Mount sinai spinal cord injury community advisory committee meeting

# Monday, May 15,2017

**Meeting called to order at 11:00**

## **Welcome and Introduction**

* All attendees introduced themselves including:
* Christopher Noel- Coordinator of Accessibility NYC Parks [Christopher.noel@parks.nyc.gov](file:///C%3A%5CUsers%5Cp857tbr%5CAppData%5CLocal%5CMicrosoft%5CWindows%5CTemporary%20Internet%20Files%5CContent.Outlook%5C9KBQN1XG%5CChristopher.noel%40parks.nyc.gov)
* Susan Howley, Director of Research, Christopher Reeve Foundation showley@crpf.org, showley@christopherreeve.org
* Dr. Thomas Bryce- Mount Sinai Medical Director of Spinal Cord Injury Program Thomas.Bryce@mountsinai.org
* Jill Wecht-Bronx VAMC SCI Research jill.wecht@mountsinai.org
* Laurie Allen Schneider- Do-It Program Coordinator Mount Sinai laura.allenschneider@mountsinai.org
* Ana Oliveros- Alan T Brown Foundation Director of Development ana@atbf.org
* Fran Brown- President of Alan T Brown Foundation fran@atbf.org
* Chung- Ying Tsai (Owen)- Mount Sinai SCI Research chung-ying.tsai@mountsinai.org
* Rose-Marie Faotto- Therapy Manager for Inpatient Spinal Cord Injury Unit rose-marie.faotto@mountsinai.org
* Melissa Gunning- Administrator Mount Sinai Department of Rehabilitation Medicine Melissa.gunning@mountsinai.org
* Lori McKenna- Administrator Mount Sinai Department of Rehabilitation Medicine lori.mckenna@mountsinai.org
* Valerie Miller- Recreational Therapist, Department of Rehabilitation Medicine Valerie.miller@mountsinai.org
* Jose Hernandez- Program Specialist for United Spinal Association jhernandez@unitedspinal.org
* Woody Wood- SCI Outreach Coordinator, Department of Rehabilitation Medicine Richard.wood@mountsinai.org
* Angela Riccobono- Psychologist Department of Rehabilitation Medicine angela.riccobono@mountsinai.org
* Jim Cesario- SCI Outreach Coordinator, Mount Sinai james.cesario@mountsinai.org
* Sugenny Flowers- Coordinator SCI Program, ICS [sugenny.flowers@icsny.org](sugenny.flowers%40icsny.org)
* Elaine Castelluccio- ICS elaine.castelluccio@icsny.org
* Rachael Stacom- ICS Rachael.stacom@icsny.org
* Debra Poli- NYC Chapter of United Spinal Association dpoli597@gmail.com
* Dr. Kristjan Ragnarsson- Chairman Emeritus, Mount Sinai Department of Rehabilitation Medicine kristjan.ragnarsson@mountsinai.org
* Dr. Joseph Herrera- Chairman, Mount Sinai Department of Rehabilitation Medicine joseph.herrera@mountsinai.org
* Alex Elegudin- Founder and President of Wheeling Forward Foundation and The Axis Project goonie718@netscape.net
* Victor Calise- Commissioner at the Mayor’s Office for People with Disabilities vcalise@cityhall.nyc.gov
* Nancy Leiberman- NYS Spinal Cord Injury Research Board member nancy.lieberman@skadden.com

## **Mount sinai department of rehabilitation vision**

**Joseph Herrera, DO, Lucy G. Moses Professor and Chairman**

* Dr. Herrera presented his vision of the future.

## **SCI Clinical Program**

**Thomas Bryce, MD**

* Acute Inpatient SCI Rehabilitation
* Average number of individuals with traumatic injury admitted per year- 60-70
* SCI Medicine Fellowship
* 1 year fellowship
* 1 position per year
* Accredited since 2000
* Craig H. Neilsen Foundation primary sponsor along with United Spinal Association

## **SCI research**

**Thomas Bryce, Jill Wecht, Owen Chung-Ying Tsai**

* Model systems for SCI
* Funded 1986-2011 and 2016-2021 as full participant
* Contributes to national database (over 30K participants)
* Modular Projects
	+ Impact of pain at follow-up in individuals with SCI
		- Collaborators: University of Miami (lead), Craig Hospital, Rancho Los Amigos, TIRR (Houston), and University of Alabama Birmingham
		- Type of study: Phone interview at anniversary date (1,5 10,15,…, 40 years)
		- Goals of study: Characterize types of pain people have (neuropathic, musculoskeletal, etc.); Characterize impact on mood and daily function;
		- Document pain treatments used by individuals with SCI
	+ Residential Instability in Chronic SCI: An Investigation of Patterns and Consequences
		- Collaborators: Kessler (lead), Craig Hospital, Pitt, Rancho, Case Western
		- Type of study: Phone interview at anniversary date (1,5 10,15,…, 40 years)
		- Goals of study: Characterize where people move to after SCI
	+ Equity and Quality in Assistive Technology (EQuATE)
* Collaborators: University of Pitt (lead), Ability (RIC), UAB, OSU, BMC, Miami, Kessler
* Type of study: Phone interview at anniversary date (1,5 10,15,…, 40 years) and mobile application to document wheelchair breakdowns
* Goals of study: Characterize wheelchair breakdowns and its impact
* Local Project
* Treatment of Post-SCI Hypotension: A randomized controlled study of usual care versus ant-hypotension therapy
* Randomized non-blinded allocation of a group where antihypotension medicines are given to keep systolic BP above 110mmHG taken while sitting and another group who are only prescribed medication if symptomatically hypotensive
* All Model System enrollees are eligible to participate if sitting blood pressure is <110mmHg
* Jill Wecht is the project principal investigator
* Effects of Botulinum toxin on at-level pain for persons with SCI
* A double blind ransomized controlled crossover trial in which persons with chronic SCI with at-level SCI pain are treated with subcutaneously injected botulinum toxin
* Study remains open for enrollment
* Future Projects
* Spinal Cord Injury Pain Evolution (SCIPE)
* A RCT for the effects of ReWalk training on trunk control and seating balance in SCI
* Feasibility, Safety and Limited Efficacy of A Phase 1 Clinical Trial for The Use of Powered Exoskeletons during Inpatient Acute Rehabilitation for Spinal Cord Injury
* Using advanced MRI imaging as possible biomarkers for severity of injury and motor recovery

## **SCI research discussion**

Question/Comment by Victor Calise: Can you comment on MRI studies and relevance of strong magnets for evaluating SCI?

Response by Dr. Bryce: There are MRIs with larger magnets (available at Mount Sinai) that can produce greater resolution of images and provide better idea of what is happening anatomically. Gordon Xu is an MRI researcher with an interest in spinal cord injury imaging especially of the spinal cord. The department has been collaborating with Dr. Xu in grant applications to evaluate use of MRI imaging as a biomarker in evaluating neurological recovery especially in the setting exoskeleton use.

Comment by Dr. Kristian Ragnarsson: I praise the new VA and Mount Sinai research collaboration, and emphasize the need to work closely with community partners represented here to improve quality of life for individuals with SCI.

Question/Comment by Alex Elegudin: Is there any interest in beginning epidural electrical stimulation for neurological recovery at Mount Sinai?

Response by Dr. Bryce: The premise behind and current research in the world with implanted epidural stimulation is described. Mount Sinai is very interested in partnering with others in participating in a multicenter trial on this technique.

Question/Comment by Victor Calise: With regards to technology (Bluetooth and implants), what is happening at Sinai? Can we connect Mount Sinai with Tech groups such as NYC tech center pop-ups?

Response by Dr. Herrera: Mount Sinai is funding a new research center in the department focus on technology. The department has hired a PhD technology research expert, Dr. Petrino to lead the research efforts in this area.

Question/Comment by Elaine Castelluccio: Can ICS collaborate with Mount Sinai to decrease rehospitalization?

Response by Dr. Herrera: TeleMedicine might aid subacute home programs. We look to partner with Subacute care home programs for decreasing gap in reaching people at home with SCI who are unable to easily come to Mount Sinai.

**Community reintegration programs**

Transitions Group

* Counseling, support, and education to all members, with an emphasis on facilitating adjustment to those who are more recently injured.
* Weekly topic-based group discusses a wide range of issues including loss and grief, overcoming fear, pitfalls of isolation, self-image, guilt

Women on Wheels

* Women on Wheels (W.O.W.) is a sisterhood of women with spinal injuries dedicated to living life to the fullest.
* Weekly discussion group with topics include dating and sexuality, self-image, relationships with family, partners and friends, education, independence, co-dependence, self-advocacy, and dis/Ability as identity.

Life Challenge Program

* The Life Challenge Program enables individuals with SCI opportunities to participate in activities that may seem impossible because of their disability like skiing, kayaking, skydiving, jet skiing, and horseback riding

Do-It! Program

* SCI Outpatient Program designed to flexibly address patients’ needs as they adjust to their disability. We can adjust components of the consumer–driven program as needs arise and change. Classes include: weight training, mat mobility, computer education, spin class, wheelchair mobility, and peer support.

Peer Mentoring

* The SCI Peer Mentoring Program matches recently injured persons with trained mentors who are living successfully with SCI. They act like Big Brothers and Sisters and assist newly injured SCI transition in the community

Community Access ReEntry Program

* The Mount Sinai Community Access ReEntry (CARE) program promotes socialization, independence, and active leisure participation post injury this by participating in community outings at various venues throughout the city. Individuals learn about accessibility and strategies for overcoming barriers to achieve optimum independence and quality of life.

Meditation Group

* In the SCI Meditation Group, we use guided meditation to help patients develop a sense of mental and physical balance, build a foundation to nurture and grow. And learn to move through life with grace and ease.

**Community reintegration program discussion**

Comment by Alex Elegudin: The Axis Project, NYC Parks, Life Challenge, CARE program, Do-It Program need to collaborate and create unified schedules and present a united front to aid the community. We would like to see Mount Sinai have more community participation with the partners represented here today.

Comment by Woody Wood: need to expose everyone to every possibility not just immediate community program within NYC but to things outside the city.

Question by Nancy Lieberman: How does Life Challenge Programs Work? Specifically Water Skiing and I-Fly.

Response by Woody Wood: Waterskiing is sitting in a seat that sits on skis and allows anyone of any level the opportunity to water ski. Adaptive Equipment and Leaps Of Faith (LOF) Adaptive program aids in educating and assisting everyone how to waterski. I-Fly works with individuals to aid in flying in Air tube (simulating skydiving) and having a weightless experience where they can manipulate their environment.

Comment by Chris Noel: NYC Sports and Parks Department sponsors adaptive sports, acts as apartner with the Life Rolls On surfing event, partners with Wheelchair Sports Federation for softball and other sports like wheelchair football program, and US Open Tennis. We would like to partner as much as possible with all organizations including Mount Sinai.

Response by Dr. Herrera: We can offer our Sports Fellows to assist with sports coverage and to help classification of players.

Comment by Alex Elegudin: With regards to sports, The Axis Project could use help with greater coordination in helping with programs and would like to have a Mount Sinai therapist present at The Axis Project to teach their staff how to work with SCI population. The Axis Project has a large group that does not go to Mount Sinai and how Mount Sinai can help with including not only SCI but everyone even those that are not Mount Sinai patients.

Comment by Alex Elegudin: The caregivers support group is a great program. Once people leave Mount Sinai, where do they go? How does Mount Sinai keep track of people over time, 1 year, 5, year, etc.

Response by Dr. Bryce: Model System requires Mount Sinai to follow up with patients 1, 3, and five years after inpatient this is done through various outreach measures by data collectors.

Comment by Chris Noel: Parks Membership is $25. When patients are discharged from inpatient and either done with outpatient or still in outpatient, they could participate in NYC parks and gyms with little cost.

Comment by Debra Poli: Perhaps Mount Sinai and CARE program could should work (with Valerie Miller) closely with NYC Parks to improve community integration?

Comment by Jim Cesario: I would like to see committee formed to make sure that these issues do not continue to next year.

Comment by Fran Brown: Different members of this board have different strengths. If you give me names and numbers and what you are best at, the Alan T Brown Foundation can aid in bridging the gaps and getting people connected to the resources they need.

Comment by Alex Elegudin: Angela Riccobono does reach out to me, but only in traumatic cases, and we would like for Mount Sinai to reach out more so we can help.

Comment by Woody Wood: Mount Sinai Patients are given information about community programs, and continue to give information regarding programs.

Comment by Laurie Allen-Schneider: Our website has community resources for patients which reinforce the community programs and organizations available.

Question by Elaine Castelluccio : Is there room for future collaboration to train home PT/OT to specially work with people who have SCI? This could help with gap in care.

**Community partnerships**

Embracing Sexuality After SCI: A series of conferences

* Educate persons with SCI and medical professionals about sexuality and intimacy through a series of conferences, videos and workshops that address the pragmatics of sex after injury, as well as foundations needed for developing meaningful intimate relationships.
* Collaborated with NYC chapter of USA, ICS, The Axis Project, Neilsen Foundation, NIDILRR
* Website: [www.SexualitySCI.org](http://www.SexualitySCI.org)

The Future of Home Evaluations

* 3 year Quality of Life Sustainable Impact Grant from Craig H Neilsen Foundation
* Evaluation and further development of a mobile application for home evaluation and Durable Medical Equipment fit to space decisions
* Industry partner is Sensopia.
* To further develop, test and disseminate a method for performing home evaluations including the virtual assessment of durable medical equipment for fit within the available space, using a mobile application

**Community partnerships discussion**

Question by Dr. Bryce: What should we be doing for the Next Four years as educational projects along the lines of our consumer and professional sexuality conferences and educational videos. Potential topics could include: bladder, bowel, return to work, etc

Comment by Chris Noel: Do all of the above, get people out the door and confident to go back to work.

Comment by Alex Elegudin: Tough subjects, going back to work is like opening up Pandora’s Box. It is a big issue and is not an educational issue. A topic that may be low hanging fruit is sports.

Comment by Dr. Bryce: Another approach is having multiple classes for specific issues, like pain rather than big yearly themes. Another approach could be a combination of big themes and smaller conferences.

Comment by Nancy Lieberman: Information on things that were not necessarily covered while inpatient might be an interesting topic. This could include for instance, information on Heimlich maneuver and other things which may not come up during the acute hospitalization.

Comment by Alex Elegudin: Pigging back on what Nancy is saying, some topic that you want consumer to benefit on like pain, might be better for professionals, because what would consumers get out of it?

Response by Woody Wood: Conferences, or educational series, would open the door to options on what is out there to consumers, like options to aid with pain relief Education Conference not just for professionals but for consumers as well.

Comment by Alex Elegudin: I suggest that Mount Sinai create a sub-committee to take more action on what we talked about today. I feel Mount Sinai perhaps has had a protectionist attitude against us and other community organizations. I would like to open up barriers especially since I do not feel welcome at Mount Sinai all the time. I would like to have Mount Sinai open up and invite me to come.

Comment by Debra Poli: Organizations need to work together to not duplicate services either and it is a waste of money to not work together and need to play on each programs strengths and organize better to benefit the community.

**Meeting adjourned at 1300.**