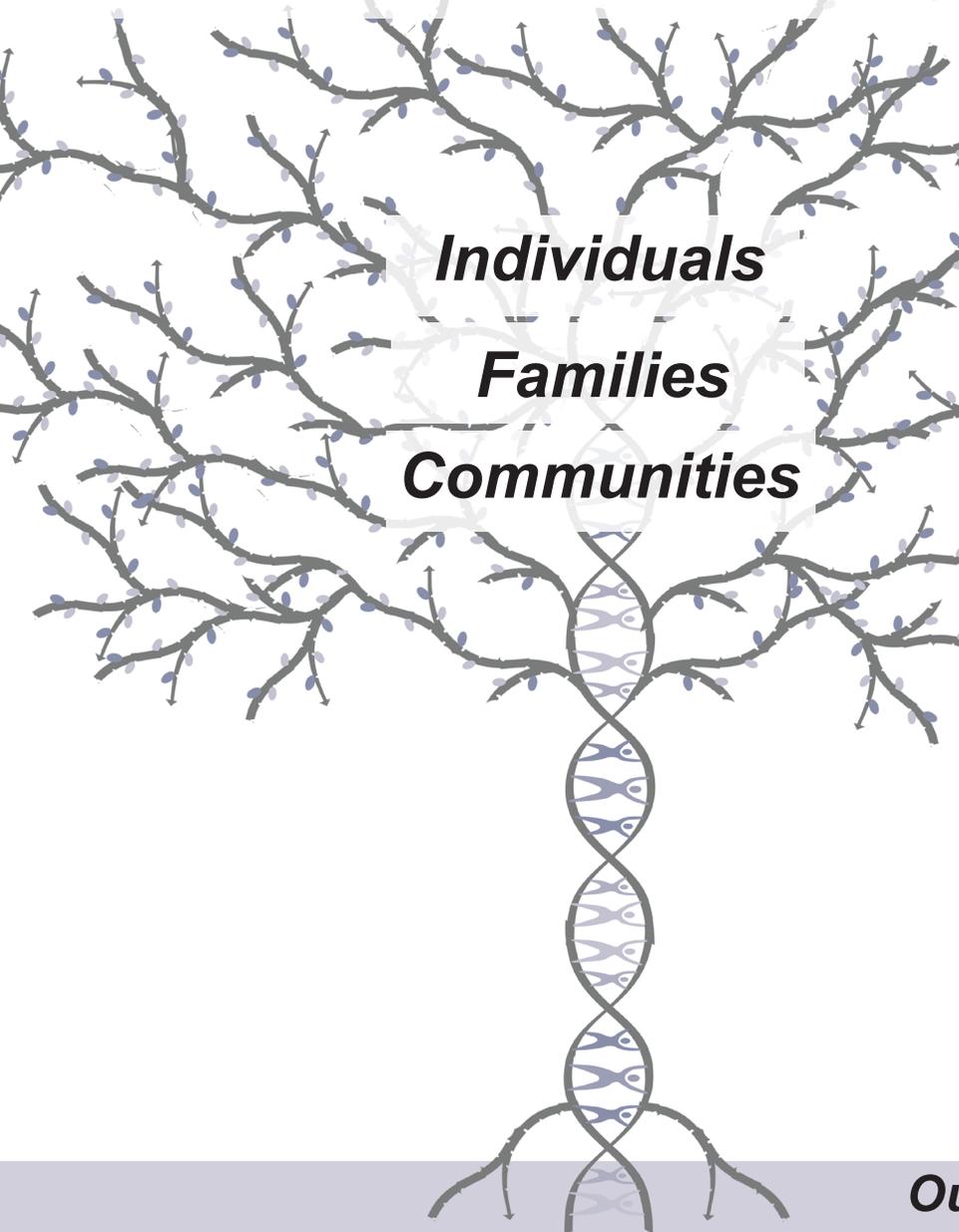


Genetic Alliance transforms health by engaging individuals, families, and communities.

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 holds the space for individuals, families, and communities to participate in translational research. The revolution in health will only happen with people at the heart of it. BioTrust examines and influences policies, and provides novel tools for participants to actively engage in research. The BioTrust Ethics Team, together with the Genetic Alliance Institutional Review Board, provides oversight.

Genes In Life

With better health as the goal, Genetic Alliance puts genetic and genomic information into context for individuals and families. Our tools increase access to services and provide the information people need, when they need it. From family health history to whole genome sequencing, our combination of accessible, culturally competent print and web resources, multimedia, and health information technologies empower people to make healthy decisions.

Expecting Health

Engaged families are informed, educated and have access to information and services when they need them most. If you are planning a family or advocating for your child, Expecting Health meets a critical need in the health delivery landscape. We have 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

Platform for Engaging Everyone Responsibly (PEER)

Together with partner Private Access, Genetic Alliance has created PEER to collect self-reported clinical data, and eventually electronic health record data, transmitted by participants' providers. PEER enables participants to share their clinical information and biological specimens under access-permission rules the participants define themselves.

Patient-Focused Drug Development

PEER is presently deployed in our Patient Focused Drug Development Initiative, providing individuals with a vehicle to bring their perspectives about the risks and benefits of drug development to the FDA.

GenesInLife.org has Launched!

This web resource provides individuals, families, and healthcare professionals with accurate and accessible information on genetics and health. Information is packaged in five main topic areas, and each section highlights additional print and web resources from both Genetic Alliance and our network of partners.

A New Interface for DiseaseInfoSearch.org

DiseaseInfoSearch.org is an online database of nearly 10,000 conditions that includes information about the signs and symptoms of each condition, the latest research, and how to access support. The new interface has improved usability and facilitated the expansion of our disease database. With our partners, we created algorithms that pull information from public databases to complement information provided and vetted by the Disease Advocacy Organizations (DAOs). We were also able expand our list of updated DAOs to 650 organizations and garnered almost 40,000 unique views in seven months.

Survey on Access to Care for Individuals with Genetic Conditions

The survey had 1,895 valid responses. The data collected is the first of its kind, summarizing responses on access to care and support from individuals reporting one or more genetic condition across the life course. Further data analysis and report writing will be used to inform future efforts around access to care and support.

Innovation in Screening Funded

Genetic Alliance entered its third year of funding projects that integrate Baby's First Test into new or existing outreach, engagement, or educational efforts. Each year, Genetic Alliance funds proposals up to \$20,000 each that detail innovative solutions to challenges in the newborn screening system including training of labor, delivery, and/or nursery staff; evaluation of educational interventions and outreach to rural and under resourced communities.

PCORI Grants CENA Proposal!

Under the CENA proposal, Genetic Alliance and partners will collaborate with ten competitively selected DAOs. This project employ Genetic Alliance's award-winning PEER Platform to launch and/or upgrade online registries for each of the ten conditions to engage additional participants in participant-centric biomedical research. Genetic Alliance will provide technical assistance to help communities safely share their information online and facilitate community building and collaboration among condition communities as well as with other PCORI projects.

