

2008 MSG Annual Meeting agenda
Beaver Hollow Conference Center, Java Center, NY

Day 1: Monday, September 15, 2008

- 2 – 4 pm MSG Executive Committee meeting – Rm C (in the Aud building)
- 4 – 6 pm CINCH investigators' meeting – Rm C (in the Aud building)
- 6:00 – 7:30 pm Social hour and Introductions – Main Lodge
- 7:30 pm Dinner – Room L1 (in the Main Lodge)
After dinner speaker – *Michael Brooke*: “Seven Ages of Academics”

Day 2: Tuesday, September 16, 2008

- 7:00 – 8:00 am Informal Breakfast Seminar for new members/guests [open to all]: -
Room L1
Investigator Networks –
“The MSG and TREAT-NMD”
Moderator: *Robert C. Griggs*
Speakers: *Tawil/Bushby/Korinthenberg*
- 8:10 – 8:15 am Welcome – Robert C. Griggs - Auditorium
- 8:15 – 12 noon Neuromuscular Disease: Bench-to-Bedside - Session I
Moderators: Rabi Tawil/Charles Thornton
- 8:15- 8:45 Facioscapulohumeral dystrophy - *Silvere van der Maarel*
- 8:45 – 8:50 Discussion
- 8:50 – 9:20 Limb girdle muscular dystrophies - *Kate Bushby*
- 9:20 – 9:25 Discussion
- 9:25 –9:55 New Therapeutic Strategies for DMD - *Ellen Welch (PTC Therapeutics)*
- 9:55 – 10:00 Discussion
- 10 – 10:15 BREAK
- 10:15-10:45 Molecular therapies for the muscular dystrophies: Status 2008
George Karpati
- 10-45–10:50 Discussion
- 10:50 -11:10 Myotonic dystrophy type 1: Treatment strategies for the future -
Thurman Wheeler
- 11:10 – 11:15 Discussion
- 11:15–11:45 Myotonic dystrophy-2 - *John Day*

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- 11:45 – 11:50 Discussion
- 11:50-12:10 Iplex treatment of myotonic dystrophy - *Richard T. Moxley, III*
- 12:10-12:15 Discussion
- 12:15 - 1:30 pm Lunch – Concurrent sessions:
- PI's/Co-I's: "Mentoring and training strategies for a career in clinical/translational research" - Mallard Room
Karl Kiebertz and Darryl DeVivo
- CE's/Coordinators: "Trial implementation strategies" - Drake Room
Laura Herbelin and Cornelia Kamp
- 1:30 – 3:30 pm Bench to Bedside - Session II
Moderator: Steve Cannon
- 1:30 – 2:00 Immunopathogenesis of ALS - *Stan Appel*
- 2:00 – 2:05 Discussion
- 2:05 – 2:35 Ion channelopathies - molecular genetics and therapy - *Michael Hanna*
- 2:35 – 2:40 Discussion
- 2:40 – 3:10 Therapeutic strategies in mitochondrial encephalomyopathies
Michio Hirano
- 3:10 – 3:15 Discussion
- 3:15 – 3:30 Cornelia Kamp, Executive Director Strategic Initiatives,
Clinical Trials Coordination Center, U. of Rochester
- 3:30 – 5:30 Free time for informal discussions/meetings/networking
- 5 – 6 pm HYP HOP Investigators' meeting – *Patty Smith*
- 5:30 – 6 pm Poster Set up (Posters up by 5:45 pm) – Mallard Room
- 6:00 – 7:00 pm Hors d'oeuvres and 1st Poster Session
- 6:30 – 7:00 pm Poster discussion - *Stan Appel/Steve Cannon/Lud Gutmann/George Karpati*
- 7:00 – 10 pm Dinner – L1
After-dinner speaker - Lord John Walton of Denchant
"Sixty Years in Myology: A Retrospect"

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Day 3: Wednesday, September 17, 2008

- 7 – 8:15 am Breakfast (in Room L1)
2nd Poster Set - Up (Posters up by 6:45 am) – Mallard Room
- 7:45 – 8:15 am Authors by posters – Mallard Room
- 8:15 – 8:45 am Highlights/discussion of posters –
Stan Appel/Lud Gutmann/George Karpati
- 8:45 – 9 am MSG constitution/Amendments – *Rabi Tawil* – in Auditorium
Publications/Authorship Policy – *Don Sanders*
Nominating Process – *Steve Greenberg*
Financial statement/R. Griggs
- 9 – 9:45 am Keynote speaker – *Andrew Engel*
Title: Sleuthing targets for disease in muscle
- 9:45 – 10 am BREAK
- 10 – 12:00 noon Trial Design Session: Patient-reported outcome measures
Moderator: Mike McDermott
- 10 – 10:20 Determinants of QOL - *Reza Seyedsadjadi*
- 10:20 – 10:25 Discussion
- 10:25–10:45 Spinal muscular atrophy - “Quality of Life measures”
Susan Iannaccone
- 10:45 – 10:50 Discussion
- 10:50–11:10 Behavioral measures – *Veronica Hinton*
- 11:10-11:15 Discussion
- 11:15–11:45 Patient reported outcome measures in neuromuscular disease
Stefan Cano
- 11:45- noon Discussion
- 12 noon – 1 pm Lunch (in Room L1):
- 1:00 – 1:30 pm Updates from NIH (in Auditorium):

John Porter - Developing Novel Therapeutics for Motor Unit Diseases
John Ferguson – Office of Rare Diseases

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1:30 – 3:30 pm **Progress/Status reports (approximately 10 minutes each):**

FOR-DMD – Kate Bushby
HYP HOP – Robert C. Griggs
CMT – Michael Shy
Inflammatory Myopathies – Anthony Amato
Ocular MG – *Michael Benatar*
SMA - Petra Kaufmann
MG Thymectomy – Michael Pulley
CINCH – Robert C. Griggs

3:30 – 4 pm **Wrap-up – Robert C. Griggs**

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This meeting is sponsored by:

- National Institutes of Health (NIH):
 - National Institute of Neurological Disorders and Stroke (NINDS)
 - Office of the Director (OD)
 - National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

- Muscular Dystrophy Association

- Acceleron Pharma