

DS-Connect: The Down Syndrome Registry

<https://dsconnect.nih.gov/>

National Institutes of Health establishes Down syndrome patient registry

A new Down syndrome patient registry will facilitate contacts and information sharing among families, patients, researchers and parent groups. The National Institutes of Health has awarded a contract to PatientCrossroads to operate the registry. The company has created patient-centric registries for muscular dystrophy and many rare disorders.

People with Down syndrome or their family members will be able to enter contact information and health history in an online, secure, confidential database. Registry participants will be able to customize their profile, update it online, and choose which information they would like to display, including reminders about their own medical care and general information about Down syndrome. They also will be able to compare their own medical information to that of other registrants in a confidential and anonymous manner.

If a participant gives permission to be contacted, clinicians and researchers who are authorized to access the database will be able to contact these individuals to see if they are interested in participating in a research study.

Ultimately, the registry will be able to link to biorepositories of tissue samples and other resources, with the goal of making it easier for patients to take part in clinical studies for new medications and other treatments for Down syndrome.

Goals of NICHD Research on Down Syndrome

The NICHD has a long history of conducting and supporting research on Down syndrome and related disorders. When the Institute was established in 1962, one of its primary charges was to encourage investigations on human development throughout the lifespan, with an emphasis on understanding IDD, including Down syndrome.

Since then, researchers have explored the chromosomal causes of the syndrome, created animal models to test interventions, assessed long-term outcomes for people living with the syndrome, and addressed many other biomedical and behavioral topics.

Many of the NICHD's goals for research on Down syndrome align with topic areas described in the [NIH Research Plan on Down Syndrome](#). The Institute played a lead role in developing the Research Plan as part of the trans-NIH Working Group on Down Syndrome, which aims to build on the existing research foundation and to coordinate Down syndrome research at the NIH.