Mount sinai spinal cord injury community advisory BOARD meeting

# Monday, September 20,2021

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

## **Welcome and Introduction**

* Attendees

Thomas Bryce, Vincent Huang, Miguel Escalon, Chung-ying Tsai, Jill Wecht, Ann Spungen, Arianny Ramirez, Andrew Delgado, Laiba Afzal, Angela Riccobono, Arlene Reisman, Noam Harel, James McKay, Victor Calise, Debra Poli, Jose Hernandez, Rose-Marie Faotto, Joseph Herrera, Elaine Castelluccio, Nancy Lieberman, Christopher Noel, Lori Allen-Schneider, Vincenzo Piscopo, Eli Ramos, Lawrence Harding, Corey Lewis, Lynda Murray, Bernadette Mauro, James Cesario, Alex Elegudin

## **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- 55-70
* Every patient receives a minimum of 15 hours of therapy per week.
* Advanced rehabilitative technologies: functional electrical stimulation (FES) cycle ergometry, over ground body weight-supported ambulation training, and powered exoskeletons
* iPads provided to facilitates follow-up, SCI resources, and virtual group/peer mentoring
* The AIR Unit has capacity to treat 5 persons with ventilator support

SCI Medicine Fellowship

* 1 year fellowship
* 2 positions per year; Current Fellows: Jennifer Chui, MD & Rachel Santiago, MD
* 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
* Intense clinical and research training and education
* Weekly lectures, journal club, and interdisciplinary conferences

## **SCI research**

* Model systems for SCI
* Awarded the Spinal Cord Injury Model Systems (SCIMS) grant for new cycle 2021-2026
* Only SCI Model Systems in NY
* Contributes to national database (over 30K participants in national database)
* Basic requirements:
	+ Complete site-specific research project
	+ Participate in collaborative modules with other centers
	+ Educate consumers & professionals
* 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 participated in last cycle
	+ 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
		- Goals of study: Characterize types of pain people have (neuropathic, musculoskeletal, etc.); Characterize impact on mood and daily function and document pain treatments used by individuals with SCI
		- Progress:Enrolled: 391. Data collection completed.
		- 56 % participants screened positive for NeuP; the top three most effective treatments were opioids, cannabinoids and antiepileptics.
		- Manuscripts: Tsai CY, Bryce TN, Delgado AD, Mulroy S, Maclntyre B, Charlifue S, Felix ER. Treatments that are perceived to be helpful for non-neuropathic pain after traumatic spinal cord injury: a multicenter cross-sectional survey. Spinal Cord. 2021 May;59(5):520-528. doi: 10.1038/s41393-021-00621-9. Epub 2021 Mar 19. PMID: 33742116.

Felix ER, Cardenas DD, Bryce TN, Charlifue S, Lee TK, MacIntyre B, Mulroy S, Taylor H. Prevalence and impact of neuropathic and non-neuropathic pain in chronic spinal cord injury. Arch Phys Med Rehabil. 2021 Jul 31:S0003-9993(21)00913-8. doi: 10.1016/j.apmr.2021.06.022. Epub ahead of print. PMID: 34343523

* + 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: Identify individual, health, and neighborhood predictors of and why people with SCI move place to place
		- Progress:
			* Enrolled: 4599. Data collection completed
			* Manuscripts: Botticello AL, Murphy L, Bogner J, Boninger M, Bryce TN, Chen Y, Heinemann AW, Roach MJ. Who Moves After SCI? Individual, Health, and Neighborhood Predictors of Residential Mobility Among Participants in the National Spinal Cord Injury Model Systems Database. Arch Phys Med Rehabil. 2021 May 15:S0003-9993(21)00368-3. doi: 10.1016/j.apmr.2021.03.039. Epub ahead of print. PMID: 34004163.
	+ 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
* Past Cycle Site Specific Project
* Treatment of Post-SCI Hypotension: A randomized controlled study of usual care versus ant-hypotension therapy
* Randomized, Usual-Care Controlled, Clinical Trial
* Goals of study: To determine the effects of anti-hypotensive treatment initiated based upon a blood pressure threshold, regardless of symptoms to treatment of symptomatic hypotension and orthostatic hypotension alone
* Progress: Enrolled: 66. Data collection completed
* Manuscripts: Noonavath, M., Bryce, TN., Weir, JP., Vaccaro, DH., Escalon, MX., Huang, V., Delgado, A., Maher, MT., Wecht, JM. Evaluation of cardiovascular autonomic function in newly injured patients with traumatic spinal cord injury
* Vaccaro, DH., Weir, JP., Bryce, TN., Escalon, MX., Huang, V., Delgado, A., Wecht, JM. Orthostatic systemic and cerebral hemodynamics in newly injured patients with spinal cord injury – under review Autonomic Neuroscience
* Current Cycle Site Specific Project
	+ Safety, Feasibility, and Efficacy of Transcutaneous Spinal Cord Stimulation (TSCS) on stabilizing Blood Pressure for Acute inpatients with SCI
	+ Phase II Clinical Trial to determine feasibility, safety, and efficacy of TSCS to restore blood pressure control
	+ Goal: Determine best positioning and stimulation parameters for each person, incorporate TSCS into daily physical therapy and Develop and teach others an easy-to-follow algorithm for customizing stimulation parameters for each individual
* The Experience of persons with Spinal Cord Injury or Disease during the COVID-19 Pandemic
	+ Investigators: T. Bryce, A. Spungen, S. Kirshblum, O. Bloom
	+ Goal: Describe how the COVID-19 pandemic affected persons with SCI/D in relation to health, services, equipment, employment & psychosocial
	+ Progress: Enrolled: 243. Data collection completed
* Improving Healthcare Access for Women with Spinal Cord Injury Study
	+ Goals: Focus Groups which included: women with SCI and family and professional caregivers (i.e., doctors, therapists, etc.) & Identify the 3 most important factors women with SCI who live in NYC consider deficient when working with different healthcare professionals.
	+ Study Outcomes:Develop a training module on PEAK to facilitate sensitivity and quality improvement training for physicians who specialize in OB/GYN, Urology, and ER Medicine.
	+ Progress:Focus groups and a qualitative reviews are complete; we are presently working on Sinai’s internal PEAK Training. Complete by October 2021.
* Enhancing Healthcare for Women With Spinal Cord Injury through a Web-based Information Resource
	+ Goals: Focus Groups which included: women with SCI and family and professional caregivers (i.e., doctors, therapists, etc.)

Identify the 5 most important factors women with SCI consider when selecting healthcare professionals including web-resources currently available

Develop new educational resources for needs that currently do not have sufficient resources available

* + Study Outcomes: Produce a web-based national resource (i.e., website) that can serve as a comprehensive directory for the most important healthcare factors to all stakeholders.
	+ Progress: Focus groups and a qualitative reviews are complete; we are presently working on the website. Overall, we found the 5 most important areas were:
	(1) Access, (2) Advocacy, (3) Bowel & Bladder, (4) Gynecology, (5) Mental Health

* Spinal Cord Injury Pain Evolution (SCIPE) Study
	+ Collaborators: Kessler, Rancho Los Amigos, Univ. Miami
	+ Goals:
		- Present a comprehensive description of prevalence of pain subtypes and treatments used by individuals with SCI within the first year post-injury
		- Projected Study Outcomes: Understanding how various subtypes of pain present and change over time, both with regards to severity and interference with life activities, can provide clinicians with prognostic tools and potential biomarkers to guide clinical decisions and inform newly-injured patients on what to expect in the long-term with regard to their pain.
		- Progress: Enrolled: 66/142. Data collection ongoing
* Validity of an Interview and Online Version of the International Standards for the Neurological Classification of Spinal Cord Injury
	+ Collaborators: Kessler (Kirshblum), Univ Washington (Burns), Thomas Jefferson Univ (Marino), Dijkers
	+ Goal of study: To design and validate the use of interview and online versions of the International Standards (ISNCSCI) exam that could possibly allow the determination of the approximate level of spinal cord injury and injury severity without a hands-on physical exam
	+ Study design: Part 1- development of interview and online versions including cognitive interviewing assessments of individuals completing the questionnaires. Part 2- validation of measures through testing in comparison to standard exam performed in persons with chronic SCI
	+ Progress: Questionnaire developed and is being revised before cognitive interviewing begins

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

* Goal: To test the effect of early incorporated EAW training in AIR on accelerating functional recovery and reducing pain and inflammation
* Progress: Enrolled: 18. Data collection ongoing
* Manuscripts: Tsai CY, Delgado AD, Weinrauch WJ, Manente N, Levy I, Escalon MX, Bryce TN, Spungen AM. Exoskeletal-Assisted Walking During Acute Inpatient Rehabilitation Leads to Motor and Functional Improvement in Persons With Spinal Cord Injury: A Pilot Study. Arch Phys Med Rehabil. 2020 Apr;101(4):607-612. doi: 10.1016/j.apmr.2019.11.010. Epub 2019 Dec 28. PMID: 31891715.

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

* Stentrode implantable brain-computer interface
	+ David Putrino, PhD, PT, Director of Rehabilitation Innovation for the Mount Sinai Health System and a Principal Investigator of the study
	+ National Institutes of Health to study whether a first-of-its-kind brain implant can improve the ability of severely paralyzed patients to communicate
	+ The first implantation of the Stentrode technology in the United States is expected to take place within the next 12 months.
	+ Researchers will perform imaging studies on healthy participants and those living with paralysis
	+ Having this information will allow them to create protocols for selecting patients for the study who will have good outcomes with implantation.
* Consumer Guide for Exoskeletal Assistive Walking for Individuals with SCI
	+ Goals of study: To increase knowledge and awareness on the use of different FDA approved Exoskeletal Assistive Walking (EAW) device for individuals with SCI
	+ Projected Study Outcomes:
		- With consumer and caregiver input, develop a user-friendly, visually appealing, engaging and easy to read and understand evidence-based consumer guide
		- With consumer and caregiver input, evaluate the content of the consumer guide for level of engagement, ease of use, and level of understanding
		- Disseminate material and monitor analytics such as number of views, likes and re-post on partner websites
* Ongoing Grant Application: Incorporation of exoskeletal-assisted walking during SCI acute inpatient rehabilitation to accelerate functional, motor, bowel, bladder, and neural connectivity recovery
	+ Type of study:Randomized control trial
	+ Goals of study:
		- Determine the effects of AIR+EAW versus AIR-alone on improving functional independence and motor, bowel, and bladder functions
		- Determine the effects of AIR+EAW versus AIR-alone on improving corticospinal connectivity to leg muscles below the neurological level of injury.
		- Explore the associations between walking training parameters (methods, training time, frequency, number of steps) during AIR and the outcomes of functional independence and motor function
* Research Protocols Available for Veterans and Non-Veterans with SCI at the James J. Peters VA Medical Center, Bronx, NY
	+ Studies with aspects on Neurorehabilitation:
		- Priming with Transpinal Stimulation to Augment Locomotor Training Benefits in SCI
		- Effects of Remote Ischemic Conditioning on Hand Use in Individuals with Spinal Cord Injury: A Preliminary Study
		- Motor Cortex Plus Spinal Cord Stimulation for Chronic Cervical Spinal Cord Injury
		- Alterations of Brain Resting State Networks Following Spinal Cord Injury
		- Clinical Assessment of Upper Extremity Performance in Individuals with SCI Using the LIFT System to Deliver Non-Invasive Electrical Spinal Stimulation
	+ Studies on Exoskeletal-assisted Walking
		- The Effects of Exoskeletal-Assisted Walking on Seated Balance using the IndegoTM
	+ Studies on Thermoregulation
		- Developing a Feedback-Controlled Heated Vest to Address Thermoregulatory Dysfunction in Persons with Spinal Cord Injury
		- Thermal Comfort and its Effects on Routine Daily Activities in Persons with SCI During Seasonal Hot Temperatures

## **Post Acute Rehabilitation Services**

* Life Long Medical Services: Resumed
* Outpatient PT, OT, Nueropsych: 45 min therapy treatment sessions for the newly injured and the complex patients were resumed. 34 patients currently on program
* Do It! Group Program: still on hold to maintain social distancing in the OPD gym
* Wheelchair Seating Clinic: Resumed
* Life Challenge program: 3 water skiing event this summer

## **weekly virtual Groups**

* Virtual Classes will be permanent part of program
* Onsite live classes planned for the future, with hybrid classes being the ultimate goal
* Meditation Group: 10 - 15 participants averaged per class
* Sitness Fitness Class: 20 – 25 participants averaged per class
* Transitions SCI Support Group: 10 -15 participants averaged per class
* Zumba Dance Class: 10 – 15 participants averaged per class
* Women on Wheels Support Group: 5 - 7 participants averaged per class
* Family Support Group: 2 – 4 participants averaged per class
* Boxing Fitness Class: 20-25 participants averaged per class

**Social Media Outreach**

Departmental Social Media: Twitter: 1,948 Followers Instagram: 1,691 Followers

Social Media Pages for Mount Sinai SCI

* As of March 2021, new pages focusing on SCI related content with goal of expanding exposure and engagement from the SCI community.
* Facebook, Instagram, Twitter
	+ Analytics:
		- Facebook: 55 Followers
		- Instagram: 724 Followers
		- Twitter: 109 Followers
		- YouTube: 717 subscribers
		- “The Spinal Connection” Monthly Newsletter: 1058 subscribers

**Community Outreach**

Professionally developed SCI Educational Videos

* [Bladder Self-Catheterization by a Male with Limited Hand Function](https://www.youtube.com/watch?v=mNnJrYUJQL4)

Professionally developed SCI Educational Factsheets

* [Opioids and your Health](https://msktc.org/sites/default/files/SCI-OpioidsYourHealthFS-508_0.pdf)

Educational Webinars for Consumers

* [Returning to work after a disability, part 3](https://www.youtube.com/watch?v=05udT57fWdI&list=PLn7vN6HThxD0-2fzQM-lnNhOtDmOkiigS&index=7)
* [Returning to work after a disability, part 2](https://youtu.be/kKDgDFXgwKA)
* [Returning to work after a disability](https://youtu.be/4PXGBionAos)
* [Blood pressure disorders in people with SCI: what you need to know](https://youtu.be/XFpITnbC_l8)
* [Spasticity and spinal cord injuries](https://youtu.be/NKhBUhDxfnc)
* [Providing resources for people with SCI during the pandemic](https://youtu.be/_p1e41pixiY)
* [Nutrition for SCI and paralysis](https://www.youtube.com/watch?v=DH9-qfoGw-Q)
* All can be accessed via our [MountSinaiSCI](https://www.youtube.com/channel/UCwVomnPxRwyRHiM1wSbi2ig) YouTube channel

 Logitech G Adaptive Esports Tournament

* In partnership with tech company Logitech and Ablegamers, Putrino Lab organized an e-sports video gaming competition
* Players with disabilities are group according to their level of ability and compete online with players with similar abilities
* $10,000 total grand price for the tournament

## **Open Discussion**

* There was discussion regarding the women with SCI research studies
	+ Positive feedback for both studies. Bernadette Mauro highlighted that both studies are highlighting different aspects of healthcare disparities for women with SC (Web based resource for consumers; sensitivity and quality improvement training for physicians)
	+ Elaine will reach out to Andrew and share ICS list of accessible centers for women with SCI to include in women website.
* There was discussion regarding SCI Educational Videos
	+ Positive feedback regarding Catheterization video. Debra noted that the video was created in good taste and very educational.
	+ Positive feedback on our consumer zoom webinars. Elaine commented that the information and flyers on the upcoming webinars are decimated in a timely matter and they are always able to share to their ICS members.

**Meeting adjourned at 1300.**