Atypical Alzheimer's disease and Associated Syndromes PIA Business Meeting Summary

Location: Novotel Hotel, Room: London II

Date: Wednesday, July 19, 2017

Time: 7 - 8 a.m.

PIA Chair(s)/Meeting Facilitator(s): Melissa Murray

Attendees:
- Dean Harley
- Baayla Boon
- Jeroen Hoozemans
- Victoria Pelak
- Melissa Murray
- Rik Vanderberghe
- A new individual that I did not recognize

Introductions were made.

Future requests to Alzheimer’s Association:
- Email by specific individual Alz Assoc representative to perhaps overcome issue of emails not received
- Business meeting in 2018
  - 6 pm
  - Lunch

PCA support:
- Goal was family support
- Victoria provided summary
- Jon and Seb gave updates on research
- 70-80 people attended
- Videoconference
- Future plans for PCA 2018
  - Discussion regarding another PCA support in Chicago
  - Need to identify a local group to help with logistics
  - Janette Youngouse (spelling?) was suggested to help as coordinator
Major points of discussion:
- Considerations for dovetailing with imaging
- Featured Research Symposium (FRS)
- PCA replication (Schott)
- Atypical AD website
  - Who to contact?
- Management “post diagnosis”
  - Compensatory mechanism
  - Therapeutics
  - Non-drug options
  - “What are you doing?”

Goals:
1. What do clinicians/caregivers do regarding atypical AD diagnosis?
2. Communication website
3. White paper
4. Featured Research Symposium (FRS)