What is DS-Connect®?

DS-Connect®: The Down Syndrome Registry is a voluntary, confidential, online survey that collects basic health information about people with Down syndrome.

This resource was launched by the National Institutes of Health with help from the Down Syndrome Consortium, a group of national and international organizations that focus on and support the Down syndrome community (see below).

Why should I join DS-Connect®?

DS-Connect® participants can:

- Print out a summary of their health history
- Find health care providers in their area who care for people with Down syndrome
- Help health care providers improve care for people with Down syndrome
- Explore trends in the overall health of people with Down syndrome based on survey results
- Learn about new studies for people with Down syndrome
- Connect with scientists who study Down syndrome
- Help scientists develop new treatments for people with Down syndrome

How do I join DS-Connect®?

It’s easy, confidential, and secure:

1) Go to https://DSConnect.nih.gov.
2) Click the “Join the registry” link on the homepage.
3) Set up an account by creating a username and password.
4) Complete the consent/assent form.
5) Once you’ve created your profile, fill out the information about the person with Down syndrome, including the Initial Health Questionnaire and other related surveys.

Questions?

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