



**American Brain Foundation
Research Advisory Committee Meeting
July 24, 2017**

**11:00 a.m. ET/ 10:00 a.m. CT/ 9:00 a.m. MT/ 8:00 a.m. PT
Conference Call**

In attendance: Robert Griggs, MD; Ralph Sacco, MD; Ira Shoulson, MD; Eugene Scharf, MD; John Morris, MD; Raymond Roos, MD

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

Excused: Carsten Bonnemann, MD; Merit Cudkowicz, MD; Shafali Jeste, MD; Natalia Rost, MD; Christy Phelps, Deputy ED AAN.

Dr. Griggs welcomed everyone and discussed the agenda for the meeting. Dr. Griggs asked that the Research Advisory Committee minutes from June 19, 2017, be reviewed.

MOTION to approve the minutes from June 19, 2017.

Approved (Unanimous).

- 1. Crowdfunding:** Dr. Griggs asked for the Committee's feedback on the Research Project applications provided in the meeting materials. Dr. Griggs led the discussion by stating that he preferred an NIH bio sketch, which was being set in place for future applications. He also questioned how many reviewers were looking at individual projects. Ms. Sherman stated that there were 30 reviewers, with 10-12 responses on Letters of Intent. Reviewers struggle to respond in the time frame given. Dr. Griggs asked Ms. Sherman to send him the list of people who have and have not responded to her requests for application review. He wanted to reach out to them.

Dr. Griggs also wanted to know if any submitted projects had been rejected. Ms. Sherman agreed to the earlier request and stated that none of the 18 LOIs have been rejected. Many applications are still pending the full applications. Dr. Griggs asked why three quarters of full applications only had two reviewers. Ms. Sherman explained that each disease area had specific group of specialized reviewers, some of which only have two reviewers in the group. The goal is to expand these disease groupings to five reviewers each. Dr. Griggs asked Ms. Sherman to forward who was in each group so that he could send additional reviewers names to expand these groups further.

Dr. Griggs questioned if researchers were given reviewer comments. Ms. Sherman said that they were not. The Committee agreed that the researchers would benefit from reviewer comments.

The Committee discussed the crowdfunding site's public impact. They questioned how many hits the website was getting and how much impact these projects were having on the public. The Committee recognized that there were key departments within the Academy that still do not know about the crowdfunding site and that public awareness

has been put on the back burner until the Foundation's marketing strategy has been formalized.

Ms. Ransom responded to these concerns. The crowdfunding site has not been pushed to the public yet, but the Foundation recently hired marketing support in the form of Joanna Wasmuth, who will be putting together an 18-month plan. The marketing plan will emphasize the crowdfunding site. The Foundation is looking at a marketing plan that can be methodically implemented and will focus on paid and unpaid social media marketing and advertising. Ms. Ransom also mentioned that 2018 CRTS recipient projects will be posted on the crowdfunding site to support the Foundation's share and to continue to build public awareness for their CRTS's.

The Committee wanted to know if it was possible for the Foundation to get on the front page of *Neurology Today* to build awareness amongst neurologists. They also wanted to know if there was a marketing plan geared toward international applications. Ms. Ransom stated that there was no current international public awareness plan, but the Foundation could start reaching out to neurological associations of other countries. The Committee liked the idea of getting more international reviewers as a precursor to international applicants.

Dr. Griggs asked the Committee if they saw any negative aspects to having more international involved both as researchers and reviewers. The Committee expressed a general concern about cultivating potential funders. Getting a marketing plan in place is essential, but the implementation of a marketing plan could take months. They also wanted to look at each project granularly to understand who might be potential donors to each project. The Committee discussed the possibility of a commercial entity funding projects. They were concerned that a marketing company might not know anything about the potential audiences available and would cause the Foundation to miss opportunities. Dr. Griggs agreed that it is important to be aware of potential market, but a good marketing company will be able to market to commercial and international entities with ease. Marketing internationally might help the Foundation's image and build international donors.

Ms. Ransom wanted to clarify that when the Committee was talking about commercial opportunities, they were thinking about Pharma. The Committee identified Pharma, medical device start-ups, and biotech companies as potential groups that might be interested in developing these projects.

Dr. Griggs returned to the discussion on project applications. The applications are hard to read all the way through and need to be shorter. The Committee agreed with Dr. Griggs. Ms. Ransom stated that the Foundation could put a space limitation into their application system. It might be worthwhile to count the number of words in a good length proposal and encourage brevity.

2. **Report from AAN Science Committee Meeting:** Ms. Ransom filled in for Dr. Jeste, who gave a live presentation of the crowdfunding site for the new Clinical Research Training Scholarships being received from the McKnight Foundation. The response was favorable, but the only question was around the category "Seizure Disorders". The

Committee thought that the category would better serve patients and caregivers if it were “Epilepsy and Seizure Disorders”. Dr. Griggs asked the Committee their thoughts on this change.

The Committee recognized that the title might have to be “Epilepsy/Seizure Disorders” because of a space limitation in each category’s title. The Committee recommended that the Foundation’s team play around with the exact wording but agreed that it was important for patients and caregivers to see “epilepsy” in one of the categories.

- 3. Clinical Research Training Scholarships & Sustainable Growth:** Ms. Ransom focused on the challenges faced. In the past, the Foundation has never raised any funding for indirect costs. The Academy was paying all operational costs, but that is declining. The Foundation is responsible for recouping those costs. Additionally, the cost of the CRTS has gone up from \$130,000 to \$150,000 this year. The Foundation needs to ask partner organizations to absorb the changing funding or participate in joint fundraising. The Foundation may also have to speak to the Academy about making a coordinated ask for Pharma to fund CRTS’s.

Dr. Griggs stated that he agreed with the Academy that the stipend for the CRTS’s needed to be increased. He also stated that it may be too much to ask partner organizations to pay more toward CRTS’s and cover the indirect costs. Originally, partner organizations would supply funding, and the Foundation covers administrative costs, reviews of all applications, PR, and marketing. Now, to tack on administrative costs with an increase in the stipend, that’s too much. If the Foundation needs to make a change, they should increase the stipend before asking for indirect funding. The Committee agreed that it is time to increase the stipend; it was well overdue, but to approach partner organizations cautiously.

Ms. Ransom stated that their insights were a good reality check. The Foundation will need to have an open discussion around CRTS funding with the Academy about how to make coordinated approaches to Pharma companies, especially when companies like Biogen have asked the Academy if they do joint funding with the Foundation.

Dr. Griggs stated that it would need to be a creative discussion with the Academy. There is no question that the Foundation need to fund the gap between the actual CRTS and the administrative costs. Dr. Morris mentioned that he would be happy to approach the Alzheimer’s Association.

- 4. X-Prize Proposal for Jeff Bezos:** Dr. Morris introduced the letter written to Jeff Bezos, CEO of Amazon, after he publicly requested ideas for his philanthropy. The letter was drafted by Ms. Ransom, and together they sent the letter. There has been no response to-date.

Ms. Ransom stated that X-Prizes were something that the Foundation wanted to pursue more with mega donors in the future. The Foundation will try to develop their X-Prize strategy more to put the Foundation forward when these opportunities arise. The Committee discussed how this process would work. Dr. Griggs suggested that Dr. Morris visit Jeff Bezos in person, or that the Foundation should follow-up on his request by sending him more information. Ms. Ransom agreed.

Meeting adjourned at 10:46 a.m. (Central).