Mount sinai spinal cord injury community advisory BOARD meeting

# Monday, May 6,2019

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

## **Welcome and Introduction**

* All attendees introduced themselves including:

Thomas Bryce, Vincent Huang, Stephanie Kolakowsky-Hayner, Miguel Escalon, Chung-ying Tsai, Jill Wecht, Ann Spungen, Kristell Taylor, Arianny Ramirez, Andrew Delgado, Debra Poli, Richard Wood, Victor Calisi, Jose Hernandez, Rose-Marie Faotto, Selina Lavache, Paul Ward, Angela Riccobono, Joseph Herrera, Elaine Castelluccio, Jenny Lieberman, Christopher Noel, Susan Howley, Lori Allen-Schneider, David Putrino, Samantha Gorea, Katherine Canela

## **SCI Clinical and PROFESSIONAL education Program**

Acute Inpatient SCI Rehabilitation

* Average number of individuals with traumatic injury admitted to Mount Sinai Hospital acute inpatient rehabilitation per year- 60-70
* 25 bed inpatient unit
* Outcomes: 47% traumatic 53% non-traumatic etiology

SCI Medicine Fellowship

* 1 year fellowship
* Typically 1 position per year; 2 for upcoming year
* Accredited since 2000
* Craig H. Neilsen Foundation primary sponsor along with United Spinal Association

SCI Rotation for Physical Medicine and Rehabilitation Residents

* Inpatient and outpatient experience
* Weekly lectures, journal club, and interdisciplinary conferences
* 3 residents rotating at a time

## **SCI research**

* Model systems for SCI
* Funded 1986-2011 and 2016-2021 as full participant
* Contributes to national database (over 30K participants in national database)
* Basic requirements:
  + Complete site-specific project
  + Participate in collaborative modules with other centers
  + Educate consumers
* Inclusion criteria:
  + First rehab post-injury
  + SCI of traumatic etiology
  + Participation includes Form I interview, Form II interview, and/or modular interviews
* Modular Projects that Mount Sinai is participating
  + 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, identify demographic, neighborhood, and health-related risk factors related to moving
    - Preliminary data:
      * Most people have moved after injury
      * People who move have relocated two times on average after injury
      * Movers more likely to be racial and ethnic minorities, those who did not complete high school, younger, unmarried or previously married, insured by Medicare/Medicard or uninsured, recipient of housing assistance
  + 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 therapies (including medications if necessary) are given to keep systolic BP above 110mmHg taken while sitting and another group who are only prescribed therapies (including medications if necessary) 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:
  + 11 subjects (31%) reported symptoms of autonomic dysreflexia during the course of their inpatient hospitalization,
  + 22 of the 36 subjects (61%) reported symptoms of orthostatic hypotension, primarily during transfers and therapy sessions
  + 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
  + Current therapy vitals recording compliance 90%
  + Symptoms of blood pressure dysregulation appear to diminish over the course of inpatient stay
* Validity of Interview Based examination for Spinal Cord Injury
  + Funded through 3/7/2019
  + 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
* Development of a Consumer Guide for the Prevention of Venous Thromboembolism
  + Term of project 6/1/2018 to 5/31/2019
  + Goal: increase knowledge and awareness of prevention and management of venous thromboembolism in individuals with SCI and their caregivers
  + Developed a user-friendly and visually appealing consumer guide
  + Will disseminate materials and monitor analytics including number of views
* Informing Identification of Neuropathic Pain Phenotypes in People with SCI
  + Goal: provide information needed to conduct large scale studies to identify neuropathic pain characteristics which might inform prognosis
  + These phenotypes can be used to study different medicines in different types of pain and provide physicians with the evidence needed to match patients to appropriate treatment
* Enhancing Healthcare for Women With Spinal Cord Injury through a Web-based Information Resource
  + Goals:
    - Conduct focus groups with women with SCI as well as family and their caregivers in order to identify the top healthcare needs of this population, which would be the focus of subsequent web-based educational programs
    - Develop criteria that women with SCI should consider when selecting healthcare professionals
    - Will invite healthcare providers to be listed on the website
* Spinal Cord Injury Pain Evolution (SCIPE) Study
  + Goals:
    - Present a comprehensive description of prevalence of pain subtypes and treatments used by individuals with SCI within the first year post-injury
    - Identify predictive characteristics and psychosocial factors for later development of persistent neuropathic pain, identify biomarkers for future development of pain
    - Explore relationships between lower baseline nociceptive pain, satisfaction with life, resilience, and other psychosocial factors and track their predictive associations with pain over the course of time
* Treatment of At-Level Spinal Cord Injury Pain with Botulinim Toxin A (BoNTA)
  + A double blind randomized controlled crossover trial in which persons with chronic SCI with at-level SCI pain were treated with subcutaneously injected botulinum toxin
  + Recruitment and enrollment took place between 2016-2018, study now closed
  + Goal: to explore whether BoNTA injections could be a safe and feasible treatment for neuropathic pain
  + Participants were randomized to receive injections of placebo (normal saline) or BoNTA with follow-up at 2, 4, 8, and 12 weeks to assess pain relief. Cross over was then performed with injection and additional follow up
  + Most participants reported change in average pain intensity from baseline to 8 and 12 weeks post BoNTA injection

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.
* Currently: testing the usability of online educational modules and the app at various sites
  + Participating SCI Model System sites: Shepherd, MetroHealth, Magee
* Feasibility:
  + Training time for app is about 10 minutes
  + Higher satisfaction rate in participants under 45 years old, regardless of education level
  + Mount Sinai clinicians actively incorporate this method for home evaluation

Effects of Incorporated Exoskeletal-Assisted Walking (EAW) in SCI Acute Inpatient Rehabilitation

* Potential benefits: neuromuscular and sensory stimuli, moderate-intensity activity, reduce pain and spasticity, improve bladder and bowel function
* Goal: to determine in exoskeletal-assisted walking could be incorporated during acute rehabilitation
* Design:
  + Participants admitted to Mount Sinai acute inpatient rehabilitation from 2016-2018
  + 2 groups: EAW (10 participants) and non-EAW (20 participants)
* Intervention:
  + 60 minutes per EAW session
  + First session: sit to stand, weight shifting, some walking
  + Other sessions: walking
* Results
  + Average walking time per session: 18 minutes
  + Average steps per session: 456
  + Average up time per session: 32 minutes
  + Total 42 sessions, 1 adverse event- minor skin abrasion
  + EAW sessions can be limited due to blood pressure issues, bladder and bowel problems, spasticity.
  + Integrating EAW into acute inpatient rehabilitation increases upright and walking time and has potential to help quicken functional and motor recovery

Future Project: NYS Postdoc Fellowship Grant

* Prospective randomized control trial- EAW vs non-EAW in inpatient rehabilitation population
* Aims: to improve motor function and independence in functional activities, reduce neuropathic pain
* Goal: enroll 30 individuals with non-progressive SCI
* 3 hour long interventions
* Will compare changes in motor function, functional activities, pain, and inflammation between enrollment and discharge

## **Other collaborative and pending research projects**

* 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
  + Thermoregulation studies
  + Wheelchair energy expenditure study
  + Studies mainly enroll subjects injured chronically (at least 6 months to 1 year).

## **Support Groups**

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

SCI Family and Friends Support Group

* Geared toward anyone who has a family member or friend with a spinal cord injury
* Wednesdays from 5-6pm KCC 2 gym (1450 Madison Avenue 2nd Floor)
* Facilitated by Samantha Gorea ([Samantha.gorea@mountsinai.org](mailto:Samantha.gorea@mountsinai.org)) and James Cesario (james.cesario@mountsinai.org)

**Community reintegration programs**

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
* Helps individuals reintegrate their lives into the community after injury and introduce them to variations of adaptive sports or activities

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
* 2019 changes: individual treatment and group
  + 45 minute treatment for patients recently discharged from SCI rehabilitation and transition them to 30 minute sessions and do-it groups

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.
* Mentor training session held April 2019

## **other additions potentially coming soon**

Heidy Latsky’s Mindfulness Activation Release

* Mindfulness activation release is designed to activate the body in a calm and relaxed way
* Involves breathing techniques and rocking of the entire body
* Practice developed by Heidi Latsky within the last 2 years- initially created to assist her dance team consisting of disabled and able-bodied individuals find fluidity in their movement and deepened then mind-body connection
* Goal: to evolve mindfulness activation release into a daily movement practice for anyone to do independently

**Social Media Outreach**

Social Media Pages for Mount Sinai SCI

* Posting 3-4 times a week on each platform, focusing on SCI related content with goal of expanding exposure and engagement from SCI community.
* Increased 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
  + Analytics:
    - Facebook: Feb 2018- 263 followers. Feb 2019- 350 followers. 33% increase
    - Instagram: Feb 2018- 228 followers. Feb 2019- 685 followers. 200% increase
    - Twitter: Feb 2018- 300 followers. Feb 2019- 807 followers. 169% increase
* Streamlining “The Spinal Connection” Monthly Newsletter
  + Improve newsletter with goal of continuing to expand mailing list
  + Analytics:
    - Feb 2018 – 439 subscribers. Feb 2019- 564. 29% increase.
  + New website URL: mountsinaiSCI.org
  + Currently updating Resource Links page (<http://labs.icahn.mssm.edu/brycelab/educational-resources/>)

**Community partnerships**

Sexuality After SCI (sexualitysci.org)

* Featured in New Mobility Magazine and FacingDisability.com
* Website Analytics:
  + 2018: 6,050 unique visitors, 6,401 visits, 18.7k page views, viewed in 116 countries
  + 2019: 8,086 unique visitors, 6,156 visits, 24.2k page views, views in 105 countries.

NYC Breaking Barriers Summit:

* Collaborating with NYC Parks and Recreation to host an adaptive sports event in Central Park
* Tentatively scheduled for Friday, September 20, 2019
* Approximately 12 adaptive sports organizations, food venders, 50 volunteers
* ESPN potentially to provide coverage for event

## **Open Discussion**

* There was discussion regarding Family Support Group and maximizing attendance
  + There was a lively discussion of the optimal start time of the group that would maximize the number of potential family member participants. The ultimate consensus was that the group should be moved to later in the day in order to better accommodate working family members. It was suggested the start time be moved to 6:00 pm from 5:00 pm.
* Question regarding why Mount Sinai is currently conducting any stem cell trials as is being done at other centers- specifically a trial being conducted by Wise Young in NJ.
* There was a response by Dr. Spungen questioning the feasibility of this trial specifically regarding the needs for concurrent intensive physical therapy of 80 hours minimum per week for several months. It was noted at Mount Sinai we currently do not have the structure to provide that amount of therapy. Also it was explained that many different variables that can determine whether stem cell therapy will work (for example: how much scar tissue has been removed before the stem cells are applied). It was also noted that stem cells can provide different kinds of growth factors which may play a role in how they could be helpful. All these points were mentioned to reinforce a point that stem cell trials may look promising in animal models, but translating to human subjects is very different and often is prone to failure. It was intimated perhaps that it was premature to embark upon another human stem cell trial here at this time for these reasons.

**Meeting adjourned at 1300.**