

**ALSRG General Meeting at the AAN Meeting, Dan Diego
Thursday, April 6, 2006, from 5 pm to 7 pm.**

28 members attended

1. DNA repository process reviewed:

- Some sites are not clear as to which project they are associated. ALSA Center sites (Rup Tandan) will list the name of the individual sites and distribute to all PI sites.
- The majority of sites are IRB approved or waiting for approval, although very few centers already have the subcontract executed.
- Rob Sufit suggested a very effective way to obtain multiple control DNA would be to recruit participants at an ALS Walk.
- The fact that Mass General and Northwestern both submitted DNA independently prior to the ALSRG project raises another question: Is this DNA outside of ALSRG DNA repository, or part of ALS effort? From budgetary standpoint, if CDE is filled out, and blood draws are invoiced through 1 of the six coordinating sites, it will be treated as part of the ALSRG project.

2. Database Task Force

- Because of limited attendance, we will need to email all members to solicit their interest in a Database Taskforce Meeting.
- The members preferred a free-standing meeting.
- All members will be invited.
- We need to find a date for either a June or September meeting.
- Also, we need a clear agenda for the meeting before asking whether members are interested in attending.
- A discussion of a tissue banking project should be included in the agenda.
- There was a sentiment that the sooner the better because this is a pressing issue.
- These comments will be communicated to Angela Genge, the chair of the Taskforce.

3. Education Committee Report by David Saperstein.

- A Core Reference List has been completed.
- Training documents for allied health professionals was suggested as a new project.
- Website Issues
 - The ALSRG Website can function as an educational tool (for patients and health care professionals)
 - Consider creating a Patient Education Box and Health Professionals Box in the ALSRG website
 - List all future meetings.

- Include a hyperlink to the MDA Website with both Patient and Health Care links (Valerie can help.)
 - ALSA also has patient education material on more scientific issues. (Lucie can help.)
 - Both organizations are willing to provide links to ALSRG Website.
 - Any centers who would like to be linked to the ALSRG site should contact Eric Sorenson
4. By-laws will be modified for tax-exempt incorporated status, although the fundamental concept has not been changed.
- We thanked Mr. Hoon Lee and Ms. Becky Briber for their enormous help.
 - By-laws Committee will read the modification and clear it with the lawyers.
 - After it clears the Committee and legal counsel, the final draft will be sent to all members.
5. ALSRG will have the next general meeting in Japan, December 2006, and also the general meeting in Boston, April 2007 (we will attempt to find the better time for the members).

Prepared by HM and JS