

Partnering with the SCI Community to Address Challenges in SCI Translation

Course ID 235

Matthew Rodreick, Unite 2 Fight Paralysis

Lana Zholudeva, PhD, Research Scientist, Gladstone Institutes; Murray Blackmore, PhD Professor of Biomedical Sciences, Marquette University; Jason Biundo, BS Research Assistant, Boston Children's Hospital

Presentation Style: 60-minute course Type of Course: Expert Panel Title: "Partnering with the SCI Community to Address Challenges in SCI Translation" Educational Objectives: Describe incentives and challenges for different stakeholders in SCI research and medicine, based on interview data Understand the potential value added to SCI research and clinical practice from strategic partnerships including individuals with lived experience Discuss how partnerships between clinician, researcher, and SCI stakeholder groups can be facilitated, effective, and sustained Summary This course is designed to engage clinicians, researchers, funders, industry stakeholders and individuals with SCI. Research discoveries have the potential to improve function and quality of life for individuals with SCI, but many research discoveries fail to advance to clinical practice. There are significant challenges to advancing these discoveries through the translation pipeline. Some of those challenges were well articulated within the NIH 2020 Decade of Disruption session "With Us Not For Us". These challenges are systemic, and not merely due to the complexities of biology or technology. SCI Community advocates suggested they can play a role in the facilitation of stakeholder groups, including researchers, clinicians, and industry partners, to improve the system for discovering, advancing, and delivering effective therapies. In 2020, representatives from these stakeholder groups who share this concern were invited to U2FP's' T4 Workgroup in an effort to understand the systemic challenges for efficient delivery of therapies to the SCI consumer. Our workgroup has conducted discovery interviews with 65 key stakeholders to identify emerging themes in how to engage the translation pipeline's challenges and opportunities. Findings from the interviews will be presented and discussed. Draft Agenda 0:00-0:05 Matthew Rodreick, E.D. U2FP; Overview 0:06-0:10 Lana Zholudeva, PhD; Summary of Discovery Interviews 0:11-0:17 Murray Blackmore PhD; Discussion of Incentive Structures 0:18-0:29 Jason Biundo, Research Assistant with SCI; Preliminary Proposed Solutions 0:30-1:00 Discussion/Questions (with all participants) Course Chair Matthew Rodreick Executive Director, Unite 2 Fight Paralysis, family of person with SCI matthewrodreick@unite2fightparalysis.org Zholudeva, PhD Research Scientist, Gladstone Institutes lana.zholudeva@gladstone.ucsf.edu Murray Blackmore, PhD Professor of Biomedical Sciences, Marquette University murray.blackmore@marquette.edu Jason Biundo, BS Research Assistant, Boston Children's Hospital jasonbiundo321@gmail.com

Learning Objective 1 Describe incentives and challenges for different stakeholders in SCI research and medicine, based on interview data

Learning Objective 2 Illustrate the potential value added to SCI research and clinical practice from strategic partnerships including individuals with lived experience

Learning Objective 3 Discuss how partnerships between clinician, researcher, and SCI stakeholder groups can be facilitated, effective, and sustained