

**DEMENTIA IN INTELLECTUAL DISABILITIES
SPECIAL INTEREST GROUP**

Minutes 12th February 2016

No	Item	Action
1.0	<p>Present: Andre Strydom, Richard Hillier, Cerne Felstead, Dawn Butt, Ken Courtenay, Rory Sheehan, Rupal Patel, Sheetal Gopal, Sophie Langford, Swapnil Palod, Yasmin Bandali, Stephano Kustermann, Helen Behlens, Daniele Parker</p>	
2.0	<p>Apologies: Stuart Todd, Caroline Bartle, Marie Houston, Clare Farelly, Steph Hovey, Sherry Forchione, Steve Stirk, Suzanne Wilson</p>	
3.0	<p>Presentations:</p> <p>Tamara Al Janabi:</p> <ul style="list-style-type: none"> • Tumour suppressor genes Aβ and Chr21 <p>Dr Rupal Patel and Dr Richard Hillier:</p> <ul style="list-style-type: none"> • Case based discussion workshop on a Fronto-Temporal Dementia case. 	
4.0	<p>Minutes 16th October 2015:</p> <p>Approved. Proposed by Dr. Rupal Patel, seconded by Dr Ken Courtenay.</p>	
5.0	<p>Matters Arising:</p> <p>We discussed that the case presentation format allows for more open discussion and it was suggested that we do more case presentations in future. This was approved by those present. We could conduct a Doodle Poll of members to see if this were desirable, or we could ask again at the next few meetings if this is still thought to be a good idea.</p>	
6.0	<p>Research:</p> <p>The LonDowns Project continue to recruit people under 30. There were crossed wired recently when a school told potential recruits that the project was not recruiting between 16 and 18 years. This is not the case and this group is included in the study. Contact: a.strydom@ucl.ac.uk</p> <p>Daniel Herron from Keele is recruiting for a study entitled: "People with intellectual disabilities and dementia: Exploring holistic care and support". - The aim of the research is to explore the experiences of people with ID and dementia, and carers (both family and paid carers). Contact: d.l.herron@keele.ac.uk</p> <p>Dr Afia Ali is looking into the feasibility of a "Randomised</p>	

	Controlled Trial on Individual Cognitive Stimulation Therapy on People with Dementia and Learning Disabilities”. She will be presenting to us at a future meeting. Contact: afia.ali@ucl.ac.uk	
7.0	Upcoming Conferences: The 31 st Conference of Alzheimer’s Disease International is in Budapest 21 st to 24 th April 2016. http://www.adi2016.org/index.php The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) is in Melbourne, August 14 th to August 19 th , 2016. https://www.iassidd.org/conference/index.php/HPC/IWC The 11th European Congress of Mental Health in Intellectual Disabilities will be in Luxembourg on 21 st -23 rd September 2017. http://www.eamhid.lu/index.php	
8.0	A.O.B. We are thinking about setting up a website where resources for Dementia in Intellectual Disability can be collected. Tamara Al-Janabi will look at options with the UCL IT Dept. The Meeting Venue may be booked late as booking UCL rooms is becoming more difficult – Richard Hillier will inform as soon as a room is confirmed. The OT Dementia Toolkit that Dawn Butt mentioned is here: http://www.cot.co.uk/living-well-care-homes	Tamara Al-Janabi, Andre Strydom, Richard Hillier Tommy Coyle, Richard Hillier
9.0	Topics future meetings: 1. Cognitive Stimulation Therapy Study – Dr Afia Ali 2. Music Therapy in Dementia 3. Dementia Cafe - Alzheimer’s Disease Society 4. ‘Singing for the Brain’ - ? email Chris Eastwood 5. Genetics in Alzheimer’s Disease (John Hardy) 6. Involving GPS’s in Dementia Screening (Gill Rasmussen) 7. Looking towards ICD 11 in the light of DSM V 8. <i>A Palliative Care Pathway in Dementia</i> – Daniel Heron, Irene Tafney 9. Nutrition and Dementia –runs as a workshop 10. Working with Challenge – Trish O’Hara, Caroline Bartle Workshop on sharing Dementia Care Pathways Danielle Parker, Richard Hillier	R Hillier to approach speakers
10.0	Next Meeting: Day and Date: Friday 10 th June 2016 Venue: TBC	A Strydom, R Hillier T Coyle – room booking