The 12th Annual Meeting of The Muscle Study Group

1998-2009

Robert C. Griggs, M.D.
Chair, MSG Executive committee
“For a few seconds I think Griggs changed his mind about polymyositis.”
MSG Executive Committee
2009-2010

Chair: Robert Griggs, MD (2014)
Co-Chair: Richard Barohn, MD (2014)
Investigator Members: Petra Kaufmann, MD (2010)
Anthony Amato, MD (2009)
Donald Sanders, MD (2009)
Evaluator Member: Laura Herbelin (2011)
Study coordinator: Kristen Whiteside (2011)
Biostatistician: Michael McDermott, PhD (2011)
Director, MSG Coordination Center: Rabi Tawil, MD (2011)
MSG History

• Mid 1970’s: CIDD Group Michael Brooke, Jerry Mendell, Gerald Fenichel, Robert Griggs, Wendy King, Shree Pandya, Julaine Florence
• Mid 1980’s: CIDD added Alan Pestronk and Richard T. Moxley, III
• Early 1990’s: Canadian Collaborators
• Mid 1990’s: FSH-DY and PP Working Groups
• 1998: Muscle Study Group formed
MSG Organizational Steps

• Modeled constitution on Parkinson Study Group
• Michael McDermott: Biostatistician
• Rabi Tawil: MSG Coordination Center
• Studies of IBM, FSHD, ALS: John Kissel, Carlayne Jackson
• MG: Donald Sanders
Diseases Studied: Support

ALS: Foundation
SMA: Foundation
MG: FDA, industry
CMT: MDA, Foundation
FSHD: NIH, MDA
DMD: NIH, MDA
Periodic Paralysis: NIH, MDA
Myotonia: NIH, FDA
Successes of the MSG

- Ten multicenter trials
- Many other multicenter studies (quality of life, other outcome measures)
- Annual meeting: Extramural support, mentoring focus
- Mentoring activities for other investigators/groups
MSG: Work-in-Progress

• Regulatory approval? (Periodic paralysis – dichlorphenamidine; DMD – deflazacort)
• Large international collaborations: Periodic Paralysis (5 countries, 13 centers): DMD with Treat-NMD (10 countries, 41 centers)
• Pharma collaborations
• Integration with Rare Disease Network; CTSA/CTSI
MSG: Possible Future Goals

- Mentoring session for junior investigators/trainees – annual or biannual
- Pilot grant funding ?
- Fellowship support ?
- Expanding the international reach
  - China
  - India
  - Africa
MSG Challenges (1)

- Infrastructure support
  - Administration
  - Biostatistics
  - Coordination Center
  - Too much work vs too little work
  - Meeting expenses
MSG Challenges (2)

• How big is too big?
• Investigator support
• Authorship issues
• Building collaborations with other groups for shared projects
• “Rochester’s thing”
The Authorship Lottery: An Impediment to Multicenter Studies

- Authorship credit
- The problem with first-final author conventions
- The case for “Muscle Study Group” as author
- Having your cake and eating it too.
I’m fifty-three, but I have the résumé of a much younger man.
Genomewide Association Studies of Stroke

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Authorship Credit – Essential for:

- Academic credentials
- Appointments, promotions
- Grant submissions
- Grant renewals
Authorship Credit – Necessary or Advisable for:

- Team building
- Decisions of mentees
  - A clue as to generosity of mentor
  - Evidence of mentoring experience
- Intellectual property
- Sense of self-worth
Authorship: The Case for “Study Group as Author” (1)

• Identifies a collaborative team: “The whole is greater than the sum of the parts”

• Examples:
  – Parkinson Study Group
  – CIDD group
  – Cardiology, diabetes, oncology many other specialties
“You definitely qualify for final author”
Authorship: The Case for “Study Group as Author” (2)

- Avoids assigning one *first* and one *final* author
- A foot-note or table gives each person’s role in the study
- Arguably more important to be the “Biostatistician” or a large clinical contributor than merely a position in a list
The Risks of Not Addressing and Fixing Authorship Issues:

- Discourages multicenter, multi-laboratory research
- Discourages longitudinal research projects
- Breeds competition instead of collegiality
- Perpetuates misjudgment of research skills and accomplishments (both over- and under-estimation.)
Another Risk of Not Addressing Authorship Issues

If each relatively senior author and each younger person mentored by a senior person needs a final/first-authored paper, then the research will be reported in multiple papers as opposed to one complete paper.
Having Your Cake and Eating it Too?

• Study group authorship with authorship table
• Ancillary, subgroup, extension, other papers allowing individual authors plus the study group
• Earlier papers (before big study completed) by specific authors:
  – reviews,
  – study design
  – cross-sectional