DS-Connect™
The Down Syndrome Registry

A national registry for people with Down syndrome

What is DS-Connect™?

DS-Connect™ is a voluntary, confidential, online survey tool to collect basic information about people with Down syndrome. This information can:

- Help connect people with Down syndrome to scientists who study Down syndrome
- Promote research in Down syndrome by collecting information that scientists can use
- Help health professionals improve how they treat people with Down syndrome
- Help scientists develop new treatments that may improve the quality of life for people with Down syndrome

Once a person has registered, DS-Connect™ may contact eligible members to participate in clinical studies.

Who is sponsoring DS-Connect™?

The National Institutes of Health (NIH) has launched DS-Connect™, supported by the Down Syndrome Consortium. The Down Syndrome Consortium fosters communication and idea-sharing about Down Syndrome. The Consortium members listed below will help spread the word about the registry.

What can I do?

You can register and enter the basic health information about your loved one with Down Syndrome. You can also view the aggregate health data of all members of the registry and compare it to your information.

How do I register for DS-Connect™?

1) Go to http://DSConnect.nih.gov
2) Click the button "Join the registry" on the DS-Connect™ registry homepage
3) Create an account by entering your name, email, username, and password
4) Read the consent form and check the appropriate consent/assent boxes
5) Enter the Security code and click "Register"
6) Fill out the information about the person with Down syndrome and answer the Initial Health Questionnaire

And explore the data!

Who do I contact with questions?

You can reach us at DSConnect@nih.gov or at http://DSConnect.nih.gov

NIH National Institutes of Health
Down Syndrome Working Group
American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™
aaidd
AUCD
ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
DOWN SYNDROME AFFILIATES IN ACTION
DSMIG-USA
Down Syndrome Medical Interest Group-USA
DSRTF
Down Syndrome Research and Treatment Foundation
GLOBAL DOWN SYNDROME FOUNDATION
International Mosaic Down Syndrome Association
Jérôme Lejeune FOUNDATION
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