What is DS-Connect®?

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

The National Institutes of Health (NIH) launched this resource with help from the Down Syndrome Consortium, a group of self-advocates and national and international organizations that focus on and support the Down syndrome community.

Why should I join DS-Connect®?

People who join DS-Connect® can:
- Print out a summary of their health history.
- Compare the growth of a person with Down syndrome to standard growth charts for people with Down syndrome.
- Find healthcare providers for people with Down syndrome in their area.
- Help providers who care for people with Down syndrome improve that care.
- See trends in the overall health of people with Down syndrome, based on answers to questions in DS-Connect®.
- Learn about new studies that people with Down syndrome can join.
- Stay up to date on healthcare guidelines 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®?

2. Select 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.

Once you’ve created a profile, tell us about the person with Down syndrome and his or her health by answering questions and completing surveys.

Joining is easy, confidential, and secure.

Questions?

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

DS-Connect® is funded by NIH and supported by the Down Syndrome Consortium, which includes the following members:

American Academy of Pediatrics

American Association on Intellectual and Developmental Disabilities

Association of University Centers on Disabilities

National Down Syndrome Congress

Down Syndrome Affiliates in Action

Special Olympics

Alzheimer's Association

Global Down Syndrome Foundation

International Mosaic Down Syndrome Association

Jérôme Lejeune Foundation

Lumind

Down Syndrome Medical Interest Group-USA

National Down Syndrome Society

Self-advocates

t2i Research Society

Down Syndrome International

National Task Group on Intellectual Disabilities and Dementia Practices

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