

ALS-RG Conference Call Minutes- Wednesday September 6th 2006

Attendees:

- U of Kentucky: Dr. Edward Kasarskis
- U of Vermont: Marilee Jones
- Mass General: Brenda Thornton & Bryan Sweet
- CA Pacific: Terrence Santos
- Columbia: Dr. Hiroshi Mitsumoto, Dr. Paul H. Gordon, Kate Bednarz, & Alex Barsdorf
- NIH: Dr. Jonathan Horsford
- MDA: Dr. Valerie Cwik
- ALSA: Dr. Lucie Bruijn

1. **Introduction** - Dr. Hiroshi Mitsumoto

2. **Status report from each lead site:**

- Mass General-172 Total
 - i. 75 Patients & 38 Controls, 55 samples in review & 4 rejects
- CPMC-330 Total (increase in 22 samples)
 - i. 215 Patients & 115 Controls
- Vermont-137 Total (increase of 34 samples)
 - i. 76 Patients & 61 Controls
- Columbia-CoQ-617 Total (increase of 46)
 - i. 254 Patients & 317 Controls
- Columbia-Mino-290 (increase of 53)
 - i. 157 Patients & 133 Controls
- Kentucky-441 Total (increase of 64)
 - i. 250 Patients & 191 Controls
- Mayo Rochester-583 (increase 59)
 - i. 330 Patients & 253 controls

3. Most centers have fewer controls than cases. Need effort to increase control numbers. Suggest to use a certain event to solicit people to give DNA from healthy controls. It is usually very successful.

- Fundraisers
- Group gathering

4. NIH: End of fiscal year was 9/31/06 which ends the first year of funding

- \$500,000 remains for NIH to award for DNA Banking supplements (we will know how to be divided, perhaps \$83,333 per Center)
- New 660 samples started October 2006
- Lead sites need to submit Extended Application for 10/06-9/07
 - i. Dr. Jonathan Horsford instructions on how to reapply:
 1. Calculate the numbers of controls and patients submitted as of 7/31/06; ensure that they have been accepted by Coriell. Email the numbers to Jonathan Horsford at

horsforj@ninds.nih.gov and he will compare this number to what Coriell has on record.

2. Dr. Horsford will commence the process to get the supplement out. NIH will pay \$300 for each case-control pair, the minimum is \$5,000 to per NGA.
 3. I have been informed that due to the delay in Congress approving the NIH budget, we will not be awarding supplements until December. Sorry about that, but this is one of the perils of the appropriations process.
 - ii. There is no carry-over funding for the first year of supplement
 - iii. Continue to enroll
 - Supplements enrolled prior to July 31st 2006 will be deducted from last years supplement funding & supplements enrolled from 7/31/06 on will be funded by 2nd supplement
 - Depending on the lead site's Clinical Trial Office may need new subcontracts with subsites.
5. ALSA & MDA praised DNA Banking group for their achievements
6. Summary of Database Meeting held on 9/11 in Chicago
- Angela Genge held one day meeting about Clinical Data Elements and Database
 - i. Discussed general principals about national database & the rules for depositing and accessing data
 1. Everyone will get access to all database except for new studies
 - ii. Minutes being finalized and will be sent to everyone
 - iii. Next spring will need more extensive talk about database.
 1. It must stand alone-? NIH for R13 support or other support
 2. Must be attractive to disciplines
 3. Ability to print out copy of medical record
7. Write up of ALS-RG DNA Banking project
- Ask Dr. Gwinn-Hardy what specifically she was interested in
 - Possible general publication in the neurology journal
8. **Next conference call is**
9. **ALSRG general meeting will be held in Yokohama Japan on Wednesday 11/29/06 from 10-12 am**