Mount sinai spinal cord injury community advisory BOARD meeting

# Monday, October 17,2022

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

## **Welcome and Introduction**

* Attendees

Thomas Bryce, Vincent Huang, Chung-ying Tsai, Jill Wecht, Ann Spungen, Arianny Ramirez, Garrison Redd, Laiba Afzal, Arlene Reisman, Noam Harel, Lisa Spielman, Alfred Tadatada, Angela Riccobono, Marissa Mccay, Omar Walli, Theodore Hsu, Mary Hodge, Debra Poli, Jose Hernandez, Rose-Marie Faotto, Joseph Herrera, Elaine Castelluccio, Laura Tabacof, Christopher Noel, Lori Allen-Schneider, Vincenzo Piscopo, Eli Ramos, Jorge Chavez, John Hamre, Jimmy Mckay, Ryan Martin, Tanjum Nusrat, Varsha Ganesh, Ralph Jean, Shakila Foster, Yesenia Torres, Doug Olson, Christian Valle

## **Medical Rehabilitation Services**

* The MSH SCI Acute Inpatient Rehabilitation (AIR) Unit is self-contained with all services located on the same floor. 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
* The aim is for the person with SCI to achieve complete independence in ADLs or to learn to be independent in instructing care providers on the most appropriate ways to aid them in their ADL needs.
* All patients participate in 1:1 educational sessions with nursing and each therapy discipline.
* Various weekly support groups available.
* iPads provided
* Includes Zoom and EMR patient portal apps
* Facilitates follow-up, access to individualized SCI resources, and virtual group/peer mentoring contacts.
* The AIR Unit has capacity to treat 5 persons with ventilator support.
* Historically, ~60% of those admitted who initially required ventilator support have been completely weaned from the ventilator during the AIR stay.
* Individuals are assessed for diaphragmatic pacing systems if they are unable to be weaned from the ventilator.
* 40% of individuals who sustain a traumatic SCI concurrently sustain a traumatic brain injury (TBI). All individuals are screened, monitored, and treated for TBI if present.

## **Post Acute Rehabilitation Services**

* Life Long Medical Services: Resumed
* Outpatient PT, OT, Nueropsych:
  + 45 min therapy treatment sessions for the newly injured
  + 36 patients currently on program
* Do It! Group Program:
  + Patients are referred to the virtual groups.
  + Wheelchair mobility has been done individually.
  + Outdoor wheelchair mobility group to restart.
  + 45 minute treatment sessions
  + Andago coming 10/22
    - The Andago utilizes mobile robotic technology to sense the patient’s movement intention and actively while providing dynamic body weight support.
    - It bridges the gap between treadmill-based gait training and free over ground walking.
* Wheelchair Seating Clinic
* Life Challenge Program
  + 16 events in total for the year  6-8  participants averaged per class

## **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: 7 - 10 participants averaged per class
* Sitness Fitness Class: 15 – 20 participants averaged per class
* Transitions SCI Support Group: 15 -20 participants averaged per class
* Zumba Dance Class: 15 – 20 participants averaged per class
* Women on Wheels Support Group: 8 - 16 participants averaged per class
* Boxing Fitness Class: 15-20 participants averaged per class

## **SCI Life Challenge Program Recent Events**

* Adaptive Water Skiing with the LOF Adaptive Skiers 08/10/2022
* Adaptive Surfing with “Life Rolls On” 09/10/2022
* Partnered with the US Open which provided us with the opportunity to watch the Wheelchair US Open 09/08/2022
* Adaptive Sailing on the Catamaran 09/20/2022
* Adaptive indoor sky diving 08/28/2022
* Adaptive outdoor sky diving 04/28/2022
* Cuny adaptive basketball demo 10/13/2022

## Adaptive Gliding 06/02/2022**Mount Sinai SCI Future Events**

* Adaptive Rock Climbing- At Brooklyn Boulders Long Island City.
* Adaptive Gliding- With Freedom Wings International Flying For Persons With Disabilities
* Adaptive Wcmx – with Life Rolls on Foundation
* Fashion Show- Highlighting Adaptive/Universal design Clothing –with the “Runway of Dreams”
* Adaptive Cooking Class- At Mount Sinai KCC3 Women on Wheels Group
* Self-defense class- With Supreme Martial Arts NYC
* Adaptive indoor Skydiving- at iFly
* Adaptive Outdoor Skydiving- with Sky dive the ranch
* Adaptive Skiing event- taking place at Pico Mountain in Vermont
* Adaptive Water Skiing- With Leaps of Faith Adaptive Skiers
* Adaptive Surfing- With the Life Rolls on Foundation

**Educational Outreach 2021-22**

Webinars for Consumers

[Vocational Services for People with Disabilities Monthly Series Part 5](https://www.youtube.com/watch?v=vrYOZAQipII&feature=youtu.be)

[Vocational Services for People with Disabilities Monthly Series Part 6](https://www.youtube.com/watch?v=05udT57fWdI)

[Vocational Services for People with Disabilities Monthly Series Part 7](https://www.youtube.com/watch?v=O79PdHbzYRQ)

[Vocational Services for People with Disabilities Monthly Series Part 8](https://www.youtube.com/watch?v=t0TodbBBwXk&t=1s)

[Electrical Spinal Cord Stimulation in People with SC](https://www.youtube.com/watch?v=Zr3LrrBhfe8)

[Pharmacological Approaches to Prevent or Reverse Bone Loss in Persons with Spinal Cord Injury](https://www.youtube.com/watch?v=bIf0InZ547w)

All can be accessed via our [MountSinaiSCI](https://www.youtube.com/channel/UCwVomnPxRwyRHiM1wSbi2ig) YouTube channel.

Upcoming Webinars

* Exoskeletons
* Gun Violence
* Finding Employment After Injury
* Living With SCI

We welcome you all to collaborate with us for future webinar topics and themes. Contact Arianny for planning or comments/suggestions.

**Monthly Newsletter**

The online “The Spinal Connection” newsletter to provide persons with spinal cord injury (SCI) and their friends and families with current information on events, programs, new treatments, research developments, and other issues.

* Spinal Connection e-Newsletter
  + 1,258 subscribers | [Newsletter Archive](https://labs.icahn.mssm.edu/brycelab/newsletter-2/)
  + 2021 -2022 Analytics: 19% Increase in Subscribers

**sOCIAL mEDIA oUTREACH**

As of March 2021, new pages focusing on SCI related content with goal of expanding exposure and engagement from the SCI communities.

* Instagram
  + [1,210 followers](https://www.facebook.com/Mount-Sinai-Spinal-Cord-Injury-106017601561378)
* Twitter
  + [338 followers](https://twitter.com/MountSinaiSCI)
* Facebook
  + [130 followers](https://twitter.com/MountSinaiSCI)
* YouTube
  + [819 subscribers](https://www.youtube.com/channel/UCwVomnPxRwyRHiM1wSbi2ig)
* 2021-2022 Analytics
  + Instagram
    - September 2021 (724 Followers)- September 2022 (1,210 Followers)
    - 67% Increase in Followers
  + Twitter
    - September 2021 (109 Followers) - September 2022 (338 Followers)
    - 210% Increase in Followers
  + Facebook
    - September 2021 (55 Followers) - September 2022 (130 Followers)
    - 136% Increase in Followers
  + YouTube
    - September 2021 (717 Followers) - September 2022 (819 Followers)
    - 14% Increase in Followers
* Future Outreach Goals
  + Update our website online platform with the goal of:
    - Making it more user friendly
    - Embed Educational Videos
    - Linking to our social media platforms
    - Easier to access and read on mobile phones
* Continue to update our SCI resource page on our website with important links relevant to the SCI community
  + Review current resource page, open for suggestions on what topics and links we should add/update: [Useful Resources Page](https://labs.icahn.mssm.edu/brycelab/educational-resources/)

## **SCI research**

* Model systems for SCI
  + The Spinal Cord Injury Model Systems (SCIMS) program, established in 1970, is a network of 18 comprehensive SCI systems of care.
  + SCIMS study the course of recovery, health, and social outcomes beginning with the initial injury and extending throughout life.
* 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
* 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
  + Study Deliverables:
    - Report on the safety of TSCS for use in newly injured patients with SCI.
    - *Levels of pain, discomfort, and skin integrity*
    - Develop a standard approach for implementing TSCS to stabilize blood pressure in newly injured patients with SCI.
    - Identify factors that impede/promote use of TSCS during AIR therapy.
    - Determine the effectiveness of TSCS to facilitate better orthostatic hemodynamic responses.
    - Explore off-target effects of TSCS targeted for blood pressure control on upper and lower extremity motor function.
* 2021 to 2026 SCIMS Module Project
  + Safety, feasibility, and efficacy of transcutaneous spinal cord stimulation on stabilizing blood pressure for acute inpatients with spinal cord injury (ISAFSCI)
    - Assesses autonomic control of multiple organ systems:
      * Objective measurements
        + Cardiovascular – heart rates and blood pressures
        + Thermoregulation – core body temperatures
        + Bronchopulmonary – ventilator support & forced vital capacity
      * Subjective questions
        + Sudomotor – sweating capacity above and below injury
        + Bladder – sensation of fullness ability to prevent leak
        + Bowel - sensation of fullness ability to prevent leak
        + Sexual – orgasm, erection, lubrication
      * Study aims
        + Aim 1a: To document the percent of complete ISAFSCI data collected by clinicians (Feasibility #1).
        + Aim 1b: To document the reasons for the missing ISAFSCI data (Feasibility #2).
        + Aim 2: To compare scoring on the ISAFSCI between two clinicians on the same participant: (Reliability #1).
        + Aim 3a: To explore associations among the ISAFSCI and other measures of ANS function
        + Aim 3b: To explore associations between ISAFSCI score at discharge and self-reported levels of life satisfaction and participation, depression at 12-month follow-up. (Predictive Validity)
* Validity of an Interview and Online Version of the International Standards for the Neurological Classification of Spinal Cord Injury
  + Term of project: 7/31/2021 through 7/30/2024
  + PI: Thomas N. Bryce, MD.
  + 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 based on cognitive interview results
  + Next step:
    - Further testing the new version to see if we still need to fine-tune the questions and figures
    - Validate the questionnaire with the standard ISNCSCI exam
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  + 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
* The effects of incorporated exoskeletal-assisted walking during acute inpatient rehabilitation (AIR)
  + Principal investigator: Ann M. Spungen
  + Post-doctoral Fellow: Chung-Ying (Owen) Tsai
  + Term of Project: 08/01/19 – 07/31/22
  + Type of study: Randomized control trial
  + Goals of study: To test the effect of early incorporated EAW training in AIR on accelerating functional recovery and reducing pain and inflammation.
  + Progress: Finished: 16 participants in the EAW group and 12 in the control
  + Summary: EAW in AIR may have the potential to accelerate motor and functional recovery during AIR
  + Future study: The study still had a small sample size and did not have enough power. We are trying to apply funding for conducting a bigger study and follow-up assessments.
  + 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.
* ExaStim Upper Limb Pivotal Clinical Validation Study
  + Principal investigator: Chung-Ying Tsai
  + Term of Project: 01/01/23 – 12/31/24
  + Type of study: Randomized control trial
  + Goals of study: To test the safety of a new investigational noninvasive spinal cord stimulation device called ExaStim and to see if it will help improve movement and sensation in the upper body, arms, and hands of individuals with spinal cord injury.
  + Study protocol: Participants will have an 8-week training with a real ExaStim or a sham stimulation. Assessments will be conducted at baseline, 4th week and 8th week of the training, and a follow-up at 4 weeks after training
  + Inclusion criteria: Chronic (>12 months post SCI) and traumatic SCI between C2 and T2
  + Progress: IRB preparation and personnel training.
* Consumer Guide for Exoskeletal Assistive Walking for Individuals with SCI
  + PI: Vincent Huang, MD. Term of Project: 08/2022 – 07/2023
  + Type of study: Consumer Guide
  + 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
* Spinal Cord Injury Pain Evolution (SCIPE) Study
  + PI: Thomas N. Bryce, MD. Term of Project: 09/30/19 – 09/29/23
  + Collaborators: Kessler, Rancho Los Amigos, Univ. Miami
  + Type of study: interview (within 30 day of injury, 6 months, 1 year) and bedside testing (within 30 day of injury, 6 months, 1 year)
  + Goals of study: Present a comprehensive description of pain sub-types and pain treatments used by persons with SCI in the US over 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: 144/193. Data collection ongoing.

## **Spinal Cord Injury Medicine (SCIM) Fellowship for Physicians**

* 1 year fellowship duration- completed after residency
* 3 positions this year for 2022-2023
* Omar Walli, MD
* Melissa McCay, MD
* Theodore Hsu, MD
* Intense clinical and research training and education
* Weekly lectures, journal club, interdisciplinary conferences
* Past alumni include
  + Miguel Escalon, MD- Mount Sinai
  + Vincent Huang, MD- Mount Sinai
  + Jennifer Chui, MD – Hackensack Meridian JFK
  + Tariq Rajnarine, MD- Moss Rehabilitation
  + Tiffany Wong, MD- NYU Langone
  + Matthias Linke, MD- Barrow Neurological Institute
  + Audrey Chun, MD- Indiana University

## **Open Discussion**

* Elaine Castelluccio: (posted the zoom chat) the employment webinars you did this past year were really great, very useful and practical information, Thank you! We referred many of our members to those webinars.
* John Hamre: In New York City, and we have a very healthy, adaptive sports program but we have an issue with wheelchair athletes. Right now, there is zero referrals from NYC to our adaptive sports programs. Would like to brainstorm how we can work better to get referrals to the Wheelchair Sports Federation from acute rehab. Perhaps we can work with Garrison on streamlining a referral process to get people more active in our programs.
* Thomas Bryce: Agreed and added that getting the information out via our social media/newsletter about available adaptive sports programs would be a great first step and with Garrison involved in your programs he can assist in identifying our target audience and planning outreach.
* Debra Poli: The one quick point is that the age the average age of people with SCI newly injured is rising so you are dealing with an older population. I think for myself, one of the issues with sports adaptive sports in New York City, it is very much geared towards young people and intimidating towards older people, that is the impression. For ex, when you look at social media and you see the photographs, it is all young people. I am not going to feel real comfortable going out with a bunch of kids who are much more physically active, so I think that one of the ways you could be more inclusive is to kind of brainstorm ways to get older people involved, because I think that population is very isolated.
* John Hamre: Perhaps that is the impression, but the reality is most of those people at the clinic you were talking about over the age of 50. Therefore, that is a perception that we are going to have to keep working on that. The perception is that Adaptive sports is scary, that is at the young age that is at middle age, and all ages adapt to sports is scary. The average time from the injury, to actually doing adaptive sports is 10 years. So whatever age you are injured or find out you have that injury, it is a 10 year on the couch that we want to try to get sooner to them because we all know the health benefits are better for that group. We can work with that on the perception. If the perception is older, we will do something just for the older audience.
* Chris Noel: I would agree. There were a number people out there playing wheelchair softball that are 50 and older in the program. I know that Kessler, Bennett, Lakeshore, Texas male clinic, they all collaborate with outside adaptive groups, so that they can have a seamless transition. I coach younger kids, and when we go to these tournaments you see them being supported by a larger hospital systems that deal with spinal cord injuries as such. Therefore, I think that would be a great collaboration.
* The question I had was the pressure mapping systems; I hear that currently we do not have any working pressure mapping systems at Mount Sinai. And I know that's a huge, I think they're 15 grand a pop for each one, but is that something that's looking to get funded soon in terms of having pressure mapping system in the wheelchair clinic, and in the inpatient unit?
* Rose-Marie Faotto: We have two in inpatient rehab. The vendor just came and adjusted for us. He also given in service to the staff that they should be able to utilize the one we have. As for outpatient, I was not aware that anything was wrong. I will follow up.
* Chris Noel: One other question I have is I know that to make appointments at Mount Sinai, it is getting longer, meaning 6 months or longer to make it appointment with a doctor. Is there is there talks in terms of shortening that length?
* Thomas Bryce: Yeah, I do admit we do have a long waiting list, but you know we try to get people in as soon as we can. Other comments, questions, things that we should be doing, or things that we should change?
* Christian Valley: I was wondering regarding spinal stimulation study, just wondering how would that work?
* Thomas Bryce: Thank you, I can tell you a little bit about it, it is a small portable stimulator, and there is kind of electrodes that are placed over the back of the neck over the spinal cord. In addition, they change the settings to see if you can improve hand motor function with specific hand therapy with the simulator either turned on or not turned on and to see if it will help improve. We are still getting it through the IRB, the study has not started yet, but as soon as we get approval, we will send out an e-blast on our social media and our newsletter when we are starting to recruit, and we will then call people in to be evaluated. However, just to keep it on your radar that we are hoping to start that in the beginning next year.
* Chris Noel: Well, Dr. Bryce, if one quick thing I just want to say once again, welcome to Garrison Redd. He is a great role model for I think a lot of the inpatients and out patients. That will be going through Mount Sinai is a very good role model for them. He has done a lot for himself, and for others, and I think that was a very good choice.
* Elaine Castelluccio: Just wanted to ask for some of your research studies where you are looking for participants. I know it is on your new monthly newsletter but if there is an electronic like Pdf filer or flyer that you can send out to us, I can also market it on our social media pages.
* Thomas Bryce: Our website, MountSinaiSCI.org that Arianny maintains and has a list of all our active, research studies. We certainly have advertisements for the various different studies that we have ongoing, that that can be disseminated as well, Arianny can be a good person to be in contact with.
* Douglas Olson: With all the participants, here on the call, there are many groups doing great work, I think the coordination is important so that we are not, duplicating services that were supporting each other. So if there's a group going to have some event in the city, that we can help all of us get participants out, I think that's really important as I think we don't want to duplicate services.
* Chris Noel: Right now, it is an individual organization putting out their information and everyone distributing, so I agree there should be some type of blog where we can get people out, and all of the information is contained in one place. Maybe, that is something Mount Sinai could put together where we have these partnering groups all be able to contribute information so that you can always have something for people to refer to.
* Thomas Bryce: This is an excellent point. I think the easy thing would be for us to promote all activities on our social media and our newsletter, please feel free to get that information to us so we can share. We want to promote whatever is out there that will benefit you know people with final cord injury, and that is kind of the approach that we have taken over the last couple of years. We will problem solve here to kind of figure out another way of potentially have an ongoing showing what is going to be upcoming. You know whether that is a blog or a page on our website, or something like that, we can kind of figure that out, so that is a good thing we will try to work on it for next year.
* The big point I took home today is, we wanted to get people into like the wheelchair sports, and all this happening a little bit easier and then potentially change the marketing, so we get older individuals who may feel intimidated by advertising for younger individuals.

**Meeting adjourned at 1300.**