

North American Spinal Cord Injury Consortium: (NASCIC): Meeting Report

*Vancouver, British Columbia, Canada
October 21, 2018*



Prepared by: Kim Anderson-Erisman

The mission of NASCIC is to bring about unified achievements in research, care, and policy by supporting collaborative efforts across the spinal cord injury (SCI) community.

To achieve this mission, *NASCIC will identify gaps, communicate resources, and be a conduit for collaboration between the community of people living with SCI and the many stakeholders.*

To facilitate communication among members and stakeholders, NASCIC convened a face-to-face and online meeting on October 21, 2018 with the objectives to:

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

Pre-Conference Material

In preparation for the meeting, the following materials were sent to all participants:

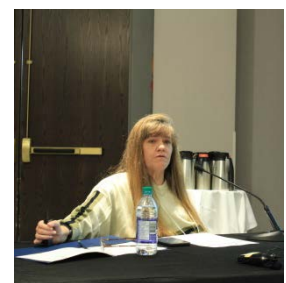
1. Meeting agenda
2. Strategic plan submitted to the Craig H. Nielsen Foundation
3. Current benefits of membership language
4. Proposed Charter amendments
5. Proposed revised project selection process
6. Description of ongoing projects

During the Meeting

Update on Progress

Kim Anderson-Erisman, current President of NASCIC, started the meeting by welcoming everyone and discussing the progress that had been made over the past year. These included:

- Revised and finalized Charter, which was then voted and approved
- Voted and approved the official NASCIC logo
- Voted and approved housing NASCIC within the non-profit/registered charity Canadian/American Spinal Research Organization
- Distributed the inaugural meeting summary report
- Approved the first 3 active projects, then approved 2 more projects during the year
- Nominated and held elections for the Executive Council (EC). The EC has met monthly. Recently, it has been meeting more frequently to boost the operational efforts of the consortium.
- At the time of the meeting, membership included 16 Principal, 20 Patron, and 5 Advisory members
- Communication modes that have been created for the consortium (website, newsletter, email, Facebook, Twitter)
- Review of current financials
- Goals for 2019-2021



Strategic Planning

Jen French, current Delegate on the EC, then lead an interactive discussion to gain member input on three key strategic goals:

- Membership and outreach
- Financial sustainability
- Project outcomes

Table discussions and written feedback was obtained specifically on:

- 2019 action items and volunteers for those items (See final assignments in the Outcomes and Deliverables section)
- Value proposition and benefits for Principal and Patron members
- Value proposition and benefits for Advisory members



Charter Amendments

Barry Munro, current Treasurer of NASCIC, led a discussion on 4 proposed revisions to the Charter. Suggestions were developed and incorporated for later voting on the revisions.



Revision to project selection process



John Chernesky, current Vice-President of NASCIC, described the proposed revised process for selecting projects. The changes were to add more clarity to the process and to create a Project Review Committee composed of member delegates. The idea of projects was also reframed to 'Project Partnership Process' to reinforce the concept that NASCIC does not take ownership over projects, rather NASCIC facilitates partnerships. The new outlined Project Partnership Process is provided in the Outcomes and Deliverables section.

Nominations for Elections

Kim Anderson-Erisman briefly reviewed the open positions for the upcoming elections – Treasurer and Delegate on the EC. Results from the elections are provided in the Outcomes and Deliverables section.

Project Presentations

Matthew Rodreick, current Delegate on the EC, then facilitated the session regarding projects. Brief updates on 4 current projects were provided:

- Neuromodulation for Bladder and Bowel Function – Dennis Bourbeau
- Exoskeleton Advisory Input – Jen French
- SCITT – Rob Wudlick
- Integrated Knowledge Translation – Heather Gainforth



Discussion of 3 possible new project ideas were provided:

- Building Capacity: Educate, Engage, and Empower People with Lived Experience (PLEx) in Research – Anita Kaiser and John Chernesky
- Neurological Disorder Registry Working Group – Jane Weirbicky and Bill Fertig
- Spinal Cord Injury Patient Preference Risk Benefit Study and Registry – Rob Wudlick



Open Discussions

Following the presentations, the group revisited the summary of proposed value proposition and benefits gathered from the table discussions. This summary highlighted common themes among the table discussion as well as sparked conversation about how the value propositions will be communicated. An additional discussion point resulted in agreement to change the name of the Advisory member to Partner member. The final value proposition and benefits for the member categories is provide in the Outcomes and Deliverables section.

Discussions also ensued around each of the proposed projects. The Building Capacity project proposed by Anita Kaiser and John Chernesky focused on how to encourage people living with spinal cord injury, also people with lived experience, to become educated, empowered, and engaged in current research. Following the presentation, there was discussion as to whether or not this project may be complimentary to the on-going project of Enhancing Partnerships. There were also questions around the definition of meaningful research, how to identify which research was meaningful, as well as building an understanding of the current challenges faced by researchers. The Neurological Disorder Registry Working Group was another project proposed by Jane Weirbicky of United Spinal Association. The project would advocate for spinal cord injury to be included in the new neurological disorders registry to be designing and managed by the US Center for Disease Control. The discussion around this project addressed the methods of NASCIC involvement as well as the potential of this project to have broad implications, learn from other registries, particularly in Canada, and prospects for private enterprise interest. The final proposed project was brought forward by Rob Wudlick, SCI Patient Preference Risk Benefit study. The project would create, administer, and disseminate a broad preference study for people living with SCI. The project discussions centered around the need for a definition of the study parameters, a focus of preferences for a specific target, and

concerns of this being a high capacity project. All presenters were encouraged to take the feedback from the discussions and submit a formal project proposal through the established NASCIC project partnership process.

The final open discussion centered around key definitions that are also provided in the NASCIC Charter. Since a person living with a spinal cord injury may morph into various roles depending on the setting, the discussion centered around what language should we adopt for this. The consensus was around referring to PLE_x, people with lived experience. Also to refer to friends and family members as FLE_x, family and friends with lived experience. The discussions also surfaced definition clarity for SCI community and Research Partner. Please see the Definitions section of the Outcomes and Deliverables section.



Outcomes and Deliverables

- Value proposition and member benefits
- 2019 action item teams
- Defining the SCI Community
- Project review committee and revised process
- NASCIC Charter Amendments and Elections

Value Proposition Member Benefits

Patron & Principal Member

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
- 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

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

2019 Action Items

Below are the action items for NASCIC for 2019, the Executive Council lead for each, and attendees who volunteered to help. Additional members are very welcome to volunteer for actions they are interested in at any time throughout the year.

Communications

Led by Kim Anderson-Erisman, President

- Penny Clarke-Richardson, Suzette Hart, Shelly Towle, Jennifer French, Barry Munro

Financial Planning

Led by Barry Munro, Treasurer

- Camille Rammer, Ben Mortensen, Keiko Honda, Zahra Bhatia, Doug Manderville

Membership Efforts

Led by Sasha Rabchevsky, EC Delegate

- Teri Thorson, Marcia & Paul Cook, Tara Jeji, Marie Blanche Remillard, Heather Gainforth, Alan Stanley, Kim Beer, Teren Clarke, Anita Kaiser

Project Outcomes

Led by John Chernesky, Vice-President

- Karen Hodge, Jen French, Anita Kaiser, Jane Wierbicky, Ian Burkhart

Annual meeting for 2019

Led by Matthew Rodreick, EC Delegate

- Kim Anderson-Erisman, Camille Rammer, Peter Athanasopoulos, Tara Jeji, Tim Erisman

Connecting Policy Initiatives

Led by Rob Wudlick, EC Delegate

- Cynthia Templeton, Vivian Kiggins

Sharing Engagement Resources

Led by Bill Fertig, EC Delegate

- Heather Gainforth and Anita Kaiser join forces on their interests, plus Jane Wierbicky, Karen Hodge, Teri Thorson, John Chernesky, Shelly Towle, Rob Wudlick, Kim Beer, Zahra Bhatia, Benveet Gill, Doug Manderville, Chris McBride

Defining the SCI Community

Person with lived experience - Phrase used to reference a person living with SCI and acknowledge their unique expertise of that realm. Sometimes referred to 'PLEx'.

Family member/Friend with lived experience – Phrase used to reference family members or friends living with or caring for a person living with a SCI and acknowledge their unique expertise of that realm. Sometimes referred to 'FLEx'.

Patient – Person receiving or registered to receive medical treatment (as in-patient or out-patient).

Consumer/End User – a person who purchases, uses, or seeks information on goods and services for personal use.

Advocate – Organizations or individuals who work to influence the decision making processes of governments, regulatory bodies, funders, and health care systems. This influence can be utilized to support the needs of individuals, groups, or the entire SCI population.

Research Participant – Individuals who contribute to the development of research knowledge by participating as research subjects. These individuals provide their body and/or experiences to be used to inform the creation of new knowledge about living with SCI.

Research Community – Includes Principal investigators, Co-investigators, collaborators, advisors, consultants, research coordinators, research assistants, trainees, ethics boards, funders, industry. Organizations or individuals who work in partnership to define and answer research questions.

Healthcare Community - Includes physicians, therapists, nurses, social workers, hospital systems, insurers, etc. Organizations and individuals who work in partnership to deliver medical care and adopt new medical knowledge into best practices.

Project Partnership Process

- a. Project Review Committee
 1. Chair – Vice-president
 2. Members – Karen Hodge, Jen French, Anita Kaiser, Jane Wierbicky, Ian Burkhart
- b. Revised selection process

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, cure, 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.

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.

NASCIC Charter Amendments and Elections

Following Charter discussions at the meeting, revisions were incorporated and sent to voting delegates.

Results:

Amendment # 1 - Change the Mission Statement to include the term Cure -
Approve 88.24%
Disapprove 11.76%

Amendment # 2 - Amend the wording in Article II - b. Rights and Duties, regarding Membership Fees
Approve 91.18%
Disapprove 8.82%

Amendment # 3 - Change the name of Advisory Member to Partner Member
Approve 97.06%
Disapprove 2.94%

Amendment # 4 - Adopt the proposed Reimbursement Policy
Approve 100%
Disapprove 0%

Proposed Revised Project Selection Process
Approve 97.06%
Disapprove 2.94%

After nominations were opened at the meeting, election ballots were sent to voting delegates.

Results:

Treasurer
Barry Munro 100%
Other 0% (no other names nominated)

1 Year Delegate position on Executive Council
Peter Athanasopoulos 36.36%
Teren Clarke 13.64%
Tim Erisman 9.09%
Bill Fertig 40.91%

From January 1 to December 31, 2019, Barry Munro will serve as the Treasurer and Bill Fertig will serve as a Delegate representative on the Executive Council.

Conclusion: The Future

In summary, the annual meeting brought together NASCIC members from across North American both in-person and online. The goals of the meeting were accomplished. NASCIC will look forward to implementing the Action Items for 2019 as outlined in the strategic plan, vote in new EC members, and engage members. NASCIC will move forward to continue to gather more memberships, build collaborative partnerships, achieve meaningful project outcomes, and establish financial sustainability. We can achieve change by working together.

NASCIC operates by facilitating communication, sharing resources, and enhancing collaboration.

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.

Membership applications are available on the website: <https://nasciconsortium.org/membership/>

Register to receive email news updates by send a request to info@nasciconsortium.org .

Sponsors

Cleveland FES Center

The Cleveland FES Center is a consortium of four nationally recognized institutions: Louis Stokes Cleveland VA Medical Center, Case Western Reserve University, MetroHealth Medical Center, and University Hospitals of Cleveland. With the support of these partners, the Cleveland FES Center is able to be at the forefront of academic and clinical research, furthering the advancement of neural technology into clinical standards of care.

<http://fescenter.org/>



DP Clinical

DP Clinical, Inc. (formerly DP Clinical Associates, Inc.) is a privately-held, minority and woman owned contract research organization (CRO) located in the I-270 Technology Corridor in Rockville, Maryland serving pharmaceutical and biotechnology clients. DP Clinical was established in 1994 and is a Maryland corporation.

<http://www.dpclinical.com/home.html>



Rick Hansen Institute

The Rick Hansen Institute is a Canadian-based not-for-profit organization committed to accelerating the translation of discoveries and best practices into improved treatments for people with spinal cord injuries.

<http://www.rickhanseninstitute.org>



Rick Hansen Institute
Institut Rick Hansen

Push to Walk

Push to Walk provides individualized workouts and resources to people with spinal cord injuries and other forms of paralysis to optimize current quality of life and to prepare for future medical advancements.

<https://www.pushtowalknj.org/>



The Miami Project to Cure Paralysis

The Miami Project to Cure Paralysis, a Center of Excellence at the University of Miami Miller School of Medicine, is considered the premier investigative research program conducting cutting edge discovery, translational, and clinical investigations targeting spinal cord and brain injuries. The Miami Project's international team includes more than 200 scientists, researchers, clinicians, and support staff who take innovative approaches to the challenges of spinal cord and brain injuries.

<http://www.themiamiproject.org/>



Vertex Pharmaceuticals

Vertex creates new possibilities in medicine to cure diseases and improve people's lives. We work with leading researchers, doctors, public health experts and other collaborators who share our vision for transforming the lives of people with serious diseases, their families and society.

<https://www.vrtx.com/>



Appendix 1: NASCIC Agenda

2nd 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:

5. Develop NASCIC strategic goals for 2019
6. Update charter and project selection process
7. Discuss current and future projects
8. Network across membership

AGENDA AND TIMELINE:

TIME	DESCRIPTION	SPEAKER
8:00	Registration and Breakfast	
9:00	Opening/Welcome	
9:10-9:30	Accomplishments and Challenges <ul style="list-style-type: none"> • History, accomplishments, governance, current projects, current membership, financial status 	Kim Anderson-Erisman
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	
	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
10:45-11:30	<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 	John Chernesky Kim Anderson-Erisman

11:30-12:30	LUNCH	
12:30-2:00	On-going Project Status and Update (5 min each) New Project Discussions: <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	Finish any unfinished topics discussed earlier in the day Open discussion and idea formulation from current events	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

Appendix 2: Post-Meeting Survey Summary

1. Overall, how successful was this workshop from your perspective?

2.

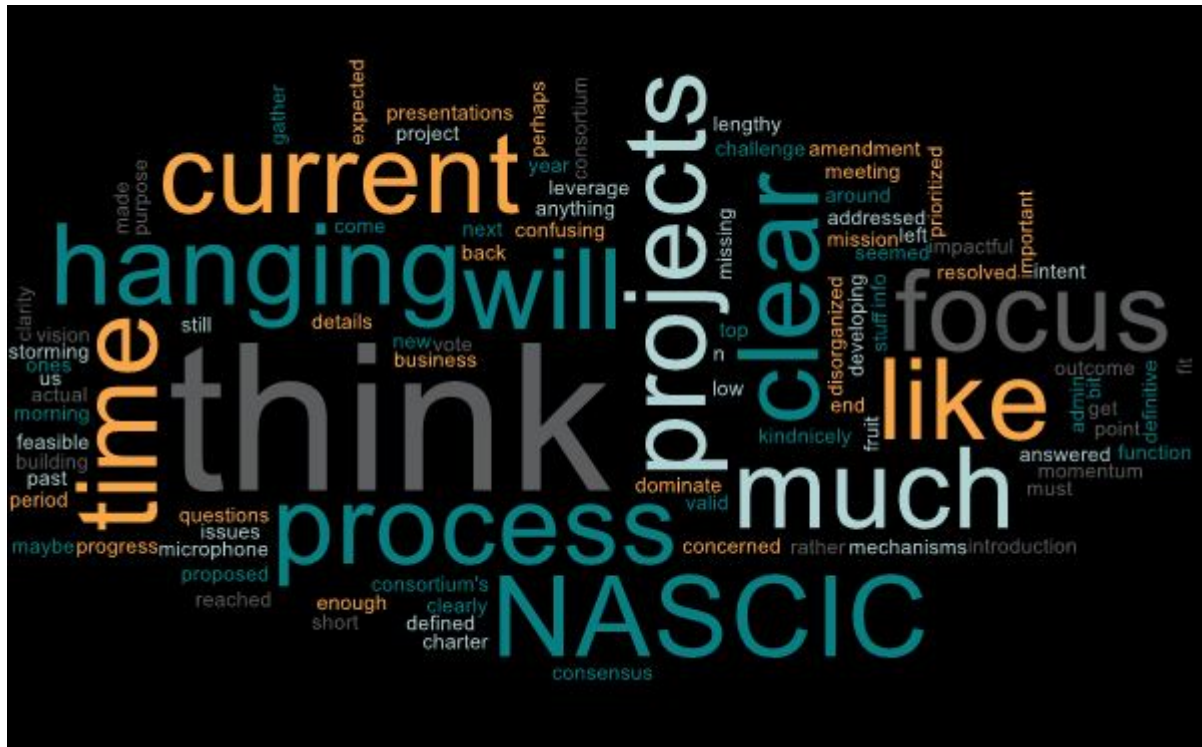
Response Choice	Number of Responses	Percent of Total
1 Not Successful	0	0%
2	0	0%
3	4	22.22%
4	8	44.44%
5 Successful	6	33.33%

N = 18, Average = 4.11

3. What did you like most about the workshop?



3. What did you like least about the workshop?



4. What comments or suggestions do you have with respect to the project selection process?

- Great first year
- Glad to be a part of this!
- Well run- good day with progress made.
- The streaming was nice, but there should be more notice on the availability of it.
- I feel like many people are very willing to assist and be part of this but I am still confused as to how we will recruit the different group of members and what the mission actually is - it seems quite large and perhaps setting ourselves up to fail.
- Bringing clarity and focus to the consortium's mission, structure, and priorities will help the membership identify and rally around opportunities to undertake activities aligned with the mission.
- We need to clearly define the role of NASCIC and each of its 3 types of members and then follow through...not trying to be negative. we did a great job in year 1, got a lot of stuff accomplished, got our feet wet. now we need to really focus and clearly outline our objectives.
- Although these are tedious tasks to get the organization going, you are doing a great job! Congratulations!
- Just too bad I couldn't stay for the afternoon! ;-)
- Would love to have an opportunity to attend next year's event.
- I really enjoy this phase of storming and norming in a venture that is truly unique, and commend the executive for taking us a great distance in one year!
- I participated online and it was still good but sometimes people commented on somethings spontaneous in the room but they don't have a mic so there were somethings from the room that we couldn't hear

List of meeting attendees:

Name	Email	Affiliation
Alan Stanley	alanjarlathstanley@gmail.com	SCI PEI
Alton Paas	a.paas@fundashonaltonpaas.org	Fundashon Alton Paas
Anita Kaiser	anita.kaiser@uhn.ca	Canadian Spinal Research Organization
Aura Telman - Meeting Volunteer	atelman@rickhanseninstitute.org	Rick Hansen Institute
Barry Munro	bmunro@csro.com	American Spinal Research Organization
Bastien Moineau	bastien.moineau@uhn.ca	Toronto Rehabilitation Institute
Ben Mortensen	gr8tful2jam@gmail.com	N/A
Benveet "Bean" Gill	bean@reyu.ca	ReYu Recovery Centre
Brittany Dejean	brittany@ablethrive.com	AbleThrive
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Camille Rammer	csrammer@gmail.com	Individual
Carey Lee - Meeting Volunteer	clee@rickhanseninstitute.org	Rick Hansen Institute
Chris McBride	cmcbride@sci-bc.ca	Spinal Cord Injury BC / Spinal Cord Injury Canada
Cynthia Templeton	cynthia.templeton@gmail.com	Individual
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Dion Regular	dregular@sci-nl.ca	Spinal Cord Injury NL
Douglas Manderville	doug.manderville@sci-ab.ca	Individual
Emily Giroux	emily.giroux@ubc.ca	University of British Columbia - recent MSc graduate from Dr. Gainforth's lab.
George Woodworth	gfw73@hotmail.com	Ability New Brunswick
Heather Gainforth	heather.gainforth@ubc.ca	Individual
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Mary-Jo Fetterly	maryjofetterly@gmail.com	Individual

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