



**American Brain Foundation  
Research Advisory Committee Meeting  
October 16, 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; Merit Cudkowicz, MD

**Staff:** Jane Ransom, Suzi Sherman, Natalie Baumgartner

**Excused:** Carsten Bonnemann, MD; Shafali Jeste, MD; Raymond Roos, MD; Natalia Rost, MD; Christy Phelps, Deputy ED AAN; 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. He requested that an approval vote be sent out to all Committee members.

1. **Research Updates – AANI Research Program:** Dr. Griggs talked about a pharma-supported CRTS, which might lead to covering more of the Foundation's operational costs. Ms. Ransom stated that covering operational costs for crowdfunding has been discussed, but to-date the committee's position has been to not ask nonprofit partners for operational costs relating to CRTS's, because the award is already increasing from \$130,000 to \$150,000.

Ms. Sherman updated the Committee on the 2018 award applications. Two awards, muscular dystrophy and Tourette's, did not receive any applicants. The Foundation is working with AANI staff on a solution. For the muscular dystrophy award, the solution may include taking applications from a different award and applying it to the CRTS in question. The Tourette's award may not be awarded this year.

The committee discussed the process AANI uses to review applications. Are they getting the best applications by dividing them into disease categories and then selecting from each category? Would it be better to have one pool of applicants? ABF staff will discuss the committee's input with our AANI colleagues.

2. **Research Updates – Crowdfunding:** A new application has been approved for crowdfunding. Until the Foundation's marketing is up and running, we will not hold the researchers to the 90-day limit on the length of campaigns. Suzi Sherman reported that the subcommittee appointed by Dr. Griggs has agreed to releasing partial funding to projects, on a case-by-case basis, if there is a written commitment from the researcher's mentor. The subcommittee also recommends that the ABF support up to 10% of institutional indirects, but only if included in the budget for the project of the crowdfunding researcher. Dr. Ong's \$8000 has been approved for release.

3. **Marketing Plan:** The Foundation's new marketing plan will include 3-4 disease-specific crowdfunding campaigns over the next 15 months. The first campaign will be for an MS project, where there is a donor lined up to assure that we have an "early win" with full funding for the project. The Committee liked the idea of tying crowdfunding projects to a disease of the month.

The Foundation is also talking to all its CRTS partners about putting their projects on the crowdfunding site. The National Multiple Sclerosis Society has already agreed to a co-branded crowdfunding project.

4. **Alzheimer's X-Prize:** Dr. Morris mentioned that Ms. Sherman had sent out invitations to a group of neurologists to participate in the X-Prize committee. He wanted to know if anyone had responded. Ms. Sherman stated that 11 people received a letter, but that she would reach out to those invitees again via email. The Committee will need to create a clear X-Prize proposal before Mr. Bezos is contacted again.

Dr. Morris suggested that those participating in this initial committee should not be excluded from submitting their own project proposal for the X-Prize. Dr. Sacco agreed that this committee was a "think tank" to get the ball rolling. People often start these X-Prize deliberations and apply later.

Dr. Cudkowicz suggested that there may already be another group working on an Alzheimer's X-Prize. The Foundation will consider this before proceeding further.

5. **Information Tracking of Past CRTS Recipients:** Meeting participants discussed the survey which AANI is currently using to track outcomes on the CRTS program. Should current questions be revised in any way? Suggestions including having applicants send in their bio sketches and to track progress for 5-10 years.

**Adjourn 10:45 a.m. (Central).**