

## The National Database for Autism Research announces its first data release

November 30 2010

Autism Spectrum Disorder (ASD) researchers now can use data from over 10,000 participants enrolled in ASD studies. The National Database for Autism Research (NDAR), created by the National Institutes of Health, recently made the data available. Researchers can now use the NDAR portal to perform queries that simultaneously yield results from multiple datasets. The portal was designed to provide tools to define and standardize data collected by different laboratories under different protocols. It was also built to ensure a collaborative approach and open data access to the whole ASD research community.

Researchers supported through the NIH <u>Autism</u> Centers of Excellence were the first to contribute data to NDAR in 2008. Since then, NDAR staff has been working to define, standardize and transfer data into NDAR from earlier NIH programs, such as the Collaborative Programs of Excellence in Autism (CPEA) and Studies to Advance Autism Research and Treatment (STAART).

Data from the majority of ASD grants that were recently funded under the American Recovery and Reinvestment Act of 2009, as well as data from other ASD studies conducted at NIH, also will be submitted to and shared through NDAR. It is expected that data from newly-initiated NIH-funded autism research will be added to NDAR. Other ASD researchers have also been encouraged to contribute their study data, regardless of funding source.

Two goals were outlined in the Interagency Autism Coordinating



Committee 2010 Strategic Plan for ASD Research. The first goal is to create mechanisms to specifically support the contribution of data to NDAR from 90 percent of newly initiated projects by 2012. The second goal is to link NDAR by 2012 with other significant existing data resources including the Autism Genetic Resource Exchange; the Interactive Autism Network; the National Institute of Mental Health's (NIMH) Genetics Repository; the NIMH Transcriptional Atlas of Human Brain Development; and the Pediatric MRI Data Repository.

The Autism Genetic Resource Exchange is an electronic data repository housing information from more than 1,000 families affected by ASD. It is created by the advocacy group Cure Autism Now and is currently supported by Autism Speaks.

The Interactive Autism Network is an online project of the Kennedy Krieger Institute with funding from Autism Speaks, which contains data on 30,000 individuals with an ASD diagnosis whose families have voluntarily submitted information of interest to scientists.

The NIMH Genetics Repository stores clinical data, biological materials, and genetic analysis data from more than 3,000 individuals with ASD.

The NIMH Transcriptional Atlas of Human <u>Brain Development</u> aims to map when and where in the brain genes are transcribed through development.

The Pediatric MRI Data Repository receives support from four NIH institutes including the National Institute of Mental Health, and stores data from more than 500 typically developing children, from birth to young adulthood.

More information: <a href="https://www.hhs.gov/recovery">www.hhs.gov/recovery</a>



## Provided by National Institutes of Health

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