Sam Schmidt Foundation/Conquer Paralysis Now
- Rick Hansen Institute
- SCI Canada
- Get Up Stand Up 2 Cure
- Ontario Neurotrauma Foundation
- Canadian and American Spinal Research Organization
- Institute for Functional Restoration
- United Spinal Association Research Committee
- Facing Disability
- Morton Cure Paralysis Fund
- SCI Ontario
- SCI British Columbia
- Unite 2 Fight Paralysis
- Neurotech Network
- The Miami Project to Cure Paralysis

On October 12th, 2017 people living with spinal cord injury, their caregivers, and those who work for organizations that represent their interests gathered in Miami. This was the first meeting of the North American Spinal Cord Injury Consortium (NASCIC) with an attendance of nearly 60 people. The purpose of the meeting was to bring together organizations in North America that advocate, represent, or communicate with people living with spinal cord injury to create a project-focused consortium.

Objectives of the inaugural meeting were to:

1. Convene North American organizations focused on people living with SCI
2. Come to agreement on a proposed governance charter for NASCIC
3. Come to agreement on a method for identifying promising projects to support.

A top priority was the adoption of an organizational Charter. The proposed Charter was prepared and discussed extensively by the Organization and Preparation Committees prior to the meeting. On-site, participants worked in table groups to review the proposed Charter section by section. In plenary, tables indicated with a card whether they were comfortable (green), had reservations or questions (yellow), or completely opposed (red) with each section. At the end of the day, this question was proposed to “Given our discussions today, do you agree to the foundation of the North American Spinal Cord Injury Consortium?” Participants were asked for a show of either their green (yes) or red (no) card.

Participants were unanimous in electing to move forward with NASCIC, and a new consumer-led advocacy organization was formed.

APPENDIX B

CURRENT PROJECTS

Consumer Advisory Team for Neuromodulation Working Group for Bladder & Bowel

This project is seeking to create an Advisory Team comprising 5-6 people living with SCI to collaborate with the Neuromodulation for Bladder and Bowel Working Group. Initiated by the Craig H. Neilsen Foundation Neurogenic Bladder and Bowel Workshop, this Neuromodulation Working Group was created out of a team of approximately 12 individuals from research, industry, clinical, and advocacy organizations to explore neuromodulation interventions for bladder and bowel function for individuals living with SCI. The goal of the Working Group is to promote adaptation and translation of neuromodulation technologies to meet the functional goals of individuals with neurogenic bladder and bowel dysfunctions within a 10-year timeframe. The purpose of the Neuromodulation Working Group is to (1) Identify existing or emerging neuromodulation technology that can be leveraged in our timeline to meet this goal; (2) Identify and describe the steps that the field should take to achieve this goal; (3) Identify the opportunities and barriers that exist in accomplishing this goal; and (4) Create a roadmap and manuscript to publish the working group's recommendations.

The role of the Advisory Team will be to help identify and define the bladder and bowel goals of individuals with SCI and provide a critical perspective for creating a roadmap that balances individuals' needs, concerns, preferences, and goals with available and emerging neuromodulation approaches to address them. This will be accomplished by surveying NASCIC members and incorporating their feedback into a written document.

Spinal Cord Injury Trials Toolkit (SCITT)

Full and timely recruitment for SCI clinical trials was identified as a significant barrier to trial completion in 2 separate 2016 SCI meetings (PRAXIS and Ittingen). A SCITT working group was subsequently tasked with finding solutions to this barrier. SCITT envisions a one-stop shopping website with integrated portals for all clinical trial stakeholders (people with SCI, clinicians referring patients to clinical trials, clinical trial Investigators and Sponsors of clinical trials). Each portal will be customized to each stakeholder with clinical trial information, links, downloadable documents and tools, and more. Unique to the SCITT website is an intent to curate the information available on clinicaltrials.gov and subsequently sorted by SCOPE. Objective data on protocol design, availability of preclinical evidence, regulatory oversight, appropriateness of hypothesis and outcome assessments, etc. will be presented in lay, clinical and scientific summaries. These are intended to assist people with SCI and clinician stakeholders when considering participation and referring patients for clinical trials. Investigators and Sponsors will also be given the opportunity to provide curation input if relevant data is not obvious from the published trial information. On the portal for people with SCI, not only will curated trial summaries and practical information about clinical trials and participation be available, the clinical trial matcher (CTM) is to be developed using artificial intelligence (AI) software. AI matching is increasingly enhanced with personal health information provided through a patient self-classicator, uploaded documents or full electronic medical records. NASCIC is collaborating with the SCITT team on the development of the portal for people with SCI.

Enhancing Partnership: Guiding Principles for Conducting and Disseminating Research in Partnership with the SCI Community

Integrated KT (IKT) is an approach to doing research whereby research users as partners alongside researchers throughout the entire research process. The resulting research is more applicable, useful and translatable to end-users than research conducted by researchers alone. Despite the advantages of an IKT approach, only a small minority of KT activities have been planned and implemented in partnerships between researchers and the community. SCI researchers have often been accused of tokenism (i.e. people with SCI are asked to only endorse research to legitimize research programs over which they have little real control) and recent calls have highlighted the need for further support for SCI researchers and research users adopt IKT partnerships. While recommendations for adopting IKT approaches have been put forth, these recommendations are not informed by a process that uses a rigorous methodology (e.g. systematic review) and meaningful engagement of SCI stakeholders to develop IKT best practices. The objective is to develop and implement the first IKT guiding principles for conducting and disseminating research in partnership with the SCI community. Several members of NASCIC are members of this consensus panel providing input as stakeholders, potential advocates, and adopters of the principles.

Consumer Advisory Team for Robotic Exoskeleton Working Group for Increased Mobility

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 is 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 role of the Advisory Team will be to help identify and define the mobility goals of individuals with lower limb paralysis and provide a critical perspective for creating a roadmap that balances individuals' needs, concerns, preferences, and goals with available and emerging approaches to address them.

Members of the Advisory Team will provide direct feedback to members of the Working Group through the attendance of at least one member of the Advisory Team at monthly Working Group teleconference meetings (1 hour/meeting) and through online communications with Working Group members (e.g. email, Slack, etc.). We will schedule one in-person Working Group meeting to be held this summer at IHMC (travel for Working Group members will be paid for using the Discovery Award). The project is expected to begin in June 2018.

APPENDIX C

ADMINISTRATIVE ASSISTANT JOB DESCRIPTION

The Administrative Assistant is responsible for handling the daily administrative operations of the Consortium which includes:

- Researching and identifying potential members
- Soliciting organizations and SCI community patrons for membership
- Attending Conferences on behalf of NASCIC
- Responsible for the monthly newsletter, social media, and marketing
 - Assist with the production of marketing materials and literature, such as the newsletters, brochures, and press releases
 - Assist with the collation of information for promotional literature
 - Compose and post online content on the organization's website and social media accounts
 - Liaise with graphic/website designers and be the main point of contact for external designers and printers
 - Assist in organizing events and the annual meeting
 - Help with presentations by assembling slideshows and videos
- Project facilitation
- Website maintenance
- Member database management
- Member correspondence and communications
- Liaison to the Executive Council
- Scheduling and planning meetings and appointments
- Recording all meeting minutes
- Handling incoming calls and other communications i.e. info emails

BENEFITS OF MEMBERSHIP

Value proposition for a Patron or Principal member = Change happens collectively

- Contribute to the mission of NASCIC – Our mission is to bring about unified achievements in research, care, and policy by supporting collaborative efforts across the spinal cord injury community.
- Promote an exchange of information, experience, and networking across the spinal cord injury community.
- Access more opportunities to engage with researchers, medical professionals, and companies working to improve the lives of people with SCI.
- Contribute to strengthening the voice of people living with spinal cord injury in North America.
- Have your organization's logo (or your name) placed on the NASCIC website as a member.
- Approval to place the NASCIC logo on your organizations' website.
- Ability to pitch projects and participate in engaging projects to change conditions for people living with SCI.
- Receive training to become a “certified” SCI engagement professional.
- Visibility as a leader in the SCI community.
- Access to a larger platform/stage for awareness of issues important to the SCI community than an individual or single organization would have.
- Raise awareness of your organization/self via the Member Spotlight in Newsletters and events.

Value proposition for Advisory members = Your conduit to engagement of persons with lived SCI experience

- Gain access to the largest community of SCI organizations and people with lived experience.
- Ability to pitch projects with NASCIC members.
- Have your organization's logo placed on the NASCIC website as a member.
- Approval to place the NASCIC logo on your organizations' website.

PROPOSED CHARTER AMENDMENTS

NASCIC Proposed Charter Amendments

Charter Article	Currently in Charter	Amendment
1. Article I – a. Mission	The North American Spinal Cord Injury Consortium (NASCIC) has the mission to bring about unified achievements in research, care and policy by supporting collaborative efforts across the spinal cord injury community.	The North American Spinal Cord Injury Consortium (NASCIC) has the mission to bring about unified achievements in research, care, cure and policy by supporting collaborative efforts across the spinal cord injury community.
2. Article II – b. Rights and Duties	The NASCIC Executive Council will determine the membership fee structures, keeping in mind that NASCIC is meant to be inclusive of a broad spectrum of SCI stakeholders interested in the overall mission of NASCIC. Membership begins upon receipt of payment, and membership fees are processed annually beginning in January.	The NASCIC Executive Council will propose a membership fee structure on an annual basis at the Annual Meeting, to be ratified by the Assembly of Delegates, keeping in mind that NASCIC is meant to be inclusive of a broad spectrum of SCI stakeholders interested in the overall mission of NASCIC.
3. Article II – a. Membership (Advisory Member)	Advisory member: Any organization or individual with an interest or activities related to people living with SCI but do not meet the above membership categories. Examples may be clinical care facilities, professional associations, funding agencies, for profit entities, government agencies, research institutions, etc. This membership category can advise Principal and Patron members and participate in meetings and discussions, but does not have a voting delegate representative.	To change the title of Advisory Member. Item to be discussed at the Annual Meeting with the Assembly of Delegates.
4. Reimbursement Policy	No Reimbursement currently in place	See draft Reimbursement Policy attached



Reimbursement Policy

Travel, Meal and Hospitality Expenses

Executive Council Members

Reimbursement for expenses incurred by Executive Council members as it relates to their position will be determined on a case by case basis by the acting President of the Executive Council. If the acting President sees fit to reimburse Executive Council members, members are to follow the established reimbursement policy and submit an expense claim form to the acting President for review and approval.

Assembly of Delegates

Reimbursement for expenses incurred by the Assembly of Delegates as it relates to their position as members of the North American Spinal Cord Injury Consortium will be determined on a case by case basis by the Executive Council. If the Executive Council sees fit to reimburse members, members are to follow the established reimbursement policy and submit an expense claim form to the Executive Council for review and approval.

Policy and Rates

Transportation

Airplane/Train – Economy (coach) class is the standard option for ticket purchase. Travel in business class must have prior approval by the Executive Council President or Vice-President.

Vehicle – When renting a vehicle, a compact model or its equivalent is required. When using a personal vehicle, reimbursement for mileage is as follows – \$0.54 per kilometer.

Parking and Tolls – Reimbursement is provided for necessary and reasonable expenditures on parking as well as tolls.



Taxis/Public Transit - Reimbursement is provided for necessary and reasonable expenditures on taxis and public transit.

Accommodation

Reimbursement will be made for single accommodation in a standard or accessible room. There will be no reimbursement for hotel suites, executive floors or concierge levels. Reimbursement will cover room and tax only.

Meals

Reasonable and appropriate meal expenses will be reimbursed. The rates are an allowance and include taxes and gratuities.

Meal Type	Reimbursement Rate
Breakfast	\$10.00
Lunch	\$12.50
Dinner	\$22.50



North American
Spinal Cord Injury
— Consortium —

Expense Claim Form

Name: _____

Payable To: _____

Address: _____

Reason for Travel: _____

Statement of Expenses (Please attach *original* receipts)

Air Travel: _____

Rail Travel: _____

Car Rental/ Mileage: _____

Meals and Incidentals: _____

Accommodations: _____

Other Expenses: _____

(Please Explain)

TOTAL : _____

Signature: _____

Date: _____

Eligible Expenses

Travel

Travel expenses, where not paid directly by NASCIC, can be claimed for Economy Class travel unless specifically authorized by the NASCIC Executive Council.

Mileage

When claiming mileage for the use of your personal vehicle, please indicate the total kilometers claimed @ \$0.54 per Kilometer. Print out the Google map. There is no reimbursement for traffic or parking violations.

Hotel Accommodations, Attendant Services and Meals

When hotel accommodations have not been arranged by NASCIC, accommodations may be claimed for 1 single standard or accessible room.

Meals: (Alcoholic beverages are not eligible for reimbursement). All maximum amounts include taxes and tips. Please attach the original receipts.

Breakfast - up to \$ 10.00 per day Lunch - up to \$12.50 per day Dinner - up to \$22.50 per day

CURRENT PROJECT SELECTION PROCESS

NASCIC Project Selection Guidelines

Introduction

From the proposed NASCIC Charter:

The purpose of the North American SCI Consortium (NASCIC) is to convene organizations in North America that advocate, represent, or communicate with people living with spinal cord injury.

NASCIC's mission is to bring about unified achievements in research, care, and policy by fostering collaborative efforts across the spinal cord injury community.

NASCIC will accomplish its mission by bringing together like-minded organizations, individuals, and groups to improve research, care, and policies impacting people living with spinal cord injury, families, and the community. Working collaboratively, the organization is structured to effectively bring out collective change through approved projects.

Project Selection Criteria

NASCIC will evaluate potential projects based on their likelihood to bring about positive change for persons living with spinal cord injury by improving their care and quality of life. Advocating for research that more accurately reflects the needs of the SCI community and includes members of the SCI community as equal partners is an important first step in NASCIC's evolution.

NASCIC members assess proposed projects using the following criteria:

1. The potential to form relationships between the individuals and organizations representing spinal cord injury;
2. The potential for the exchange of valid, trustworthy, and useful information, experience, and knowledge;
3. The potential for promotion of and involvement with 'best practices' in research, treatment, and care;
4. The potential to create and/or strengthen a unified voice for SCI in North America;
5. The potential to promote collaboration among experts in the fields of research, clinical care, and advocacy of participating members
6. The resources required of NASCIC, and
7. The potential impact (considering both breadth and depth) of the proposed project.

Each criterion will be given a score on a scale 1-5, with 1 being the lowest score. A final score will be the sum score of all 7 criteria.

NASCIC's Role and Expectations for Projects

Project submissions to NASCIC must include:

- A brief (500 word) overview, including goals, objectives, outcomes, and timeline of the project related to the involvement of NASCIC.
- A description of the requested involvement or partnership with NASCIC, such as design input, advisory committee, legislative/reimbursement advocacy, recruitment assistance, implementation, etc.
- A commitment to NASCIC regarding level of engagement, remuneration, etc.
- An estimated budget for NASCIC's portion of the project, including both human and financial resources.

NASCIC must be acknowledged for its role in a given project in any publications, promotional or communication material, etc. On project approval by NASCIC, the consortium expects to be a fully involved and equal partner in all project activities and decisions.

NASCIC will evaluate its participation in a project on the basis of that project's potential to advance its mission, scoring on the criteria described above, and voting by the Assembly of Delegates as described below.

Projects selected by the NASCIC will be responsible for their own budget and financial resources to cover expenses related to NASCIC involvement. Project budgets involving NASCIC activities should also include a 10% add-on for the administrative support provided by the consortium as it specifically relates to the project.

Project Selection Process



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graph TD; A[Internal or external group submits a project proposal, including budget, to NASCIC.] --> B[Executive Council reviews project; can work iteratively with submitting group to suggest revisions or clarifications.]; B --> C[Executive Council approves project to be scored and voted on by the Assembly of Delegates.]; C --> D[Assembly of Delegates has 14 days to score, comment, and vote on project.]; D --> E[A 2/3 majority of the Assembly of Delegates is required for project approval, with quorum being 2/3 of the membership.];
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Internal or external group submits a project proposal, including budget, to NASCIC.

Executive Council reviews project; can work iteratively with submitting group to suggest revisions or clarifications.

Executive Council approves project to be scored and voted on by the Assembly of Delegates.

Assembly of Delegates has 14 days to score, comment, and vote on project.

A 2/3 majority of the Assembly of Delegates is required for project approval, with quorum being 2/3 of the membership.

- Once a project is approved, a committee is created and committee chair appointed.
- Each project committee will assign a treasurer who will manage and oversee the committee's finances. The committee treasurer is responsible for management of monetary resources and reporting the financial status to the Executive Council.
- The Vice President of NASCIC will oversee all project committee chairs.

PROPOSED REVISED PROJECT SELECTION PROCESS



North American
Spinal Cord Injury
— Consortium —

Tel: 1-800-361-4004

Email: info@nasciconsortium.org

Website: www.nasciconsortium.org

NASCIC Project Partnership Selection Guidelines

The purpose of the North American SCI Consortium (NASCIC) is to convene organizations in North America that advocate, represent, or communicate with people living with spinal cord injury.

NASCIC's mission is to bring about unified achievements in research, care, and policy by fostering collaborative efforts across the spinal cord injury community.

We do this by:

- bringing together like-minded organizations, individuals, and groups,
- advocating for research that more accurately reflects the needs of the SCI community, and
- partnering on projects that bring about positive change for persons living with SCI.

Project Partnership Submission Requirements

Project submissions should be a brief (500 word) overview providing details including the:

- goals, objectives, outcomes, and timeline of the project,
- level of engagement and resources required of NASCIC, and
- an estimated budget for the project, including both human and financial resources, based on the resources required of NASCIC; include a 10% add-on for the administrative support provided by the consortium for resource-heavy projects.

Project Partnership Criteria

NASCIC evaluates project partnership opportunities based on their likelihood to:

1. form relationships between the individuals and organizations representing spinal cord injury;
2. exchange valid, trustworthy, and useful information, experience, and knowledge;
3. promote best practices in research, treatment, and care;
4. create and/or strengthen a unified voice for SCI in North America;
5. promote collaboration among experts in the fields of research, clinical care, and advocacy;
6. positively impact the lives of people living with SCI;
7. meaningfully and actively engages persons with lived experience of SCI.

C/O Canadian/American Spinal Research Organization
1623 Military Road, #271, Niagara Falls, NY 14304



Project Partnership Scoring Process

Project submissions will be directed to the NASCIC Vice President (VP), who will share all project submissions with the NASCIC Project Review Committee (PRC). This committee, chaired by the VP, will evaluate projects based on alignment to the above criteria. The PRC will work iteratively with the submitting group to suggest revisions or clarifications to the proposal, if needed, to ensure alignment with the project partnership criteria. The PRC will score the final submission from 1-5 on each of the above criteria, for a maximal score of 35. Those scoring above 23 will be approved for the NASCIC Executive Council (EC) to review.

The EC will review and vote on the submission. Approval by a simple majority will advance the submission to a vote by the NASCIC Assembly of Delegates (AoD). If the submission is not approved by the EC, it can be returned to the PRC for further modification if warranted.

The AoD will review and vote on the submission with 14 days of receiving it. Approval by a simple majority of the membership grants the submission status as a NASCIC Project Partnership. If the submission is not approved by the AoD, it can be returned to the PRC for further modification if warranted.

There will be opportunity for comments on the submission by all NASCIC members. This commentary will be compiled by the PRC and shared with the submitting group.

Upon project approval, the consortium expects to be a fully involved and equal partner in all project activities and decisions.

NASCIC Project Partnership Oversight

Following approval as a NASCIC Project Partnership, the VP will make an open call to the AoD to form a project committee, specific to the needs of that project. The project committee will be responsible for representing NASCIC in all activities related to that project; the committee members will select a committee chair to interact with the VP.

The VP will interact with and assist all project committee chairs.

NASCIC must be acknowledged for its role in a given project in any publications, promotional or communication material, etc.

CURRENT PROJECTS

2018 NASCIC PROJECT SUMMARIES

Consumer Advisory Team for Neuromodulation Working Group for Bladder & Bowel

This project has created an Advisory Team comprising 6 people living with SCI to collaborate with the Neuromodulation for Bladder and Bowel Working Group.

Initiated by the Craig H. Neilsen Foundation Neurogenic Bladder and Bowel Workshop, this Neuromodulation Working Group was created out of a team of approximately 12 individuals from research, industry, clinical, and advocacy organizations to explore neuromodulation interventions for bladder and bowel function for individuals living with SCI. The goal of the Working Group is to promote adaptation and translation of neuromodulation technologies to meet the functional goals of individuals with neurogenic bladder and bowel dysfunctions within a 10-year timeframe. The purpose of the Neuromodulation Working Group is to (1) Identify existing or emerging neuromodulation technology that can be leveraged in our timeline to meet this goal; (2) Identify and describe the steps that the field should take to achieve this goal; (3) Identify the opportunities and barriers that exist in accomplishing this goal; and (4) Create a road map and manuscript to publish the working group's recommendations.

The role of the Advisory Team is to help identify and define the bladder and bowel goals of individuals with SCI, and provide a critical perspective for creating a road map that balances individuals' needs, concerns, preferences, and goals with available and emerging neuromodulation approaches to address them. This will be accomplished by surveying NASCIC members and incorporating their feedback into a written document.

Spinal Cord Injury Trials Toolkit (SCITT)

Full and timely recruitment for SCI clinical trials was identified as a significant barrier to trial completion in 2 separate 2016 SCI meetings (PRAXIS and Ittingen). A SCITT working group was subsequently tasked with finding solutions to this barrier.

SCITT envisions a one-stop shopping website with integrated portals for all clinical trial stakeholders (people with SCI, clinicians referring patients to clinical trials, clinical trial Investigators and Sponsors of clinical trials). Each portal will be customized to each stakeholder with clinical trial information, links, downloadable documents and tools, and more. Unique to the SCITT website is an intent to curate the information available on clinicaltrials.gov and subsequently sorted by SCOPE. Objective data on protocol design, availability of preclinical evidence, regulatory oversight, appropriateness of hypothesis and outcome assessments, etc. will be presented in lay, clinical and scientific summaries. These are intended to assist people with SCI and clinician stakeholders when considering participation and referring patients for clinical trials. Investigators and Sponsors will also be given the opportunity to provide curation input if relevant data is not obvious from the published trial information.

On the portal for people with SCI, not only will curated trial summaries and practical information about clinical trials and participation be available, the clinical trial matcher (CTM) is to be developed using artificial intelligence (AI) software. AI matching is increasingly enhanced with personal health information provided through a patient self-classificator, uploaded documents or full electronic medical records.

NASCIC is collaborating with the SCITT team on the development of the portal for people with SCI.

Enhancing Partnership: Guiding Principles for Conducting and Disseminating Research in Partnership with the SCI Community

Integrated KT (IKT) is an approach to doing research whereby research users as partners alongside researchers throughout the entire research process. The resulting research is more applicable, useful and translatable to end-users than research conducted by researchers alone. Despite the advantages of an IKT approach, only a small minority of KT activities have been planned and implemented in *partnerships* between researchers and the community. SCI researchers have often been accused of tokenism (i.e. people with SCI are asked to only endorse research to legitimize research programs over which they have little real control) and recent calls have highlighted the need for further support for SCI researchers and research users adopt IKT partnerships. While recommendations for adopting IKT approaches have been put forth, these recommendations are not informed by a process that uses a rigorous methodology (e.g. systematic review) and meaningful engagement of SCI stakeholders to develop IKT best practices. The objective is to develop and implement the first IKT guiding principles for conducting and disseminating research in partnership with the SCI community.

Several members of NASCIC are members of this consensus panel providing input as stakeholders, potential advocates, and adopters of the principles.

Consumer Advisory Team for Robotic Exoskeleton Working Group for Increased Mobility

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 is 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 role of the Advisory Team will be to help identify and define the mobility goals of individuals with lower limb paralysis and provide a critical perspective for creating a road map that balances individuals' needs, concerns, preferences, and goals with available and emerging approaches to address them. Members of the Advisory Team will provide direct feedback to members of the Working Group through the attendance of at least one member of the Advisory Team at monthly Working Group teleconference meetings (1 hour/meeting) and through online communications with Working Group members (e.g. email, Slack, etc.). We will schedule one in-person Working Group meeting to be held this summer at IHMC (travel for Working Group members will be paid for using the Discovery Award).

Research Funding Advocacy

Within the mission of the North American SCI Consortium is to bring unified achievements in both research and policy. A key funding agency of SCI research is the National Institute of Neurological Disorders and Stroke (NINDS), which is an institute within the National Institutes of Health in the United States. NINDS spends approximately \$80M per year on research dedicated toward spinal cord injury. Within each institute is a national advisory council consisting of established research scientists and academics. The National Advisory Neurological Disorders and

2018 NASCIC PROJECT SUMMARIES

Stroke (NANDS) Council has two general functions: (1) to advise the NINDS on policy and procedures affecting the extramural research programs and (2) to provide a second level of review for all grant and cooperative agreement applications considered by the Institute for funding. They meet 3 times per year. More about the NANDS Council may be viewed here (<https://www.ninds.nih.gov/About-NINDS/Who-We-Are/Advisory-Council>)

NASCIC members have decided there is a need to advocate for a redistribution of the research funding to have more emphasis on 1) chronic injury, 2) translational and clinical research to improve care and quality of life, and 3) incorporating the input and voice of those living with SCI and their caregivers in the entire process. The first step of this advocacy effort was to submit a letter to the NANDS Council regarding these three issues with the listing of the NASCIC members that support this effort at the time of submission. The letter was submitted prior to the September 13, 2018 council meeting. A copy may be viewed here - [NASCIC Letter to NINDS Advisory Council](#)