

April 11, 2022

Your advocacy is making a difference! The Down Syndrome Coalition, along with our colleagues from the Down Syndrome Diagnosis Network (DSDN), Down Syndrome Medical Interest Group-USA (DSMIG), International Mosaic Down Syndrome Association (IMDSA), and National Task Group on Intellectual Disabilities and Dementia Practices (NTG), and in partnership with our self-advocates and families, succeeded in removing discriminatory language from an important healthcare coverage determination that would have excluded people with Down syndrome from clinical trials for a new class of Alzheimer's treatments. With more than 1,800 individual comments submitted by the Down syndrome community, this community's voice was too loud to ignore, and we are one step closer to our goal of making sure adults with Down syndrome have equitable access to treatment options for Alzheimer's disease.

Together we strive to ensure that governmental entities, such as Centers for Medicare & Medicaid Services (CMS), the Food and Drug Administration (FDA), and the National Institutes of Health (NIH), as well as private pharmaceutical companies, are all working to provide equitable access to Alzheimer's treatments for the Down syndrome community now and in the future. This work is critical because it is estimated that the lifetime risk for people with Down syndrome to develop Alzheimer's disease is over 90%. Alzheimer's disease is the leading cause of death for members of our community. **The next phase of our collective advocacy must be focused on supporting the inclusion of people with Down syndrome in clinical trials for Alzheimer's treatments.**

The Down Syndrome Coalition includes the following national organizations (in alphabetical order): Down Syndrome Affiliates in Action (DSAIA), GiGi's Playhouse Down Syndrome Achievement Centers, Global Down Syndrome Foundation (GLOBAL), LuMind IDSC Foundation (LuMind IDSC), National Down Syndrome Congress (NDSC), and the National Down Syndrome Society (NDSS).



DOWN SYNDROME
AFFILIATES IN ACTION

DSMIG-USA
Down Syndrome Medical Interest Group-USA

DSDN
DOWN SYNDROME DIAGNOSIS NETWORK
inform • connect • support

GiGi's
PLAYHOUSE
Down Syndrome Achievement Centers
educate. inspire. believe.

GLOBAL
DOWN SYNDROME FOUNDATION

International
Mosaic Down Syndrome
Association

LuMind
IDSC
DOWN SYNDROME FOUNDATION

NATIONAL
DOWN SYNDROME
CONGRESS

NATIONAL DOWN SYNDROME SOCIETY
ndss

ntg
National Task Group
on Intellectual Disabilities
and Dementia Practices