DSMIG-USA®
Down Syndrome Medical Interest Group

NIH INCLUDE Project: Community-Engaged Research to Advance Clinical Care Across the Lifespan

Melissa A. Parisi, MD, PhD
National Institutes of Health

ANNUAL symposium

Disclosures

None

Learning Objectives

At the conclusion of this session, participants will be able to:

1. **Describe** the mission and scientific priorities of the **NIH INCLUDE** (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) **Project.**
2. **Explain** how **DS-Connect®: The Down Syndrome Registry** and the **INCLUDE Collaboration for Down Syndrome Progress (CDP)** can accelerate clinical research and improve participant engagement across the lifespan.
3. **Discuss** the role of community-engaged research in strengthening study design, recruitment, retention, and dissemination of research findings.

A Few Questions....

Let's get a sense of the room...

How many of you...

- ☐ Provide clinical care for individuals with Down syndrome?
- ☐ Conduct research involving individuals with Down syndrome?
- ☐ Refer patients or families to research studies?
- ☐ Have used or referred families to **DS-Connect®**: The Down Syndrome Registry?
- ☐ Have heard about the INCLUDE Collaboration for Down Syndrome Progress (**CDP**)?

Why Community-engaged Research?

Improving research by partnering with the Down syndrome community.

Why It Matters

- Ask the right research questions
- Design studies that reflect real-world needs
- Improve recruitment and long-term participation
- Increase trust, transparency, and communication
- Accelerate translation of research into clinical care

What is the NIH INCLUDE Project?

INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) **Project**

The INCLUDE Project launched in June 2018 to address a Congressional directive that called for a new **NIH-wide research initiative** on critical health and quality-of-life needs for individuals with Down syndrome (DS).

The INCLUDE Project:

- **Supports research that investigates conditions** that affect individuals with DS and the general population, such as Alzheimer's disease, autism, cataracts, celiac disease, congenital heart disease, and diabetes.
- **Aims to increase the number of investigators and trainees** studying DS.
- **Works in partnership with the Down syndrome community** to identify areas of need and **support work that benefits everyone.**

NIH National Institutes of Health
Turning Discovery Into Health

DSMIG-USA®
Down Syndrome Medical Interest Group

ANNUAL symposium

July 23-25
Orlando, Florida

Timeline of Key Events

2005
Formation of NIH Down Syndrome Working Group (DSWG)

2007
NIH Down Syndrome Research plan

2011
Creation of DS Consortium

2013
Launch of DS-Connect

2014
NIH Down Syndrome Research Plan

2015
Launch of ABC-DS

ABC-DS
Alzheimer Biomarker Consortium-Down Syndrome

2018
Launch of INCLUDE

2019
Launch of 1st INCLUDE-sponsored clinical trial

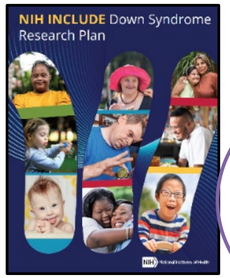
2020
Launch of INCLUDE Data Coordinating Center

INCLUDE
Data Coordinating Center

INCLUDE Data Hub

2022
Launch of INCLUDE Data Hub

2022
INCLUDE Research Plan



2024
INCLUDE DS-CDP Awards Made

2025
DCC Animal Model Portal

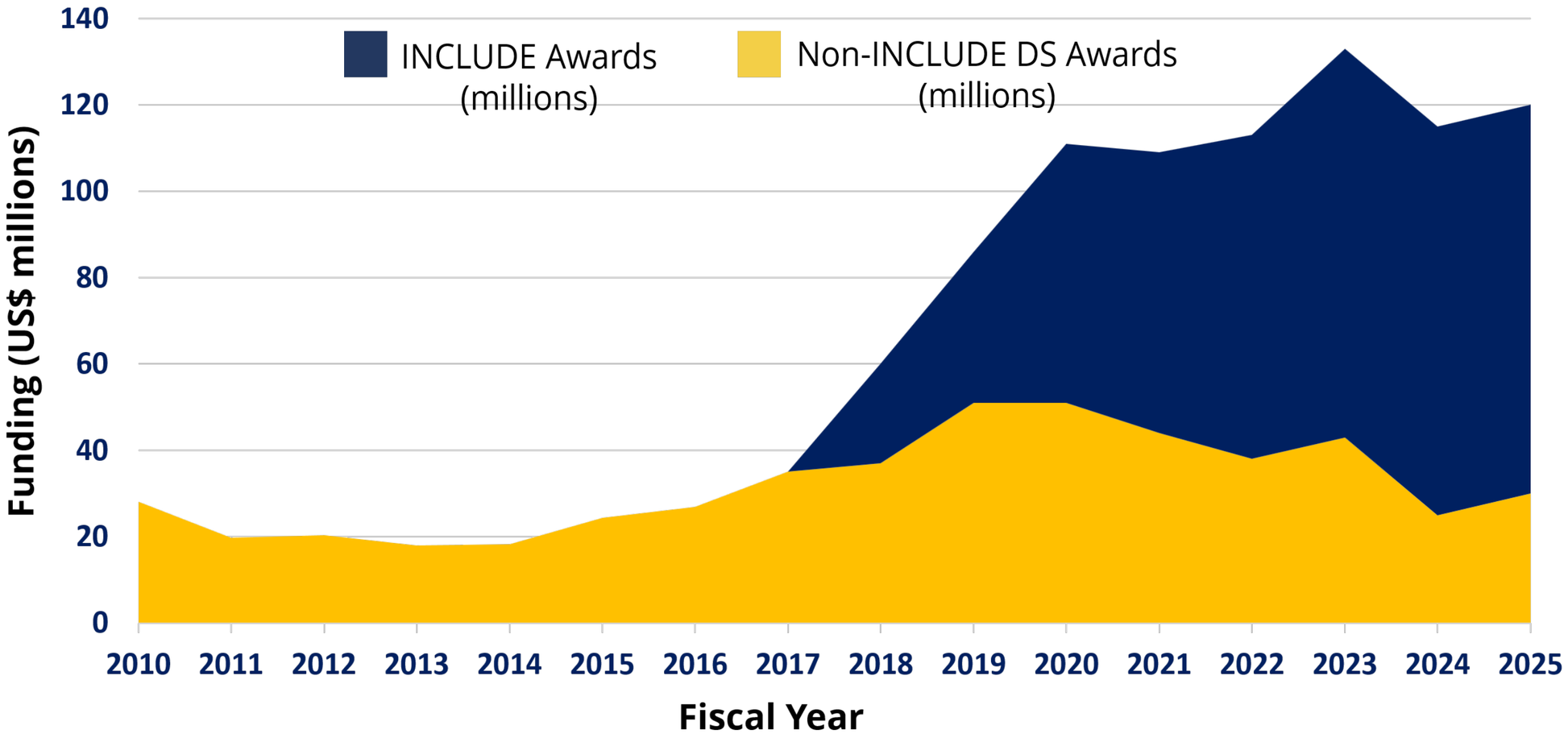
2025
Relaunch DS-Connect®
The Down Syndrome Registry

2026
Soft Launch of INCLUDE DS-CDP Common Protocol

2006 2008 2010 2012 2014 2016 2018 2020 2022 2024 2026

NIH National Institutes of Health
Turning Discovery Into Health

Down Syndrome Funding at NIH, 2010-2025



NIH has invested more than $528 million over the past **8 years** through the **INCLUDE Project**

INCLUDE Project *at a glance*

412

Awards Made

600+

Publications

20+

Community-Engagement and Outreach Events Hosted by INCLUDE Team Annually

19

IC’s Participating

26

Clinical trials

15,800

Individuals with DS Represented in the INCLUDE Data Hub

Two NIH INCLUDE Resources

INCLUDE

Collaboration for Down Syndrome Progress

- Longitudinal natural history study
- Comprehensive clinical phenotyping
- Supports future clinical trials

DS-Connect®

The Down Syndrome Registry

- National participant registry
- Connects individuals and families with research opportunities
- Supports participant engagement

Together, these resources strengthen research across the lifespan.

DS-CDP: A $32 million program established in 2024 to study Down syndrome from birth to adulthood

INCLUDE

Collaboration for Down Syndrome Progress

GOAL: DEVELOP A COHORT OF INDIVIDUALS WITH DOWN SYNDROME ACROSS THE LIFESPAN

- Improve our understanding of heterogeneity and the natural history of Down syndrome
- Better determine the frequency and variability of co-occurring conditions in Down syndrome
- Examine the impact of demographic, social, experiential, and environmental factors on outcomes
- Expand our understanding of currently used therapeutics and interventions to inform clinical trials

RESEARCH AND CLINICAL TEAMS HAVE DEVELOPED THE COMMON PROTOCOL.

STUDY ENROLLMENT BEGAN IN SPRING 2026.

INCLUDE

Collaboration for Down Syndrome Progress

CDP ORGANIZATION

DS-CRS RESEARCH SITES

INCLUDE
Collaboration for Down Syndrome Progress

ALLY-DS

Advancing the Lives & health of Youth and young adults with Down Syndrome

AGE | 6 years and up

ENROLLMENT | 400 participants

SCIENTIFIC FOCUS

- Natural history
- Co-occurring conditions
- Social determinants of health (SDOH)
- Structural ableism

PI: Andrea B. Kelly

INSTITUTION
Children's Hospital of Philadelphia

DECODE

Down syndrome Early Childhood Omics, Deep phenotyping, and Epidemiology

AGE | 0–2 years

ENROLLMENT | 400 participants

SCIENTIFIC FOCUS

- Deep phenotyping
- Structural birth defects
- Hematopoietic development
- Neurodevelopment

PI: Philip J. Lupo

INSTITUTION
Emory University

HTP-LAN

Human Trisomy Project – Latin America Network

AGE | All ages

ENROLLMENT | 1,500 participants

SCIENTIFIC FOCUS

- Clinical health
- Neurodevelopment
- Latinos with Down syndrome

PI: Joaquin M. Espinosa

INSTITUTION
University of Colorado, Denver

IBIS-DS

Infant Brain Imaging Study in Down Syndrome

AGE | 0–12 months

ENROLLMENT | 100 participants + 50 controls

SCIENTIFIC FOCUS

- Neurobehavioral development
- Cognition, language, motor, social
- Multimodal neuroimaging

PI: Natasha Marrus

INSTITUTION
Washington University in St. Louis

MET-DS

METabolic, health, lifestyle, and risk of co-occurring health conditions in Down Syndrome

AGE | 6–24 years

ENROLLMENT | 200 participants

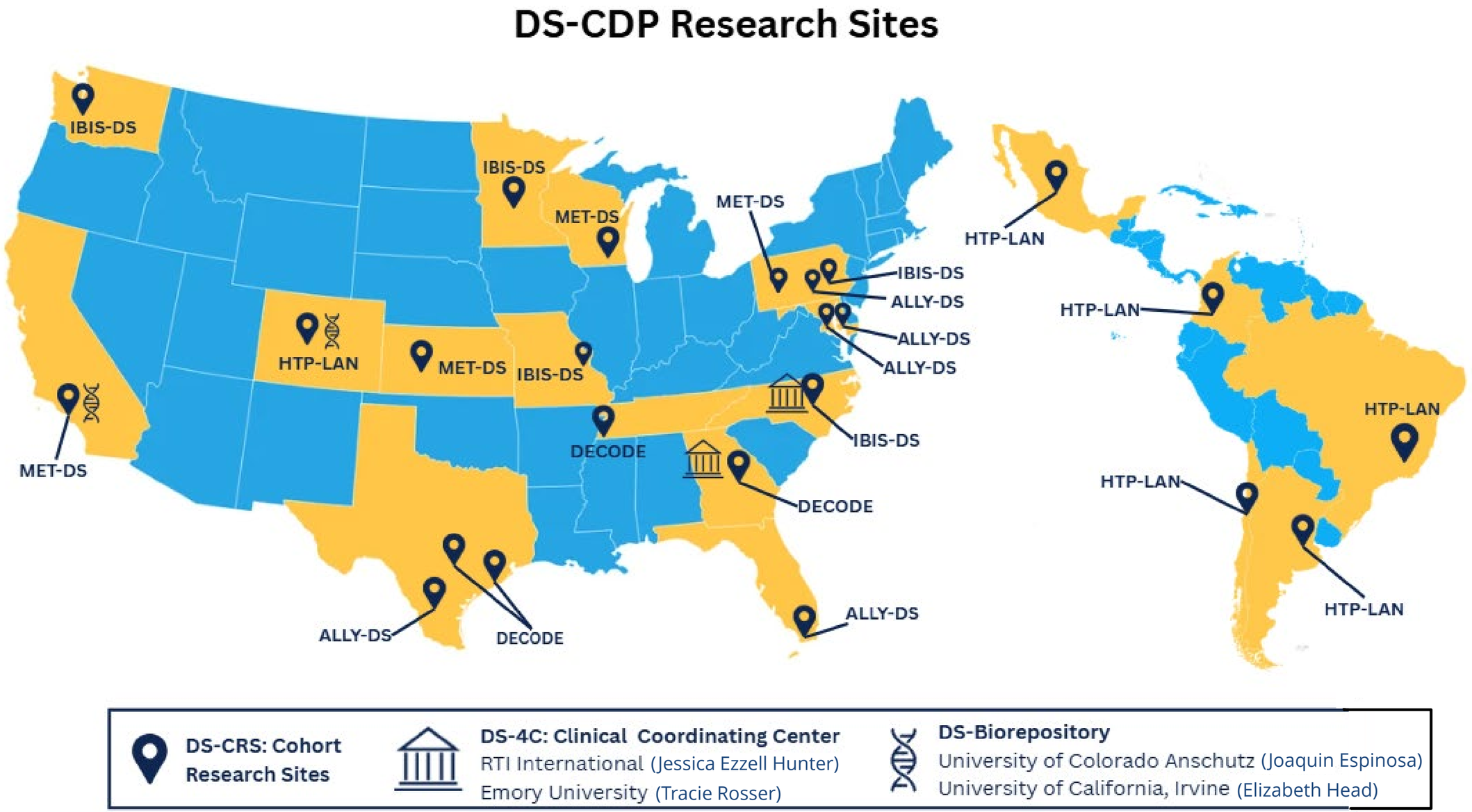
SCIENTIFIC FOCUS

- Metabolic dysregulation
- Obesity
- Lifestyle
- Co-occurring conditions

PI: Sigan Hartley

INSTITUTION
University of Wisconsin–Madison

Where is the INCLUDE CDP taking place?



Common Protocol Components

Common Protocol Collection

Assessments & Questionnaires

Medical data & EHR

Key Biospecimen Collection

Collected from all age-appropriate participants

In-person Enrollment

- On-site assessments
- Medical exam
- Biospecimen collection
- Optional sub-sample studies
- Questionnaires online or in-person

Participants may switch from remote to in-person

Remote Enrollment

- All participation is virtual
- Remote biospecimen kits
- Online questionnaires

Optional Subsample Studies

Sleep Studies

Activity & Wearables

Imaging Data

Clinical Labs

Collected from a subset of participants

INCLUDE
Collaboration for Down Syndrome Progress

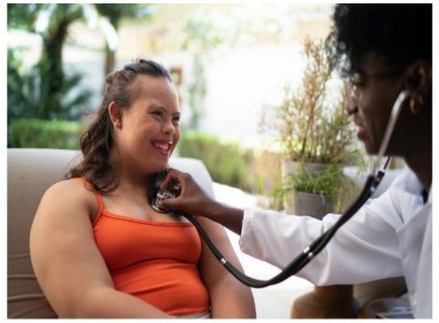
Return of Results

Participants receive results from study assessments and optional subsample studies.

Neurocognitive Testing

A letter with testing results

Medical Exam



Medical exam report

Clinical Labs

Results from the Metabolic and Endocrine panel

Subsample Studies

Activity & Wearables

Sleep Studies

Basic reports from activity and sleep studies

INCLUDE

Collaboration for Down Syndrome Progress

Stay Connected with the INCLUDE CDP

EXPLORE THE INCLUDE CDP

- Learn about participating
- Read frequently asked questions
- Complete the interest form

FOLLOW THE INCLUDE CDP

Facebook
INCLUDE CDP

Instagram
@includecdp

Scan to explore the INCLUDE CDP

COLLABORATE

Email dscdp@emory.edu to:

- Share speaking or exhibiting opportunities
- Promote research, training opportunities, or open positions
- Join the INCLUDE CDP Researchers ListServ

INCLUDE
Collaboration for Down Syndrome Progress

What is DS-Connect?

DS-Connect®

The Down Syndrome Registry

A secure, NIH-supported online registry

Developed with input from the Down syndrome community to connect individuals and families with research opportunities and advance scientific discovery.

How does DS-Connect support research?

Connects
individuals and families with research opportunities.

Engages
the Down syndrome community in research across the lifespan.

Collects
secure health information that advances scientific discovery.

Healthcare professionals are trusted partners in connecting individuals and families with **DS-Connect** and opportunities to participate in research.

DS-Connect®

The Down Syndrome Registry

A **secure, online survey-based** tool to collect basic information about people with Down syndrome

6200+ registered globally as of July 2026

ds-connect.org

Connecting families with researchers since 2013!

Key registry functions

How it Works

Surveys

Fill out confidential health-related surveys written by researchers who are studying Down syndrome.

Research

Researchers use data from thousands of participants to make discoveries.

Participate

When researchers design new studies or clinical trials, you can opt-in to be notified and participate.

Resources

Find expert news, links and events, and see how the data from studies you've completed drives discoveries.

ds-connect.org

DSMIG-USA®
Down Syndrome Medical Interest Group

ANNUAL symposium

July 23-25
Orlando, Florida

DS-Connect®
The Down Syndrome Registry

Top Metrics

6200+

Families Registered

- Across the USA and some international participants
- **1000s** of health surveys completed

130+

Research Studies Promoted

- 30 studies now recruiting and listed on the website!

7000+

Email Subscribers

Countless

Outreach Events Organized

- Conferences, webinars, newsletters, and more

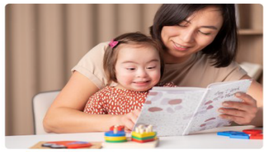
JOIN THE COMMUNITY

Be a member of an active community with a common cause

Join the DS-Connect Community

Studies which are Now Recruiting

Do you want to participate in research? These organizations and institutions are looking for individuals with Down syndrome to join their studies. Pick a study you're interested in to learn more and see if you meet the eligibility requirements. If you qualify, reach out to the study team today!



Exploring Quality of Life in Children With Down Syndrome After Leukemia

Karla Ausderau, PhD
Multiple locations within United States
5 to 21 years old

This study explores how children with Down syndrome in remission from leukemia and their families experience survivorship, focusing on their daily lives, support systems and strengths and skills gained through their experience.

Nutrition and Activity Program for Families of Children with Down Syndrome: HomeGrown

Erik Willis, PhD
Virtual
2 to 6 years old

HomeGrown is an online program designed specifically to help families of young children with Down syndrome improve nutrition and physical activity practices at home.

Caregiver and Self-Advocate Perspectives on Research Design and Information (PARDI)

A. Nicole White, PhD
Virtual
18 years and older

The purpose of this study is to focus on how individuals from the Down syndrome community (caregivers and self-advocates) understand how to participate in research studies, how they perceive

View All 30 Studies
Now Recruiting on the Website!

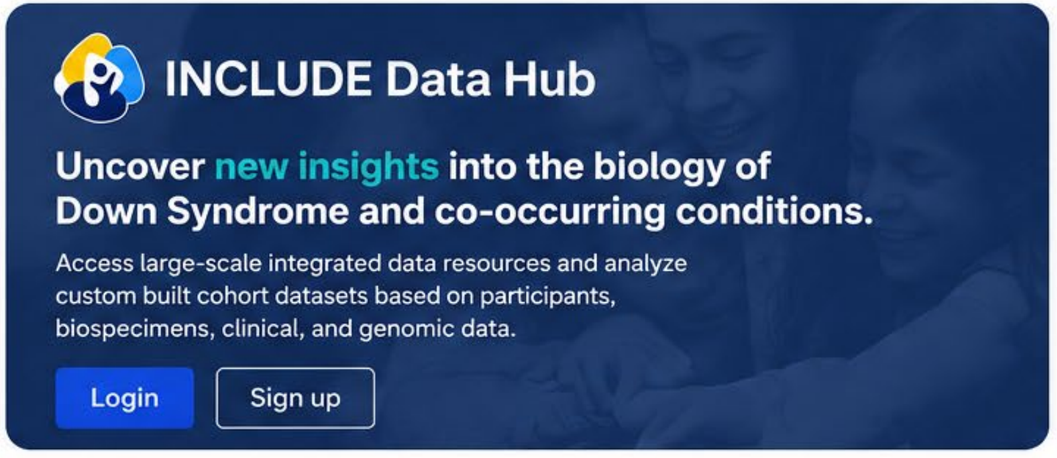
Scan to view the studies

How are DS-Connect data shared?

Only de-identified information is shared with scientists.

De-identified information does not contain any of the so called 'HIPAA identifiers': no names, no dates, no account numbers, nothing that could be tied to a given individual.

De-identified data is shared through the INCLUDE Data Hub.



INCLUDE
Data Coordinating Center

https://portal.includedcc.org/

A researcher portal supported by NIH

DS-Connect®
The Down Syndrome Registry

Empowering families with their own data

DS-Connect turns family-reported information into meaningful insights and practical resources.

Complete a survey
Share information about your health and well-being.

See your data in comparison
See how your data compares with the DS community.

Get your summary
Get an easy-to-understand summary of your data.

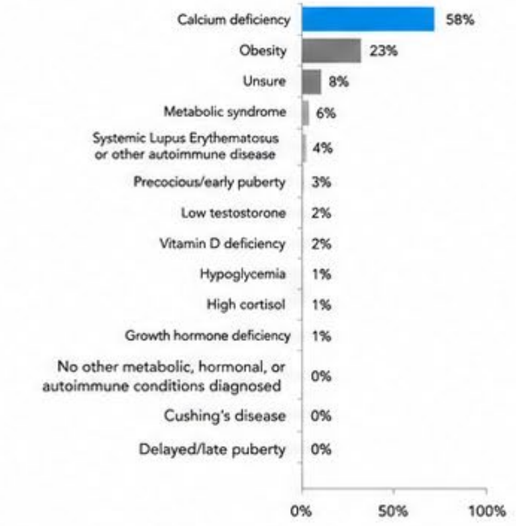
Access your care checklist
Access a personalized medical care checklist.

Surveys

Complete health surveys to provide researchers with valuable data.

- Basic Health Survey
- Celiac Disease Survey
- Consent to Enroll in DS-Connect Registry
- Development Survey
- Diabetes Survey
- Gastrointestinal Survey
- Heart Survey
- Leukemia Survey
- Prenatal and Birth History
- Sibling Survey
- Skeletal Survey
- Sleep Survey
- Thyroid Survey

Has the participant ever been diagnosed with any of the following metabolic, hormonal, or autoimmune conditions?



DS-Connect® The Down Syndrome Registry

Health Snapshot

This summary was generated from your survey responses in DS-Connect. It is not a substitute for medical advice. Please discuss any concerns or questions with your healthcare provider.

Participant Information
Name: Participant
Date of Birth: 01/01/2010
Age: 14 years

Survey Information
Survey: Health Snapshot – Core and Specialty Surveys
Completed On: 06/01/2024

Medical Conditions
Compared to the DS community, your child reported higher rates of:
- Asthma
- Sleep apnea
- Thyroid disorders

Similar rates of:
- Celiac disease
- Ear infections

Development
Compared to the DS community, your child reported:
- Similar developmental milestones
- Similar communication skills
- Similar behavior and emotional well-being

Strengths
Your child's strengths reported:
- Social skills
- Family support

Next Steps
Continue regular check-ups and recommended screenings. Share this summary with your healthcare provider.

Generated on 06/01/2024 by DS-Connect • ds-connect.org

GLOBAL MEDICAL CARE GUIDELINES
2020 Edition

GLOBAL

Age: 14 yeers

☐ **Behavior**
- At annual visit behavioral, functional, adaptive, and psychosocial topics should be performed evaluation. Screen at each visit for new concerns from the family.
- Evaluation for behavior problems may be appropriate for participants at increased risk or when concerns are raised.

☐ **Development**
- Monitor development at annual visits, with more in-depth evaluation for those with developmental delay.
- Provide appropriate therapies and supports based on individual needs.

☐ **Diabetes**
- People with Down syndrome have an increased risk of diabetes. Screening for diabetes should be considered beginning at age 10, and earlier with symptoms.
- For those with prediabetes or diabetes, monitor at least annually.

☐ **Celiac Disease**
- People with Down syndrome have an increased risk of celiac disease. Screening should be considered at diagnosis and again at 2–3 years of age, earlier if symptomatic, and repeated if symptoms develop.
- If celiac disease is diagnosed, a gluten-free diet should be initiated.

Learn more and access DS-Connect today!
Visit ds-connect.org or scan the QR code.

Your data helps drive discoveries that **improve health and well-being** for people with Down syndrome.

DS-Connect®
The Down Syndrome Registry

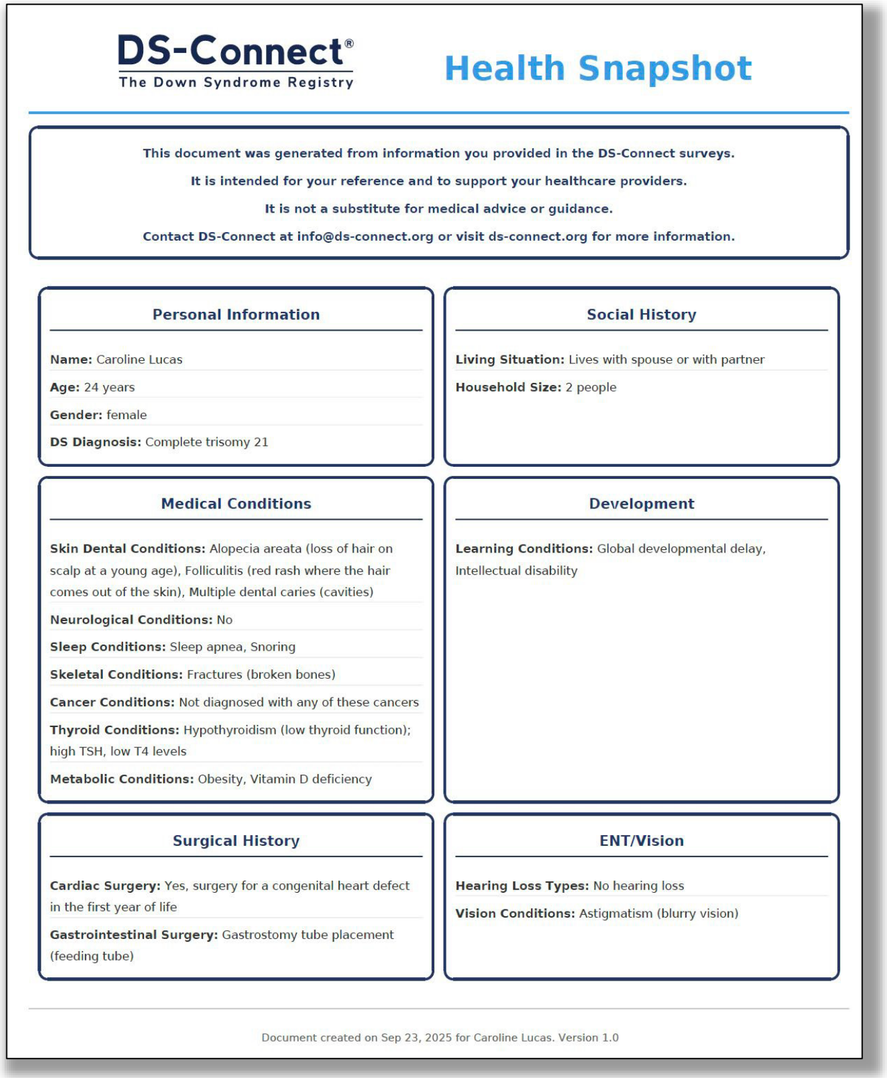
The DS-Connect Health Snapshot

A friendly summary of the survey answers provided

Can be downloaded as a PDF and shared with caregivers, physicians, and researchers.

Updates with any new survey completed and revised answers.

Your data. Your summary. | Empowering individuals and families with information that can inform care and advance research.



DS-Connect®
The Down Syndrome Registry

Health Snapshot

This document was generated from information you provided in the DS-Connect surveys.
It is intended for your reference and to support your healthcare providers.
It is not a substitute for medical advice or guidance.
Contact DS-Connect at info@ds-connect.org or visit ds-connect.org for more information.

Personal Information

Name: Caroline Lucas
Age: 24 years
Gender: female
DS Diagnosis: Complete trisomy 21

Social History

Living Situation: Lives with spouse or with partner
Household Size: 2 people

Medical Conditions

Skin Dental Conditions: Alopecia areata (loss of hair on scalp at a young age), Folliculitis (red rash where the hair comes out of the skin), Multiple dental caries (cavities)
Neurological Conditions: No
Sleep Conditions: Sleep apnea, Snoring
Skeletal Conditions: Fractures (broken bones)
Cancer Conditions: Not diagnosed with any of these cancers
Thyroid Conditions: Hypothyroidism (low thyroid function); high TSH, low T4 levels
Metabolic Conditions: Obesity, Vitamin D deficiency

Development

Learning Conditions: Global developmental delay, Intellectual disability

Surgical History

Cardiac Surgery: Yes, surgery for a congenital heart defect in the first year of life
Gastrointestinal Surgery: Gastrostomy tube placement (feeding tube)

ENT/Vision

Hearing Loss Types: No hearing loss
Vision Conditions: Astigmatism (blurry vision)

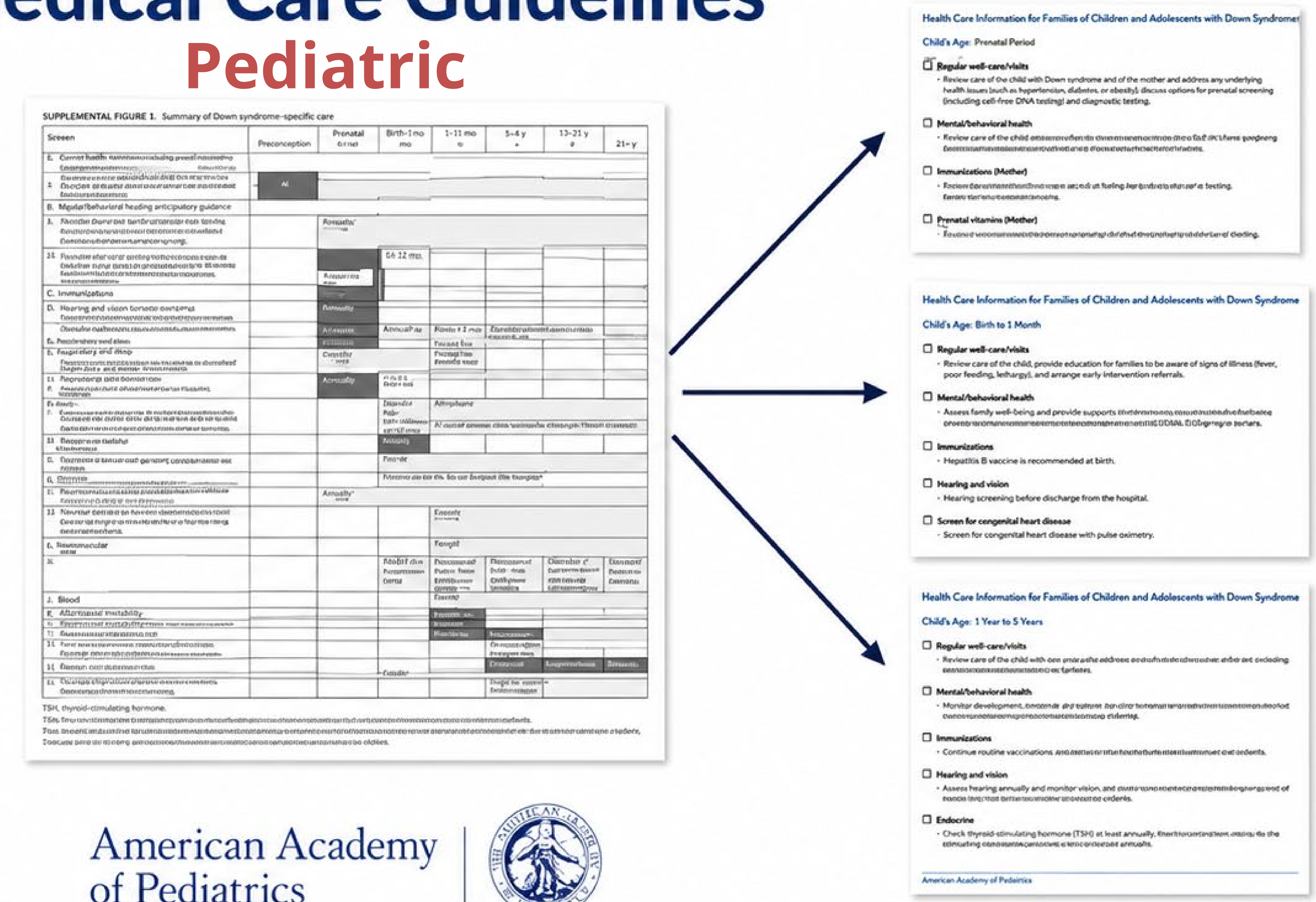
Document created on Sep 23, 2025 for Caroline Lucas. Version 1.0

Facilitating Access to Medical Care Guidelines

Pediatric

American Academy of Pediatrics (AAP):

- Prenatal period
- Birth to 1 month
- 1 month to 1 year
- 1 year to 5 years
- 5 years to 12 years
- 12 years to 21 years or older



American Academy of Pediatrics

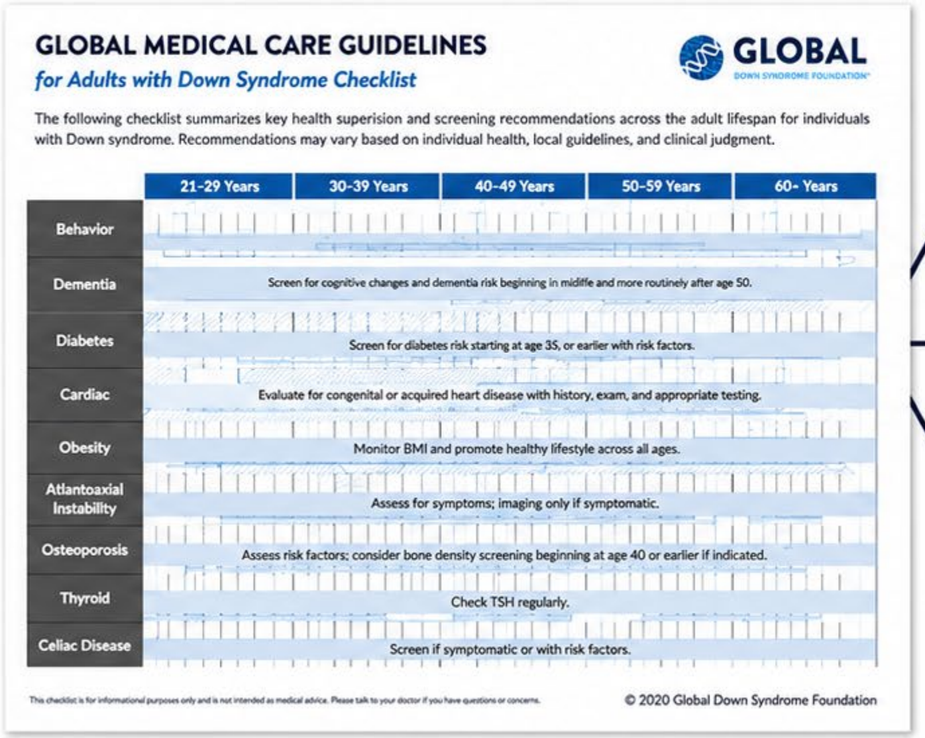
DEDICATED TO THE HEALTH OF ALL CHILDREN®

Facilitating Access to Medical Care Guidelines

Adult

GLOBAL Adult Medical Care Guidelines:

- 21–29 Years
- 30–39 Years
- 40–49 Years
- 50–59 Years
- 60+ Years



GLOBAL MEDICAL CARE GUIDELINES

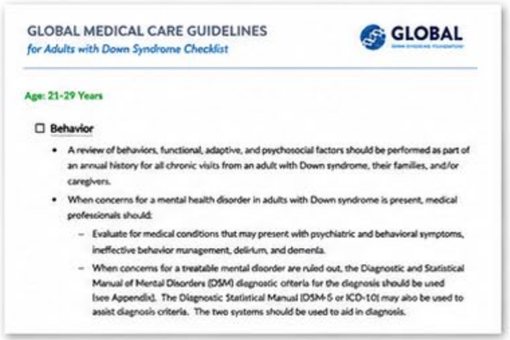
for Adults with Down Syndrome Checklist

GLOBAL DOWN SYNDROME FOUNDATION®

The following checklist summarizes key health superision and screening recommendations across the adult lifespan for individuals with Down syndrome. Recommendations may vary based on individual health, local guidelines, and clinical judgment.

	21–29 Years	30–39 Years	40–49 Years	50–59 Years	60+ Years
Behavior					
Dementia	Screen for cognitive changes and dementia risk beginning in midlife and more routinely after age 50.				
Diabetes	Screen for diabetes risk starting at age 35, or earlier with risk factors.				
Cardiac	Evaluate for congenital or acquired heart disease with history, exam, and appropriate testing.				
Obesity	Monitor BMI and promote healthy lifestyle across all ages.				
Atlantoaxial Instability	Assess for symptoms; imaging only if symptomatic.				
Osteoporosis	Assess risk factors; consider bone density screening beginning at age 40 or earlier if indicated.				
Thyroid	Check TSH regularly.				
Celiac Disease	Screen if symptomatic or with risk factors.				

This checklist is for informational purposes only and is not intended as medical advice. Please talk to your doctor if you have questions or concerns.



GLOBAL MEDICAL CARE GUIDELINES

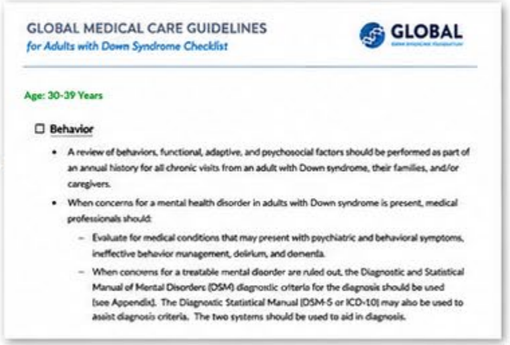
for Adults with Down Syndrome Checklist

GLOBAL

Age: 21-29 Years

☐ **Behavior**

- A review of behaviors, functional, adaptive, and psychosocial factors should be performed as part of an annual history for all chronic visits from an adult with Down syndrome, their families, and/or caregivers.
- When concerns for a mental health disorder in adults with Down syndrome is present, medical professionals should:
  - Evaluate for medical conditions that may present with psychiatric and behavioral symptoms, ineffective behavior management, delirium, and dementia.
  - When concerns for a treatable mental disorder are ruled out, the Diagnostic and Statistical Manual of Mental Disorders (DSM) diagnostic criteria for the diagnosis should be used (see Appendix). The Diagnostic Statistical Manual (DSM-5 or ICD-10) may also be used to assist diagnosis criteria. The two systems should be used to aid in diagnosis.



GLOBAL MEDICAL CARE GUIDELINES

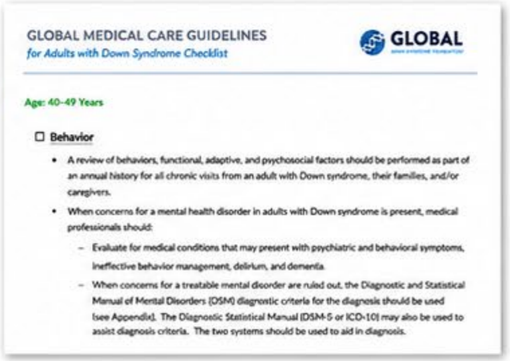
for Adults with Down Syndrome Checklist

GLOBAL

Age: 30-39 Years

☐ **Behavior**

- A review of behaviors, functional, adaptive, and psychosocial factors should be performed as part of an annual history for all chronic visits from an adult with Down syndrome, their families, and/or caregivers.
- When concerns for a mental health disorder in adults with Down syndrome is present, medical professionals should:
  - Evaluate for medical conditions that may present with psychiatric and behavioral symptoms, ineffective behavior management, delirium, and dementia.
  - When concerns for a treatable mental disorder are ruled out, the Diagnostic and Statistical Manual of Mental Disorders (DSM) diagnostic criteria for the diagnosis should be used (see Appendix). The Diagnostic Statistical Manual (DSM-5 or ICD-10) may also be used to assist diagnosis criteria. The two systems should be used to aid in diagnosis.



GLOBAL MEDICAL CARE GUIDELINES

for Adults with Down Syndrome Checklist

GLOBAL

Age: 40-49 Years

☐ **Behavior**

- A review of behaviors, functional, adaptive, and psychosocial factors should be performed as part of an annual history for all chronic visits from an adult with Down syndrome, their families, and/or caregivers.
- When concerns for a mental health disorder in adults with Down syndrome is present, medical professionals should:
  - Evaluate for medical conditions that may present with psychiatric and behavioral symptoms, ineffective behavior management, delirium, and dementia.
  - When concerns for a treatable mental disorder are ruled out, the Diagnostic and Statistical Manual of Mental Disorders (DSM) diagnostic criteria for the diagnosis should be used (see Appendix). The Diagnostic Statistical Manual (DSM-5 or ICD-10) may also be used to assist diagnosis criteria. The two systems should be used to aid in diagnosis.

GLOBAL
DOWN SYNDROME FOUNDATION®

DS-Connect®
The Down Syndrome Registry

Other Resources for Families

Curated resources in partnership with leading national Down syndrome organizations.

Browse by Topic

- About Down Syndrome
- Down Syndrome Clinics in the United States
- New and Expectant Parents
- Newborn to School Age
- Teenagers to Adults
- Siblings
- Learn About Down Syndrome Research
- Resources for Health Care Providers

Featured Resources

- INCLUDE Project Down Syndrome Research Plan (NIH)
- Language Guidelines (NDSS)
- Medical Resources (NDSC)
- Facts and FAQ About Down Syndrome (GLOBAL)
- GLOBAL Webinars (GLOBAL)
- Centers for Disease Control and Prevention (CDC) Down syndrome page (CDC)
- What is Down syndrome? (NDSC)
- Words Can Hurt (GLOBAL)
- An Overview of Down Syndrome (NDSS)
- Ages and Stages (NDSC)
- Mosaic Down Syndrome (IMDSA)
- Down Syndrome Misconceptions vs. Reality (GLOBAL)

Explore all resources on DS-Connect

Scan the QR code or visit
ds-connect.org/resources

A Central Hub for Approved Research Studies

Studies are approved by a Research Review Committee (RRC) that includes scientists, physicians, and community members

Connect Your Research with the Down Syndrome Community

Promote recruitment for your study through DS-Connect

Did you know that 75% of families with a loved one with Down syndrome are interested in participating in research? A main goal of DS-Connect is to connect families who want to participate in research with the research community. You can request to share your study information with DS-Connect participants here.

Get started

RRC review and approval

Studies which are Now Recruiting

Down Syndrome Health Measure (DSHM) Survey

Stephanie Santoro, MD
Virtual
0 to 21 years old

The Down Syndrome Health Measure (DSHM) is a new, short survey that was created specifically with people with Down syndrome in mind, and asks questions about aspects of overall health. Now that this final measure is available, we're interested in collecting feedback on the survey from caregivers of individuals with Down syndrome age 0 to 21.

Workshop to Help Reduce Stress for Caregivers: CarePRO Virtual-DS/ID

David Coon, PhD
Virtual
18 years and older

Family caregivers of adults living with Down syndrome or another intellectual disability who are experiencing memory changes are invited to participate in CarePRO Virtual-DS/ID, a free 5-week online workshop designed to reduce distress and improve quality of life.

Treatment of Obstructive Sleep Apnea with Personalized Surgery in Children with Down Syndrome (TOPS-DS)

Derek Lam, MD, MPH
Multiple locations in the United States
2 to 17 years old

The purpose of this study is to test how well personalized surgical treatment helps children with Down syndrome (DS) who have obstructive sleep apnea (OSA).

Healthcare Professionals Can Advance Community-Engaged Research

Sign up for a webinar

DS-Connect®
The Down Syndrome Registry

Webinar

Presentation Topic:
Autism & Down Syndrome:
How to Recognize the Signs and
Support Your Child

Presented by Meghan O'Neill, MD, FAAP
Assistant Professor of Pediatrics
Neurodevelopmental Physician

Recording Available: May 2026 Webinar Hosted by DS-Connect

June 11, 2026

We appreciate your interest in the recent DS-Connect webinar featuring Dr. Meghan O'Neill, and members of the DS-...

Promote DS-Connect

Join DS-Connect®

Your First Name *
Enter your first name as the DS-Connect account holder

Your Last Name *
Enter your last name as the DS-Connect account holder

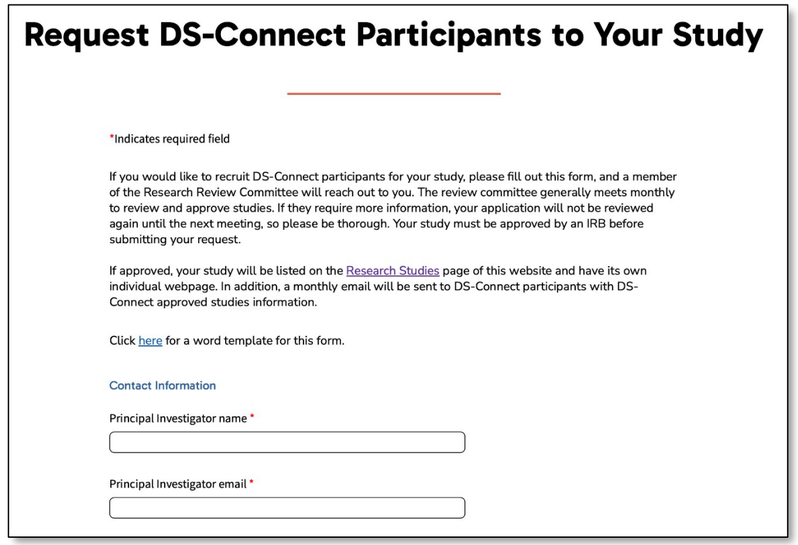
Email address *
This email address will be used for DS-Connect communications with your consent. It will never be shared outside the DS-Connect team.

Username *
This username will be used as your login id. Special characters are allowed, including space, period (.), hyphen (-), apostrophe ('), underscore (_), and the @ sign.

Password *
Password strength:

Confirm password *
Passwords match:
Provide a password for the new account in both fields.

Submit your study request



Request DS-Connect Participants to Your Study

*Indicates required field

If you would like to recruit DS-Connect participants for your study, please fill out this form, and a member of the Research Review Committee will reach out to you. The review committee generally meets monthly to review and approve studies. If they require more information, your application will not be reviewed again until the next meeting, so please be thorough. Your study must be approved by an IRB before submitting your request.

If approved, your study will be listed on the Research Studies page of this website and have its own individual webpage. In addition, a monthly email will be sent to DS-Connect participants with DS-Connect approved studies information.

Click here for a word template for this form.

Contact Information

Principal Investigator name *

Principal Investigator email *

Upcoming activities

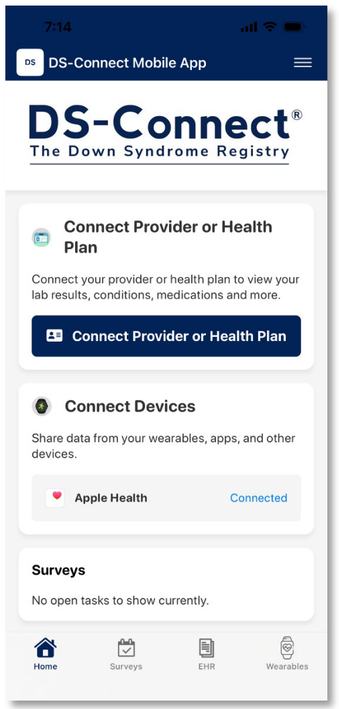
DS-Connected workshops

Partner with us to host one!

Social media platforms

Coming soon, be ready to follow us!

DS-Connect mobile app



Stay tuned, DS-Connect at your thumbtips…

DS-Connect®

The Down Syndrome Registry

WE'RE HERE TO HELP!

The best way to get all of the following is to email **info@ds-connect.org.** We're happy to help!

- **Order** DS-Connect materials.
- **Request** an in-person workshop or presentation.
- **Contact** the DS-Connect team.
- **Learn** more about the registry.

EMAIL US

Scan the QR code to visit our email page.

STAY CONNECTED

Scan the QR code to sign up for our emails via Constant Contact.

Email us anytime at **info@ds-connect.org**

Key takeaways

- The **NIH INCLUDE Project** is a major 8-year investment in research to improve quality of life for people with Down syndrome.
- The **Collaboration for Down syndrome Progress (CDP)** is a new longitudinal, lifespan cohort project under a Common Protocol.
- The revamped **DS-Connect Registry** is connecting families with research opportunities and providing dynamic resources for them.
- **Family and self-advocate engagement** improves all of our research efforts.
- Stay connected through **newsletters**, share materials about **DS-Connect**, and **help recruit families** for these studies!

Acknowledgements

- The NIH-wide Down Syndrome INCLUDE Working Group
- Investigators and Trainees
- Children and adults with Down syndrome and their families

National Institutes of Health
The Down Syndrome Consortium

Thank you to our self-advocates who serve in the DS Consortium

Karen Gaffney

David Egan

Mitchell Levitz

aaidd

ALZHEIMER'S ASSOCIATION

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN

AUCD
Association of University Centers on Disabilities

DSMIG-USA
Down Syndrome Medical Interest Group

dsaia
Down Syndrome Affiliates in Action

DSDN
DOWN SYNDROME DIAGNOSIS NETWORK

FOUNDATION Jerome Lejeune
research, care, advocacy

GLOBAL
DOWN SYNDROME FOUNDATION

national down syndrome society
ndss

NATIONAL DOWN SYNDROME CONGRESS

ntg
National Task Group on Intellectual Disabilities and Dementia Practices

DSi Down Syndrome International

Special Olympics

t2i
RESEARCH SOCIETY

International Mosaic Down Syndrome Association