

The Changing Landscape of Care for Adults with Down Syndrome at Risk for Alzheimer's Disease: Preparing for Improvements in Diagnostic Assessments, Biomarkers, and Medical Therapeutics

An ICW Event Organized by the National Task Group on Intellectual Disabilities and Dementia Practices and the LuMind IDSC Foundation

Adults with intellectual disabilities, including those with Down syndrome, are living longer and consequently are more at risk for aging-associated neuropathologies. These risks include aging-related decline as well as the onset of dementia -- especially for adults with Down syndrome (due to their inherent genetic propensity in an over production of beta amyloid). The National Task Group on Intellectual Disabilities and Dementia Practices (NTG), the AAN's Section on Adults with Intellectual and Developmental Disabilities, and the LuMind IDSC Foundation have organized an 'In Conjunction With' (ICW) event to discuss a variety of current issues related to diagnostics and treatment. This event will occur on Tuesday April 25th, 2023, during the annual meeting of the American Academy of Neurology (AAN) in Boston, Massachusetts..

The focus of the discussions will be viable current and future clinical assessment and care practices of adults with intellectual disabilities suspected or diagnosed with Alzheimer's disease and other forms of dementia. Important areas and concerns of assessments, diagnostics, biomarkers, and medical research will be on the table. Of particular interest is recognizing signals of early symptoms prior to overt presentation of classic symptoms, the implications of newly FDA approved therapeutics, and options for recommending changes in State prescribing criteria related to measuring presence of mild cognitive impairment and early-stage dementia in anticipation of being eligible to receive the FDA approved or forthcoming Alzheimer's drugs.

The aim is to frame a 'steps-forward' approach and strategic plan to how to best prepare and plan for prescribing access to new medications, and education, training, and awareness related to this group of adults affected by Alzheimer's disease and 'related dementias', and defining post-diagnostic supports particular to the work of neurologists and other relevant healthcare providers. We anticipate producing a statement that will represent the notions discussed and be made available to the AAN and other stakeholders.

Organizer: Seth M. Keller, MD. [sethkeller@aol.com]

Support: Underwriting is provided by the Butz Family Aging Research Fund

Date/Time: Tuesday April 25, 2023,
2:30pm – 6:00pm ET
Boston, Massachusetts

Location: Element Seaport Boston
Meeting Room A and B
391-395 D Street
Boston, Massachusetts 02210
(Adjacent to the Boston Convention Center)

Virtual: Join Zoom Meeting
<https://us02web.zoom.us/j/81261117170?pwd=ellqSWRGbndGU284RIVBdkZFTXJyUT09>
Meeting ID: 812 6111 7170
Passcode: 383016

Agenda

2:30 - 2:40 pm **Introductions**

2:40 – 2:50 pm **Statement of Goals and Scope of Meeting (S. Keller)**

Discussion around neurological bases for older age neuropathologies in adults with intellectual disability and in those with Down syndrome; Place on the table various perceptions of the conditions, and suggestions for assessment and use of therapeutics; Arrive at a general statement of concern and needs for further activities and actions.

2:50 – 3:10 pm **Assessments: Informant Based vs Neurocognitive Tests**

Current clinical assessment tools are not often applicable for those with ID/DS to help make a diagnosis of MCI/dementia. What is the current and future status of these tools to help with this as well as to track changes after the diagnosis is made?

3:10 – 3:30 pm **Diagnostics/Biomarkers**

Biomarkers will soon be available to help make diagnoses of ADRDs, possibly before clinical symptoms begin. What is the status of this and how will this impact upon their usage by all involved in their care and support?

3:30 – 4:10 pm **Alzheimer's Disease Research DS/IDD Updates (H. Hillstrom)**

Anti-amyloid therapeutics for the treatment of AD are now available and more will be developed in the future. The research has not yet shown the safety and clinical benefit to adults with DS. What is the current impact and what will be the impact over the next years?

4:10 – 4:20pm **Break**

4:20 – 4:40pm **Wellness and Health Promotion**

Research has shown that health and wellness may be able to mitigate cognitive dysfunction and dementia. How can this information be used effectively to help promote brain health and mitigate development of brain conditions leading to dementia?

4:40 – 5:00pm **Providing Updates to IDD/DS Networks**

What messaging should be done now to prepare the networks of what's coming next, including the training of HCP's?

5:00 – 6:00 pm **Synthesis, Statement & Next Steps**

6:00pm **Adjourn**

Attendees (others pending):

Liana Apostolova	Neurologist, AD Research, Indiana University
Kendra Croker	Neuroscience Medical Science Liaison, Lilly
Lucy Esralew	Geriatric Neuropsychology, California DDS/NTG
Richard Fisher	Chief Scientific Officer, LuMind IDSC Foundation
Forrest Foster	Neurologist, University of Cincinnati
Maureen Gallagher	Exec Dir, Mass Down Syndrome Congress
Hampus Hillerstrom	President, LuMind IDSC Foundation
Tom Hubbard	Sr VP for Policy Research, NEHI
Matthew Janicki	NTG/University of Illinois Chicago
Joseph Jeret	Neurologist (NY)
Seth Keller	NTG/AAN/AADMD
Florence Lai	Neurologist, Mass General
Philip McCallion	Aging Center, Temple University, NTG
Julie Moran	DS geriatrician, Harvard Medical
Steve Perlman	AADMD, Special Care Dentistry Special Olympics
Kandi Pickard	CEO, National Down Syndrome Society
Daniel Press	Chief, Cognitive Neurology, Harvard Medical School
Margot Rhondeau	Sr Dir, Health & Wellness, NDSS Washington DC
Jessi Solomon Sanders	Neurodevelopmental Disabilities, Denver, CO
Kathy Service	NTG/Mass DDS (ret.)
Jo Ann Simons	Ex Dir, Arc Northeast
Brian Skotko	Mass General DS Clinic
Heather Snyder	VP, Medical/Scientific Relations, Alzheimer's Association