FOR IMMEDIATE RELEASE

Empowering Individuals and Families as Advocates

The Advocacy ATLAS: Accessible Tools for Leadership and Advocacy Success

Washington, DC- October 10, 2013- Genetic Alliance, in partnership with Family Voices and Parent to Parent USA, announced today the launch of a new online resource for individuals with special healthcare needs and their families. The Advocacy ATLAS: Accessible Tools for Leadership and Advocacy Success, features over 250 tools and resources to help new and experienced advocates communicate their needs around services, support, and access.

These resources aim to help individuals with special healthcare needs and their families navigate a world often full of barriers and inaccessibility. The Advocacy ATLAS features resources and perspectives on youth leadership, transition to adulthood, insurance and financial assistance, communicating about your health, access to healthcare, and more. Genetic Alliance, Family Voices, and Parent to Parent USA will continue to reach out to partners for new resources to expand the utility of the Advocacy ATLAS with new and experienced advocates alike.

“Advocacy is an important part of life for individuals and families with genetic conditions, disabilities, and special healthcare needs,” explains Sharon Romelczyk, Programs Manager of the National Genetics Education and Consumer Network at Genetic Alliance. “When faced with barriers, challenges, or even new experiences, individuals may have to speak up to have their voices and needs heard. In creating the ATLAS, we have compiled the best resources to empower individuals to advocate and take steps to get what they want and need.”

Kathy Brill, Executive Director of Parent to Parent USA says, “the ATLAS is different from other advocacy tools because it is not only useful, but also empowering. Every topic in the ATLAS is accompanied by a personal story to show examples of advocacy success, and each of the hundreds of tools has already been fully evaluated by parents and advocates and deemed to be useful and effective. The Advocacy ATLAS is the toolkit to visit to find useful tools, all in one location, needed for creating strong, effective advocacy efforts!”

It can be a challenge for both new and experienced advocates to locate quality resources that will help them get the services, support, and access they need. Each of the featured tools and resources was drawn from a vast combined network of parents, parent advocacy groups, disease-specific advocacy groups, disability groups, and other relevant partners. Prior to being included, all resources were carefully vetted by a development committee using standardized criteria to ensure that each resource was relevant and provided quality information.

Bev Baker, Co-Director of the National Center for Family Professional Partnerships (NCFPP) at Family Voices says, “In merging our networks, we have been able to make the Advocacy ATLAS a truly collaborative effort to distribute the best and most credible resources available. By incorporating individuals and families with special healthcare needs from the start, we have created a go-to resource that will empower individuals to advocate throughout the lifespan.”
About The National Genetics Education and Consumer Network (NGECN)

The Advocacy ATLAS was created as part of a larger initiative called the National Genetics Education and Consumer Network (NGECN). NGECN is a three-year program led by Genetic Alliance, a non-profit dedicated to transforming health through genetics. The program is funded by the Health Resources Services Administration (HRSA) to create a network of partnerships and accessible tools. Our goal is to improve consumers’ (individuals with genetic conditions and their families) access to and knowledge about genetic services. By working with partners such as Parent to Parent USA and Family Voices, we hope to empower individuals and families by making resources and information more accessible.

The Advocacy ATLAS was developed by Genetic Alliance in partnership with Parent to Parent USA and Family Voices. This project is funded by the Health Resource and Service Administration (HRSA), Grant no. U22MC04100, National Coordinating Center for the Regional Genetic Services Collaboratives.