

# Agenda



**Strategic Planning Committee**  
**January 11, 2016**  
**9:45 a.m. EST/8:45 a.m. CST/7:45 a.m. MST/6:45 a.m. PST**  
**Conference Call**  
**Call-in number: (866) 740-1260**  
**International Numbers:**  
<https://www.readytalk.com/rt/an.php?tfnum=8667401260>  
**Access code: 9286317**

<b>Committee Members</b>	Lisa Shulman, MD, Chair; Kevin Goodno ex officio; Jane Ransom ex officio; Jeffrey Rosenfeld, MD; Martin Shenkman; Gordon Smith, MD; Ben Utecht	
<b>Guests</b>	Robert Griggs, MD, Chair of ABF Research Advisory Committee, ABF Strategic Planning consultants	
<b>Staff</b>	Suzi Sherman	
	<b>AGENDA ITEM</b>	<b>PRESENTED BY</b>
8:45 a.m. CST	Welcome and review objectives for today's meeting <ul style="list-style-type: none"><li>• Report from ABF Research Advisory Committee</li><li>• Second review of Case Statement for philanthropic assessment</li><li>• In-person meeting in Minneapolis on March 25, 2016 (8:00 am-4:00 pm)</li></ul>	Dr. Shulman
8:55	Report from ABF's Research Advisory Committee	Dr. Griggs
9:15	Review Case Statement	Jane Ransom & Lela Diaz
9:40	In-person meeting in Minneapolis on March 25, 2016 (8:00 am-4:00 pm)	
9:45	Adjourn	

**American Brain Foundation  
Strategic Planning Committee Meeting Summary  
Monday, December 14, 2015  
Teleconference**

**Attendees:** Kevin Goodno; Jeffrey Rosenfeld, MD, PhD, FAAN; Martin Shenkman, CPA; Lisa Shulman, MD, FAAN, Chair; A. Gordon Smith, MD, FAAN; Ben Utecht

**Staff:** Jane Ransom; Suzi Sherman

**Welcome and review of objectives for meeting**

**Calendar:** Confirmed the meeting schedule and Dr. Shulman noted that an in-person meeting is going to be scheduled for February/March.

**Update on Strategic Planning Activities:** Jane provided an update on the Strategic Planning process.

- **ABF Program/Funding Focus:** The Research Advisory Committee had a call on 12/7 and will have another one on 1/4/16. On their 12/7 call they discussed how to take their research funding ideas and create messaging that can be applied to marketing pieces that ABF staff can share with donors and prospective donors at meetings.
- **Philanthropic Assessment:** The ABF hired Carter Companies to conduct the philanthropic assessment. Jane introduced Lela Diaz, from Carter Companies, and they shared that they are creating a 3-4 page case statement that will be used at meetings with prospective donors and major donors and corporations to get reactions and responses to the specific program ideas. Their responses will be shared with the Research Advisory Committee to help guide their funding priorities. The committee will have a special call at the end of December to discuss and provide feedback on the drafted case statement.

Lela will interview members of the committee in the coming weeks.

- **Business Model:** The business model assessment is underway and all of the interviews with individuals are complete. Henrichs & Associates is now working on getting interviews with medical research foundations and volunteer health organizations scheduled.
- **Signature Program:** In the Alford Group's report, they suggested the ABF consider funding a signature program – to take one issue and raise it up in the public eye to raise awareness about the foundation.

Jane and Ben suggest that we consider including a signature program around traumatic brain injury and concussion education for youth sports in the strategic plan. They asked for the committee's view on whether it was worth considering, in which case they will do some further planning with potential stakeholders. Committee members expressed that, while such an initiative would require careful consideration, it would be worth doing the initial planning and thinking about what the program might look like.

## REPORT FROM THE RESEARCH ADVISORY COMMITTEE OF THE AMERICAN BRAIN FOUNDATION

DR. ROBERT C. GRIGGS, CHAIR

### **BACKGROUND**

I'd like to thank the Science Committee for the opportunity to discuss the emerging research funding program of the American Brain Foundation, as envisioned by the Foundation's Research Advisory Committee (RAC). The RAC was established last year when the Academy made the decision to invest in positioning the ABF as a highly influential, publicly-facing foundation—one that rallies the hearts, minds and pocketbooks of the American people, and even beyond, in the battle to cure diseases of the brain and nervous system.

Since the Science Committee is also concerned with the future of research on brain disease, I believe it is crucial that we share agendas and collaborate. Best case scenario from the ABF's perspective is for the Foundation to provide substantial, growing support for the evolving research agenda outlined in the Science Committee report from Dr. DeAngelis for last September's meeting of the AAN Board. We also envision providing funding outside of the Academy for other high-risk research projects.

The current work of our RAC is to determine the future of research funding by the ABF. This work is one leg of a larger strategic planning process recently undertaken by the ABF. The members of our committee include Drs. Carsten Bonnemann, Merit Cudkowicz, Shafali Jeste, John Morris, Ray Roos, Ralph Sacco, Ira Shoulson and myself as Chair.

### **EMERGING VISION OF ABF FUNDING**

The ABF's RAC has met three times over the past four months. We've agreed upon an underlying philosophy to guide our approach to research. It includes three principles:

- Recognition of the need to continue and expand supporting young investigators
- Working in partnership with disease-specific organizations
- Funding high-risk but highly innovative research aimed at disease treatment

In this context we are considering a multi-tiered research funding program consisting of:

1. Great Minds: Cornerstone program which identifies the best and the brightest early career clinical neuroscientists and funds their innovative research on diseases of the brain. Scientific and medical communities have called the shortage of investigators a crisis that will impact far more than the 100 million Americans currently affected by a neurologic disease or disorder. Through funding clinical research training fellowships, the ABF will continue to create the next generation of premiere minds that will impact the study of diseases of the brain and nervous system in ways we can only imagine.
2. Breakthrough Discoveries: Higher-risk research to prevent or delay the onset of diseases such as Alzheimer's disease, dementia with Lewy body, Parkinson's disease, Lou Gehrig's disease (ALS) and others. Impact research across a wide-ranging set of brain and neuromuscular diseases through discovery of fundamental common mechanisms. For example, the ABF envisions supporting:
  - 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.

- 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.
3. The X-Prize: An ABF prize attracting venture capital to invest in cutting edge, innovative and high-risk research that could forever change the landscape of brain disease. The prize (monetary value yet to be determined) will be awarded to the first team to reach the audacious goal of delaying the onset of a major neurological disease, such as Alzheimer's, multiple sclerosis, Parkinson's, MSA, diffuse Lewy body disease, Progressive Supranuclear Palsy, muscular dystrophy and ALS.

### **PRACTICAL APPLICATION**

Already the ABF is seeing interest from some major donors in this approach—where we give them a “menu” of options along the continuum, starting with clinical research training fellowships and stretching all the way to the X-prize. In recent weeks we have provided such a menu to two different donors interested in each of two diseases/disorders—autism and ADHD. Disease-specific experts on the RAC have helped the staff to frame and propose much-needed research projects on the high-risk end of the scale.

### **QUESTIONS & OBSERVATIONS**

- There are obvious overlaps between the preliminary research agendas sketched out by the ABF's RAC and the Science Committee. We should be collaborating for success all around. A good start at formalizing collaboration and communication might be to have overlapping memberships, i.e., a member of the Science Committee sits on the ABF's RAC and vice versa.
- We could be using the AAN's big awards, as well as the Public Leadership in Neurology Award, to educate the public, highlight research successes and secure donor funds. We could partner to develop a more exciting, more public platform for these awards.
- Similarly, the ABF public board members and donor base could be mobilized to strengthen the hand of the science constituency of the AAN in areas such as advocacy, Federal funding of research and in show-casing of AAN members making scientific breakthroughs.

Investment Brief for the American Brain Foundation  
**A cure for one is a cure for many**

**It is time to take on brain disease.** Throughout our history, the American public has successfully rallied to beat back pervasive threats to our personal and public health, such as polio, cancer and HIV/AIDS. The time is now to take up the fight to defeat brain disease. This is the goal of the American Brain Foundation. It is no small project, especially in light of highly under-funded, incremental federal research and the pharmaceutical sector's increasing aversion to investing in high-risk clinical research trials that determine whether specific drugs are effective.

Everyone knows someone afflicted with a brain disease. Over 100 million Americans suffer from some disease or disorder of the brain at some point in their lives. So why isn't brain disease a "thing"? We don't see it as a pervasive national (or international) health emergency. Because for too long our gaze has been fixed upon specific diseases, with strange and dissimilar names (like epilepsy, Alzheimer's or Parkinson's), to the exclusion of the bigger picture. Underlying all of them are common mechanisms producing neurodegeneration. By following a disease-specific approach to research, neuroscience has failed to uncover a single means to prevent the progress of a single neurodegenerative brain disease. It is time for a new approach.

**Why ABF**

The American Brain Foundation (ABF) is uniquely positioned to have a significant impact on the lives of millions of people that suffer one of the more than hundreds of brain diseases because:

- The ABF takes a "whole brain" approach and seeks out research on mechanisms of neurodegeneration and neurodevelopment held in common by multiple diseases will create opportunities for discoveries and cures of many brain disease
- ABF has a unique research partnership with the American Academy of Neurology (AAN), the most elite international professional association of more than 29,000 neurologists and neuroscience professionals at the forefront of their field.



Over the past 20 years the ABF, has raised \$20 million for research and has supported more than 190 researchers of the AAN, creating the next generation of premiere minds that will impact the study of the brain. The ABF works with these outstanding AAN neuroscience professionals to identify the most needed, yet most difficult to fund, research on diseases of the brain and nervous system. This success and commitment to the field has supported some of the most advanced science of this generation.

However, despite all this effort, every year gifted researchers and cutting-edge projects go unfunded. It's why at this moment, the ABF has identified a need to extend its reach to meet the needs and challenges associated with brain diseases and funding for cures. It is time to step up and tackle the issues of the brain as a comprehensive unit versus approaching it in disease-specific silos.

### **The ABF Plan**

The ABF has outlined specific areas of focus that will forever change brain disease research, education and advocacy.

### **Building the Brain Trust (RESEARCH)**

The ABF funds innovative research on brain disease utilizing its global network of experts to ensure the most critical and transformative research, spanning many brain diseases, receives funding.

1. Great Minds: Cornerstone program which identifies the best and the brightest early career clinical neuroscientists and funds their innovative research on diseases of the brain. Scientific and medical communities have called the shortage of investigators a crisis that will impact far more than the 100 million Americans currently affected by a neurologic disease or disorder. The ABF continues to create the next generation of premiere minds that will impact the study of diseases of the brain and nervous system in ways we can only imagine.

### **A Recent Success**

Hristelina Ilieva, MD, PhD, a Clinical Research Training Fellowship cosponsored by the American Brain Foundation and The ALS Association in ALS Research. Ilieva, a native of Bulgaria, completed medical school and residency there, and eventually found her way to the lab of Don W. Cleveland, PhD, of the University of California, San Diego. "Dr. Ilieva's work in that lab really changed the field of neurodegeneration altogether," said Jeffrey D. Rothstein, MD, PhD, of Johns Hopkins School of Medicine, who is serving as Ilieva's mentor in her current fellowship. "She was the first to rigorously demonstrate that non-neuronal cells, microglial cells, are active participants in ALS through a series of truly elegant transgenic rodent and molecular genetic studies."

According to Dr. Ilieva, "ALS can present in different ways and be driven by different genes, but identification of common pathways may lead to feasible and realistic breakthroughs for a wider variety of patients." ABF continues to observe science discoveries that can impact multiple aspects of the brain and believes future investments need to be made.

2. Breakthrough Discoveries: Higher-risk research to prevent or delay the onset of Alzheimer's disease, dementia with Lewy body, Parkinson's disease, Lou Gehrig's disease (ALS) and others. Impact research across a wide-ranging set of brain and neuromuscular diseases through discovery of fundamental common mechanisms.
3. The X-Prize: An ABF prize attracting venture capital to invest in cutting edge, innovative and high-risk research that could forever change the landscape of brain disease. The prize (monetary value yet to be determined) will be awarded to the first team to reach the audacious goal of delaying the onset of a major neurological disease, such as Alzheimer's, multiple sclerosis, Parkinson's, MSA, diffuse Lewy body disease, Progressive Supranuclear Palsy, CPG, muscular dystrophy and ALS.

### **Campaign for the Brain (EDUCATION & ADVOCACY)**

ABF mobilizes resources for brain health through education and advocacy by asking the public to join in a Campaign for the Brain to leverage a larger constituency of advocates and investors.

4. Mobilize for the Brain. Enlisting our network of supporters in reaching government officials to press for more public funding for brain disease research.
5. Protecting Young Brains. A national youth sports outreach campaign to promote concussion safety and education. A brain injury is a silent epidemic that changes, alters or takes a life every 19 seconds and affects all walks of life. The only cure is prevention. By starting with organized youth sports in select markets and then growing nationally ABF will help educate future generations about all aspects of brain disease.
6. Brain Awards. An awards program that raises national awareness of the fight against brain disease by spotlighting both neurologists, as well as non-scientific members of the public, on the front lines of the fight against brain disease.

