2006 MSG Annual Meeting Beaver Hollow Conference Center, Java Center, NY May 31 – June 2, 2006

Wednesday, May 31, 2006

4:00 – 6:00 pm MSG Executive Committee meeting – L3 (lower level of main lodge)

6:30-7:30 Social hour – main lodge

7:30 pm Dinner – main lodge

Thursday, June 1, 2006

7:00 am New MSG member/MSG Visitor Information Breakfast – Drake Room

R. Griggs, M. McDermott, R. Tawil, C. Jackson, R. Barohn,

J. Kissel, M. Rose, L. Herbelin, Don Sanders, Anthony Amato, Wendy King

and Pam Kitrell

7:30 – 8 am Breakfast - main lodge

8 am - 8:15 am Welcome and Introductions -R.Griggs - Auditorium - across from main lodge

8:15 - 8:45 am State of MSG (Plenary) – R. Tawil

8:45 – 9:30 am Committees Reports (Plenary)

Nominating Committee – S Greenberg

Publications Committee – D. Sanders

Constitution Committee - C. Jackson/D. Sanders

9:30 am - 12:15 pm Contemporary Issues in Clinical Trial Design - Moderator - M. McDermott

9:30-10 am Wilson Bryan – Drug development for myopathies: A regulatory perspective

10 – 10:30 am Bruce Levin – Innovative statistical designs for studies of

small numbers of patients

10:30-11 am Shree Pandya — Outcome measures and trial designs — finding the right mix

11 – 11:30 am Richard Moxley/John Porter – Issues in translational research

11:30 – 12 noon James Cleland – The n of 1 trial

12 – 12:15 Panel Discussion

12:15 – 1:30 pm Lunch - main lodge

```
MSG project Steering Committee/investigators' meetings:
   1:30 - 5:00 \text{ pm}
          1:30 - 2 \text{ pm}
                         FOR-DMD – R. Griggs/M.McDermott
          2 - 2:30 \text{ pm}
                         CMT trial - M. Shy/R. Lewis
          2:30 - 3 \text{ pm}
                         MG-mycophenolate – D. Sanders
          3 - 3:30 \text{ pm}
                         Arimoclomal Therapy for IBM - R. Barohn
          3:30 - 4 \text{ pm}
                         Dermatomyositis – Etanercept investigators' meeting – A. Amato
          4 - 4:30 \text{ pm}
                         SMA – P. Kaufmann
          4:30 - 5 \text{ pm}
                        InQol – M. Rose
  5-6 pm
                        Free Time
  6 pm
                        Social hour
  7:00 pm
                        Dinner
  Friday, June 2, 2006
  7:00 - 8 am
                        Breakfast - main lodge
  8:00 - 8:30 am
                        Review of MSG Conflict of Interest Policy - Auditorium - across from main lodge
 8:30 - 11:45 am
                        Translational Research in Neuromuscular Disease - Moderator, Charles Thornton
         8:30 - 9:00 am
                               Edward Kaye - Regulatory approval for a neuromuscular treatment:
                                                      Lessons learned from Pompe Disease
        9 - 9:30 \text{ am}
                               Karl Kieburtz - Perspectives on FDA reviews and approval process
        9:30-10 \ am
                               Jerry Mendell - Therapeutic developments in Duchenne and Limb Girdle
                                                     muscular dystrophy
        10 - 10:30 am
                               Lee Sweeney - Phase 1 clinical trials
        10:30 -11 am
                              Duygu Selcen - Myofibrillar myopathies
        11: -11:30 \text{ pm}
                              Andrew Engel - Congenital myasthenias
        11:30-11:45 pm
                              Panel Discussion
11:45 - 1 \text{ pm}
                      Lunch/Group Photo
1 - 1:15 \text{ pm}
                      NIH/NINDS Report – John Porter
1:15 - 1:30 \text{ pm}
                      NIH/NINDS Report on NIH-funded ALS trials - Robin Conwit
1:30 - 1:45 \text{ pm}
                      NIH/NIAMS Report – Glen Nuckolls
1:45 - 2 \text{ pm}
                      MDA Report – Valerie Cwik
2 - 3:00 \text{ pm}
                      Investigator meetings (Continued):
                      HYP HOP Trial – R. Griggs
```

CINCH - R. Griggs/B. Herr