

# DS-Connect<sup>®</sup>

## The Down Syndrome Registry



### What is DS-Connect<sup>®</sup>?

**DS-Connect<sup>®</sup>: 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<sup>®</sup>?

**People who join DS-Connect<sup>®</sup> 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<sup>®</sup>.
- 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<sup>®</sup>?

1. Visit <https://DSConnect.nih.gov>.
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](mailto:DSConnect@nih.gov) or at <https://DSConnect.nih.gov>.