

THIS STUDY NO LONGER RECRUITING

Name of Study: Factors Influencing the Utilization of Genetic Services for Families of Children with Autism Spectrum Disorders

Institution: Stanford University School of Medicine in conjunction with Stanford Hospital and Lucille Packard Children's Hospital

Location: Web-Based Survey: No geographic limitation within the United States

Eligibility Criteria: Parents, Guardians or Primary Caregivers above the age of 18 currently living with a child under the age of 18 who has a professional diagnosis of autism spectrum disorder (ASD)

Principal Investigator: Dr. Jon Bernstein, M.D., Ph.D.

Contact Information: Kimberly Vande Wydeven; email: kvandewy@stanford.edu; phone: (650) 725-4644

Study Link: <https://med.stanford.edu/survey/utilizationgeneticsASD/>

You are invited to join a study that seeks to identify factors that limit families' access to genetics doctors and genetic counselors. Genetic counselors work with families to help them understand the results of genetic testing, and how a genetic condition may affect their family. This survey explores whether a family has used genetic testing, doctors or counseling services, what they know and understand about the potential usefulness of these, and whether they are able to access such services (in terms of availability, money, insurance, etc). With the information gained from this survey, we hope to learn how genetics doctors and genetic counselors can better serve families who have children with ASD.

The study will consist of a **10-15-minute survey**. If you are interested in participating, please click on the following survey link: <https://med.stanford.edu/survey/utilizationgeneticsASD/>

Your responses are completely voluntary, anonymous and confidential. All responses will be compiled together and analyzed as a group and no information will be linked back to your child. While results of this survey may not impact your child directly, we do hope that it will help many children with autism spectrum disorders like yours and their families in the future.

As our way of saying "thank you," there will be an optional drawing for two \$50 gift cards from Amazon.com. To participate in the drawing, all you need to do is follow the link at the end of the survey to let us know your email address. You do not need to enter the drawing to participate in the survey and you do not need to complete the survey in order to enter the drawing. The winners will be informed via the email address provided. Email addresses entered as part of the drawing will not be associated with individual responses to the survey questions. The drawing will take place on May 30, 2011.

If you have any questions or concerns, please contact Kimberly Vande Wydeven, the protocol director for this survey, at (650) 724-7190 (box #7), or kvandewy@stanford.edu.

THIS STUDY NO LONGER RECRUITING

If you would like to see the results of the survey, please email Kimberly Vande Wydeven at kvandewy@stanford.edu with the subject line “ASD Genetics Study Results” and we will send you a copy of the paper following its publication in a peer-reviewed journal.

Thank you in advance for your time and assistance.

Jon Bernstein M.D., Ph.D.
Stanford University School of Medicine

Kimberly Vande Wydeven
M.S. Candidate in Human Genetics and Genetic Counseling
Stanford University School of Medicine

IAN Research ID SR00327