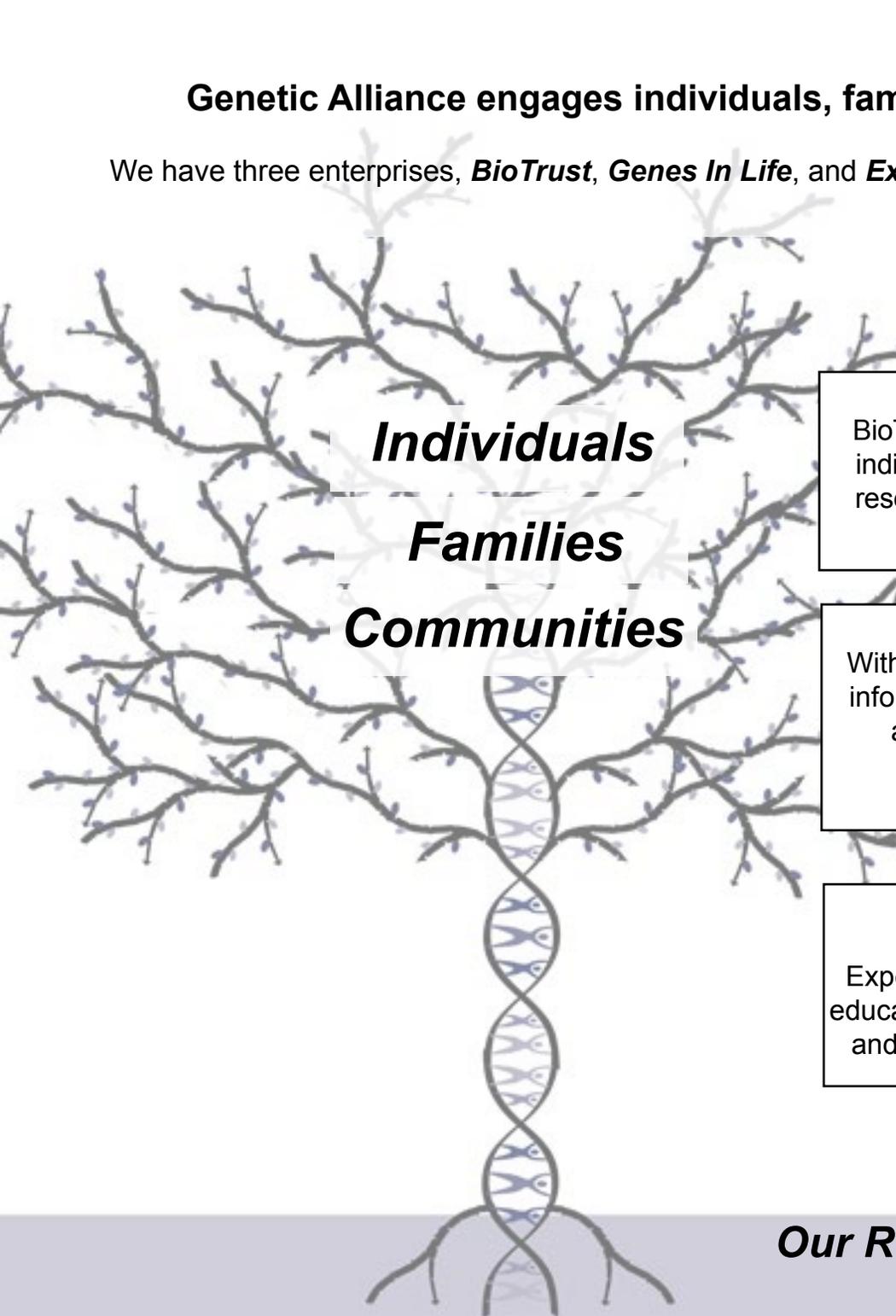


Genetic Alliance engages individuals, families, and communities to transform health.

We have three enterprises, *BioTrust*, *Genes In Life*, and *Expecting Health* as well as a number of cross-cutting programs.



Individuals

Families

Communities

BioTrust

BioTrust examines and influences policies, and provides novel tools for individuals, families, and communities to actively engage in biomedical research. The BioTrust Ethics Team, together with the Genetic Alliance Institutional Review Board, provides oversight.

Genes In Life

With better health as the goal, Genes In Life puts genetic and genomic information into context for individuals and families. Our tools increase access to services and our combination of accessible, culturally competent print and web resources and health information technologies empower people to make healthy decisions.

Expecting Health

Whether you are planning a family or advocating for your child, Expecting Health has tools that lead to more informed decision-making, educate consumers around appropriate testing and public health services, and help individuals navigate the complex health care delivery system.

Our Roots: Since 1986, Genetic Alliance has been the voice of advocacy in genetics. We are dedicated to enabling consumers to be the center of the healthcare system and to take charge accordingly.

Highlighted Activities

Standards and Tools for Data Sharing Webinar Series

This webinar series is examining the plethora of tools and resources available to make use of health-related data. Throughout the series we will examine standards, common data elements, validated instruments, algorithms, queries, and methods for small and large data.

www.GeneticAlliance.org/Webinars

Pediatric Patients with Genetic Conditions: Understanding Their Needs and Experiences

This research project is designed to answer key questions about how individuals with genetic conditions access care in the context of a medical home, as well as receive transition services. The answers will be helpful in providing a snapshot of healthcare experiences of individuals with genetic conditions and their families.

The IMPACT Awards

Genetic Alliance, as part of the National Genetics Education and Consumer Network (NGECN), is funding seven proposals to expand the reach of existing outreach and education programs and improve access to genetic services and support. A total of \$175,000 will be distributed as part of the award process. The awardees have been selected, and their projects began May 1.

www.GeneticAlliance.org/ImpactAwards

Research in Premature Babies

With 1 in 8 babies born prematurely in the United States, Genetic Alliance is committed to ensuring the continuation of ethical and appropriate research on this vulnerable population. In the upcoming months, Genetic Alliance will hold meetings and a range of activities to gather information and support for the beneficial research of premature babies.

Guide to Successful Outreach and Education Programs

This web-based guide focuses on elements of successful outreach and education programs, highlighting at least one project in four categories: improving access to screening, services, support, and empowering consumers. Each highlight example focuses on specific elements that go into planning, developing, implementing, and evaluating a successful outreach program.

www.GeneticAlliance.org/OutreachEducGuide

PCORnet: The National Patient-Centered Clinical Research Network

PCORI's National Patient-Centered Clinical Research Network was created to help improve patient outcomes by connecting researchers, clinicians, health systems, patients, and others. Sharon Terry is leading these efforts as chair of the steering and executive committees in addition to Genetic Alliance's project, Community Engaged Network for All (CENA).

www.GeneticAlliance.org/CENA

