

AMERICAN BRAIN FOUNDATION

Research Advisory Committee

September 27, 2015

Summary Notes

PARTICIPANTS: Doctors Griggs (Chair), Roos, Morris, Shoulson, Bonnemann, Jeste, Cudkowicz, Sacco

STAFF: Jane Ransom, Executive Director

1. Welcome/Introductions/Meeting Goals

Dr. Griggs reviewed the reasons for establishing the ABF Research Advisory Committee. The ABF is making two broad changes: (1) Turning to the public for financial support; and (2) Building on the success of the clinical research training fellowships (CRTFs) by adding grants for higher risk research. The charge of the committee is to determine ABF funding priorities. Committee members were selected because all are leading authorities interested in clinical results of basic research.

2. American Brain Foundation Mission & Vision

Jane Ransom introduced herself and spoke about the strategic implementation planning the ABF is undertaking in order to establish a roadmap toward the broader vision described by Dr. Griggs. The three areas of inquiry are (1) Research Funding Agenda; (2) Fundraising Potential & Strategy; and (3) Business model. A compelling research agenda is crucial if ABF fundraising is to be successful. We must strive for a unique niche—an area of need which nobody else is funding.

3. Perspectives from the AAN Board

Dr. Sacco discussed the financial investment which the AAN/AANI is making in the ABF as it evolves into an organization which raises money from the public, builds a fundraising board, and brings on an executive director. At the same time, revenue-generating programs such as CRTFs, Corporate Roundtable, and CTU [?] were revenue sources for the ABF which have been transferred to the AANI. Another step toward separating the two organizations is that the ABF chair no longer sits on the AAN/AANI board. CRTFs have been highly successful, but the ABF needs to look beyond them at what else it wants to do. The AAN/AANI also has a strong interest in public awareness and an evolving research agenda. A number of new research training fellowships are under discussion, as are 3-year career development awards.

4. Targeted Funding in Neurological Research

Doctors Cudkowicz, Jeste and Shoulson presented ideas for the ABF's research funding agenda which were discussed by the whole committee.

The Committee proposed that the ABF should invest in research for:

- a. Prevention of specific diseases: e.g. Stroke, Alzheimer's disease, brain trauma, Parkinson's disease, Huntington's disease, ALS, many rare diseases. Prevention is an important concept but must be disease-specific to attract donors. ABF grants would promote the development and study of preventive measures for people at high risk (e.g., presymptomatic genetic diseases, prior stroke, prior concussions).
- b. High risk, patient-centered discovery of new treatments: It is hard to find funding for the early phase therapeutic space, research showing that a drug reaches the target and has a measurable beneficial on the course of the patient's disease. Grants in the \$1.5-2 million range are needed. Pharma has pulled back from funding this type of high risk research and Federal funding is limited and tends to favor studies de-risked by having the type of preliminary data that such high-risk research would facilitate.
- c. Common mechanisms of neurodegeneration and neurodevelopment: This research would need to be directed to specific diseases to attract donors who care about their own diseases primarily but would have the potential to benefit research in many diseases.

The ABF's approach in the above areas should include:

- Recognition of the need to continue supporting young investigators
- Building partnership of disease-specific organizations
- An orientation toward funding the gaps where funding is needed