



AMERICAN BRAIN FOUNDATION

Research Advisory Committee

August 2, 2019

9:00 a.m. EST/ 8:00 a.m. CST/ 7:00 a.m. MST/ 6:00 a.m. PST

Call-in number: 866-740-1260

Access code: 9286317

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| Committee Members | Robert Griggs, MD, Chair; Raymond Roos, MD, Vice Chair; Carsten Bonnemann, MD; Jose E. Cavazos, MD; Merit Cudkowicz, MD; James Grotta, MD; Mark Mehler, MD; John Morris, MD; Ralph Sacco, MD; Ira Shoulson, MD; Eugene Scharf, MD; Sue Rodmyre; Natalia Rost, MD; Christy Phelps, Deputy ED AAN; Catherine Rydell, CAE; Phyllis C. Zee, MD |
| Staff | Jane Ransom, ED; Natalie Baumgartner, Lisa Deutsch |

| AGENDA ITEM | PRESENTED BY |
|---|------------------|
| 1. Review/approval of the March 22, 2019 minutes (pg. 2) | Dr. Griggs / RAC |
| 2. Chair's Report | |
| a. Research Program Breakfast debrief | Dr. Griggs |
| b. Commitment to Cures event | Jane Ransom |
| 3. LBD award update | Dr. Morris |
| 4. CRTS/CSDA program bias | Dr. Morris |
| 5. Targeting Research Awards to Regions or Institutions | Jane Ransom |
| 6. Cure One, Cure Many Award | Dr. Griggs |
| 7. ABF Status Update | Dr. Griggs |
| 8. CRTS / crowdfunding update (pg. 4) | Jane Ransom |
| Adjourn | |
| <p>Dr. Griggs asks committee members to review pg. 6 – 7 in the attached materials on these topics:</p> <ul style="list-style-type: none"> • 2021 CRTS/CSDA Renewals • Potential funders for CRTS and other research grants • AAN Industry Round Table | |



**American Brain Foundation
Research Advisory Committee Meeting
March 22, 2019**

**3:00 p.m. ET/ 2:00 p.m. CT/ 1:00 p.m. MT/ 12:00 p.m. PT
Conference Call**

Meeting Minutes

In attendance: Robert Griggs, MD, Chair; Jose Cavazos, MD; James Grotta, MD; Mark Mehler, MD; John Morris, MD; Ralph Sacco, MD; Ira Shoulson, MD; Phyllis Zee, MD

Staff: Jane Ransom, Suzi Johnson, Natalie Baumgartner

Excused: Raymond Roos, MD, Vice Chair; Carsten Bonnemann, MD; Merit Cudkowicz, MD; Christy Phelps, Deputy ED AAN; Sue Rodmyre, Director ED AAN; Natalia Rost, MD; Eugene Scharf, MD, Catherine Rydell, CAE

The meeting was called to order by Dr. Griggs at 2:00 pm CT. The meeting minutes of January 25, 2019 need edits and will be sent via email for digital approval by the Research Advisory Committee.

1. **Mendell Prize:** The Foundation has decided to give Dr. Mendell the Cure One, Cure Many award at Commitment to Cures on May 8, 2019, for his work in spinal muscular atrophy. Dr. Mendell's work is a great example of research's impact. There are over 100 other diseases that could be impacted directly by his research findings. Dr. Mendell will also be presenting during the spinal muscular atrophy section.

The RAC is encouraged to purchase their ticket to the Commitment to Cures event.

2. **Research Program Breakfast at Annual Meeting:** The Committee should RSVP to Ms. Johnson if they would like to attend the Research Program Breakfast on Tuesday, May 7 from 7:00 – 8:30 am. This is an opportunity to meet the funded CRTS/CSDA researchers and learn about their project. Ms. Johnson will be preparing a document about the 2019 awardees and asks that the RAC members come prepared to ask questions after each presentation.

This is the first time that the Committee has been invited to attend the Research Program Breakfast. The Foundation's funding partners and AAN leadership will also be in attendance.

Ms. Johnson will send another email reminder with information on Commitment to Cures and the Research Program Breakfast.

3. **Section Presentations at Annual Meeting:** If possible, RAC members should attend section meetings to promote the Foundation's research program. There are several

awards that have not received as many applications, such as the ALS awards, neuromuscular, and Tourette's. It would be great to boost the interest in these awards for the 2020 round of applications.

Ms. Johnson will provide promotional materials and schedule calls with volunteers to discuss talking points.

Adjourn 2:16 p.m. (Central).

DRAFT



**AMERICAN
BRAIN
FOUNDATION**

TO: American Brain Foundation Research Advisory Committee

FROM: Jane Ransom, Executive Director & Natalie Baumgartner, Executive Coordinator

DATE: July 25, 2019

SUBJECT: Research Program Summary to Date

Dear Research Advisory Committee,

Below is a summary of the progress for the research program as of July 25, 2019. Jane and I request you review the following items for discussion and feedback at the August 2 Research Advisory Committee Meeting:

- 2021 CRTS/CSDA Renewals
- Potential funders for CRTS and other research grants
- AAN Industry Round Table

Thank you,
Natalie



Crowdfunding Summary

- I. There have been no changes in the Crowdfunding site since the last meeting, but the Foundation is going to build a Crowdfunding campaign around Tourette's Awareness Month. The campaign will include a patient story of high school sophomore, Zoe Koep, and highlight the research of Dr. Jennifer Vermilion, recipient of the 2019 CRTS in Tourette's.

Research Program Summary

I. Confirmed 2019 awards:

1. CRTS in Cognitive Aging and Age-Related Memory Loss
2. CRTS in Cognitive Aging and Age-Related Memory Loss
3. CRTS in Stroke (AHA)
4. CSDA in Myasthenia Gravis
5. CRTS in Epilepsy
6. CRTS in Alzheimer's
7. CRTS in Parkinson's disease
8. CRTS in Parkinson's disease
9. CRTS in Multiple Sclerosis
10. CRTS in Headache
11. CRTS in ALS
12. CSDA in ALS
13. CSDA in Multiple Sclerosis (NMSS)
14. CSDA in Interventional Neurology (SVIN)
15. CRTS in Tourette's
16. CRTS in Neuromuscular disease

II. Confirmed 2020 awards:

1. CRTS in Alzheimer's
2. CRTS in Cognitive Aging and Age-Related Memory Loss
3. CRTS in Cognitive Aging and Age-Related Memory Loss
4. CRTS in Parkinson's disease
5. CRTS in ALS
6. CSDA in ALS
7. CRTS in LBD
8. CRTS in Epilepsy
9. CRTS in Stroke (with AHA) – AHA will be charging the ABF an 8% administrative



- fee for all awards moving forward
10. CSDA in Multiple Sclerosis (NMSS)
 11. CRTS in Neuromuscular disease
 12. CRTS in Tourette
- III. **Confirmed 2021 awards:**
1. CRTS in Cognitive Aging and Age-Related Memory Loss
 2. CRTS in Cognitive Aging and Age-Related Memory Loss
 3. CRTS in Parkinson's disease
 4. CRTS in Stroke (with AHA) – AHA will be charging the ABF an 8% administrative fee for all awards moving forward
- IV. **2021 (and beyond) award renewals:** The Foundation is currently engaging 2020 partners with the following organizations to continue our relationship in funding CRTS/CSDA's. If you know of anyone at these organizations or would like to support the Foundation in these calls, please let us know.
1. ALS Association for 2021 for CRTS & CSDA in ALS
 2. Alzheimer's Association for 2021 CRTS in Alzheimer's & Dementia
 3. American Epilepsy Society for the 2021 CRTS in Epilepsy
 4. Epilepsy Foundation for the 2021 CRTS in Epilepsy
 5. American Heart Association for the 2022 CRTS in Stroke
 6. Muscle Study Group for the 2021 CRTS in Neuromuscular disease
 7. Myasthenia Gravis Foundation of America for the 2022 CSDA in Myasthenia Gravis
 8. National Multiple Sclerosis Society for the 2021 CSDA in Multiple Sclerosis
 9. Tourette Association of America for the 2021 CRTS in Tourette Syndrome
 10. Muscular Dystrophy Association for a CRTS in Muscular Dystrophy
- V. **Other potential funders:** We are asking the following funders for CRTS funding with AAN permission, please let us know if you have contacts at either of these pharmaceutical companies:
1. van Ameringen Foundation, Inc.
 2. Allergan Foundation
 3. If you have suggestions of other organizations or pharmaceutical companies the Foundation should approach, please let us know.
 - i. The AAN requests that the Foundation avoid approaching Industry Round Table Members, which includes:
 1. Abbvie
 2. Acadia Pharmaceuticals



3. Acorda Therapeutics
4. Amgen
5. Avexis
6. Biogen
7. Celgene
8. Eisai
9. EMD Serono
10. Genentech
11. Greenwich Biosciences
12. Lilly
13. Lundbeck
14. Neurocrine Biosciences
15. Novartis
16. Sanofi Genzyme
17. Sunovion
18. Supernus Pharmaceuticals
19. TEVA
20. Avanir Pharmaceuticals, Inc.
21. Mitsubishi Tanabe Pharma America, Inc.
22. Adamas Pharmaceuticals, Inc.
23. Akcea Therapeutics
24. Alder BioPharmaceuticals, Inc.
25. Allergan, Inc.
26. Amneal Specialty, a division of Amneal Pharmaceuticals LLC
27. CSL Behring
28. IPSEN Biopharmaceuticals Inc.
29. Medtronic, Inc.
30. Merck & Co., Inc.
31. SK life science, a subsidiary of SK biopharmaceuticals
32. Alexion Pharmaceuticals, Inc.
33. Neurelis, Inc.
34. Ovid Therapeutics
35. Philips
36. Viela Bio