24th Annual Neuromuscular Study Group Scientific Meeting

Thursday, September 21, 2023
We will have check in Thursday evening and Friday morning

Day 1: Friday, September 22, 2023

6:30am-8:00am  Buffet Breakfast and Check-In
8:00am-8:20am  Welcome and State of the Neuromuscular Study Group
                Dr. Richard Barohn and Prof Michael Hanna

Session I: Motor Neuron and Neuromuscular junction

8:20am-8:40am  Simon Rinaldi - Inflammatory neuropathy
8:45am-9:05am  David Hermann, MBBCh - Towards Clinical Trial Readiness for Charcot Marie Tooth Neuropathies
9:10am-9:30am  Riccardo Zuccarino - Resp involvement in neuropathy
9:35am-9:55am  Stephan Zuchner, MD, PhD – hereditary neuropathies
10:00am-10:15am Refreshment/Exhibitor Break
10:15am-10:35am Jon Katz, MD – Updates on ALS

Session II – Flash Presentations - Moderator, Dr Michael Pulley

11:05am-11:15am  Marwah Almadhi, Investing to Save: Evaluation of Unplanned Hospital Admissions of Neuromuscular Patients in Greater Manchester, UK.
11:17am-11:27am  Michael Hehir, Measuring Adverse Event Burden in Myasthenia Gravis: Retrospective Validation of the Adverse Event Unit (AEU) with MGTX Trial Data
11:29am-11:39am  Elie Naddaf, A systematic review and meta-analysis of the placebo effect in inclusion body myositis

11:41am-11:51pm  Shaweta Khosa, The Inclusion Body Myositis Health-Index (IBM-HI): Development of a Novel, Disease Specific Patient-Reported Outcome Measure for IBM in Clinical Trials

11:53pm-12:03pm  Zhihao He, Relationships of Lower Leg Fat Fraction among antagonistic and synergistic muscles and a potential Fat Fraction threshold for functional performance in Myotonic Dystrophy Type 1

12:05pm-12:15pm  Katy Dodd, Mycophenolate is better tolerated than azathioprine in myasthenia gravis

12:17pm-12:27pm  Iwona Skorupinska, A UK experience of symptomatic treatment of myotonia with Lamotrigin

12:30pm-1:30pm  Lunch

Muscle Study Group Executive Committee Meeting Breakout

Session III: Platform Presentations – Moderator Kris Kelly

1:30pm-1:45pm  William Macken, Improving diagnostic rates for mitochondrial diseases using enhanced WGS analysis and RNA-seq.

1:50pm-2:05pm  Vinojini Vivekanandam, MEND: MExiletine versus lamotrigine in Non-Dystrophic Myotonia

2:10pm-2:25pm  Giorgia Coratti, Scoliosis progression in type II SMA at the time of treatment: a comparative study with untreated patients

2:30pm-2:45pm  Michael Hehir, Remote Monitoring and Management of Myasthenia Gravis (REMOTE-MG): A Pilot Feasibility Study

2:50pm-3:00pm  Refreshment/Exhibitor Break
3:00pm-5:00pm  Young Investigator Session/Evaluator Session Breakout; Coordinator Breakout

*ALL NEW*

Session Moderators – Dr W. David Arnold, Dr Karen Suetterlin, Dr Katherine Dodd, Dr Heidi Fuller, Prof Valeria Sansone, Marie Wencel, CCRP

● How to give an effective elevator pitch
● Failing well, overcoming rejections, criticisms and changing direction
● Networking

6:00pm-8:00pm  Reception and poster walk through session

8:00pm-9:00pm  Dinner

9:00pm-11:30pm  Reception

Day 2: Saturday, September 23, 2023

7:00am-8:00am  Buffet Breakfast

8:00am-8:15am  Dr Barohn and Prof Hanna Opening

Session V: Biomarkers (new) - Moderator Donovan Lott, PT, PhD, CSCS

8:15am-8:35am  Lisa Hobson Webb, MD - Shear wave electrography/ultrafast ultrasound use for neuromuscular disorders

8:40am-9:00am  Professor Anna Rostedt Punga, M.D; Ph.D., Uppsala University, Sweden -

Circulating microRNAs as biomarkers in Myasthenia Gravis

9:05am-9:25am  Robert Bowser, PhD – Neurofilament as a biomarker for everything

9:30am-9:50am  Eric Wang, PhD - Alternative splicing DM1

9:55am-10:15am  Glenn Walter, PhD – MRI as a biomarker in MD

10:15am-10:30am  Refreshments/Exhibitor Break
Session VI Aging

10:30am -10:50am  Thomas Wishart, PhD  - proteomic analysis of differentially vulnerable synaptic populations to identify regulators of stability

10:55am-11:15am  Dr Matthew Birkbeck  - Changes in Motor Unit MRI with age/sarcopenia

11:20am-11:40am  Roger Fielding, PhD  - Clinical aspects of sarcopenia

11:45am-1:00pm  Lunch

Session VI: Exercise – Moderator Dr. Miguel Chuquilin

1:00pm-1:20pm  Elisa Duchesne, PHT, PhD  - Université du Québec à Chicoutimi. Effect of exercise on functional outcomes and disease pathophysiology in DM1

1:25pm-1:45pm  Jackie Montes, PT, EdD, NCS  - Exercise in SMA: More than just an intervention

1:50pm-2:10pm  Tanja Taivassalo, PhD  - has multiple ongoing projects on exercise in DMD, impacts on functional outcomes and disease biomarkers

2:15pm – 2:35pm  Gita Ramdharry, PhD  - Exercise, rehabilitation and physical activity in Charcot-Marie-Tooth disease

Session VII

2:40pm-3:10pm  Refreshments/Exhibitor Break

3:10pm-3:30pm  UCB Update

3:35pm-3:55pm  Argenx Update

4:00pm-4:20pm  Sarepta Therapeutics Update

4:25pm-4:45pm  Fulcrum Therapeutics Update

4:50pm-5:10pm  Catalyst Pharmaceuticals Update

5:15pm-5:35pm  Pfizer Update

7:30pm – 8:30pm  Robert C. Griggs Annual NMSG Keynote Speaker

The Circle of Translation

Professor Mary M Reilly
Day 3: Sunday, September 24, 2023

7:00am-8:00am  Breakfast

8:00am-8:10am  Dr Barohn and Prof Hanna opening

Session VII – NMSG Young investigators projects – Moderator  Dr Karen Suetterlin

8:10am-8:25am  2022 NMSG Fellow Tyler Rehbein, MD - Neuromuscular ultrasound as a biomarker to improve clinical trial readiness in Charcot Marie Tooth Neuropathies

8:30am-8:45am  2023 NMSG Fellow Dr Natalie Katz, MD - Development of novel imaging biomarkers for use in pediatric facioscapulohumeral muscular dystrophy

8:50am-9:05am  2022 Shark Tank Award update Alex Oldroyd, University of Manchester

Quantifying Idiopathic Inflammatory Myopathy-Associated Cancer Risk via Comprehensive Phenotyping of a Large UK-Wide Cohort

9:10am-9:25am  2022 Shark Tank Award update Giorgia Coratti, PhD, Pediatric Neurology and Centro Clinico Nemo Rome

Predictive models in spinal muscular atrophy treated patients using machine learning

9:30am-10:45am  Shark Tank Session

Moderator: Aziz Shaibani, MD, FACP, FAAN, FANA

Shark Panel: Mazen Dimachkie, MD, Amanda Guidon, MD and Laurie Gutmann, MD

Presentations:
Determination of the unique genotypic/phenotypic characteristics of South East Asia FSHD1 patients in Singapore Dr Zhiyong Chen, UCL Queen Square Centre
Perceived Fatigability Tracker: Improving Assessment to Enhance Spinal Muscular Atrophy (SMA) Patient Outcomes Rafael Rodriguez-Torres DPT, Columbia University Irving Medical Center

Markers of respiratory progression in Duchenne Muscular Dystrophy – systemic inflammation and diaphragm thickness and motion (“DMD-InflUS”) Federica Trucco MD, PhD, University of Milan

LITEBulb SMA - Lingual Intervention of Tongue Exercises for Bulbar SMA Carla Zingariello DO, University of Florida College of Medicine, Gainesville, FL

10:45am-11:00am Refreshments/Exhibitor Break

Session VIII Emerging Phenotypes - Moderator Dr. Katy Dodd

11:00am-11:20am Aziz Shaibani, MD, FACP, FAAN, FANA – Neuromuscular implications of placebo research

11:25am-11:40pm James Lilleker, MBChB, Ph.D. - Adult SMA

11:45am-12:05pm Amanda Guidon, MD, MPH - checkpoint inhibitors

12:10pm-12:30pm Katherine Mathews, MD – Peds FSHD

12:35pm-12:55PM Valeria Sansone, MD, PhD - CNS and cognitive in SMA across the lifespan

1:00pm-2:00pm Lunch

Closing