Join DS-Connect® and help Families with Down syndrome

What is DS-Connect®?
DS-Connect® is a resource to better understand the health characteristics and needs of people with Down syndrome. The purpose of the DS-Connect® Registry is to store health and other basic information about people with DS in a secure online format. DS-Connect® makes the de-identified data available to any approved scientists, health care providers, members of DS organizations, industry representatives, research foundation members, or other qualified professional interested in Down syndrome through the Professional Portal. This resource has been launched by The National Institutes of Health (NIH) with help from the Down Syndrome Consortium.

Why should a professional join DS-Connect®?
The information in DS-Connect® can be used by approved professionals to develop research projects and recruit for clinical trials, while still protecting the privacy of the registry participants. The data can be used to:

- View aggregate de-identified registry data and perform advanced searches
- Identify medical needs among those living with Down syndrome
- Determine study feasibility and plan for clinical trials and research studies
- Post notices about clinical studies on DS-Connect®
- Recruit subjects through DS-Connect® for research or a clinical trial
- Use registry data in a public presentation or publication
- Propose new survey modules or tools

How can a professional register for DS-Connect®?
The registry has established three “levels of access” to reflect the differing needs of professional users because projects vary in the types of information required and in their need to have access to participants.

- Go to https://DSConnect.nih.gov
- Click the button “Set up a Professional Account” on the homepage
- Enter your contact information, name of institution or organization, a contact person at your institution, a username and password
- Click “register” button. This will allow you level 1 access and you can use this level of access to request higher levels of access depending on your research and interests.

Questions?
Contact us at DSConnect@nih.gov or at https://DSConnect.nih.gov.