

ALS-RG Conference Call Minutes- Wednesday November 1st 2006

Attendees:

- U of Kentucky: Dr. Edward Kasarskis
- U of Vermont: Marilee Jones
- Mass General: Francesca Belouin & Bryan Sweet
- CA Pacific: Terrence Santos
- Columbia: Dr. Hiroshi Mitsumoto, Dr. Paul H. Gordon, Kate Bednarz, & Alex Barsdorf
- NIH: Dr. Katrina Gwinn-Hardy
- Coriell: Cindy Royds & Rod Corriveau

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

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

- Mass General-191 Total (increase of 19 samples)
 - i. 120 Patients & 45 Controls, 22 samples in review & 4 rejects
- CPMC-373 Total (increase in 43 samples)
 - i. 233 Patients & 140 Controls
- Mayo Rochester-607 Total (increase 24)
 - i. 333 Patients & 274 controls
 - ii. Of the above #s 136 patients & 77 controls are funded in yr 2
- Vermont-161 Total (increase of 24 samples)
 - i. 90 Patients & 71 Controls
- Kentucky-484 Total (increase of 43)
- Columbia-CoQ-644 Total (increase of 27)
 - i. 304 Patients & 340 Controls
 - ii. Of the above #s 90 patients & 136 controls are funded in yr 2
- Columbia-Mino-425 Total (increase of 135)
 - i. 220 Patients & 205 Controls
 - ii. Of the above #s 136 patients & 77 controls are funded in yr 2

First year of funding completed as of July 1st 2006. All samples collected after that date will be funded by 2nd year.

3. **NIH update**

- Dr. Gwinn-Hardy clarified that lead sites will not have supplement money from Congress until after November elections
- Ran Zhang has joined group and will be taking over Dr. Horsford's responsibilities. Will receive tallies for reimbursement
- 4 supplements due to be paid by December (Both CUMCs, CPMC, and Mass General)
- Waiting for Kentucky to submit enrollment numbers for their December payment.
- There is no need to reapply for 2nd year of supplement.

- Dr. Gordon clarified that lead sites should continue to enroll and encourage their sites to keep enrolling until an estimated time of June 2007.
 - Lead sites can restart to enroll up to the \$100,000 for 2007 but when money is exhausted enrollment must stop. Will probably happen before a lead site reaches 100K.
 - Dr. Kasarskis raised the fact that if we continue to enroll the total enrollment may exceed the initial goal of 2000 patients and 2000 controls.
 - The following NGA after December will come around March or April 2007. At that time will reassess how far the enrollment can continue.
4. Dr. Mitsumoto questioned how to renew commitment to the project. Fewer cases are coming into clinic and enrollment as slowed.
- Need to encourage sites that have not started to enroll to get started
 - New idea of doing site visits or some event
 - Continue to conference call the sites for encouragement of enrollment
5. Question arose about the subsites that were under Mayo Rochester transferring to Mass General
- i. Kate will generate email to start communication on if they 2 sites will go to Mass General or stay with Mayo Rochester
 - Dr. Gwinn-Hardy emphasized not to worry about 100k because it is more of a bureaucratic number.

6. Database Update

- Rod and Dr. Sherman exchanged contact information
- Kate to send out entire ALSRG DNA Repository contact list
- Meeting developed database that will be used for all database centers

7. Coriell Update

- According to Cindy 360 samples were uploaded into Coriell's catalog today. 85% of samples in catalog are the samples collected by the ALSRG group
- Since January 2006 the catalog went from 27 samples to 1820 samples
- Usually a good epidemiological study uses 1,000 patients and 1,000 controls

- Dr. Gwinn-Hardy encourage writing a paper on group's efforts
- Paper of Chicago meeting in 2005 is coming out hopefully in the next ALS journal
- Kudos on a great collaboration among NIH, ALSA, and MDA.

8. ALSRG general meeting will be held in room 211 and 212 at the Pacifico Yokohama in Yokohama Japan on Wednesday 11/29/06 from 10-12 am

Prepared by KB

