

Down Syndrome Research Resources from the National Institutes of Health (NIH): DS-Connect® and the Registry Professional Portal

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BACKGROUND

The National Institutes of Health (NIH) has supported research in Down syndrome (DS) to better understand and to develop treatments for those with this chromosomal disorder. This poster will highlight some of these resources:

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), NIH, launched *DS-Connect®: The Down Syndrome Registry* (<http://DSConnect.nih.gov>) in 2013 to facilitate information sharing among persons with DS, families, and researchers. The Registry has been supported by the Down Syndrome Consortium. As of May 2020, the registry has reached 5000 participants.

Participants enter demographic and health information into the online, secure, confidential *DS-Connect®* database. They can answer surveys, see graphs of their child's growth parameters, add medication information, look up local health care providers, and view aggregate de-identified data from all participants. A Spanish language version as well as a mobile-device interface has also been launched. We have also added COVID-19 related questions within the Initial health questionnaire and other surveys. Accessing information on clinical trials in DS funded by NIH (<https://clinicaltrials.gov/>) will soon be launched on the website as a resource.

Opportunities for clinicians and researchers to access the *DS-Connect®* professional portal include 3 levels of access depending on their needs. A summary of research projects that have used *DS-Connect®* is described.

DS-CONNECT®

DS-Connect®: The Down Syndrome Registry
A secure, confidential, online survey tool to collect basic health information about people with Down syndrome

Goals of DS-Connect®:

- To identify the various phenotypic manifestations of DS
- To identify individuals with DS who may be eligible for research studies
- To allow individuals with DS and their families to look at their information and compare it to de-identified information from other Registry participants

Features:

- Potential to aggregate data from individuals with DS globally
- Provide a patient-centered system that has value for individuals with DS
- Enable researchers to use de-identified data to develop studies on etiology, natural history, and treatments



NIH National Institutes of Health
Down Syndrome Registry

DS-Connect® is a powerful resource where people with Down syndrome and their families can:

- Connect with researchers and health care providers.
- Express interest in participating in certain clinical studies on Down Syndrome, including studies of new medications and other treatments.
- Take confidential health-related surveys. These surveys are aimed at better understanding of the health of people with Down Syndrome across their lifespan.

[Join the Registry](#) [Set up a Professional Account](#) [Information an español](#)

<https://DSConnect.nih.gov>

DS-CONNECT: EXPLORE THE DATA

DS-Connect Registrants: North America



3917 as of May 31st, 2020

Professional Portal: Level 3 Access

- **Access Level 1:** View data identical to Registrant's view and perform basic searches of de-identified data
- **Access Level 2*:** More customized searches, statistical analysis, publication or presentation
- **Access Level 3*:** For study recruitment, posting a study announcement, to propose a new survey module, or for commercial purposes.

*Requires submission of a summary of protocol, purpose and IRB Status and review by the Research Review Committee for approval

In the past 6 years:

- 21 applications have been submitted for level 2 access
- 54 studies have been submitted for level 3 access (92% success rate)
- 5 INCLUDE projects have received recruitment support

REGISTERED PROFESSIONALS



Almost 447 researchers have registered a professional account (Level 1 access)

PUBLICATIONS

- Marie Moore Channell: Cross-Sectional Trajectories of Mental State Language Development in Children With Down Syndrome. *Am J Speech Lang Pathol* 2020 May 8;29(2):760-775
- Michele Polfuss: The influence of a developmental disability on the child's weight-related behaviors: A parent's perspective. *Journal of Pediatric Nursing*, 47 (2019), 121-130
- Randall Roper: Usage of and attitudes about green tea extract and Epigallocatechin-3-gallate (EGCG) as a therapy in individuals with Down syndrome- (*Complementary Therapies in Medicine*, 45 (2019) 234-241)
- Amy Lewanda: Patterns of Dietary Supplement Use in Children with Down Syndrome, *The Journal of Pediatrics*, Volume 201, 100 - 105
- Yingying Yang and Edward C. Merrill: Parent reports of wayfinding by their children with Down syndrome, *Journal of Intellectual & Developmental Disability*, 43:4, 483-493
- Michele Polfuss: Parental Feeding Behaviors and Weight-Related Concerns in Children with Special Needs, *Western Journal of Nursing Research*, 1-24
- Jennifer Price Corder: Demographics and co-occurring conditions in a clinic-based cohort with Down syndrome in the United Arab Emirates. *American Journal of Medical Genetics*, 1-13

CONCLUSIONS

- ❖ **DS-Connect is a powerful online family registry that connects families to research opportunities**
- ❖ **With a professional account, you can use DS-Connect to help recruit for your studies**
- ❖ **Survey based research has tremendous success rate of completion**