

DS-Connect[®]

The Down Syndrome Registry

Join DS-Connect[®] and help families with Down syndrome



What is DS-Connect[®]?

DS-Connect[®], a resource to better understand the health characteristics and needs of people with Down syndrome, stores health and other basic information about people with Down syndrome in a secure, online format. Through its Professional Portal, DS-Connect[®] makes de-identified data available to any approved scientist, healthcare provider, Down syndrome organization or research foundation member, industry representative, or other professional interested in 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 Down syndrome and support the Down syndrome community.

Why should a healthcare professional join DS-Connect[®]?

Approved professionals can use DS-Connect[®] to:

- View aggregate, de-identified registry data.
- Perform advanced searches.
- Identify medical needs of people with Down syndrome.
- Determine study feasibility.
- Plan for research studies and clinical trials.
- Post notices about clinical studies.
- Inform public presentations or publications.
- Propose new survey modules or tools.
- Request a letter of support.
- Request row-by-row de-identified participant data.
- Recruit research participants.

How can a professional register for DS-Connect[®]?

1. Visit <https://DSConnect.nih.gov>.
2. Select **Set up a Professional Account** on the homepage.
3. Enter information about your institution or organization and contact information. Then create a username and password and agree to the Terms of Use and the Research Review Policy.
4. Finalize your registration by selecting the **Register** button.

DS-Connect[®] offers three levels of access to reflect professional users' differing needs for information and access to participants. You will receive level 1 access when you register. Once you have level 1 access, you can request higher levels of access, depending on your research interests and needs.

Down Syndrome Consortium

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

