



# Challenging Childhood Dementia Symposium

March 1 2022  
Fishburners, Sydney

**PROGRAM**

**childhood  
dementia**  
INITIATIVE

## Morning presentations

- 0900 Welcome**  
Tiffany Boughtwood, Managing Director, Australian Genomics and Director, Childhood Dementia Initiative
- 0905 Why we are here: the family perspective**  
Gail Hilton, Head of Programs - Care & Quality of Life, Childhood Dementia Initiative
- 0915 The Childhood Dementia Initiative**  
Megan Donnell, Founder and Director of Childhood Dementia Initiative

### Session 1 Early diagnosis and intervention

**Session chair - Professor John Christodoulou, the Murdoch Children's Research Institute and the University of Melbourne**

- 0925 Introduction**
- 0930 Childhood dementia - a window of opportunity**  
Dr Nick Smith, Women's and Children's Health Network, South Australia.
- 0950 CLN5 Batten disease: from sheep to bedside**  
Dr Nadia Mitchell, Lincoln University, New Zealand
- 1010 Patient-customized oligonucleotide therapy for rare genetic diseases**  
Assistant Professor Jinkuk Kim, Korea Advanced Institute of Science and Technology
- 1030 Session questions**
- 1045 Morning break**  
15 minutes

### Session 2 Panel Session - Research Funding

**Session chair - Professor Peter Schofield, University of NSW and Neuroscience Research Australia (NeuRA)**

- 1100 Research funders discuss and respond to questions on funding for childhood dementia research.**  
Panel members: , Dr Lisa Melton (Sanfilippo Children's Foundation), Dr Ineka Whiteman (Batten Disease Support and Research Association Australia and Mito Foundation), Dr Kaele Stokes (Dementia Australia) and TBC (Australian Government Department of Health).

### Session 3 Extending research on one disorder to multiple

**Session Chair - Professor Kim Hemsley, Flinders University**

- 1135 Introduction**
- 1140 Breaking Down Batten Disease - iPSC modelling of a childhood dementia**  
Associate Professor Anthony Cook, University of Tasmania

- 1200 mRNA: a new weapon to fight rare genetic diseases**  
Dr Ya Hui Hung, Florey Institute of Neuroscience and Mental Health
- 1220 Pre-clinical treatments for Lafora disease - a childhood dementia driven by perturbed metabolism**  
Professor Matthew Gentry, University of Kentucky
- 1240 Session questions**
- 1255 Symposium close**  
Tiffany Boughtwood
- 1300 Lunch break**  
45 minutes

## Afternoon workshops

The aim of these workshops is to increase the treatment options for children with dementia, including experimental treatments in trials. The workshops will prioritise activities and infrastructure needed and build teams to take action.

An experienced facilitator will guide these workshops. Participants will break out into small multidisciplinary groups of ~6. Each group should have at least one clinician, bench researcher, Early Career Researcher, industry representative and patient representative.

- 1345 Workshop 1**  
Addressing the barriers to developing new treatments
- 1515 Afternoon break**  
15 minutes
- 1530 Workshop 2**  
Increasing the number of (high quality) trials for childhood dementia in Australia
- 1700 Wrap up and actions**  
30 minutes



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