



alzheimer's  association\*

**Professional Interest Area:**  
*Down Syndrome and Alzheimer's Disease*

*Monday, October 19, 2015*  
*Chicago, United States: 7 - 8 p.m. CDT*

Hyatt Regency Downtown  
151 E. Wacker Dr., Plaza Ballroom AB  
Chicago, Ill., United States

### Meeting Summary

#### I. **Roll Call**

Melisa Alldred  
Helen Chao  
Jean Delabar  
Maria del Carmen Cardenas-Aguayo  
Eric Duran (Ira Lott)  
Stephen Ginsberg  
Lotta Granholm  
Michael Harpold  
Dean Hartley  
Florence Iulida

Matt Janicky  
Florence Lai  
Cindy Lemere  
Christopher Williams

#### **Association Staff:**

Keith Fargo  
Megan Mitchell  
Yumeka Brown  
Heidi Jurgens

#### II. **Update on election results and membership numbers** **2015-2016 Executive Committee Members**

**Chair:** Cindy Lemere  
**Chair-Elect\*:** Elliott Mufson  
**Past Chair:** Lotta Granholm  
**Program Director\*:** Elizabeth Head  
**Communications Director\*:** Jill Rasmussen  
**Secretary\*:** Juan Fortea  
**Secretary Elect\*:** M. Florencia Lulita

**Treasurer\*:** Bill Mobley  
**Treasurer-Elect\*:** Peter Paul de Deyn  
**Council Member:** Ira Lot  
**Council Member:** Wayne Silverman  
**Council Member:** Claudio Cuello  
**Council Member\*:** Jean Delabar  
**Council Member\*:** Marwan Sabbagh  
**Council Member\*:** Mary Sano

\*Newly elected (DS-AD PIA Membership has grown to 225 members from 28 countries).

#### III. **Brief overview of the May Workshop** - Dean Hartley and Cindy Lemere

Dean Hartley described the outcome of the workshop, and mentioned that the Neuropathology group has moved forward with distinct results since the workshop. The 5 work groups will continue to work on their respective areas, and will be contacted regularly to ensure success. We need to start sharing the resulting information and materials: Write a white paper? How do we move the groups along? Use the outlines and contact the groups again. Flo Lai mentioned the results from the workgroup (Intervention/Prevention Committee) meeting at the 2015 AAIC in Washington DC. **A document was sent out and can be shared via Dropbox with all members of the PIA.**

**IV. DSAD RFA results and a discussion to help promote funding of those who were not funded**

Two grants were awarded: 1. focusing on imaging from Ben Handen (PA), Marwan Sabbagh (AZ) and Brad Christian (WI), and 2. Another focusing on biomarkers and clinical/cognitive changes from Nicole Schupt (NY), Florence Lai (MA), Wayne Silverman (MD) and Ira Lott (CA). The two awards have been changed to a U01 award and are merged to ensure contingency of the research and clinical outcomes. We will approach NIH to see if there is funding for the neuropathology and brain banking portion of the network.

**V. DSAD Biorepository: Common protocols, sharing samples, DS Connect, NCRAD, DS Achieves**

Michael Harpold said he has ideas about what we are looking at, it has to be sustained, sustainable funding, what do we want; what is the estimate etc. what are the costs per site? He suggested that a consensus information package could be developed by the PIA regarding brain donations and biobanking, to send out to families and distributed via the DS organizations. Action item: training sessions how to approach families, can we give the same information to all sites? The University of Maryland brain bank has a pre-registration for brain donation, such that only registered members are allowed to donate their brains. We need to work with DS Connect and make sure information goes out to: Neurobiobanks, to families, to researchers etc. Neurobiobanks do not always collect tissue in the way that benefits current research protocols and do not always have meaningful cognitive and clinical data attached to donors. Discussion between ADNI vs. ADCC protocols: Elliott Mufson commented that they are very different, and that tissues are sometimes treated too harshly and do not receive the best fixation protocol. Action item: Come up with consensus.

**VI. DS presentations at SFN**

Cindy Lemere and Lotta Granholm provided a meeting planner including SFN presentations directly related to Down syndrome.

**VII. Upcoming Event**

[Keystone Symposium – Biology of Down Syndrome: Impacts Across the Biomedical Spectrum](#)

January 24-27, 2016

Sante Fe, New Mexico

**VIII. FRS proposal - AAIC Toronto 2016**

A suggestion was made that Flo Lai and others in the Intervention/Prevention subcommittee could organize a Featured Research Symposium (FRS) proposal for the next AAIC meeting in Toronto in July 2016. The FRSs host 4 speakers, and are 90 minutes long. We should submit at least two of these as they are highly competitive. Flo Lai said she would consider organizing such a session. The deadline is early February, 2016. If PIA members are interested in submitting an FRS via the PIA, please contact the Program director (Liz Head) or the Communications Director (Jill Rasmussen) via the PIA office (Yumeka Brown).

**IX. Updates from any/all subcommittees (subcommittee members are welcome to provide updates)**

Dean Hartley reported from the PIA telephone meeting with NCRAD (National Cell Repository for Alzheimer's disease). The National Institutes on Aging (NIA) has asked NCRAD to add a DS

segment. NCRAD needs to have a funding mechanism (PIA members can include NCRAD in future grant applications) in order to include blood samples to plug in together. A question was raised whether we can include the NCRAD storefront software also for brain bank tissue requests and distribution. We need to include NCRAD in future grant applications. Keith and Dean commented that the National Alzheimer Association can help investigators in terms of including NCRAD in future applications, and how to connect with NCRAD and other programs.

## **X. Adjourn**

### **Action Items:**

- A. Send out the committee report from Flo Lai via Drop Box to all PIA members; ask them to join the subcommittee.
- B. FRS for next AAIC meeting: Intervention/Prevention session? Ask Flo Lai: Request additional FRS topic nominations.
- C. Implement a job market site that will be shared with T21 org as well for postdocs and students/faculty.
- D. Include NCRAD in future applications and make sure our protocols cohere with NCRAD protocols.