

## ALS-RG Conference Call Minutes- Wednesday February 7<sup>th</sup> 2007

### Attendees:

- U of Kentucky: Marsha Sams
- U of Vermont: Marilee Jones
- Mass General: Dr. Bob Brown, and Donna Crowe, Alex Sherman, Francesca Belouin
- CA Pacific: Dallas Forshew
- Mayo Rochester: Sue Paxton
- Columbia: Dr. Hiroshi Mitsumoto, Dr. Paul H. Gordon, Dr. Petra Kaufmann, Kate Bednarz, & Alex Barsdorf
- NIH: Dr. Katrina Gwinn
- Coriell: Rod Corriveau

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

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

- Vermont-198 total samples enrolled
  - i. 103 patients
  - ii. 95 controls
- Mass General/Dr. Brown-271 total enrolled
  - i. Patients: 131
  - ii. Controls: 116
  - iii. Parents: 24 (12 TDT sets)
- Mass General/Dr. Cudkowicz- 349 total samples enrolled
  - i. 219 patients
  - ii. 126 controls
  - iii. 4 rejected
- Kentucky-646 total samples enrolled
  - i. 312 patients
  - ii. 277 controls
  - iii. 57 pending
- Mayo Rochester-666 total samples enrolled
  - i. 333 patients
  - ii. 333 controls
- CPMC-508 total samples enrolled
  - i. 271 patients
  - ii. 237 controls
- CUMC/Dr. Gordon-576 total samples enrolled
  - i. 288 patients
  - ii. 283 controls
- CUMC/Dr. Kauffman-677 total samples enrolled
  - i. 328 patients
  - ii. 349 controls

### 3. **Final Enrollment # as per Coriell and Dr. Alex Sherman**

- 3008 total subjects enrolled

- i. 1543 patients
- ii. 1465 controls
- iii. 23 pending
- iv. 45 rejected
- **\*\*Does not include Dr. Bob Brown's enrollment numbers\*\***

#### **4. NIH update**

- Dr. Gwinn explained outstanding clinical data is holding up payment
- Dr. Gwinn will check with Ran Zhang to see if they can proceed with generating the pay memo for those sites that have all data completed
- There was a question about payment process. Dr. Gwinn outlined the steps:
  - i. Numbers collected from Coriell and give to Ran Zhang of NIH who confirms with lead sites
  - ii. Pay memo is generated to NIH grants and contracts division
  - iii. Once budget is passed funding will be distributed for the initial collection pay memo (up to August 2006) and the upcoming pay memo (August-January 15<sup>th</sup> 2007)
- Cut off for data completeness will be 1 month from today-March 7<sup>th</sup> 2007
- Dr. Mitsumoto had previously sent draft article on ALSRG collaboration to all lead site PIs. Urged PIs to reply with comments and to suggest which journal to publish in.

#### **5. Funding update**

- A message from Lucie Bruijn via Dr. Mitsumoto
  - i. Dr. Bruijn and Dr. Gwinn are thinking of ways to move forward with the project or collection
  - ii. Future discussion is needed on the appropriate scientific direction; ie, the focus is on the scientific goals, and any gaps or new directions that are appropriate at this point, rather than, a focus on "more money, more dna" per se.

#### **6. Database Update/Longitudinal data collection**

- Dr. Sherman is working on data cleaning with Coriell
- Database has not been collecting longitudinal data but will make effort to interface the data with database.
- Kate to email directions to Rod Corriveau
- For data clean up Marilee Jones will email all coordinators standard email that she was send to site with instructions on how to update missing data
- Dr. Mitsumoto reminded everyone this followup data is so important to increase the value of DNA we collected.

#### **7. Other discussion**

- Dr. Brown expressed that this DNA collection scheme and system is unprecedented and important to move forward to collecting a nationwide autopsy tissue collection.

- Dr. Gwinn to add a line in the article about pathology
  - Dr. Brown explained how the collection works
    - i. We partner up with ADRC
    - ii. Any time a new hypothesis is formed we can go back and use the ALSRG DNA to test the hypothesis
8. **ALSRG general meeting will be held Monday, April 30<sup>th</sup> from 2-4 in conjunction with AAN conference.**
- **We will ask Dr. Larry Refolo to attend this meeting.**

Prepared by KB