

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 the NDSS Scientific and Clinical Advisory Board (SciCAB), affiliate organizations, Down syndrome and intellectual and developmental disability clinics, researchers, government agencies, and other key stakeholders, NDSS develops tailored and accessible resources for individuals with Down syndrome, families, caregivers, and professionals. Addressing topics across the lifespan from prenatal diagnosis to aging adults, NDSS offers guidebooks, one-pagers, online resources, and conferences to provide information and support to the Down syndrome community.

Resource Development:

The Health and Wellness Program offers detailed information on the NDSS website to support individuals with Down syndrome, their families, caregivers, clinicians, and other members of the community. These resources, created in partnership with subject matter and clinical experts and based on community feedback, include webpages, printed guides, and webinar recordings.



Health Promotion:

The NDSS Health and Wellness Program promotes the wellbeing of individuals with Down syndrome across the lifespan and encourages members of the community to take control of their own health. NDSS provides resources for families, caregivers, and clinicians to increase awareness of common co-occurring conditions. In addition, NDSS creates resources that encourage individuals to be proactive about healthy aging.



Aging Adults:

Through medical intervention and more supportive communities, individuals with Down syndrome are now living longer than ever before. NDSS aims to fill the gap in information about aging through a whole-person, comprehensive approach. Based on feedback from the Down syndrome community, NDSS addresses the needs of aging adults with Down syndrome by providing practical resources and educational opportunities for individuals, families, and caregivers.



Alzheimer's Disease:

The significantly higher risk of Alzheimer's disease in adults with Down syndrome can cause feelings of worry and fear for families, caregivers, and loved ones. NDSS creates research-based resources to empower individuals, families, caregivers, and professionals with knowledge about the connection between Down syndrome and Alzheimer's disease. NDSS resources give advice about evaluating changes that may be observed with aging and provide guidance about adapting in an ever-changing caregiving role after a diagnosis is made.



Caregiving:

"Caregivers" encompasses a diverse group of people including, but not limited to parents, siblings, extended family members, friends, volunteers, and paid professionals. The caregiving role can often bring a combination of joy and fulfillment along with frustration and confusion. NDSS recognizes how complex caregiving can be and provides support through all stages of life with practical resources and educational opportunities.

Research:

Research provides us with invaluable answers to many of our most pressing questions. Along with the Scientific and Clinical Advisory Board, NDSS partners closely with researchers and subject matter experts to share information about the research process, participating in studies, and understanding how the latest findings can be applied to families and individuals with Down syndrome.



Local Affiliate Support:

NDSS engages with a network of over 300 local affiliate organizations nationwide. These local organizations directly engage with individuals with Down syndrome, their families, and professionals to support them in enhancing or maintaining all aspects of their health. NDSS' Health and Wellness Program connects affiliate organizations to resources that help improve health outcomes for their communities.

Health Policy & Advocacy:

As part of NDSS' focus on advocacy and public policy, 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 prohibiting discrimination against individuals who require an organ transplant, and laws ensuring that families receive the most accurate, evidence-based information available about Down syndrome when receiving a diagnosis. In addition, NDSS has partnered with other national level organizations to advocate for inclusion in trials for Alzheimer's disease treatments as well as equal access once safe and effective treatments are identified.



For more information, visit ndss.org or email:
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