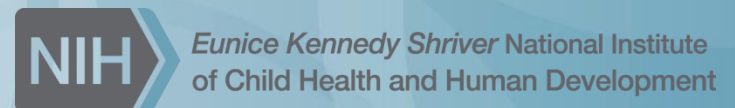
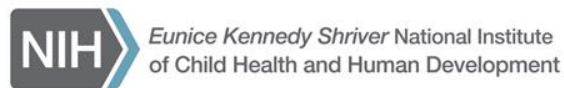


DS-Connect[®]: Why Should We Consider Signing Up?

Lisa Kaeser, J.D.

Director, Office of Legislation and Public Policy

April 23, 2016





DS-Connect[®]

What it is:

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

Features:

- Collects information from individuals with DS globally
- Provides a database and educational system for those with DS
- Enables researchers to use de-identified data to develop studies on the medical issues and treatments for DS

People with DS and their families can:

- Connect with researchers and health care providers.
- Take confidential health-related surveys. These surveys are aimed at better understanding of the health of people with Down Syndrome across their lifespans.
- Participate in clinical studies on Down Syndrome, including studies of new medications and other treatments.



**Who knows
them best?**





YOU!!





A new model: Family-centered registries



- 1** *Foundations, Institutions, or the Government* sponsor registries, act as the trusted gatekeeper.
- 2** *Families or Self Advocates* register and provide health history information.
- 3** *Coordinators* may curate data, answer questions, assist with participation.
- 4** *Clinicians/Researchers* have access to aggregated, de-identified data.
- 5** *Industry* uses the de-identified data for study planning and pre-screening for enrollment.



NIH CLINICAL RESEARCH TRIALS AND YOU

NIH Clinical Research Trials and You

- [The Basics](#)
- [Finding a Clinical Trial](#)
- [List of Registries](#)
- [Personal Stories](#)
- [For Parents and Children](#)
- [For Health Care Providers](#)
- [Resources for Trial Sites](#)
- [Educational Resources](#)
- [Glossary of Common Terms](#)
- [If You Have a Question](#)
- [In the News](#)

“Why should I participate in a clinical trial?”



Highlights



Taking a swing at Alzheimer's disease



Kayla's Story: A Bright Future Through NIH Research



Working to Prevent Breast Cancer

[View all highlights »](#)

Help Get the Word Out!

You can help raise public awareness



Your/your child's information is valuable, even if you choose not to participate in a clinical trial...



A partnership with families...

- What do Families want?
 - Document the growth of my child



Questionnaire Healthcare Providers Growth Measurements Account Info Attachments Contacts Newsletters

Notes

Measures

Height [+ Add value](#)

Please enter your current height

Date	Value	Unit
2002-07-01	20.00	centimeters
2003-07-01	25.00	centimeters
2004-07-01	30.00	centimeters
2005-07-01	35.00	centimeters
2006-07-01	40.00	centimeters
2007-07-01	45.00	centimeters
2008-07-01	50.00	centimeters
2009-07-01	55.00	centimeters
2010-07-01	60.00	centimeters
2011-07-01	65.00	centimeters



A partnership with families...

➤ Access the health care provider list



Questionnaire Healthcare Providers Growth Measurements Account Info Attachments Contacts Newsletters

Notes

Search the directory for your health care provider(s) by name, facility name, city or state (2 letter abbreviation). If your health care provider is not in the directory, use the Add a New Health Care Provider link to add them in the directory. Note that you will need to search for each physician individually before the Save button will be enabled.

Please note that this list of healthcare providers does not imply endorsement or recommendation of their services.

Name/Institution Specialty City State

Country

Search

Leave blank to list all

[Add a New Health Care Provider](#) Click the to add the healthcare provider to your account.

Name	Specialty	Sees Adults or Youth?	Institution	City	State	Country	
John Avallone	Ophthalmology		Ophthalmology Associates	Arnold	MD	UNITED STATES	My Health Care Provider
Mihee Bay	Developmental Pediatrics		Kennedy Krieger Institute	Baltimore	MD	UNITED STATES	My Health Care Provider



A partnership with families...

➤ Print out their child's medical history



Questionnaire Healthcare Providers Growth Measurements Account Info Attachments Contacts

Notes



Initial Health Questionnaire



Completed: 2013-09-25



PRINT



Sleep Questionnaire

PRINT

Jane Smith

DOB: 2011-01-01
Gender: Female
Registered By: Melissa Parisi
Relationship: Biological Parent

Initial Health Questionnaire

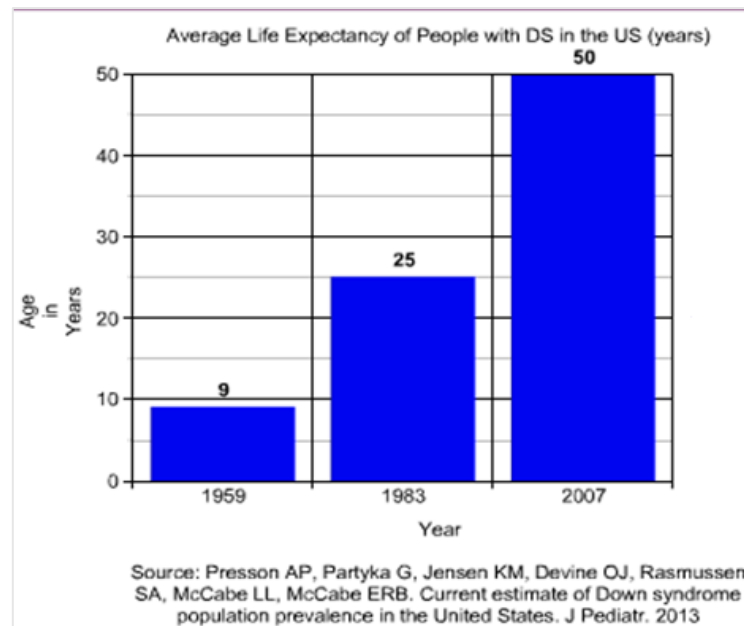
Diagnosis

- **What is the participant's Down syndrome diagnosis?**
Complete trisomy 21
- **How was the diagnosis of Down syndrome made? (Select all that apply.)**
Genetic testing in baby after birth (such as chromosome analysis, cytogenomic array, or fluorescence in situ hybridization (FISH))
- **What was the participant's age in years when the diagnosis of Down syndrome was made?**
At birth



Why should I care about research?

- People with Down syndrome are living longer, largely due to improved medical treatments



- In 1959, the life expectancy of a person with DS in the US was 9 years.
- In 1983, the life expectancy of a person with DS was 25 years.
- In 2007, the life expectancy of a person with DS was 50+ years—
an increase of 456% from 1959!



Why should I care about research?

- Children with Down syndrome have improved cognition due to educational and early intervention programs
- These programs:
 - build on a child's strengths
 - strengthen those skills that are weaker
- Part of IDEA Legislation

The screenshot shows the website for the National Down Syndrome Society (NDSS). At the top left is the NDSS logo with the text "national down syndrome society" and "ndss." in red. To its right is an orange "donate" button. Further right is a search bar with the placeholder text "Enter Search Terms". Below the logo and search bar is the tagline "The National Advocate for People with Down Syndrome". A red navigation bar contains the following menu items: "down syndrome", "resources", "ways to give", "my great story", "buddy walk®", and "advocacy". Below the navigation bar is a breadcrumb trail: "Home » Resources » Therapies & Development » Early Intervention". The main heading is "Early Intervention" in a large, blue, serif font. Below the heading is a row of social sharing buttons: "Print", "Share" (Facebook) with 1291 shares, "Tweet" (Twitter) with 9 shares, "Pinterest" with 48 shares, and "Email" with 76 shares. Below these buttons is a "ShareThis" button with 32.8K shares. The main text of the page begins with: "The first years of life are a critical time in a child's development. All young children go through the most rapid and developmentally significant changes during this time. During these early years, they achieve the basic physical, cognitive, language, social and self-help".



Why should we care about research?

- Children and adults with Down syndrome are getting recommended sleep studies
- Those with sleep disorders can get treatment to improve learning and memory
- Dr. Jamie Edgin's "Arizona Sweet Dreams Study"



DS Consortium Members



Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)



National Cancer Institute (NCI)



National Heart, Lung and Blood Institute (NHLBI)

DOWN SYNDROME
AFFILIATES IN ACTION



National Institute of Mental Health (NIMH)



National Institute of Neurological Disorders and Stroke (NINDS)

National Institute on Aging (NIA)



National Institute on Minority Health and Health Disparities (NIMHD)

National Institute on Minority Health and Health Disparities (NIMHD)



National Human Genome Research Institute (NHGRI)



The National Institute of Diabetes and Digestive and kidney Diseases (NIDDK)

Self Advocates

National Institute of Dental and Craniofacial Research (NIDCR)

DS-Connect® Home Page



National Institutes of Health
Turning Discovery Into Health

[Forgot login?](#)[Need Help?](#)[Unblock Account](#)[Home](#)[Contact Us](#)[About DS-Connect®](#)[News](#)[Resources](#)[Glossary](#)[For Professionals](#)

DS-Connect®: The Down Syndrome Registry

“The new registry provides an important resource to individuals with Down syndrome and their families,” said Yvonne T. Maddox, former deputy director of the NIH’s *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), which is funding the registry. “The registry links those seeking volunteers for their research studies with those who most stand to benefit from the research.”

[Join the Registry](#)

Launched Sept. 6, 2013



How secure is it?

- Meets stringent data security requirements to protect personally identifiable information
 - ~ 250 security controls are checked regularly (FISMA moderate level)
 - Information is encrypted
 - Password requirements (At least 8 characters long, 1 upper case, 1 lower case, 1 symbol, 1 number)
Example: **P@ssword3**
 - Passwords must be changed every 10 months
 - No social security info is collected
 - No personal bank account info is collected













Registration page for individuals and families

Steps for participating in the Registry

There are four easy steps to join DS-Connect™. This whole process should take you less than 20 minutes. If you are a self advocate, you may want to have a trusted person help you with these steps.

1. Create an account: The account can be created by choosing a user name and a password. This will be used each time you want to log in to your profile.
2. Review the online consent form.
3. Click the appropriate consent boxes, enter the security code, and click “Register.”
4. Once you are registered, you can enter basic information for the participant with Down syndrome (DS). If you are a person with DS, you may want to have someone you trust help you to join the registry.

Step 1: Create an Account

Your First Name:	<input type="text"/>	
Your Last Name:	<input type="text"/>	
Please select the best option:		
Your Relationship to Participant with DS:	<input type="text" value="v"/>	 
Your Email / Re-enter email:	<input type="text"/>	 
Secondary Email:	<input type="text"/>	
Your Username:	<input type="text"/>	 
Your Password / Re-enter password:	<input type="text"/>	 



DS-Connect[®]: Provide Consent

Consent Options

Please choose the consent that applies to you

I have read the explanation about DS-Connect[™] and have been given the opportunity to discuss it and ask questions. I hereby consent, or give permission for my child or the participant with DS to take part in this registry.

- Consent by the adult participant with DS (if the person with DS can provide their own consent)
- Permission by a Legal Guardian or Legally Authorized Representative (if the person with DS is 18 years or older and cannot provide their own consent)
- Parent's permission for minor (if the person with DS is under 18 years of age)





Sharing and Contact Preferences

Sharing and Contact Preferences

Yes



DS-Connect® has processes in place to protect your identity, including saving your information with a code instead of your name so others don't know who you are. DS-Connect® may share information with scientists for research studies or clinical trials, but it will not share your personal information—see the explanation of “de-identified” above. [Do you give your permission for DS-Connect® to share your de-identified information for research studies or clinical trials?](#)

(Please note that even if the coordinators of a clinical trial believe that you might be eligible for the trial based on your data in the Registry, it is still possible that you will not meet the trial inclusion criteria after all. Please also note that if we inform you about the existence of a trial, it does not mean that we endorse or support it. In order to take part in any trial, you will need to fill out a separate informed consent form.)

No



DS-Connect® may share your de-identified information with other registries or databases. [Do you give your permission for DS-Connect® to share your de-identified information with other registries and databases?](#)

Yes



DS-Connect® may get information about a study related to Down syndrome that may interest you. [Do you want DS-Connect® to contact you about such a study?](#)

Yes



DS-Connect® may get information about a study to donate samples of blood, tissue or other biospecimens for research. [Do you want DS-Connect® to contact you about these types of studies?](#)

Yes



If researchers learn anything interesting about your condition, [do you want DS-Connect® to contact you with this information?](#)

Yes



It is important that the DS-Connect® information is up to date. We will contact you once a year to ask about changes in your health condition. [Do you give us permission to contact you for this information?](#)



Multiple Survey Modules

Initial Health Survey with
“Trigger Questions” that lead
to other surveys:



- Initial Health Questionnaire
- Thyroid Questionnaire
- Heart Questionnaire
- Sleep Questionnaire
- Skeletal Questionnaire
- Gastrointestinal Questionnaire
- Adulthood Questionnaire
- Diabetes Questionnaire
- Celiac Disease Questionnaire
- Adulthood Questionnaire

Launched Dec 2014



- **Men’s Health Questionnaire**
- **Women’s Health Questionnaire**
- **Leukemia Questionnaire**
- Development Questionnaire
- Prenatal and Birth Questionnaire

Available to all registrants



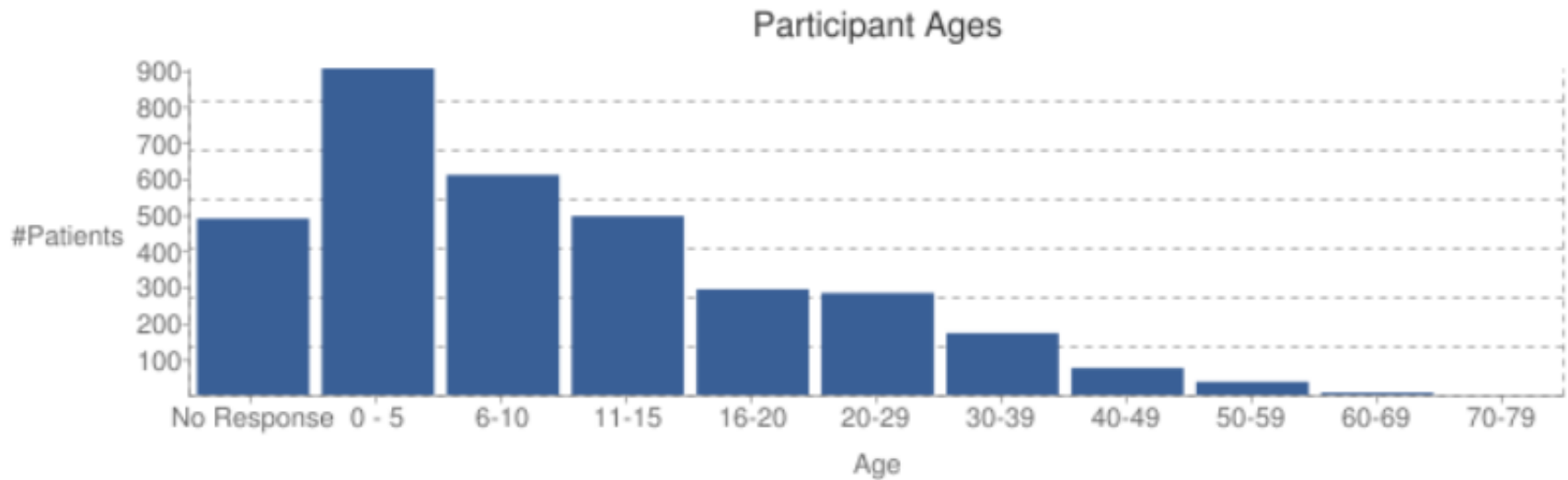
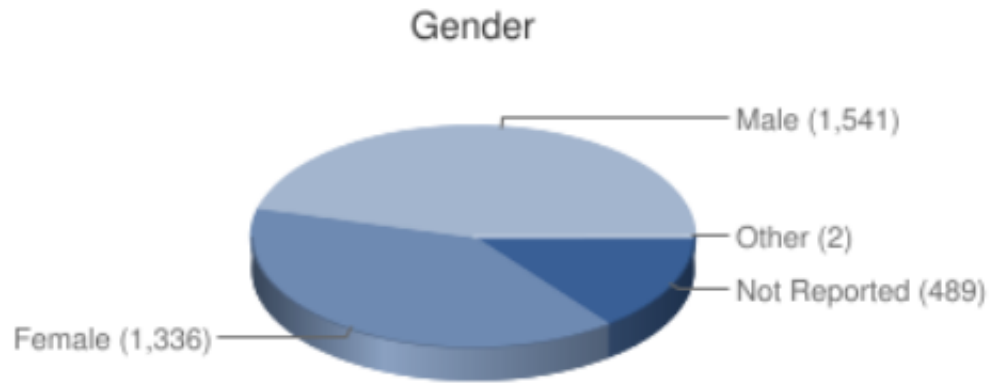


Current DS-Connect® Registrants: North America



2959 as of April 18th, 2016

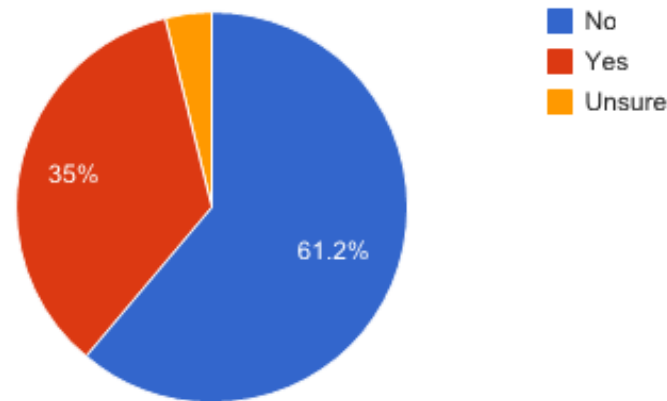
Explore the data: demographics



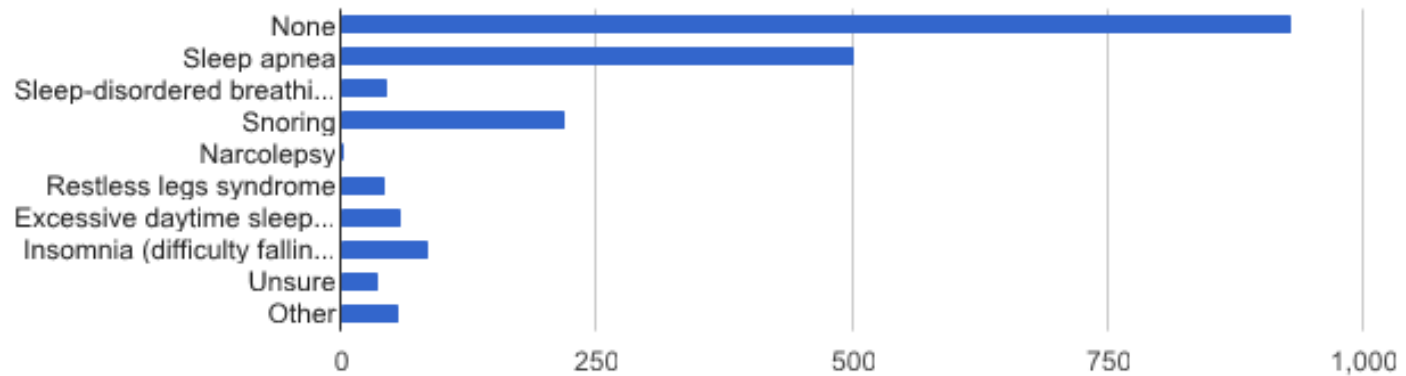


Explore the Data: Sleep

Has the participant ever been diagnosed with any sleep problems? (1803 responses)



Which of the following sleep problems have been diagnosed? (Select all that apply.)




1649 people provided 1993 response(s)



Portal for Professionals

Home About DS-Connect® News Resources Research Glossary For Professionals



How do I turn on subtitles/captions and specify their language?

[Join the Registry](#) [Set up a Professional Account](#)

DS-Connect® is a powerful resource where people with Down syndrome and their families can:

- Connect with researchers and health care providers.
- Express interest in participating in certain clinical studies on Down Syndrome, including studies of new medications and other treatments.
- Take confidential health-related surveys. These surveys are aimed at better understanding of the health of people with Down Syndrome across their lifespans.

→ **Link available on home page**



Examples of Research Requests

- Study sleep in children with Down syndrome
- Study obesity and risk of diabetes in children with Down syndrome
- Test blood samples from infants with Down syndrome for thyroid problems
- Online survey of parent experiences in feeding their children with Down syndrome
- Phone interview of parents to learn how children with Down syndrome find their way



What Can I Do to Help?

- **Sign up!**
- Spread the word
- Electronic Toolkit available:
 - Video Testimonial-YouTube
 - Facebook info-cards
 - Badges
 - Tweets
 - Flyers
- All resources free of charge
- Contact us at:
DSConnect@nih.gov



Her health information matters.

DS-Connect™: The Down Syndrome Registry
Get DS-Connected: dsconnect.nih.gov



Eunice Kennedy Shriver National Institute of Child Health and Human Development