

Program Summary

The National Down Syndrome Society (NDSS) Health and Wellness Program promotes improved health and wellbeing for all individuals with Down syndrome. Through collaboration with NDSS affiliate organizations, Down syndrome clinics, researchers, government agencies, and other key stakeholders, NDSS develops tailored and accessible resources for individuals with Down syndrome, families, and caregivers. Addressing topics across the lifespan from prenatal diagnosis to aging adults, NDSS offers guides, one-pagers, online resources, and conferences to provide information and support to the Down syndrome community.

Resource Development:

The NDSS Health and Wellness Program offers a wealth of information on the NDSS website to support people with Down syndrome, their families, and other members of the community, as well as clinicians. These resources, created in partnership with clinical experts, include webpages, printed guides, and webinar recordings.



Health Promotion:

The NDSS Health and Wellness Program promotes the wellbeing of individuals with Down syndrome during all phases of life and encourages members of the community to take control of their own health. NDSS provides resources about health complications more commonly seen in individuals with Down syndrome to raise awareness for families, caregivers, and clinicians. NDSS provides resources about these conditions to raise awareness for families, caregivers, and clinicians. In addition, NDSS advocates for the prioritization of health in the Down syndrome community and for policies that support people with Down syndrome and their families in the pursuit of living healthy lives.



Aging Adults:

Through medical intervention and more supportive communities, individuals with Down syndrome are living longer than ever before. NDSS aims to fill the gap in information about these later years of life through a whole-person, comprehensive approach addressing the needs of older adults with Down syndrome with practical resources, materials, and educational opportunities for individuals, families, and caregivers.



Alzheimer's Disease:

The risk of Alzheimer's disease in adults with Down syndrome can cause feelings of fear and anxiety for family, friends, and caregivers. NDSS creates research-based resources to empower families and caregivers with knowledge about the connection between Down syndrome and Alzheimer's disease, gives suggestions about evaluating changes that may be observed with aging, and provides guidance about adapting within an ever-changing caregiving role after a diagnosis is made.



Caregiving:

The word "caregiver" encompasses a diverse group of people including, but not limited to: parents, siblings, extended family members, friends, volunteers, and paid professional or lay staff. The caregiving role can often be a combination of joy and fulfillment along with frustration and confusion. NDSS recognizes how complex caregiving is and provides support through all stages of life across a variety of topics with practical resources, materials, and educational opportunities.

Research:

From understanding more about early childhood development to medical interventions and aging, research provides us with invaluable answers to many of our most pressing questions. Along with the NDSS Scientific and Clinical Advisory Board (SciCAB), NDSS partners closely with research organizations to help families and individuals with Down syndrome understand the advances in research and how these new findings affect their lives.



Local Affiliate Support:

NDSS engages with a network of more than 300 local affiliate organizations across the country. These local organizations directly engage with people with Down syndrome to help them improve their health and wellness. At no cost, the NDSS Health and Wellness Program offers organizations, and the people they serve, support and resources to improve health outcomes for people with Down syndrome in their communities.

Health Policy & Advocacy:

As part of NDSS' focus on advocacy and public policy, the NDSS Health and Wellness Program advocates for policies that promote equity and access to health care at the federal, state, and local levels. These include laws that prohibit discrimination for individuals who require an organ transplant as well as laws that ensure families receive the most accurate, up-to-date, evidence-based information available about Down syndrome when receiving a prenatal or postnatal diagnosis. In addition, NDSS has partnered with other national level organizations to advocate for inclusion with regards to access for Alzheimer's disease treatments.



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