

ALSRG Minutes
11/29/07
Toronto, CA

1. Report of DNA Banking Project: Dr. Mitsumoto
 - a. Still needed is longitudinal data. Goal is yearly assessment. Please keep project active, so that these data can be acquired.
2. Advocacy: Dr. Richard Bedlack
 - a. Goals of Advocacy
 - i. Assess and increase percentage of ALS patients who attend multidisciplinary clinics
 - ii. Assess and increase percentage of ALS patients enrolled in trials
 1. Video for ceftriaxone planned, effects to be assessed
 2. Survey of 2 sites suggests only 10% of patients participate
 - iii. Debunking unproven and potentially harmful therapy.
 - iv. Advocacy toward government agencies, especially FDA
 - b. Action items
 - i. Survey to clinic docs regarding alt medications
 - ii. Survey to patients regarding how they got to multidisciplinary clinic
 - iii. Survey to referring docs, maybe start with one large state
 - iv. Discuss with ALSA and MDA their advocacy strategy, attempt to coordinate efforts as much as possible.
 - v. Consider fund raising options for above efforts.
 - vi. Assemble list of unproven therapies, put on ALSRG, ALSA, MDA websites.
3. Education Committee
 - a. Report of Aug 23 teleconference; patient, clinician, and community outreach discussed. Will discuss training video, coordination with other clinical researcher training.
4. Tissue Collection Project
 - a. **Working outline of proposal:**
 - b. **400 ALS patients**
 - c. **200 Controls characteristics yet to be determined**
 - d. **4 visits: initial, 3 months, 1 year, 2 year**
 - e. **First visit**
 - i. **Demographic**
 - ii. **Disease status**
 - iii. **Blood for cell lines,**
 - iv. **plasma, serum**
 - v. **CSF**
 - vi. **Outcome measures**
 1. **Alsfers-r**
 2. **VC**
 3. **HHD**
 4. **MUNE**

- f. **Visits 2-4**
 - i. **Disease Status**
 - ii. **Med history,**
 - iii. **Meds**
 - iv. **Blood for plasma, serum**
 - v. **Outcome measures**
 - 1. **ALSFRS-R**
 - 2. **VC**
 - 3. **HHD**
 - 4. **MUNE**
 - g. **Autopsy—every effort made to obtain tissue from those enrolled in fluid protocol; however, other autopsy tissue collected.**
 - h. **Controls- Further consideration needed re important aspects of Control subjects**
 - i. **SOPs for tissue and fluid collection, epidemiology and disease status forms, SOPs for outcome measures all must be created.**
 - j. A writing group will be convened, followup to occur to group
5. Discussion regarding independent meeting was held; lack of consensus existed for this to occur.

Meeting adjourned; next meeting at AAN in Chicago