

2009 MSG Annual Meeting agenda
Beaver Hollow Conference Center, Java Center, NY

NOTE: For Sunday, September 20 arrivals – dinner buffet will be served from 7- 8 pm in the Mallard Room

Day 1: Monday, September 21, 2009

- 7:30 – 8:45 am** Breakfast buffet (Mallard Room)
- 9:00 - 4:00 pm** Sessions for individual study groups:
- 9 am – 12 noon** Methotrexate MG study group meeting (Conference Rm C (in Auditorium Bldg)
- 12 - 2 pm** CINCH study group meeting (working lunch) (Conference Rm C (in Auditorium Bldg (lunch buffet set up at 11:30 in Auditorium lobby)
- 2 – 4 pm** Mexiletine study group meeting (Conference Rm C (in Auditorium Bldg)
- 2:30 – 4:30** CMT- RDCRN study group meeting (Conference Rm A (in Auditorium Bldg)
- 4:00 - 6:00 pm** MSG Executive Committee meeting (Conference Rm B (in Auditorium Bldg)
- 5:30 – 6 pm** Poster Set up (Posters up by 5:45 pm) (ELC Building)
- 6:00 – 7:30 pm** Poster Session 1 with Hors d'oeuvres & cash bar (ELC Building)
- 7:30 pm – 8:30 pm** Dinner – (Mallard Room and Lounge)
- 8:30 -** After dinner speaker – Robert C. Griggs, University of Rochester
Topic: MSG – Past, Present, Future
(L-1 Room) [coffee and dessert served in L1]

Day 2: Tuesday, September 22, 2009 (All Sessions will take place in main Lodge- L-1 Room)

- 6:30 – 8 am** Breakfast Buffet (Mallard Rm, Lodge, deck)
- 7:00 – 8:00 am** Informal Breakfast Seminar for new members/guests [open to all]:
(Drake Rm)
Investigator Networks –
“TREAT-NMD and the MSG -- new and promising areas of collaboration
Kate Bushby, International Center for Life
Moderator: *Robert C. Griggs*
- 8:10 – 8:15 am** Welcome – Robert C. Griggs/Richard J. Barohn (Room L-1, [note: main meeting takes place in L1 for both days])
- 8:15 – 10:00** Session I: Novel Translation Approaches for
Therapy of Neuromuscular Disorders
Moderator: Charles Thornton

2009 MSG Annual Meeting agenda
Beaver Hollow Conference Center, Java Center, NY

- 8:15- 8:45 Frank Bennett, ISIS Pharmaceuticals
Antisense oligonucleotides as drugs: feasibility and applications
- 8:45 – 8:50 Discussion
- 8:50 – 9:20 Timothy M. Miller, Washington University
Antisense oligonucleotide treatment of ALS
- 9:20 – 9:30 Discussion
- 9:30 –10:00 BREAK
- 10:00 – 12:00 Session II: Hereditary Neuropathy: Clinical and Translational
Research Approaches
Moderator: David Herrmann
- 10:00-10: 30 Michael Shy, Wayne State
Molecular mechanisms for Hereditary Neuropathy
- 10-30–10:40 Discussion
- 10:40-11:10 Davide Pareyson, IRCCS Foundation
Trial Design and Outcomes for hereditary Neuropathy Studies
- 11:10 – 11:20 Discussion
- 11:20–11:50 Jun Li, Vanderbilt University – Dermal Nerve Assessment: A Window to
the Mechanism of Neuropathy in Outcome Measures
- 11:50 – 12:00 Discussion
- 12:00 - 1:30 pm Lunch (Buffet – Mallard Rm, Lodge, Deck)
- 1:30 – 3:30 pm Session III Investigator – NIH - Industry Partnerships in Drug
Development
Moderator: Petra Kaufmann
- 1:30 – 1:55 *Investigator Perspective (Don Sanders, Duke University/Kathryn
Wagner, Kennedy Krieger Institute)*
- 1:55 – 2:00 Discussion
- 2:00 – 2:25 Industry Perspective - Thomas Meier, Santhera
- 2:25 – 2:30 Discussion
- 2:30 – 2:55 *Jill Heemskerk, NIH - SMA Project*
- 2:55 – 3:00 Discussion
- 3:00 - 3:25 Michael Benatar, Emory University – EPITOME – Ocular MG

2009 MSG Annual Meeting agenda
Beaver Hollow Conference Center, Java Center, NY

- 3:25 – 3:30 Discussion**
- 3:30 - 4:00 Late-breaking news**
- 4:00 – 6 pm Free time for informal discussions/meetings/networking (Drake Rm if needed)**
- 5:30 – 6 pm 2nd Poster Set up (Posters up by 5:45 pm) (ELC Building)**
- 6:00 – 7:30 pm 2nd Poster Session with Hors d'oeuvres & cash bar (ELC Building)**
- 7:30 – 8:30 pm Dinner (Mallard Rm and Lodge)**
- 8:30 - After dinner speaker – Arthur Asbury, University of Pennsylvania
TOPIC: " The Peripheral Nerve Study Group: Its Rise and Demise" (L-1 Room) [coffee and dessert served in L1]**

Day 3: Wednesday, September 23, 2009 (All Sessions will take place in main Lodge- L-1 Room)

- 7 – 8:00 am Breakfast & checkout (Buffet – Mallard, Lodge, Deck)**
- 8:00-8:30 Update from NINDS**
- 8:00 – 8:15 NINDS: Initiatives in Muscle Diseases – John Porter, PhD**
- 8:15 – 8:30 NINDS: Perspectives on Clinical Trials – Petra Kaufmann, MD**
- 8:30 – 8:35 Discussion**
- 8:35 – 12:00 pm Session IV MSG Investigators Discuss Past, Current, and Future Protocols: Lessons Learned
Moderator: Richard J. Barohn**
- 8:35-8:50 Don Sanders Duke University – Retrospective studies- Mycophenolate in MG**
- 8:50-9:00 Discussion**
- 9:00-9:15 Anthony Amato, Brigham and Women's Hospital – Etanercept in DM**
- 9:15-9:25 Discussion**
- 9:25-9:40 Richard Lewis Wayne State University – Vitamin C in CMT**
- 9:40-9:50 Discussion**
- 9:50 - 10:05 Break and Check-out**
- 10:05-10:20 Richard J. Barohn University of Kansas Medical Center – Methotrexate in MG**

2009 MSG Annual Meeting agenda
Beaver Hollow Conference Center, Java Center, NY

- 10:20-10:30 Discussion**
- 10:30-11:00 Kate Bushby International Center for Life – DMD steroid trial**
- 11:00-11:10 Discussion**
- 11:10-11:25 Robert C. Griggs University of Rochester Medical Center – HYP HOP**
- 11:25-11:40 Mazen Dimachkie, University of Kansas Medical Center – Arimoclomol in IBM**
- 11:40-11:55 Discussion**
- 12 noon – 1:00pm Lunch (Buffet – Mallard, Lodge, Deck)**
- 1:00 – 1:15 pm Update from British Myology Society – Michael Hanna, University College of London**
- 1:15 – 1:30 pm Update from MDA- Cwik**
- 1:30 – 2:30 pm MSG Business Meeting:**
- 1:30-2:00 Executive Committee (Barohn, University of Kansas Medical Center /Tawil, University of Rochester Medical Center):
Constitution/By-laws
Dues/Financial**
- 2:00-2:10 Nominating Committee (Greenberg, Brigham and Women’s Hospital)**
- 2:10-2:30 Mexiletine/Arimoclomal - Getting Drug into the E.U. (Barohn, University of Kansas Medical Center /Hanna, University College of London /Matthews, University College of London /Herbelin, University of Kansas Medical Center)**
- 2:30 – 3:00 Wrap-up – *Richard Barohn* University of Kansas Medical Center**

This meeting is sponsored by:

- **National Institutes of Health**
- **Muscular Dystrophy Association**
- **Genzyme Corporation**
- **ISIS Pharmaceuticals**
- **PTC Therapeutics**
- **Santhera Pharmaceuticals**

Rev. 9/18/09ca