

ALSRG Meeting Minutes: Part 1

Monday, December 13, 7:30-8:30am

Marriott Orlando Grande Lakes, Orlando, Florida, Conference Room Med 6

A. New policy for membership in the ALSRG was announced.

In September 2011, the ALSRG Board of Directors (BOD) voted to formalize the new member application process, creating an amendment to our bylaws worded as follows:

“Amendment ‘New Member Application Process’

An application portal will be developed on our website. Prospective members must agree that they are: A health care professional or scientist and Involved in ALS research, patient care, teaching.

Prospective members must submit their CV which will be used by the ALSRG BOD to verify the above. If verified, prospective members can be admitted by majority vote of the ALSRG BOD”.

Since there were no strong objections at the Orlando meeting, Eric Sorenson will add this amendment and portal to our website.

B. Results of an interim election were announced.

In September 2010, Michael Benetar was elected the 13th Member of the BOD

Current ALSRG BOD (with term expiration) is as follows:

Bedlack, Richard	(Vice-Chair 3/11; Chair 3/13; BOD 3/15)
Benatar, Michael	(3/13)
Bowser, Robert	(3/13)
Cudkowicz, Merit	(Chair 3/11; BOD 3/13)
David, William	(3/13)
Forsheew, Dallas	(Allied Health Professional 3/13)
Heiman-Patterson	(3/11)
Kasarskis, E.	(3/11)
Kaufmann, Petra	(3/13)
Lomen-Hoerth, C	(3/11)
Oskarsson, Bjorn	(Young Member 3/13)
Shefner, Jeremy	(3/11)
Tandan, Rup	(3/11)

C. Upcoming regular election was announced.

In September 2010 the BOD voted to hold future regular elections via the website Ballot Bin. This allows anonymous voting and assures that each member can vote only once. An announcement with log in information will be sent by RB.

Call for nominations for next regular election made at Orlando Meeting. We need to elect 5 new BOD members, including the new vice-chair. As of 1/10/11 we have the following nominees:

Carmel Armon

Nazem Atassi

Benjamin Rix Brooks

Tim Miller

Ed Kasarskis

Jon Katz (vice-chair)

Leo McClusky

Seward Rutkove (vice-chair)

Eric Sorenson

Elijah Stommel

Ezgi Tiryaki

Tuan Vu

Nominations close Friday January 14. Email with instructions for using ballot bin will follow. Election will close January 31.

D. Enrollment boosting initiatives were updated

Survey neurologists to better understand "doctor factors" (possible AAN CRS project)

Enrollment Video (NEALS project)

"Army of PALS" Registry (NEALS project)

Clinical Research Learning Institute for patients/caregivers (possible NEALS/ALSRG project)

Faculty and curriculum being sought

Funding being sought

Goal is to have in conjunction with 2011 NEALS Meeting

ALSUntangled (ALSRG, WFN-ALS project)

Approximately 300 twitter followers

70 clinician scientists from 6 countries

30 open investigations

8 published investigations

2 grants

New partnerships with Quackwatch and Patients-Like-Me

Award

Development of Home Based Outcome Measures (NEALS project)

?Creation of new procedure code, allowing additional reimbursement for neurologists that spend time discussing research (possible AAN CRS project)

E. Dr. Tandan updated the ALSRG on the ALSA-sponsored nationwide ALS clinic mapping project.

F. Drs. Miller and Brooks updated the group on the ALS Patient Safety Organization.

G. Drs. Mitsumoto and Bedlack contracted with Demos to create the first book authored by the ALSRG with all royalties going into our treasury to help fund future meetings. This will be a patient care guide for health care professionals. The target audience will be health care professionals looking for suggestions on managing patients with ALS. The content will be organized according to the disciplines typically involved in a multi-disciplinary clinic and include evidence- and experience-based care options. An outline is attached (see Addendum 1). We now have identified lead authors for each chapter. We hope that all members of the ALSRG will participate in these chapters if the lead author or I solicit you. Authors, we need a draft outline of your chapter by March 1, and the chapter itself by July 1.

H. Dr. Mitsumoto announced a "Tarrytown 2" meeting, entitled "ALS Conference: To Promote Clinical Research to find the Pathogenesis and Cause of ALS." This will start at 8am on Wednesday September 7 and end after lunch on September 9th.

I. Our bylaws suggest an Annual Meeting. We will switch back to this schedule. Thus our next meeting will occur in late 2011 at International Symposium in Australia

J. Part 2 of the minutes, summarizing discussions with the team from the National ALS Registry appears as a separate PDF.

Addendum 1

Outline of ALS Care Guide for Clinicians. R. Bedlack and H. Mitsumoto, editors. Demos Publishing. Royalties to ALSRG

Introduction (Bedlack, Mitsumoto)

1. What is ALS? (Benjamin Rix Brooks and Elena Bravver). Diagnostic criteria, clinical features, epidemiology, fALS and sALS, pathogenesis, prognosis, FTD, introduction to treatments and multi-disciplinary care
2. Neurologist (Terry Heiman-Patterson, Carmel Armon, Jim Russell) Breaking the news, assessments (genetic testing, ALSFRS), prognosticating, riluzole, statins/Lipids, general medical management (secretions, PBA, depression, anxiety, insomnia, constipation, urge incontinence), advice on sources of information, advice on alternative/off label therapies, advice on advocacy, fundraising and research, creation, maintenance, coordination of multi-disciplinary team, research
3. Nursing (Dallas Forshew, RN) Assessments, treatments including immunizations, communication, education.
4. Speech Therapist (K Amy Wright, Laura Ball and Benjamin Rix Brooks) Assessments, swallowing tips, vital e-stim, communication tips
5. Assistive technology (Sara Feldman) AT options beyond communication.
6. Nutritionist (Ed Kasarskis) Assessments, importance of good nutrition, role of supplements, vitamins, anti-oxidants, PEG issues
7. Physical Therapist (Ronit Gorelik, Fondre Goulbourne, Hiroshi Mitsumoto) Assessments, exercise, equipment, adhesive capsulitis, head droop, back pain
8. Occupational Therapist (Amber Ward and Benjamin Rix Brooks) Assessments, ADL's, wheelchair selection, transfers, lifts, driving
9. Respiratory Therapist (Jim Caress/Connie Palandich) Assessments, breath Stacking, NIV, cough assist, vest, trach, vent
10. Social Worker (Stacey Asnani/Suzanne Gilroy) Assessments, disability, VA, support groups, living will, MOST forms, health care POA, Advocacy (MDA and Association)
11. Psychologist (Susan Wooley/Jon Katz) Assessments, cognitive/Behavioral issues and management, depression/Anxiety issues and management, intimacy
12. Web Resources (Paul Wicks PhD)
13. Ethics (Leo McClusky/Katie Hoskins)
14. Research (Rick Bedlack, Merit Cudkowicz)
15. End of Life Care and Hospice (Jerome Kurent, Meraida Polak)