

**Down Syndrome NSW Health Conference, 27 September 2019**

# **Down Syndrome and Dementia – lessons from IASSIDD**

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## Important issues:

- ❑ **The need for regular reviews/health checks**
- ❑ **Development of bio-markers**
- ❑ **Research**
- ❑ **NDIS - understanding of dementia amongst people with Down Syndrome**

## REGULAR REVIEWS

**Antonia Coppus, IASSIDD 2016 – Center for IDs, Gennep, The Netherlands**

- **Every person with DS is reviewed annually – when did most adults with DS in Australia last have a full review?**
- **Physical, medical and cognitive assessments**
- **Estimates that 98% of people with DS will have Alzheimer's by the time of their death**
- **Some have very late onset, in their 70s-80s**
- **Researching the 2% who do NOT develop Alzheimer's**
- **Early onset is related to the risk factors already outlined by Liz and Julian**

**Professor Anthony Holland, Cambridge Intellectual and Developmental Disabilities Research Group, IASSIDD 2019 – “How an understanding of biology can be a force for good in meeting the needs of people with intellectual and developmental disabilities”**

Investigating biomarkers because neuropathology associated with DS starts years before dementia manifests

These proxy markers for AD are important if preventative treatments are to be evaluated

Plasma, cerebrospinal fluid, detectable changes in the eye – require further research

Neuroimaging investigations (e.g. MRI, PET) – promising, but AD is already advanced when changes can be detected

EEG – potential tool for early detection and monitoring of AD in DS

## **Research –**

### **Horizon 21 Down Syndrome Consortium in Europe**

UK - the London Down Syndrome Consortium [LonDownS] and the Cambridge Dementia in Down's Syndrome [DiDS] cohort

Netherlands, Germany, France, Spain

Focused on delivering essential data on clinical progression of the early stages of AD in DS, while developing a clinical trials network.

Cooperation enables larger sample sizes

## **NHMRC –**

Boosting Dementia Research initiative - \$200 million over 5 years

No projects regarding DS could be located for 2019 funding round

**In the US – the National Institute on Aging, Alzheimer’s Biomarkers Consortium – Down Syndrome (ABC-DS)**

**\$46 million in funding**

**11 sites, including Cambridge**

# **NDIS - understanding of dementia amongst people with Down Syndrome**

**Limited understanding of DS, let alone AD and DS**

**Lack of knowledge about AD-specific preventative interventions**

**Inadequate recognition of the need for special programmes and therapeutic interventions**

**Possible shuttle back and forth between NDIS and Medicare**

**"They always say time changes things, but you actually have to change them yourself."**

— Andy Warhol