

NIH launches first national Down syndrome registry

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The National Institutes of Health has launched [DS-Connect](#), a Web-based health registry that will serve as a national health resource for people with Down syndrome and their families, researchers, and health care providers.

"The Down syndrome community has voiced a strong need for a centralized, secure database to store and share health information. DS-Connect fills that need, and helps link individuals with Down syndrome to the doctors and scientists working to improve their health and quality of life," said Yvonne T. Maddox, deputy director of the NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), which funded and developed the registry.

Participation in the registry is free and voluntary. Individuals with Down syndrome, or family members, on their behalf, may sign up to create personalized profiles with information about their health histories, including symptoms, diagnoses, and medical visits. The website has been designed to ensure that all information remains confidential. The site will separate users' names from their health information, so that individuals may compare their [health information](#) with that of all other participants in an anonymous manner.

If participants give permission to be contacted, the registry coordinator can inform them of research studies in which they may be interested. Results from these studies will help researchers better understand Down syndrome and how to treat its accompanying health problems across the

lifespan.

"DS-Connect is for people of all ages, not just children," said Dr. Maddox. "Right now, we don't have much data on older individuals with Down syndrome, and that's been a problem. People with Down syndrome are living longer, and researchers and physicians will require information about the health issues and needs of these individuals to make recommendations about their health care."

The [Down Syndrome Consortium](#), a public-private group established in 2011 to foster the exchange of information on Down syndrome research, will be a critical player in helping to disseminate information about the registry to the Down syndrome community. The consortium includes individuals with Down syndrome and their family members, representatives from professional societies and advocacy groups, and NIH scientists.

"We've been fortunate to have so many experts and advocates provide input on this effort," said Dr. Maddox. "The establishment of this registry is a tremendous step forward for Down syndrome research, and the resource will become all the more beneficial as more individuals join in the months and years ahead."

Provided by National Institutes of Health

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