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### **Genetic Alliance Launches National Survey on Genetic Services**

WASHINGTON, DC (September 28, 2015) –Genetic Alliance, in its role as the National Genetics Education and Consumer Network, announced today the launch of a national survey to better understand the healthcare experiences of individuals with genetic conditions. This survey is the latest keystone activity within a two-year effort to propose a framework for a new model of regional genetic services.

“To create an effective healthcare system for individuals and families with genetic conditions, we must first listen to their voices and their needs . With this new survey, Genetic Alliance will harness voices throughout our network to make clear concrete recommendations for improving genetic services and support,” says James O’Leary, Chief Innovation Officer at Genetic Alliance.

The survey explores areas in which families reported barriers, including: 1) identification of the condition; 2) finding services, information, and support; 3) accessing care; 4) telemedicine; 5) adult care; and 6) care beyond the clinician’s office. Throughout the survey development process, Genetic Alliance worked closely with healthcare advocates and individuals with a wide range of conditions and experiences. Genetic Alliance encourages partners to share this link with members, friends, and anyone who may be interested in contributing to this effort.

Individuals interested in completing the survey should visit:  
[www.surveymonkey.com/r/ImprovingGeneticServices](http://www.surveymonkey.com/r/ImprovingGeneticServices)

This survey is an activity of the National Genetics Education and Consumer Network (NGECN), an effort led by Genetic Alliance in partnership with [National Coordinating Center for Regional Genetics Collaboratives](#) (NCC), which is led by the [American College of Medical Genetics and Genomics](#) (ACMG).

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### **About Genetic Alliance**

Genetic Alliance engages individuals, families, and communities to transform health. Founded in 1986, it is the world's largest nonprofit health advocacy organization network. Genetic Alliance's network includes more than 1,200 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. *For more information about Genetic Alliance, visit [www.geneticalliance.org](http://www.geneticalliance.org).*