

## Down Syndrome and Alzheimer's Disease PIA Business Meeting Summary

**Location:** ExCel London (Platinum Suite 3)

**Date:** Saturday, July 15, 2017

**Time:** 11 a.m. - 12 p.m.

**PIA Chair(s)/Meeting  
Facilitator(s):** Donna Wilcock

### **I. Welcome and Introductions**

- Our membership number has increased from 300 to 331 participants.
- We have increased international representation on the DS-AD PIA Executive Committee

### **II. DS PIA Annual Report**

- Multiple members of the DS-AD PIA submitted grant proposals in response to the NIH R01 RFA regarding Exosomes in AD and people with DS (e.g. Lotta and Elliott, PIs).
- Members of the DS PIA published several manuscripts during the last year.
- SFN San Diego, 2016: over 40 DS-related abstracts were present on DS.
- Bill Mobley organized a DS symposium at UCSD during the SFN meeting. DS-PIA members from the USA and Europe presented interesting short talks.
- PIA members gathered at the TR21 International meeting in Chicago, USA to discuss various topics with a day dedicated to AD in DS. The next meeting will be in Barcelona, Spain in 2019. We encourage PIA members to join the T21Rs society (<http://www.t21rs.org/>).
- The Ts21R international meeting attracted over 30 members with interests in DS research:

<b>Ann</b>	<b>Baburamani</b>	<b>Kings College of London</b>
<b>mary</b>	Rutherford	King's College of London
<b>Pablo</b>	Caviedes	University of Chile
<b>Antonia</b>	Coppus	Radboud University Medical Center, Netherlands
<b>Peter</b>	De Deyn	University Medical Center Groningen, Netherlands
<b>Alain</b>	Dekker	Univ. Medical Center Groningen, Netherlands
<b>Jean Maurice</b>	Delabar	CNRS-ICM, Paris
<b>Lisi</b>	Flores Aguilar	McGill, Montreal
<b>Juan</b>	Fortea	Fundacio Catalana Syndrome de Down Hospital Sant Pau, Barcelona
<b>Benjamin</b>	Handen	Univ Pittsburgh School of Medicine
<b>Elizabeth</b>	Head	University of Kentucky
<b>Florencia</b>	Iulita	University de Montreal
<b>Sharon</b>	Krinsky-McHale	NY State Institute for Basic Res in Devel Disabilities
<b>Florence</b>	Lai	Massachusetts General Hospital, Boston
<b>Joseph</b>	Lee	Columbia University NY
<b>William</b>	Mobley	UC San Diego, San Diego
<b>Melissa</b>	Parisis	NICHD
<b>Huntington</b>	Potter	UC Anschutz, Denver
<b>Angela</b>	Rachubinski	University of Colorado
<b>Diana</b>	Rosas	Mass Gen/Harvard, Boston
<b>Wayne</b>	Silverman	Kennedy Krieger Institute; Johns Hopkins, Baltimore
<b>Andre</b>	Strydom	Univ College of London
<b>Christopher</b>	William	NYU School of Medicine, NY
<b>Lotta</b>	Granholt	University of Denver
<b>Elliott</b>	Mufson	Barrow Neurological Institute, Arizona
<b>Cindy</b>	Lemere	Brigham & Women's Hospital and Harvard Medical School, Boston
<b>Ira</b>	Lotta	UC Irvine
<b>Bill</b>	Mobley	UC San Diego, San Diego
<b>Michael</b>	Rafii	UC San Diego, San Diego

- A submeeting was arranged at the TS21r meeting by Lotta Granholm to discuss brain banking approaches with a new email list being created to continue these discussions.

### **III. Current Goals of the PIA:**

- Organize subcommittee conference calls to:
  - Continue discussions of building a brain tissue repository/bank
  - Generating harmonized protocols for minimal cognitive assessment, brain donation and processing with international partners.
  - Identify ADRCs and NIH Neurobiobanks who have the capability to collect tissues from DS.
  - Determine how to disseminate tissues and data.
- Identify a forum for communication (for example portals through DSConnect or Ts21R Society websites)
- Publish newsletters for our PIA
- Recruit more members to the PIA

#### **IV. New Business/Other discussions**

- We discussed drafting up position papers including topics such as:
  - Co-occurring illnesses, aging and dementia in DS
  - Barriers to participation in research
  - Juan Fortea noted that at a meeting in Chicago hosted by the Alzheimer Association in partnership with the Global Down syndrome groups, several workgroups were focused on drafting up position papers – follow up with Dean Hartley

#### **V. DS-AD PIA Executive Committee 2017-2018**

- We will hold elections via electronic ballot in fall of 2017
- We will ask for nominations for the following members indicated by asterisks – please volunteer or nominate a colleague!
  - Chair: Elizabeth Head
  - Chair-Elect: TBD
  - Past Chair: Elliott Mufson
  - Program Director: Donna Wilcock
  - Communications Director:
  - Secretary:
  - Secretary Elect:
  - Treasurer:
  - Treasurer-Elect:
  - Council Member:
  - Council Member:
  - Council Member:
  - Council Member:
  - Council Member:

#### **VI. Future Meeting:**

AAIC 2018 – Chicago Illinois, USA  
July 21-July 26, 2018