



**Research Advisory Committee  
Meeting of April 25, 2017  
7:45-8:45am ET  
Boston Convention Center, Room 103**

<b>Committee Members</b>	Carsten Bonnemann, MD; Merit Cudkowicz, MD, MSC; Robert Griggs, MD, FAAN; Shafali Jeste, MD; John Morris, MD, FAAN; Raymond Roos, MD, FAAN; Ralph Sacco, MD, MS, FAAN, FAHA; Ira Shoulson, MD, FAAN; Eugene Scharf, MD; Lisa DeAngelis, MD, FAAN; Christy Phelps, Deputy ED AAN.
<b>Staff</b>	Jane Ransom, Suzi Sherman, Natalie Baumgartner, Shelly Rucks

	<b>AGENDA ITEM</b>	<b>PRESENTED BY</b>
5 min.	<b>Welcome</b>	Dr. Griggs
	<b>Approve Minutes of March 20, 2017 Meeting</b>	Dr. Griggs
10 min.	<b>Presentations of Crowdfunding at Annual Meeting</b> <ul style="list-style-type: none"> <li>• NINDS</li> <li>• Experiential Learning Stage</li> <li>• Experiential Learning Stage</li> <li>• Frontiers Plenary</li> </ul>	Dr. Griggs Dr. Griggs Dr. Scharf Dr. Sacco
10 min.	<b>Behind-the-Scenes Look at Crowdfunding Site</b> <ul style="list-style-type: none"> <li>• Online LOI &amp; Application</li> <li>• Online Scientific Review</li> </ul>	Suzi Sherman, Program Officer
25 min.	<b>Feedback on Crowdfunding Site and Next Steps</b> <ul style="list-style-type: none"> <li>• Survey Feedback</li> <li>• Reviewer Feedback</li> </ul>	Jane Ransom, Executive Director Dr. Jeste & Dr. Roos
10 min.	<b>Crowdfunding &amp; Major Donor Fundraising</b>	Shelly Rucks, Dir. of Development
	<b>Adjourn</b>	



**Research Advisory Committee  
Meeting of March 20, 2017  
10:00-11:00 am CT  
By conference call**

Attendance: Robert Griggs, MD; Ralph Sacco, MD; Eugene Scharf, MD; Lisa De Angelis, MD; Ira Shoulson, MD; Jane Ransom, Suzi Sherman

Excused: Ray Roos, MD; Shafali Jeste, MD

The meeting was called to order at 10:05 a.m. by Dr. Griggs. The committee approved minutes of the meeting of Feb. 21, 2017.

ABF Major Giving

Jane Ransom provided a report on recent major gifts including:

- \$200,000 donor advised fund for MS research
- \$5,000 donor advised fund for pediatric neurology
- \$100,000 fund for humanitarian award to a neurologist working with the under-served

Update on Crowdfunding Beta Testing

The committee discussed the first beta test. The mechanics of the system worked well, but committee members would like to know why certain reviewers voted no on some LOIs.

The second beta test is scheduled to begin on March 22. Committee members expressed concern that the time between the approval of the LOI and the deadline for the full Application was too short. Staff assured that this timeline only applied to the beta test and would not be applicable once the site goes live.

The committee would like projects to have funding benchmarks showing what could be accomplished on the project with minimum, mid, and maximum funding levels.

Promotion of the Crowdfunding Site to Neurologists

The new initiative will be highlighted in several on-site publications and speeches at the AAN meeting. Committee members suggested also publicizing it at the Brain Health Fair, stressing that word must go out to the public to attract donors.

Upcoming Live Tour of the ABF Crowdfunding Platform

Jane Ransom said that a live tour of the beta site via webinar for members of the ABF Board and Research Advisory Committee would be announced soon. Members will be invited to provide feedback.

#### Increase Clinical Research Training Scholarship Award

The committee discussed a letter from Dr. Videnovic to Dr. Griggs informing the American Brain Foundation that the AAN has decided to increase CRTS awards from \$130,000 to \$150,000. The amount has not changed in many years and is becoming uncompetitive. There was agreement that the change is appropriate and overdue. But this change was not budgeted by the American Brain Foundation. Further discussion will be needed about how to persuade current partners to take on most, if not all, of the increase.

#### Adjournment

Dr. Griggs adjourned the meeting at 11:00 a.m. CDT. The next meeting will take place in-person at the Boston Convention Center, room 103, on Tuesday, April 25 at 7:45 a.m.

## Website and Crowdfunding Site Feedback

**Feedback Participants:** The following Board, staff, and RAC members provided feedback

- |                             |   |
|-----------------------------|---|
| 1. Susan Schneider Williams | 6. Lisa Shulman                         |
| 2. Ralph Jozefowicz         | 7. Anonymous                            |
| 3. Lisa DeAngelis           | 8. Jeffrey Rosenfeld                    |
| 4. Anonymous                | 9. Gordon Smith                         |
| 5. Tim Engel                | 10. David Knopman (Expert Review Panel) |

### 1. Comments on look and feel of website:

- The site looks great.
- Suggest giving more thought to what fits on the screen for different screens of computers, laptops, smartphones etc. so that the visitor sees the priority info easily. Similarly, suggest reviewing font sizes e.g. font was often small.
- Great job overall!

#### ➤ Actions Addressing Feedback

- ✓ Website development team and graphics consultant have tested the site to assure that it is user-friendly on all types of devices.

### 2. Comments on the site from point of view of donors searching for and funding projects of interest to them:

- As noted, the titles of the projects need to be understood by the general public.
- The biggest issue is the title of the projects and their "overly scientific" choice of words, even in their description. Everything needs to be at the level of a lay person - which is usually defined as about 8th grade reading level.
- Project names- move away from scientific description, needs to be written so individual donor, non-doctor can easily understand what the research project is going to accomplish. Consider displaying a patient picture for each project. Need to touch the donor's feelings regarding the impact of the neurologic disorders.
- Agree with comments by attendees on the call.
- It is hard to answer this question as we did not experience the search function. The projects need titles and descriptions that lay people will understand. Some of the disease category groupings could be improved (e.g. ALS and Neuromuscular. Why is ALS singled out?

#### ➤ Actions Addressing Feedback

- ✓ ABF has asked medical writer to rewrite the research project names to be understandable by the general public.

### **3. Comments on the site from perspective of researchers applying to have their projects crowdfunded:**

- A minor issue - I don't understand the requirement for IRB approval or exemption for laboratory-based work. The IRB doesn't "exempt" lab work and you would be asking institutions to "vet" something they don't do. This is a problem.
- The focus needs to be on the donor not the researcher.
- Also hard to answer this as one would need to submit a proposal to provide an authentic evaluation.
- As discussed on the call, a good idea to have some milestone thresholds for the funding; amount to start the project, amount to obtain preliminary results, amount to completion. Better than all or none funding on the status bar. Also, duration and timing of the posting may need more discussion. Certain times of the year will be more popular. Competing projects posted simultaneously may also be a strategic disincentive

#### **➤ Actions Addressing Feedback**

- ✓ Ask Research Advisory Committee to revisit the necessity of IRB approval or exemption for laboratory based work
- ✓ Ask Research Advisory Committee to decide whether milestone thresholds for funding should be created, and, if so, what they will be; i.e. amount to start the project, amount to obtain preliminary results, amount to completion.

### **4. Comments on informational pages on our researchers and brain diseases:**

- Again, needs to be simpler. Ultimately video is better than still photographs.
- Need to see more.
- Impossible to answer without reading them. Worry the brain disease information pages will be difficult to keep up to date. Is it wise to include these?
- These have to be worded very carefully so as not to imply a bias toward a particular area of research that may (or may not) be represented in the available projects.

#### **➤ Actions Addressing Feedback**

- ✓ ABF will ask the Research Advisory Committee or its chair's designee, to annually review and update these pages.

### **5. Comments on video on homepage:**

- On the one hand I liked the movement and "artsy" nature of it (it looked like Picasso drawings), but on the other hand I'm not certain it will "speak" to the public - no color, not real people, etc. I think people like stories of individuals that can feel relevant to their situation. However, maybe your marketing research shows I'm wrong.
- Need to view it again

- I liked the video in both the themes and the tone- not sure how the link will appear on the homepage.
- Actions Addressing Feedback
  - ✓ Keeping video as is. ABF will review video in 1-2 years and determine if a new video is needed.

## 6. Other suggestions/comments:

- Great job! Love the pride in partnership between ABF and AAN throughout.
- It isn't clear to me what happens to money donated to a project, that doesn't meet goal and the project gets taken down. I think that's critical for a donor to understand. Maybe also we should "highlight" what we think are priorities. This is thorny but could be helpful when there are a lot of projects up - or will the landing page keep circulating different people every 10-20 sec for example?
- Home page picture - is that the final. I would want to see a patient. Use layman's language in project descriptions. Donations- reverse order start with \$10,000 and then decrease. Requests always start high, if you can't do \$10,000 then what about \$5,000. Is there any space dedicated to recognizing major donors or for advertising?
- If an IRB approval has already been obtained there ought to be a way to submit that at the time a researcher first submits their project. This would save a step and fast-track a posting. Having project samples posted on the opening pages might be an unfair advantage relative to the projects that must be searched for in the body of the website.
- Actions Addressing Feedback
  - ✓ The FAQ section on the website answers questions above posed by RAC and Board.
  - ✓ ABF will evaluate the donation levels and their order.
  - ✓ Ask the RAC if some projects should be highlighted on the crowdfunding site when the list of projects grows to be more than 12.

## 7. Crowdfunding LOI/Full Application:

- In the future you consider requesting a compiled PDF. Cutting and pasting into the form results in lost formatting and is just clunky. Some will want to submit an image or graph, probably worth having rules about this. To ask that people type in references one by one is an extreme example, I've never seen this done. We all use reference management software and if you really want individual documents ask for a PDF upload.
- The website does not provide a COI form. I completed an extremely extensive online form with the LOI I believe (I was struck it was more probing than others). I tried to find a form and gave up and instead uploaded an NIH other support document. So it would go in.
- You need to provide instructions for some of the sections. I completed the abstract and narrative as I would an NIH grant, but not all will know (and perhaps I did this incorrectly).
- You asked for a CV with the LOI, but usually one submits an NIH formatted biosketch. I would suggest doing this for uniformity of formatting and ease of review.

- You don't say what you are looking for in the institutional support letter. I took my best shot.
- It's not clear how much detail you want on the budget, and there was no clear instruction regarding a justification. I put both in one document.
- There is no place to indicate co-PI or co-investigators. I'm doing this with one of our junior faculty (which is a strength in my opinion) but there was no place to put this information.

➤ Actions Addressing Feedback

- ✓ ABF will add field for them to upload images/graphs
- ✓ ABF will add field for them to upload references instead of listing them individually
- ✓ ABF will remove the COI upload request in the full application as this is requested in the LOI
- ✓ ABF will update CV area to ask for a CV or NIH formatted biosketch
- ✓ ABF will add more details about what information should be included in the institutional support letter, and will add an FAQ on this as well
- ✓ ABF will update budget language on full application to request a detailed budget and budget justification
- ✓ ABF will add fields for 2 co-investigators information
- ✓ Ask the RAC to provide more detailed instructions for the specific sections, i.e. abstract, narrative, specific aims, etc. Should provide better idea of the type of information applicant should include in the section

**Reviewer Feedback:**

- I think that a reviewer should have access to what other sources of funding the applicants have. I suppose you can be liberal on overlap, but it still seems like something I would like to know and that the AAN should know before signing off on posting the application.

➤ Actions Addressing Feedback

- ✓ ABF will ask more clearly for applicants to supply their other sources of funding.