

## **ALSRG Meeting Minutes 4/30/07**

List of attendees: Hiroshi Mitsumoto (ex-chair), Jeremy Shefner (chair), Patricia L.Andres, Irina Badayau, Rick Bedlack, Kate Bednarz, Francesca Belouin, Robert Bowser, Kevin Boylan, Benjamin Rix Brook, Andrew Caraganis, Mabel Chan, Merit Cudkowicz, Monique D'Amour, Joanna Eckenrode, Dallas Forshew, Angela Genge, Jonathan Goldstein, Daniela Grasso, Michael Graves, Walter Hader, Y. Harati, Terry Heiman-Patterson, Daragh Heitzman, Carlene Jackson, Sanjay Kalra, Ed Kasarskis, Petra Kaufmann, David Lacomis, Catherine Lomen-Hoerth, Diane Mckenna-Yasek, April McVey, Robert Miller, Kathy Mitchell, Jackie Montes, Tahseen Mozaffar, Gary Pattee, Darlene Pulley, Sandeep Rana, Lewis P. Rowland, Stacy Rudnicki, George Sachs, Steve Scelsa, Christen Shoesmith, Eric Sorenson, Khema R. Sharma, Alex Sherman, Teepu Siddique, Eric Sorenson, Frederique Souchon, Amy Swartz, Rup Tandan, Seamus Thompson, Brenda Thornell, Ashok Verma, Francine Vriesendorp, Michael Weiss, Elizabeth Welsh

Dr. Mitsumoto reviewed the success in collecting more than 1700 samples from both, patients and controls at the 7 centers.

He further reviewed that first research studies have been performed using the samples. Finally, he pointed out that one publication on the ALSRG is in print in the journal ALS, and that a second publication by Katrina Gwinn-Hardy is close to publication.

Dr. Shefner congratulated Dr. Mitsumoto for his successful term as inaugurating chair of the ALSRG, and he presented a plaque to Dr. Mitsumoto.

Dr. Shefner then reviewed some changes that were made to the bylaws, including that the steering committee is now termed the board of directors, and that new members will be solicited every year. The number of members of the board of directors has to be an odd number, and include a young investigator (under 40, Assistant Professor, or less than 5 years in ALS research). At each given election every two years one half of the members will be newly elected. The revised bylaws will be sent to membership for ratification via fax return.

Remaining issues regarding the DNA data collection project were discussed. More samples would benefit the biomaterial data collection. Also, the data collection form is intended to allow for the collection of longitudinal data. A critical piece of information is the date of death. If a site cannot enter all longitudinal data, if the date of death only could be entered, this would be an important step and would enhance the value of the data. The ALSRG has created a valuable genetic material collection and a dataset. A discussion regarding public availability of the database ensued. By majority vote, the group endorsed the widest possible availability of data. It is recognized that the data resides with Coriell; however, the ALSRG will maintain the same data although the precise mechanism for this occurring has not been determined.

Any additional longitudinal data will be very important and enhance the scientific value of the collection. The Coriell forms allows for collecting this information prospectively. Coriell is to let the investigators know if one could retrospectively enter follow-up data on patients.

The DNA/database project was very successful, and can now look at additional potential projects, such as a tissue collection. By majority vote, the group endorsed moving forward with a tissue project. A group of experts will be convened to work out task related issues, funding possibilities, and future steps. This project will necessitate an expansion of the database initiative, to support the collection of tissue in a longitudinal fashion. Establishing liaisons' with similar projects on other neurodegenerative diseases will be pursued.

Dr. Genge reported from the database committee. Three issues came up in the discussions. The first project is creating a data dictionary. There are existing resources including an Alzheimer's data dictionary and reportedly an effort by NINDS of generating a data dictionary. Having a unified data dictionary will be an important first step of any subsequent database effort. A second issue the group recognized is that important information could be collected in a modular fashion, including the epidemiology module provided by Lorene Nelson's group. This kind of collection is more likely to be feasible and receive funding when coupled with a tissue collection effort. The third issue is the interest voiced by several ALS sites to have the option to acquire a uniform "data collection" tool that could be used in ALS center to collect information. The information collected at the sites would be protected to safeguard patient privacy. However, there could be an option to contribute de-identified data more easily to a larger ALS database. The efforts to increase minority recruitment are important as there are loci that are more likely associated with minority status.

Chair called for discussion of how the group should look in five years. Important issues are educational programs, young investigator programs, and possibly involvement in clinical research or clinical trials. The group is not currently structured as a trials group, but could consider this in the future. There was discussion of an annual stand alone meeting, but it was generally felt that, currently, associating the meeting with other conferences made the most sense for now. The research and education committees will be revitalized. Solicitations for member involvement will be made via email, and the chairs of these committees will convene meetings via phone to plan new initiatives. General enthusiasm was voiced for an expanded advocacy role. A separate committee will be organized to consider such issues.

The meeting was adjourned at 4 PM. The next meeting will be at the ALSMND meeting in Toronto.