

NIH launches tool to advance Down syndrome research

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DS-Connect: The Down Syndrome Registry

The National Institutes of Health has launched a subsite of DS-Connect: [The Down Syndrome Registry](#) for researchers, clinicians, and other professionals with a scientific interest in Down syndrome to access de-identified data from the registry. This Web portal will help approved professionals to plan clinical studies, recruit participants for clinical trials, and generate new research ideas using information gathered from the registry participants.

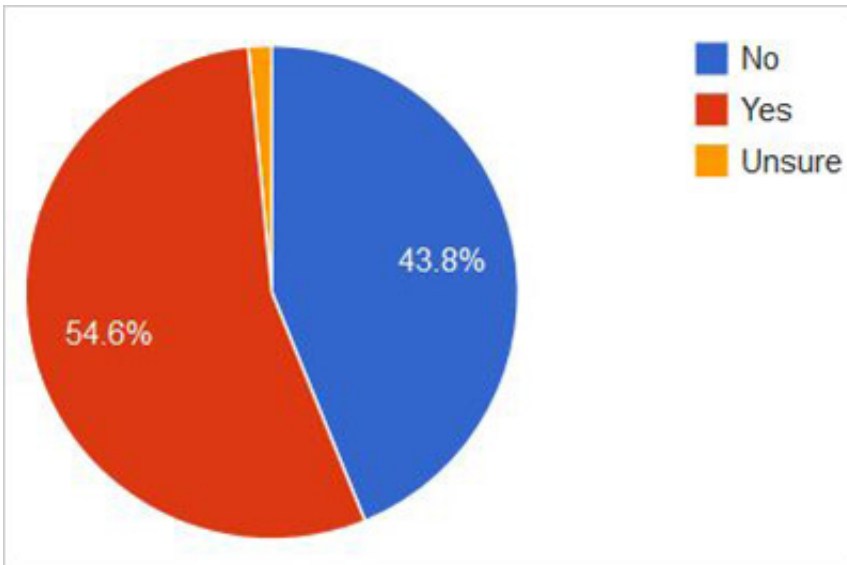
"DS-Connect is a centralized, secure website where people in the Down syndrome community can store their health information related to Down syndrome. Participation in the registry is completely voluntary and can be withdrawn at any time," said Melissa Parisi, M.D., Ph.D., of the

Eunice Kennedy Shriver National Institute of Child Health and Human Development, which funded and developed the registry. "It's also a valuable resource for professionals in health care and science, who can use the de-identified data from the registry to better understand the health characteristics and needs of people with Down syndrome."

De-identification is the process of separating personal information from the person who contributed the data. The practice is commonly used to keep [health information](#) confidential.

People with a scientific interest in Down syndrome may sign up for a free professional account to access the data. After registering, they can then view information about participants' health histories, including symptoms, diagnoses, and other medical issues. Researchers may also apply for higher-level access to perform customized searches of the data, propose new survey questions, or identify a pool of participants for a clinical trial. The DS-Connect registry coordinator will then notify eligible participants who have previously indicated a willingness to be contacted about opportunities to enroll in clinical trials.

"DS-Connect allows people to participate from all corners of the globe," said George T. Capone, M.D., director of the Down Syndrome Clinic and Research Center at Kennedy Krieger Institute in Baltimore. "They answer the same kinds of health questions, and that permits researchers to identify similarities, differences, and important trends in the population that may then be the basis for further, more focused, research studies."



Excerpt from DS-Connect Initial Health Questionnaire: Has the participant been diagnosed with a congenital heart defect (a birth defect of the heart)?

Results from these studies are intended to increase understanding of Down syndrome and how to treat its accompanying health problems across the lifespan. People with Down syndrome are at increased risk for a range of other [health](#) conditions, including [autism spectrum disorders](#), problems with hormones and glands, hearing loss, vision problems, and heart abnormalities.

"For the purpose of conducting [clinical trials](#), the DS-Connect registry can provide a large pool of potential participants who share common features, such as medical condition, age, and gender," said Dr. Capone.

DS-Connect was launched in September 2013, with input from the Down Syndrome Consortium, a public-private partnership established to foster the exchange of information on Down syndrome research.

"Our partners have played a terrific role in getting the word out to

families about DS-Connect," said Dr. Parisi. "Now that the registry's professional portal is live, we're eager to let researchers and clinicians know about this resource, too. Sharing this data will help us do the research needed to better serve people living with Down [syndrome](#)."

More information: DS-Connect: the Down Syndrome Registry: dsconnect.nih.gov/

Provided by National Institutes of Health

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