



AMERICAN BRAIN FOUNDATION  
Research Advisory Committee  
September 18, 2017  
11:00 a.m. EST/10:00 a.m. CST/9:00 a.m. MST/8:00 a.m. PST

Call-in number: 866-740-1260  
Access code: 9286317

**Committee Members**

Carsten Bonnemann, MD; Merit Cudkowicz, MD; Robert Griggs, MD; Shafali Jeste, MD; John Morris, MD; Raymond Roos, MD; Ralph Sacco, MD; Ira Shoulson, MD; Eugene Scharf, MD; Natalia Rost, MD; Christy Phelps, Deputy ED AAN

**Staff**

Jane Ransom, Shelly Collins Rucks, Suzi Sherman, Natalie Baumgartner

	<i>AGENDA ITEM</i>	<i>PRESENTED BY</i>
10:00 a.m. CT	Welcome	Dr. Griggs
	Approve Minutes of July 24, 2017 Meeting	Dr. Griggs
10:05	<p><b>1. Research Updates</b> (Robert Griggs, MD)</p> <ul style="list-style-type: none"> <li>a. AANI Research Program               <ul style="list-style-type: none"> <li>i. Clinical Research Training Scholarships</li> <li>ii. Clinician Scientist Development Awards</li> </ul> </li> <li>b. Crowdfunding               <ul style="list-style-type: none"> <li>i. Posted Projects</li> <li>ii. Pending Projects</li> </ul> </li> </ul>	Dr. Griggs
10:25	<p><b>2. Marketing Plan</b> (Jane Ransom &amp; Shelly Rucks)</p> <ul style="list-style-type: none"> <li>a. Public-facing</li> <li>b. Neurology community</li> </ul>	Jane Ransom & Shelly Rucks
10:35	<b>3. Alzheimer's X-Prize</b>	Dr. Griggs
	Adjourn	



**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. Some reviewers may respond in the timeframe 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 will reach out to them.

None of the 18 LOIs have been rejected. Several applications are pending. 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 asked 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 asked 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 is formalized.

Ms. Ransom responded to these concerns. The crowdfunding site has not been pushed to the public yet. The Foundation's marketing consultant is developing an 18-month plan by the end of August. The marketing plan will emphasize the crowdfunding site. The plan will likely focus on paid and unpaid social media marketing and advertising.

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 will put a space limitation into their application system.

2. **Report from AAN Science Committee Meeting:** Ms. Ransom reported that Dr. Jeste gave a live presentation of the crowdfunding site and reported on new Clinical Research Training Scholarship funding being developed by the Foundation. The Science Committee is excited by the crowdfunding sight. One question that came up was about the crowdfunding category called "Seizure Disorders". The Committee thought that the category would better serve patients and caregivers if it were "Epilepsy and Seizure Disorders".
3. **Clinical Research Training Scholarships & Sustainable Growth:** In the past, the Foundation has never raised any funding for its indirect costs. The Academy paid all operational costs, but AAN funding for the ABF is being phased out. 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 would administrative costs, review of all applications, and organize public relations and marketing. To suddenly tack on administrative costs with an increase in the stipend is probably too much for many of our partners. If the Foundation needs to ask for more funding from partners, it should ask for money to 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.

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.

There is no question that the Foundation needs to fund the gap between the actual CRTS and the administrative costs. Dr. Morris mentioned that he would be happy to help 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 Dr. Morris and 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 mega donors in the future. The Foundation should develop an X-Prize strategy so that we're ready to discuss how it would work with potential donors the Foundation will follow-up with Mr. Bezos.

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

# Tickler Report

## As of 9/7/2017

Report name: Tickler Action Report - Grants

Records to include: All

Include records with these dates: 7/24/2017 to 9/17/2017

Include these constituents: Inactive = Yes; Deceased = Yes; Constituents with no valid addresses = Yes

Include these priorities: High priority = Yes; Normal priority = Yes; Low priority = Yes

Include these progresses: Not Completed = Yes; Completed = Yes

Base report on: Solicitor

Phone types to include: All

Sort Order: Date Asc

Include actions from these records: Constituents = Yes; Appeals = Yes; Events = Yes

Campaigns to include: All

Funds to include: All

Constituent Codes to include: All

Gift Solicitors to include: Sherman, Suzi

Action Statuses to include: To-Do, Completed

Action Types to include: All

Action Categories to include: Phone Call

Action Tracks to include: All

Users to include: All

Solicitor					
Date	Start Time	Name/ID	Action Type	Action Priority	Detail
Category	End Time	Contact	Action Status	Action Progress	Proposal
<b>Suzi Sherman</b>					
7/24/2017	1:00PM	Epilepsy Foundation	Stewardship	Normal	(301) 918-3739
Phone Call	1:30PM	Liz Schreiber	Completed	Completed	2018 CRTS Grant
	<b>Notes:</b>	Attendees: Suzi Sherman, ABF Kristin Roehl, AANI Liz Schreiber, EFA			
		Objective: Discuss marketing plan for 2018 CRTS.			
		Meeting Notes: AES will promote as much as possible on their end - newsletters, email blasts, social media Will let ABF know if they need anything			
7/24/2017	2:00PM	The Mary Elizabeth Groff Charitable Trust	Stewardship	Normal	(267) 252-2642
Phone Call	2:30PM	Fatema E. Burkey	Completed	Completed	2018, 2020, 2022 CRTS Grants

# Tickler Report

## As of 9/7/2017

Solicitor				
Date	Start Time	Name/ID	Action Type	Action Priority
Category	End Time	Contact	Action Status	Action Progress
Detail Proposal				
<b>Suzi Sherman</b>				
		<p><b>Notes:</b> Attendees: Suzi Sherman, ABF Kristin Roehl, AANI Fatema Burkey, Groff</p> <p>Objective: Discuss marketing plan for 2018 award</p> <p>Meeting Notes: They don't currently publicize or promote their funding efforts on their website so they don't have the resources to market the award much Fatema will post as much as she is able to her LinkedIn account Kristin will reach out to the two reviewers Fatema recommended to see if they have suggestions for, or connections to, other audiences to target</p>		
7/28/2017	10:00AM	McKnight Brain Research Foundation	Stewardship	Normal
Phone Call		J. L. Dockery	Completed	Completed
		<p><b>Notes:</b> Attendees: Suzi Sherman, ABF Jane Ransom, ABF Kristin Roehl, AANI Lee Dockery, MD, MBRF Madhav Thambisetty, MD, MBRF</p> <p>Objectives: Share ABF's/AANI's marketing strategy Assist MBRF with developing their own plan</p> <p>Meeting Notes: Drs. Dockery and Thambisetty provided great feedback on the marketing plan - mainly providing names of additional organizations to reach out to to promote the awards Also provided names of conferences that the MBRF and/or ABF can reach out to to try and promote the 2018 awards on their websites and the 2019 at their conferences via poster/handout</p> <p>Next Steps: Dr. Thambisetty will email Suzi list of all the organizations and conferences they mentioned and will work together to determine who is responsible for reaching out to each group Suzi will update the marketing plan based on MBRF's feedback and send to them Kristin will do more research to identify names of fellowship directors and NINDs contacts to do soft promotion of the awards</p>		2018-2022 CRTS Grants
8/1/2017	9:30AM	Muscle Study Group	Stewardship	Normal
Phone Call	10:00AM	Kara Thompson	Completed	Completed
				2018 CRTS Grant

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Date	Start Time	Name/ID	Action Type	Action Priority	Detail
Category	End Time	Contact	Action Status	Action Progress	Proposal
<b>Suzi Sherman</b>					
		<p><b>Notes:</b> Attendees: Suzi Sherman, ABF Kristin Roehl, AANI Kara Thompson, MSG</p> <p>Objective: Discuss marketing plan for 2018 award</p> <p>Meeting Notes: Send Kara all communications so she can send to her distribution lists Provide Kara with a template for a handout and a sign to display at their Annual Conference September 23-25</p>			
8/3/2017		Society of Vascular & Interventional Neurology	Solicitation	Normal	janelfick@llmsi.com
Phone Call		Trish Shomion	Completed	Completed	
		<p><b>Notes:</b> Attendees: Suzi Sherman, ABF Kristin Roehl, AANI Trish Shomion, SVIN</p> <p>Objectives: Discuss marketing plan for 2018 CSDA Gauge their ability to partner again in the future</p> <p>Meeting Notes: SVIN has their own database they will promote the CSDA through Trish will talk with leadership about continuation of partnership and get back to us Suzi to send Toma: - best practices for sending communications (EM and social media) - sample communication blasts</p>			
8/3/2017	11:00AM	Society of Vascular & Interventional Neurology	Stewardship	Normal	
Phone Call		Trish Shomion	Completed	Completed	2018 CSDA Grant

# Tickler Report

## As of 9/7/2017

Solicitor					
Date	Start Time	Name/ID	Action Type	Action Priority	Detail
Category	End Time	Contact	Action Status	Action Progress	Proposal
<b>Suzi Sherman</b>					
		<p><b>Notes:</b> Attendees: Suzi Sherman, ABF Kristin Roehl, AANI Trish Shomion, SVIN</p> <p>Objectives: Discuss marketing plan for 2018 CSDA Gauge their ability to partner again in the future</p> <p>Meeting Notes: SVIN has their own database they will promote the CSDA through Trish will talk with leadership about continuation of partnership and get back to us Suzi to send Toma: - best practices for sending communications (EM and social media) - sample communication blasts</p>			
8/11/2017		Parkinson Study Group	Cultivation	Normal	(617) 724-9611
Phone Call		Michael Schwarzschild	Completed	Completed	
		<p><b>Notes:</b> Attendees: Suzi Sherman, ABF Jane Ransom, ABF Michael Schwarzschild, PSG Executive Committee Hubert Fernandez, PSG Executive Committee Roseanna Battista, PSG Administrative Manager</p> <p>Objectives: Discuss potential partnership opportunities which include: Co-funding existing CRTS in PD Partnering to jointly apply for grants Provide support for the ABF's crowdfunding site</p> <p>Meeting Notes:</p>			
8/16/2017	11:00AM	American Autoimmune Related Diseases Association,	Cultivation	Normal	(586) 776-3900
Phone Call	11:30AM	Virginia T. Ladd	Completed	Completed	



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Solicitor					
Date	Start Time	Name/ID	Action Type	Action Priority	Detail
Category	End Time	Contact	Action Status	Action Progress	Proposal
<b>Suzi Sherman</b>					
		<p><b>Notes:</b> Attendees: Suzi Sherman, ABF Jane Ransom, ABF Virginia Ladd, AARDA</p> <p>Objectives: Learn more about AARDA's research priorities and determine if we can partner on a CRTS in Multiple Sclerosis or Myasthenia Gravis</p> <p>Meeting Notes:</p>			
8/17/2017	2:30PM	American Epilepsy Society	Solicitation	Normal	
Phone Call		Eileen Murray	Completed	Completed	2019 CRTS Grant
		<p><b>Notes:</b> Attendees: Suzi Sherman, ABF Jane Ransom, ABF Eileen Murray, AES Penny Dacks, AES Liz Schreiber, EFA Sonya Dumanis, EFA</p> <p>Objectives: Discuss 2019 CRTS partnership - increase from \$130,000 to \$150,000 Present crowdfunding site and talk about ways the site can benefit AES and EFA</p> <p>Meeting Notes:</p>			
8/17/2017	2:30PM	Epilepsy Foundation	Solicitation	Normal	(301) 918-3739
Phone Call		Brandy Fureman	Completed	Completed	2019 CRTS Grant

# Tickler Report

## As of 9/7/2017

Solicitor					
Date	Start Time	Name/ID	Action Type	Action Priority	Detail
Category	End Time	Contact	Action Status	Action Progress	Proposal
<b>Suzi Sherman</b>					
		<p><b>Notes:</b> Attendees:            Suzi Sherman, ABF            Jane Ransom, ABF            Eileen Murray, AES            Sonya Dumanis, EFA            Penny Dacks, AES            Liz Schreiber, EFA</p> <p>Objectives:            Discuss 2019 CRTS partnership - increase from \$130,000 to \$150,000            Present crowdfunding site and talk about ways the site can benefit AES and EFA</p> <p>Meeting Notes:</p>			
8/21/2017	2:00PM	National Headache Foundation	Cultivation	Normal	(312) 274-2650
Phone Call	2:30PM	Mary Franklin	Completed	Completed	
		<p><b>Notes:</b> Attendees:            Suzi Sherman, ABF            Jane Ransom, ABF            Mary Franklin, NHF</p> <p>Objectives:            Discovery call to learn about NHF's research priorities            Introduce the Foundation's crowdfunding site            Gauge interest/ability to partner</p> <p>Meeting Notes:</p>			
8/22/2017	12:00PM	Target ALS Foundation	Cultivation	Normal	(908) 907-5670
Phone Call	12:30PM	Manish Raisinghani	Completed	Completed	

# Tickler Report

## As of 9/7/2017

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Date	Start Time	Name/ID	Action Type	Action Priority	Detail
Category	End Time	Contact	Action Status	Action Progress	Proposal
<b>Suzi Sherman</b>					
		<p><b>Notes:</b> Attendees: Jane Ransom, ABF Suzi Sherman, ABF Manish Raisinghani, Target ALS</p> <p>Objectives: Learn more about Target ALS's research priorities Talk about ABF's support for research program Introduce the ABF's crowdfunding site Gauge Target ALS's ability to partner on a CRTS</p> <p>Meeting Notes:</p>			
8/22/2017	10:00AM	Fraxa Research Foundation, Inc.	Cultivation	Normal	(978) 462-1866
Phone Call	10:30AM	Michael Tranfaglia	Completed	Completed	
		<p><b>Notes:</b> Attendees: Suzi Sherman, ABF Jane Ransom, ABF Michael Tranfaglia, MD, FRAXA Katie Clapp, FRAXA</p> <p>Objectives: Learn about FRAXA's reseach priorities Gauge if they are able to and interested in supporting a CRTS in Autism</p> <p>Meeting Notes:</p>			
8/23/2017	9:00AM	Muscle Study Group	Solicitation	Normal	
Phone Call	9:30AM	Richard J. Barohn	Completed	Completed	2019 CRTS Grant

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Category	End Time	Contact	Action Status	Action Progress	Proposal
<b>Suzi Sherman</b>					
		<p><b>Notes:</b> Attendees:            Suzi Sherman, ABF            Jane Ransom, ABF            A. Gordon Smith, ABF Board member            Richard Barohn, MSG            Kara Thompson, MSG</p> <p>Objectives:            Discuss increase in cost fo a CRTS from \$130K to \$150K            Gauge their interest/ability to continue partnership and commit to a 2019 CRTS at \$100K            Learn more about their research program/priorities            Introduce crowdfunding site and talk about the benefits it could provide for MSG</p> <p>Meeting Notes:</p>			
8/23/2017		Child Neurology Foundation	Cultivation	Normal	
Phone Call		Stephanie Mucha	Completed	Completed	
		<p><b>Notes:</b> Attendees:            Kristin Roehl, AANI            Suzi Sherman, ABF            Stephanie Mucha, CNF</p> <p>Objective:            Discuss ways in which the CNF can help promote the available 2018 awards</p> <p>Meeting Notes:</p>			
8/24/2017	11:00AM	International Headache Society	Solicitation	Normal	
Phone Call	11:30AM	David W. Dodick	Completed	Completed	2019 CRTS Grant

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## As of 9/7/2017

Solicitor				
Date	Start Time	Name/ID	Action Type	Action Priority
Category	End Time	Contact	Action Status	Action Progress
Detail Proposal				
<b>Suzi Sherman</b>				
		<p><b>Notes:</b> Attendees: Jane Ransom, ABF Suzi Sherman, ABF David Dodick, MD, IHS Carol Taylor, IHS</p> <p>Objectives: Discuss continuation of partnership - 2019 CRTS CRTS's increased to \$150,000 - determine how we will fund at this amount Can the IHS use the ABF's crowdfunding site as a resource for their researchers?</p> <p>Meeting Notes:</p>		
8/31/2017	11:00AM	American Brain Tumor Association	Cultivation	Normal
Phone Call	11:30AM	Nicole Willmarth	Completed	Completed
				(773) 577-8750 2019 CRTS Grant
		<p><b>Notes:</b> Attendees: Suzi Sherman, ABF Jane Ransom, ABF Nicole Willsmarth, ABRA Debbie Robbins, ABRA</p> <p>Objectives: Spoke with them in February of 2017 and introduced the CRTS program, also mentioned the crowdfunding site. Continue the conversation and gauge their interest in supporting a CRTS in brain tumors Introduce the crowdfunding site</p> <p>Meeting Notes:</p>		
8/31/2017		Muscular Dystrophy Association	Stewardship	Normal
Phone Call		Grace K. Pavlath	Completed	Completed
				2018 CRTS Grant
		<p><b>Notes:</b> Attendees: Kristin Roehl, AANI Grace Pavlath, PhD, Muscular Dystrophy Association</p> <p>Objectives: Review marketing plan and get Grace's feedback Determine ways the MDA can promote the award Gauge ability to partner in 2019</p> <p>Meeting Notes:</p>		

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## As of 9/7/2017

Solicitor					
Date	Start Time	Name/ID	Action Type	Action Priority	Detail
Category	End Time	Contact	Action Status	Action Progress	Proposal
<b>Suzi Sherman</b>					
9/5/2017	9:30AM	Alzheimer's Association	Solicitation	Normal	
Phone Call		Heather M. Snyder	Completed	Completed	2019 & 2020 CRTS Grants
	<p><b>Notes:</b> Attendees:            Suzi Sherman, ABF            Jane Ransom, ABF            John Morris, ABF RAC member            Heather Snyder, AA            Mary Gilli, AA</p> <p>Objectives:            Discuss change in award amount from \$130,000 to \$150,000            Gauge their ability to continue partnership, possibility of increasing support?            Introduce crowdfunding site</p> <p>Meeting Notes:</p>				
9/6/2017	2:30PM	Tourette Association of America	Stewardship	Normal	
Phone Call	3:30PM	Susan Young	Completed	Completed	2018 CRTS Grants
	<p><b>Notes:</b> Attendees:            Suzi Sherman, ABF            Kristin Roehl, AANI            Susan Young, TAA            John Miller, TAA            Amanda Talty, TAA</p> <p>Objectives:            Review ABF/AAN's marketing plan to promote the 2018 CRTS's in Tourettes and discuss TAA's marketing efforts            Also need to gauge their ability to partner again in 2019</p> <p>Meeting Notes:</p> <p>Amanda will also send information about their upcoming meeting and the ABF could have a table.</p>				
9/8/2017	9:00AM	Parkinson's Foundation	Solicitation	Normal	
Phone Call	9:30AM	James Beck	To-Do	Not Completed	2019 CRTS Grant

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Date	Start Time	Name/ID	Action Type	Action Priority	Detail
Category	End Time	Contact	Action Status	Action Progress	Proposal
<b>Suzi Sherman</b>					
		<p><b>Notes:</b> Attendees: Suzi Sherman, ABF Jane Ransom, ABF Lisa Shulman, ABF Board member James Beck, PF</p> <p>Objectives: Discuss 2019 CRTS partnership - increase from \$130,000 to \$150,000 Talk about crowdfunding site and how it can benefit the PF</p> <p>Meeting Notes:</p>			
9/8/2017	2:30PM	Pediatric Brain Tumor Foundation	Cultivation	Normal	(800) 253-6530
Phone Call	3:00PM	Joanne Salcido	To-Do	Not Completed	
		<p><b>Notes:</b> Attendees: Jane Ransom, ABF Suzi Sherman, ABF Joanne Salcido, PBTF</p> <p>Objectives: Discovery call to learn more about their research priorities Gauge interest in partnering to fund a CRTS in pediatric brain tumors Introduce crowdfunding site</p> <p>Meeting Notes:</p>			
9/11/2017	10:00AM	National Ataxia Foundation	Solicitation	Normal	
Phone Call	10:30AM	Sue Hagen	To-Do	Not Completed	2019 CRTS Grant

# Tickler Report

## As of 9/7/2017

Solicitor	Date	Start Time	Name/ID	Action Type	Action Priority	Detail
Category		End Time	Contact	Action Status	Action Progress	Proposal

### Suzi Sherman

**Notes:** Attendees:  
 Suzi Sherman, ABF  
 Jane Ransom, ABF  
 Lisa Shulman, MD, FAAN , ABF Board member  
 Sue Hagen, NAF  
 Joel Sutherland, NAF

Objectives:  
 Discuss changes to research program - increased from \$130,000 to \$150,000  
 Learn more about Joel's vision for their research program (took the ED position in 2016)  
 Gauge their ability to partner at \$100,000 level

Meeting Notes:

1 Solicitor(s) listed



## Crowdfunding Summary

### Projects live on the site:

1. Impact of immigration status on stroke
2. Improving concussion awareness
3. Virtual reality to improve stroke rehabilitation
4. A new approach to treating dementia
5. High-tech imaging of Alzheimer's brain
6. Reducing pain in breast cancer treatment
7. Detection of brain swelling
8. Treating childhood brain cancer

### Projects in the pipeline:

Approved, but waiting to receive requirements from researcher before posting on the site:

1. Genetics of familial gliomas
2. Human clinical trial to evaluate a novel combination of drugs to dramatically increase glioblastoma survival rates

LOI is approved, waiting for researcher to submit full application:

1. Teleneurology assessment program for Creutzfeldt-Jakob disease
2. Promoting remyelination to treat multiple sclerosis
3. A bid data approach to solve insomnia
4. Treating dizziness in athletes with concussion
5. GEMSTONE: Gastrointestinal microbiome and stroke outcomes network
6. Nociceptin system: a potential therapeutic target of opioid-seeking behavior and relapse in an adolescent rat model
7. Cannabidiol for the treatment of obesity
8. In vivo metabolic regulation in malignant brain tumors using <sup>13</sup>C isotopomer technology
9. Discovery of novel migraine therapeutic targets by single-cell RNA sequencing

## **Research Program Summary**

### Confirmed 2018 awards:

1. CRTS in Dementia with Lewy Bodies
2. CRTS in Headache
3. CRTS in Muscular Dystrophy
4. CRTS in Neuromuscular Disease
5. CSDA in Interventional Neurology
6. CSDA in Multiple Sclerosis
7. CRTS in Stroke
8. CRTS in Epilepsy
9. CRTS in Tourette's
10. CRTS in Tourette's
11. CRTS in Cognitive Aging and Age Related Memory Loss

## 12. CRTS in Cognitive Aging and Age Related Memory Loss

## Questions for X-Prize Development

A mega-donor calls the American Brain Foundation and says, "I would like to fund an X-Prize in Alzheimer's Disease, (or another brain disease). But before parting with a large sum of money (e.g., \$50 million), I have some questions. (Sample answers are shown in italics.)

- **How will you use my \$50M if I give it to you?**  
*Most of it will be the reward for the first team to cure or prevent Alzheimer's Disease. A portion will be used to seed projects with the most potential for success.*
  
- **How will we define "preventing or curing" a disease like Alzheimer's?**  
*The American Brain Foundation has convened a panel of the most acclaimed Alzheimer's and dementia researchers in the world, which has provided us with this definition: \_\_\_\_\_.*
  
- **What kind of guidelines would be announced about this X-Prize?**  
*The guidelines will contain the definition of "preventing or curing," as well as the rules for several stages of the competition, including:*
  - *Selection of a handful of the most promising-looking projects*
  - *Giving each of those project seed money of some kind*
  - *Judging teams coming forward to claim the prize*
  - *Awarding the prize*
  
- **Who would write the rules of the game, and who would judge whether a team was successful?**  
*The rules would be written by the Research Advisory Committee of the American Brain Foundation. The members of the Alzheimer's and dementia panel (convened by the ABF) would judge teams coming forward to claim the prize.*
  
- **Would we allow for-profits into the competition?**  
*Yes, within the bounds of the law, which would probably mean that the for-profit would need to show a charitable purpose.*