

Minutes for April 2010 ALSRG Meeting in Toronto

Administrative Items

1. Membership

- a. Contact list confirmed; no members reported problems receiving emails
- b. New member(s) role call; Andy Galbreath MD introduced
- c. Directors' proposal for new application process announced;
 - no objections voiced
 - directors to create application form and post on website
 - new prospective members will henceforth submit form to Chair
 - directors will vote to approve or deny
 - bylaws will need to be updated
- d. Directors' proposal for \$100 per member in annual dues announced;
 - no objections voiced
 - directors to elect treasurer as per bylaws
 - treasurer to create of 501C3, ALSRG account to occur over next 6m
 - billing for 2010 to occur later this year

2. Directors/executive committee

- a. Roster shown in Appendix 1 (attached) confirmed accurate
- b. Announced need for nominations from group for 1 unfilled spot
 - expect to have list of nominees by June 1, 2010
 - interim election of new director to occur via current directors
- c. Upcoming regular elections announced
 - will formally solicit new nominations beginning December 2010
 - regular elections to be held early 2011 for vice-chair, 4 other directors

Project Updates

1. Website (www.alsrg.org):

- a. Recent changes made by Eric Sorenson highlighted, including:
 - Updated executive committee roster
 - Updated documents with Berlin meeting minutes
 - Updated links with ALSU
 - Updated educational materials with AAN practice parameter slides
- b. Suggestions for additions to website were solicited; additions will include:
 - Mission statement: "To improve the infrastructure for North American ALS Research" (need comments from group on this now)
 - History of ALSRG (Dr. Bedlack to ask Dr. Mitsumoto to provide)
 - Application form (Dr. Bedlack to create and send to Dr. Sorenson)
 - ALS diagnostic criteria (Dr. Sorenson to add revised El Escorial, Awaji criteria)
 - Patient video on benefits of participating in research to be supplied by NEALS (first half of their new video for ceftriaxone sub-study)

2. Update on NEALS Video Assisted Consent Study was provided by Nazem Atassi

- a. NEALS initiative, but relevant to ALSRG missions
- b. Video will be 5 minutes, 2 parts (general, and specific for ceftriaxone)
- c. Enrollment via video-assisted consenting will be compared to standard
- d. ALSRG will be able to use first part for website

3. Update on Development of Home Based Outcome Measures was provided by Michael Benatar

- a. Some of these are being validated via current arimoclomol study

- b. He has other candidate measures and a protocol for testing these
 - c. He has some funding; is looking for another \$5,000-10,000; **need group to suggest funding sources for this**
4. Update on “Army of PALS” (online potential research subject listing, similar to the “Army of Women”) was provided by Alex Sherman.
- a. Alex presented many options for creating a similar registry
 - b. Alex suggested we try and add a field to the upcoming National Registry
 - “Do you want to be contacted about future ALS Research Studies?”
 - We agreed to try; see below action item regarding national registry
 - c. It was pointed out that this would not provide potential controls
 - d. **Alex to create a registry subcommittee to further explore ideas; make proposal in Orlando**
5. Update on ALS Clinical Research Learning Institute (similar to the Parkinson’s Clinical Research Learning Institute, which trains patients to be effective research advocates) was provided by Rick Bedlack.
- a. See Appendix 2 (attached)
 - b. **Group to review proposal and suggest funding sources**
6. Update on ALSUntangled was provided by Rick Bedlack.
- a. Twitter site has 150 followers, 33 tweets sent;
 - b. NING has 65 ALS Clinician-scientists joined, 27 active discussions
 - c. We now have 4 publications; mentioned in Time Magazine and 60 Minutes
 - d. A new website is coming soon to make interface easier
 - e. **Group to advertise program, sign up to follow us on twitter, join our ning, participate in our discussions, volunteer to lead a top priority open investigation (see Appendix 3), and suggest funding sources.**
7. Update on ALS Patient Safety Organization/Performance Measures was provided by Ben Brooks.
- a. Ben has a committee helping him; Bob Miller, Steve Ringel, Jeff Rosenfeld
 - b. Immediate issue is convincing insurers that multi-disciplinary care should be reimbursed; **Drs. Brooks and Miller will solicit help from AAN for this**
 - c. Other performance measures will be proposed at next ALSRG meeting
8. A new initiative to map distribution of ALS Clinics across the USA was proposed
- a. Underserved areas can be identified; targets for new clinics
 - b. ALSA has started doing this; really needs to be independent of any fundraising organization.
 - c. Committee was formed to take next steps: Rick Bedlack, Rup Tandan, Ed Kasarskis, Sharon Matland, Valerie Cwik; **teleconference will be scheduled soon.**
9. A new initiative to interface with CDC on design of National ALS Registry was proposed by Michael Benatar.
- a. This is necessary to be sure registry is useful to ALS researchers
 - b. Dr. Benatar has drafted letter
10. Bob Bowser’s National ALS Tissue Bank was tabled until next meeting.

Group reminded of National ALS Advocacy Days May 9-11 in Washington DC

Next steps for entire group and specific members highlighted above; Teleconference will be scheduled with directors and project leaders this Summer to check progress.

Next meeting of ALSRG in Orlando Florida in December.

Appendix 1

ALSRG Directors/Executive Committee

	Elected	Term Expires
Cudkowicz, M (chair)	3/07	3/11 (chair), 3/13 (director)
Bedlack, R (vice-chair)	3/09	3/13 (chair), 3/15 (director)
Bowser, R	3/09	3/13
Lomen-Hoerth, C	3/07	3/11
David, W	3/09	3/13
ForsheW, D (AHP)	3/09	3/13
Heiman-Patterson, T	3/07	3/11
Kasarskis, E	3/07	3/11
Kaufmann, P (?)	3/09	3/13
Oskarsson, B (YM)	3/09	3/13
Shefner, J	3/05	3/11
Tandan, R	3/07	3/11

Appendix 2
 ALS Clinical Research Learning Institute
 Brief Proposal 3/26/10

1. Background

Enrollment in ALS research studies is surprisingly low. This may be due in part to misconceptions among patients with ALS (PALS) regarding research studies and alternative and off-label therapies. Similar problems have been identified in other fields, and “clinical research learning institutes” have been used successfully to address knowledge deficits and create patient advocates for research. We thus propose creating such a program for PALS, called the ALS Clinical Research Learning Institute (ALS CRLI).

2. Goals of the ALS Clinical Research Learning Institute

- a. To educate a group of PALS and/or CALS on research
- b. To empower this educated group to be advocates for ALS research
- c. To query this group on how we can make our research studies more attractive.

3. Attendees

Patients and/or caregivers will be nominated by members of the ALS Research Group (ALSRG). Nominations should include contact information and a paragraph or two describing why the nominee would be a good future advocate. A committee will review the applications and select 10 patients 10 caregivers to invite.

4. Faculty

Faculty will be members of the ALSRG who have expressed an interest in teaching within this program. These include Richard Bedlack, Terry Heiman-Patterson, Merit Cudkowicz, Nazem Atassi, Jeremy Shefner, Erika Simpson, and Bjorn Oskarsson.

5. Structure

This will be an intensive, 1 day program. To save on faculty transportation costs, we propose having the ALS CRLI the day after the Northeast ALS Consortium Meeting in 2011.

6. Curriculum

- a. Opening Remarks (Why We Need ALS CRLI; Similar Programs in Other Diseases and What They Have Accomplished; What You As Participants Can Expect Here; What We Hope To See From You When You Leave; Sponsor Acknowledgement....15 minutes)
- b. The Clinical Research Process (Definitions; Ethics/Historical Evolution; Types of Studies/Designs; Basic Statistics; Pitfalls...2-3 hours)
- c. Workshop on Critiquing Various Clinical Research Reports (X-cell center webpage; Fornai lithium study; PLM lithium study....1-2 hours)
- d. The ALS Research Pipeline (What is currently under study, what is coming...45min)
- e. Barriers to Working Through The Current ALS Pipeline (Funding, Regulatory, Enrollment, Drop Out....45 min)
- f. Opportunities For Addressing Current and Future Barriers Through Advocacy (1 hour)
- g. Summary, Conclusions, Next Steps (15 min).
- h. Questions and Answers Dinner Session

7. Outcome Measures

We will ask each attendee to participate in chat rooms on Patients Like Me and ALS TDI. We will ask them to create a blog or facebook page through which we can track their advocacy efforts, including the number of internet chat room postings, interviews, articles, letters to the editor, congressional contact and talks they accomplish, or IRBs they join.

8. Budget

Travel	\$750 x 20 attendees	\$15,000
Hotel	\$200 per night x (20 attendees and 7 faculty)	\$5,400
Meeting Room/2 Meals	\$100 x (20 attendees and 7 faculty)	\$2,700
Dinner	\$100 x (20 attendees and 7 faculty)	\$2,700
Take Home Materials	\$20 x 20 attendees	\$400
Faculty Honoraria	\$500 x 7 faculty	\$3,500
Total:		\$29,700

9. Funding Sources

Ideally, this would be jointly funded. Discussed with ALSA and MDA and have been invited to apply for grants. Asked ALS TDI and Patients Like Me, no response to emails yet. Will also ask the following groups for help: ALS Hope, Packard Center, ALS Therapy Alliance, ALS Canada, AAN.

Appendix 3
ALSUntangled Investigations Pending
Leaders Needed!

IV Glutathione
TCA Cellular
Marty Murray
Dr. Zhu Ming at Huaihua Red Cross Hospital
Beike Clinic
Curious Case of Dr. Martz
Regenocyte Clinic by Dr. Grekos in Bonita Springs FL
Ursodiol
Cell Medicine
Cyclosporine
Eric is Winning
Nepsis
Lourdes ALS Miracle
Diaphragmatic Pacing
Dr. Zannos Grekos clinic in Dominican Republic
Equilibrium Theory
Bronx Project
Pulsed electromagnetic field therapy