Mount sinai spinal cord injury community advisory BOARD meeting

# Monday, May 18,2020

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

## **Welcome and Introduction**

* All attendees introduced themselves including:

Joseph Herrera, Thomas Bryce, Miguel Escalon, Vincent Huang, Anne Spungen, Jill Wecht, Noam Harel, Rose Marie Faotto, Angela Riccobono, Pierre, Paul Ward, Christopher Noel, Richard Wood, Jim Weisman, Debra Poli,Chung-ying Tsai, Jose Hernandez,Yu-Kwang Wu, Matthias Linke, Kristell Taylor, Andrew Delgado, Arianny Ramirez, Tara Accetta, Ola Alsalman, Laurie Allen, Laura Tabacof, Jim Cesario

## **COVID-19 Response**

During peak: 2,000+ admitted COVID-19 patients with 450 in ICUs

Precision Recovery

* Previously used for stroke patients, adapted for COVID-19 symptom monitoring

Recharge rooms for frontline providers

* 1400 providers served in recharge rooms

Plan in place for outpatient re-opening

**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: May 2019- 371 followers. May 2020- 448 followers. 21% increase
    - Instagram: May 2019- 692 followers. May 2020- 1.214 followers. 75% increase
    - Twitter: May 2019- 815 followers. May 2020- 1,244 followers. 53% increase
* Mount Sinai SCI (MountSinaiSCI.org)
  + Resources for Individuals with SCI
  + Upcoming Events
  + Recently Published Articles
* COVID-19 Guidance:
  + Information for prevention of COVID-19
  + Factsheets
  + Guide for adaptive home workouts
  + List of national resources- continuously updated
* “The Spinal Connection” Monthly Newsletter
  + Improve newsletter with goal of continuing to expand mailing list
  + Prioritized Special Edition newsletters related to COVID-19
    - Future Special Editions: Mental Health during COVID-19 and Meditation/Yoga for SCI
  + Analytics: May 2019- 566 subscribers. May 2020- 846 subscribers. 49% increase.
  + Newsletter views have increased due to COVID-19 content
* Sexuality After SCI (sexualitysci.org)
  + Increased traffic in April- perhaps due to COVID-19 stay-at-home orders
    - 321 clicks, 3.33K impressions
  + Top clicks: Adaptive Devices, Positioning Partners, External Resources

## **Virtual Support Groups**

Continuing efforts to reach out to SCI community during pandemic

* New groups:
  + SCI Well-Being Group (Mondays): Focus on breathing techniques guided by meditation
  + Movement Group (Tuesdays): Seated workout session developed by Mount Sinai Rehab occupational therapists and physical therapists

Established support groups now meeting virtually:

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

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.
* Attendance has been on average 17 participants
  + Pre-COVID group was canceled due to lack of participants

Approximately 19 regular attendees across all groups. Average age of attendees: 39.6 years. Participants have been injured an average of 10.6 years.

Those who live in areas from which it is difficult to commute to NYC are now attending online programs and are reconnecting.

## **SCI research**

* Experience of persons with SCI during the COVID-19 pandemic
* Online survey of individuals living with SCI in the tri-state area
* Aim to detail how pandemic has affected individuals with SCI
  + Caregiver services
  + Health
  + Equipment and supply
  + Employment and benefits
  + Psychosocial effects
* Potential collaboration with Social Security Administration and Department of Labor
* Attendee comments/suggestions:
  + Concerns regarding length of survey
  + Potentially add question regarding barriers to telemedicine use
  + Consider adding question regarding significance of different activities during pandemic
  + NYC Chapter of United Spinal can potentially assist with reimbursement
* 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
    - Form I
      * Collected during inpatient stay
      * Target: N=50 per year
      * 22 collected in this year thus far
    - Form II
      * Used for follow-up at years 1, 5, 10, 15, 20, etc.
      * 93.4% follow-up as of March 2020 data submission
      * Follow-up strategies: TLO, Instant Checkmate, department newsletter, Transitions, SCI Peer Mentoring
* Modular Projects that Mount Sinai is participating
  + Impact of pain at follow-up in individuals with SCI
    - Collaborators: University of Miami (lead), Craig Hospital, Rancho Los Amigos, TIRR (Houston), University of Alabama at Birmingham
    - Phone survey at anniversary (1, 5, 10, 15, 20, etc..)
    - Goal: characterize type of pain experienced (neuropathic, musculoskeletal, etc), impact on mood and function
    - Data collection completed
    - Writing two papers that are being submitted to journals:
      * Treatment of Neuropathic Pain after SCI: A Cross sectional study of both pharmacological and non-pharmacological interventions
      * Treatment of Non-neuropathic Pain after SCI: A Cross sectional study of both pharmacological and non-pharmacological interventions
  + 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
  + 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
* Papers
  + The Impact of Internet Access on Self-reported Quality of Life

in Persons with Spinal Cord Injury- Audrey Chun

* + Length of Time Required for Wheelchair Repair Among Individuals with Spinal Cord Injury- Matthias Linke
* 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
* Objectives
  + Determine impact of neurological classification of injury (ISNCSCI) and degree of autonomic impairment (IASFSCI) on cardiovascular autonomic function in newly injured patients with SCI and orthostatic changes in systemic and cerebral hemodynamics in newly-injured individuals
* 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:
  + Neither ISNCSCI or ISAFSCI were sufficiently sensitive to determine resting cardiovagal or vasomotor control
  + Change in blood pressure did not predict change in cerebral blood flow velocity, however sensory score on the ISNCSCI predicted significant amount of variance
* Spinal Cord Injury Pain Evolution (SCIPE) Study
  + Investigators: Thomas Bryce, Elizabeth Felix (Miami), Jeanne Zanca, Trevor Dyson-Hudson (Kessler), Sara Mulroy (Rancho Los Amigos)
  + 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
  + Participants will be enrolled for one year and will be evaluated at admission, 6 months post-injury, and 12 months post-injury
    - Bedside testing will be administered to evaluate whether simple tests can evoke pain at admission and 1 year visits
* Combination drug therapy to prevent bone loss in persons with SCI
  + Investigator: Ann Spungen (Bronx VA Medical Center), Thomas Bryce, William Bauman
  + Goal: Prevent bone loss after SCI
    - Maintain more than 70% of bone at the knee in 80% of intervention group at 24 months compared to control
  + Participants will be enrolled over 2 years
  + Inclusion criteria: Motor complete SCI injured 6+ months
  + Intervention group will receive 12 months of romosozumab followed by 12 months of demosumab
  + Control group: 24 months of placebo
* 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
* Effects of Exoskeleton Assisted Walking (EAW) in SCI Acute Inpatient Rehabilitation
  + Purpose: Assess effects of early EAW training vs non-EAW on functional recovery, pain, and inflammation
  + Potential benefits: neuromuscular and sensory stimuli, moderate-intensity activity, reduce pain and spasticity, improve bladder and bowel function

## **PROFESSIONAL education**

SCI Medicine Fellowship

* 1 year fellowship completed after residency
* 2 positions per year
* Accredited since 2000
* Craig H. Neilsen Foundation primary sponsor along with United Spinal Association
* Inpatient and outpatient rotations
* research training
* Current fellows: Audrey Chun, MD and Matthias Linke, DO
* Upcoming fellow for 2020-2021: Daniel Spunberg

**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
* Currently on pause due to COVID-19

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.
* Challenge: Identifying available mentors
* In-person interactions currently on pause due to COVID-19
* Attendee suggestion: consider Zoom training of peer mentors and hosting peer mentor sessions virtually

## **Open Discussion**

* Suggestion: Create project aimed to improving education among those with chronic SCI regarding preventing fragility fractures- Deb Poli

**Meeting adjourned at 1300.**