

June 1, 2023

FOR IMMEDIATE RELEASE

Contact: Kate O'Neill, LuMind IDSC 508.344.4932 koneill@lumindidsc.org
Kathryn Pears, NTG 843-503-5072 KathrynPears@the-ntg.org

Expert panel calls for policy changes to urgently address inequitable access to Alzheimer's drugs for adults with Down syndrome

BURLINGTON, MA – Seeking to rectify existing federal and state policies which prevent people with intellectual disabilities from accessing new therapies for Alzheimer's disease, a group of international experts are calling for modification of "prior authorization" criteria to address inequitable access to anti-amyloid drugs for people with Down syndrome (DS).

The expert panel was convened by the LuMind IDSC Foundation (LuMind IDSC) and the National Task Group on Intellectual Disabilities and Dementia Practices (The NTG) and is comprised of 20 clinicians and researchers from the U.S., U.K, France, Germany, Ireland, Spain, and Sweden who specialize in Down syndrome and/or Alzheimer's disease.

The expert panel's consensus statement urges public and private payers at state and federal levels, including the U.S. Centers for Medicaid and Medicare, to modify their prescription criteria to be more inclusive of people with Down syndrome. The statement includes concrete steps for adapting policies so adults with Down syndrome can be prescribed FDA-approved Alzheimer's anti-amyloid drugs, including: lowering the age of eligibility, adapting assessments scales, and not excluding population-specific co-occurring conditions.

People with Down syndrome have a 90% risk of developing Alzheimer's disease, and on average they receive their diagnosis at age 54, decades before the general population. Alzheimer's disease currently leads to 70-80% of deaths in adults with Down syndrome.

"The devastating prevalence of early onset Alzheimer's disease among people with Down syndrome makes access to new therapies a moral imperative," Hampus Hillerstrom said. "The Down syndrome community needs all stakeholders to address this situation with the urgency it deserves, so that adults with Down syndrome are no longer excluded from clinical trials or from treatment access." Hampus is the President & CEO of LuMind IDSC, a national nonprofit organization committed to accelerating Down syndrome research.

The experts' consensus statement urges the government and other payers to adopt the proposed DS-focused equivalency criteria as soon as possible and recommends initiation of Phase 4 safety clinical trials specifically for adults with DS.

The consensus statement also recommends policymakers enact "wording changes to reflect equivalencies in the prescribing criteria," and offers substantiation for such changes. The group calls upon relevant organizations to provide education to prescribers, and for professional associations to issue protocols for guiding prescribers in the use of anti-amyloid drugs with people with Down syndrome.

“People with intellectual disabilities are currently prevented from accessing this class of effective drugs, but that exclusion is a fixable problem,” Dr. Matthew P. Janicki said. Dr. Janicki is co-president of the board of directors of the NTG, a U.S.-based advocacy organization that provides services and resources to people who have both intellectual disabilities and dementia.

“What the expert panel has produced is a road map to equitable access to people with Down syndrome who are at a very high-risk of developing Alzheimer’s dementia.”

Following the release of the consensus statement, members of the expert panel plan to meet with key policymakers to further explain and advocate for the necessary changes that will bring equity to people with Down syndrome and other intellectual disabilities.



The National Task Group on Intellectual Disabilities and Dementia Practices (The NTG) is a 501 (c)-3 organization charged with ensuring that the interests of adults with intellectual and developmental disabilities who are affected by Alzheimer’s disease and other causes of dementia – as well as their families and friends – are considered. The NTG’s overall mission is to advocate for services and supports for people with intellectual disability and their families who are affected by Alzheimer’s disease and dementias. More information can be found at: www.the-ntg.org.

The LuMind IDSC Foundation (LuMind IDSC) envisions a world where every person with Down syndrome thrives with improved health, independence, and opportunities to reach their fullest potential. A 501 (c)-3 nonprofit organization, LuMind IDSC accelerates research to increase availability of therapeutic, diagnostic, and medical care options and provides resources, connections, and support to a vibrant community of individuals with Down syndrome and their families. Founded by two visionary families in 2004, LuMind IDSC has raised a total of \$100M in funding for Down syndrome research to prevent the onset of Alzheimer’s disease, improve sleep, and advance independence for people with Down syndrome. For more information, visit www.LuMindIDSC.org.

