Mount sinai spinal cord injury community advisory committee meeting

# Monday, May 14,2018

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

## **Welcome and Introduction**

* All attendees introduced themselves including:
* Thomas Bryce- Medical Director, Mount Sinai Spinal Cord Injury Program (MSSCIP) [Thomas.Bryce@mountsinai.org](mailto:Thomas.Bryce@mountsinai.org)
* Vincent Huang- Physician, MSSCIP

[Vincent.huang@mountsinai.org](file:///\\users15\users15$\ramira15\Data\Personal\DesktopFiles\Vincent.huang@mountsinai.org)

* Stephanie Kolakowsky-Hayner- Research Investigator, MSSCIP

[stephanie.kolakowsky-hayner@mountsinai.org](file:///\\users15\users15$\ramira15\Data\Personal\DesktopFiles\stephanie.kolakowsky-hayner@mountsinai.org)

* Chung-ying Tsai (Owen)- Research Investigator, MSSCIP

[chung-ying.tsai@mountsinai.org](mailto:chung-ying.tsai@mountsinai.org)

* Jill Wecht- Research Investigator, MSSCIP; Director of Cardiovascular Autonomic Research, Bronx VAMC

[jill.wecht@mountsinai.org](mailto:jill.wecht@mountsinai.org)

* Ann Spungen- Vice Chair of Research, Dept. of Rehabilitation Medicine, Mount Sinai

[ann.spungen@mountsinai.org](mailto:ann.spungen@mountsinai.org)

Kristell Taylor- Research Coordinator, MSSCIP

[Kristell.Taylor@mountsinai.org](file:///\\users15\users15$\ramira15\Data\Personal\DesktopFiles\Kristell.Taylor@mountsinai.org)

* Arianny Ramirez- Research Coordinator, MSSCIP

[Arianny.Ramirez@mountsinai.org](file:///\\users15\users15$\ramira15\Data\Personal\DesktopFiles\Arianny.Ramirez@mountsinai.org)

* Andrew Delgado- Research Coordinator, MSSCIP

[Andrew.Delgado@mountsinai.org](mailto:Andrew.Delgado@mountsinai.org)

* Debra Poli- NYC Chapter of United Spinal Association

[dpoli597@gmail.com](mailto:dpoli597@gmail.com)

* Richard Wood- Outreach Coordinator, MSSCIP

[Richard.wood1@mountsinai.org](mailto:Richard.wood1@mountsinai.org)

* Victor Calise- Commissioner at the Mayor’s Office for People with Disabilities [vcalise@cityhall.nyc.gov](mailto:vcalise@cityhall.nyc.gov)
* Jose Hernandez- President of United Spinal Association [jhernandez@unitedspinal.org](mailto:jhernandez@unitedspinal.org)
* Rose-Marie Faotto- Therapy Manager, Inpatient Spinal Cord Injury Unit, MSSCIP

[rose-marie.faotto@mountsinai.org](mailto:rose-marie.faotto@mountsinai.org)

* Selina Lavache- Nurse Manager, Inpatient Spinal Cord Injury Unit, MSSCIP [selina.lavache@mountsinai.org](file:///\\users15\users15$\ramira15\Data\Personal\DesktopFiles\selina.lavache@mountsinai.org)
* Valerie Miller- Recreational Therapist, Department of Rehabilitation Medicine [Valerie.miller@mountsinai.org](mailto:Valerie.miller@mountsinai.org)
* Angela Riccobono- Psychologist, Inpatient Spinal Cord Injury Unit, MSSCIP [angela.riccobono@mountsinai.org](mailto:angela.riccobono@mountsinai.org)
* Joseph Herrera- Chairman, Dept. of Rehabilitation Medicine, Mount Sinai

[joseph.herrera@mountsinai.org](file:///\\users15\users15$\ramira15\Data\Personal\DesktopFiles\joseph.herrera@mountsinai.org)

* Christopher Noel- Coordinator of Accessibility NYC Parks [Christopher.noel@parks.nyc.gov](file:///C:\Users\p857tbr\AppData\Local\Microsoft\Windows\Temporary%20Internet%20Files\Content.Outlook\9KBQN1XG\Christopher.noel@parks.nyc.gov)
* Alex Elegudin- Founder and President of Wheeling Forward Foundation and The Axis Project
* [goonie718@netscape.net](mailto:goonie718@netscape.net)
* Laurie Allen Schneider- Do-It Program Coordinator, Mount Sinai [laura.allenschneider@mountsinai.org](mailto:laura.allenschneider@mountsinai.org)
* David Putrino- Director of Rehabilitation Innovation, Mount Sinai [David.Putrino@mountsinai.org](file:///\\users15\users15$\ramira15\Data\Personal\DesktopFiles\David.Putrino@mountsinai.org)
* Katherine Canela- Mount Sinai Therapeutic Recreation Student [Katherine.Canela@mountsinai.org](file:///\\users15\users15$\ramira15\Data\Personal\DesktopFiles\Katherine.Canela@mountsinai.org)

## **Opening Remarks/Introductions**

**Christopher Noel**

**Thomas Bryce**

## **SCI Clinical Program**

**Thomas Bryce, MD**

* Acute Inpatient SCI Rehabilitation
* Average number of individuals with traumatic injury admitted per year- 60-70
* 25 bed inpatient unit
* Outcomes: 47% traumatic 53% non-traumatic etiology
* 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)
* Basic requirements:
  + Complete site-specific project
  + Participate in collaborative modules with other centers
  + Educate consumers
* 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
* Site Specific 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 anti-hypotension 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 seated systolic blood pressure is <110mmHg for males, <100mmHg for females
* Jill Wecht is the project principal investigator
* Interim analysis:
  + 14 subjects, majority of which are paraplegic
  + Average length of stay 51 days
  + There were no self-reported incidences of autonomic dysreflexia
  + 7 out of 14 subjects report symptomatic orthostatic hypotension
    - All within first 2 weeks of inpatient rehab
  + Most subjects have higher blood pressure at discharge than baseline
  + Subjects more compliant with therapy if blood pressure is maintained- supports study hypothesis
* Effects of Botulinum toxin on at-level pain for persons with SCI
* A double blind randomized 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
* 11 participants enrolled (9 completed both phases)
* Study target: 32
* Newly Funded Research:
* Dose Response to the Norepinephrine Precursor Droxidopa in Hypotensive Individuals with SCI
  + In 2014 Droxidopa, a norepinephrine precursor, was approved to treat hypotension in chronically injured setting. Droxidopa circulates and is appropriately bound to improve low blood pressure. Study will investigate raising blood pressure to a normal level and hopefully reduce symptoms of low blood pressure.
* Development of a Consumer Guide for the Prevention of Venous Thromboembolism in Individuals with SCI
  + Goal of study: increase knowledge and awareness of the prevention, management, and sequela of venous thromboembolism in persons with SCI and their caregivers
* Validity of Interview Based examination for Spinal Cord Injury
  + Goal: design and validate use of a comprehensive interview-based equivalent of the International Standards (ISNCSCI) exam that could possibly allow the determination for the approximate level of SCI and injury severity without physical exam
  + If patient lived far away and difficult to follow-up with, interview can be used for screening
* Thermoregulation studies
  + Test subjects in warm vs cool environment to determine how well they thermoregulate
* SCI Research projects available through ISMMS affiliates at the Bronx VA
  + Neuro-rehabilitation studies to improve function
  + Studies for bowel management improvement
  + Exoskeletal-assisted walking and Lokomat protocols
  + Low blood pressure regulation studies
  + Pharmacological intervention studies for bone loss prevention
  + Wheelchair energy expenditure study
  + Studies mainly enroll subjects injured chronically (at least 6 months to 1 year).
* Upcoming Research Fair:
  + June 4 from 5:30 to 7:30PM

Institutions expected to attend: Burke, Stevens, Columbia, CUNY

**Community reintegration programs**

Transitions Group

* Free 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
* Wednesdays at noon on KCC2

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.
* Group meets every 2 weeks and is facilitated by outpatient social worker Christina

Life Challenge Program

* The Life Challenge Program enables individuals with SCI opportunities to participate in activities that may seem impossible because of their disability such as skiing, kayaking, skydiving, jet skiing, and horseback riding
* Helps individuals reintegrate their lives into the community after injury and introduce them to variations of adaptive sports or activities
* Attendance changes in past year:
  + Total of 102 participants
  + Low attendance for less than one year post-SCI. it is difficult to recruit participants who are very newly injured. Attendance for 1-3 years post injury is relatively high.

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.
* Events include Weight Training, Mat Mobility, Spin Class, Wheelchair Mobility, Meditation Group, Aerobics.
  + Self-defense workshop: 8 week program. Learn self-defense as well as exercise.
* Facilitated by a team of PTs and OTs
* Least attended group among newly injured: Wheelchair mobility
  + It is common that those who are newly injured do not yet accept their injury and believe they will regain ambulatory ability
  + Goal: get inpatients who are soon to be discharged to make transition to participating in program as outpatients
  + Challenge: often patients become depressed once they are discharged, thus it becomes difficult for them to participate as outpatients

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
* Helps build structured community among newly and chronically injured. Allows for mutual support and provides assistance to individuals who need help in reintegrating to 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.
* Encourages participants to go out into community. ie: central park, getting haircuts, go to restaurant, see a movie, in order to slowly get comfortable with going outside.
* Funded by United Spinal Association.

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.
* Re-teaching how to breathe, which can correlate with exercise and strength training. Often patients strain and hold their breath during exercise.

Discussion:

* Suggestion to advertise groups/programs more

**Social Media Outreach**

Create Social Media Pages for Mount Sinai SCI

* Plan on posting 3-4 times a week on each platform, focusing on SCI related content with goal of expanding exposure and engagement from SCI community.
* Increase ability to get word out not just about events at Mount Sinai but also events at other facilities in order to serve SCI community in the metropolitan area
* Facebook, Instagram, Twitter
* Video channels to share videos of events taking place at mount Sinai
  + Sexuality SCI (Website: [www.SexualitySCI.org](http://www.SexualitySCI.org),) Life Challenge program, etc.
* Streamlining “The Spinal Connection” Monthly Newsletter
  + Plan to increase newsletter subscriptions, hopefully with help of social media
  + Aim to make newsletter more user friendly
  + Linking to updated website
  + Easier to access and read on mobile devices

**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
* Nielsen Foundation funded
* Goal to educate both sides: healthcare professionals and consumers
* First conference- for healthcare professionals April 1, 2017
  + Attendees from various facilities: Mount Sinai, Burke, Rusk, Helen Hayes, Kessler, Moss and Magee, other New York based hospitals and medical schools
  + Many physicians felt it was important to bring up sex with patients however did not know how to do so
  + SCI patients often did not take initiative to begin conversation with physicians on sexuality
  + Goal to give knowledge about sexuality after injury as well as how to communicate
  + Survey administered: healthcare professionals were given 6 questions to answer
    - Most physicians said they would be more likely to bring up sex with patients after conference. 50% responded “a lot more likely.”
    - Majority of physicians indicated being much more comfortable raising topic of sex with patients
* SCI Consumer Conference
  + Goal: address the void in education available regarding sexuality and intimacy for people with SCI
  + Provide the knowledge and tools necessary to rediscover intimacy and sexuality after SCI
  + 2 day conference: May 12-13, 2017
  + 100 attendees.
  + After conference most attendees said they are more likely to pursue sexual relationship
  + 100% of attendees said they believed sexual pleasure after SCI was very possible, although different than before SCI
* Dissemination of Sexuality Project
  + Created website, [www.SexualitySCI.org](http://www.SexualitySCI.org) ,which houses 16 short videos on a variety of topics
  + Website has received views internationally across 65 different countries, including Rwanda, Iran, Republic of Korea, Nigeria, Tanzania, Estonia, and Pakistan

No Barriers

* Summit event for people with physical, mental, and emotional challenges
* Scheduled for October 5-6, 2018

The Future of Home Evaluations

* 3 year Quality of Life Sustainable Impact Grant from Craig H Neilsen Foundation.
* Timeline: January 2017- January 2020
* Title: A mobile application for home evaluation and Durable Medical Equipment appropriateness for space
* Evaluation and further development of a mobile application for home evaluation and Durable Medical Equipment fit to space decisions
* Industry partner is Sensopia.
* Objective: 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
* Magic Plan app: enables individual to create floor plan showing room dimensions, door and hallway widths, and placement of objects in the home
  + Laser can be synced with app to improve accuracy of measurements
* At Mount Sinai the usability of online educational modules and of the mobile application by individuals was tested. 50 participants completed usability study
* Currently: testing the usability of online educational modules and the app at various sites
  + Collaborating with Craig Hospital and Kessler Rehabilitation Center.
  + Target N: 100 participants
  + Goal: to see whether this virtual home evaluation could be used by different populations

**discussion**

Comments regarding Life Challenge events:

Woody would like to make events less open to “returnees,” focus on new participants. Additionally, distance of some events has impacted attendance.

White water rafting event suggested.

Often participants attend events then go on their own to do activity by themselves. This is the goal of the program.

**Meeting adjourned at 1300.**