

## American Brain Foundation Research Advisory Committee Meeting September 18, 2017 11:00 a.m. ET/ 10:00 a.m. CT/ 9:00 a.m. MT/ 8:00 a.m. PT Conference Call

## **Meeting Notes**

In attendance: Robert Griggs, MD; Ralph Sacco, MD; John Morris, MD; Raymond Roos, MD

Staff: Jane Ransom, Shelly Collins Rucks, Suzi Sherman, Natalie Baumgartner

**Excused:** Carsten Bonnemann, MD; Merit Cudkowicz, MD; Shafali Jeste, MD; Natalia Rost, MD; Christy Phelps, Deputy ED AAN; Ralph Sacco, MD; Ira Shoulson, MD; Eugene Scharf, MD

Dr. Griggs greeted everyone and noted that there was not a quorum, so minutes from July 24, 2017, could not be approved. These would be carried over to the next meeting.

- Research Updates AANI Research Program: Dr. Griggs asked everyone to look at the 12 CRTS' being offered by the Foundation next year. There will be a total of 19 awards offered by AANI and ABF.
  - Dr. Morris asked for an update on the Alzheimer's Association, and Ms. Ransom confirmed that the Alzheimer's Association has previously partnered every other year, and they agreed to the increase in the CRTS amount for 2019. All off-year awards do not show up on the list provided in the meeting materials. The Tickler Report shows all the organizations that the Foundation has been communicating with.
- 2. Research Updates Crowdfunding: Dr. Griggs highlighted the Crowdfunding document, which shows how many projects are on the site and how many are still being approved. Ms. Sherman has reached out to those who have had approved LOIs to see when they are planning to finish their applications.
- 3. **Marketing Plan:** Ms. Rucks followed up on the Crowdfunding discussion by explaining that the Foundation has received its first draft of a marketing plan from a marketing firm. This proposal will be presented at the October Board meeting.

The Foundation will also be hiring a part-time marketing specialist to work in-house, and an outside marketing firm will be used to assist in the systematic marketing amongst neurology/neurologist communities. This marketing firm will help the Foundation raise money for research projects through systematic coverage of the brain community.

The Committee suggested getting a personality to provide high profile publicity to the Foundation.

The Foundation is currently talking with the AAN about having a day dedicated to the Foundation at the Annual Meeting. CRTS Awardees and Crowdfunding researchers would be involved.

Dr. Morris mentioned a connection he had with the ANA. They may have information for the Foundation and view themselves as the voice of the clinical neurologist – or the home of people looking for funding. They have a meeting in October. He stated that he would be willing to open the door for the Foundation to send a document about the Foundation and the Alzheimer's Fellowship.

4. **X-Prize Discussion:** Ms. Ransom has found someone with a real connection to Mr. Bezos, but the Foundation needs to be ready to talk about what we would do with funding from him or another X-Prize.

The Committee felt that the goal to "cure brain disease" was lofty, and it might be important to look at each brain disease or illness to develop a set of standards to determine what constitutes "prevention" or a "cure". Dr. Griggs suggested a subcommittee for one disease gather to answer the questions Jane suggested in the meeting materials and apply lessons learned to other disease areas. Dr. Morris suggested neurologists, who might join this subcommittee.

5. Crowdfunding Policy on Indirect Costs: Ms. Ransom introduced a topic not included in the meeting agenda or materials. The Committee needs to look at its current policy on indirect costs imposed by outside institutions of crowdfunding individuals. This is a concern specifically related to Dr. Ong's project, but will likely continue to be a problem in the future. Dr. Ong also wants to receive the \$8000 she has raised thus far. The Foundation's policies do not allow this, but the Committee needs to decide if this amount should be granted.

Dr. Griggs suggested that a subcommittee be formed to deal with how to tackle the indirect cost problem and Dr. Ong's request for the amount already raised.

Adjourn 10:49 am (Central).