

Autism Speaks announces the release of new genetic data for researchers

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Autism Speaks, the world's leading autism science and advocacy organization, is proud to announce the release of biological and clinical data from 383 new families participating in Autism Speaks Autism Genetic Resource Exchange (AGRE) to researchers. AGRE is a resource for scientists that is comprised of clinical and biological data from families who have two or more children on the autism spectrum. These 383 families are part of a larger pool of 653 individuals with an autism spectrum disorder (ASD) bringing the total data available on people with an ASD to 3348. The family data also includes family members without an ASD bringing the total to 9335 individuals, which reflects an over 24 percent increase.

"One of the biggest challenges for researchers is trying to recruit families and gather information for their research in a timely manner," said Autism Speaks Vice President of Clinical Affairs Clara Lajonchere. "AGRE accelerates the pace of research by taking these time-consuming steps out of the hands of researchers, so they can spend their time and effort analyzing the data and looking for answers now." AGRE's job has been to gather DNA, clinical, and medical information from families throughout the United States, making it the world's first collaborative resource for autism research worldwide.

Thus far, the data collected and made available by AGRE has resulted in 205 significant research publications. One example of the exciting research being done with AGRE data is a study published in 2011 that found that pregnancy and the birth environment may affect development

of autism in twins. The ground breaking study suggested that [environmental influences](#), which could include parental age, [low birth weight](#), [multiple births](#), and maternal infections during pregnancy, may greatly increase risk for ASD. The findings support the notion that both genetic and shared environmental factors significantly increase risk for ASD: an estimated 38 percent of risk being associated with genetic heritability and 58 percent with the environment that twins share during pregnancy and perhaps early infancy. The study also found that the relative contributions of shared genes and shared environment are similar for males and females.

"The data on these new families, also available through the National Database for Autism Research (NDAR), further enhances the informatics infrastructure developed by Autism Speaks and the NIH," commented Dan Hall, NDAR project science manager. Combining these data, with those collected across many other projects gives researchers an unprecedented opportunity to accelerate scientific discovery."

Though AGRE was able to collect data on over 1,700 families nationwide, it became apparent that this in-home model of collection needed to adapt in order to meet the growing needs of the autism research community. In an effort to continue its mission to accelerate the pace of [autism research](#), Autism Speaks has decided to transition AGRE to an outsourced model of collection. In this innovative new model, data collection will take place at a variety of centers nationwide (most immediately at several sites in Autism Speaks Autism Treatment Network) and be centralized and made available through AGRE. This creates a one-stop shop for researchers to access an exponentially growing resource and allows the studies to focus on collection.

More information: Approved researchers have access to AGRE's pedigree catalog which is downloadable from the website (research.agre.org/). This file is only available within the password

protected area of the AGRE website. To become an approved researcher, simply fill out an application online (research.agre.org/application/researcherapp.cfm).

Provided by Autism Speaks

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