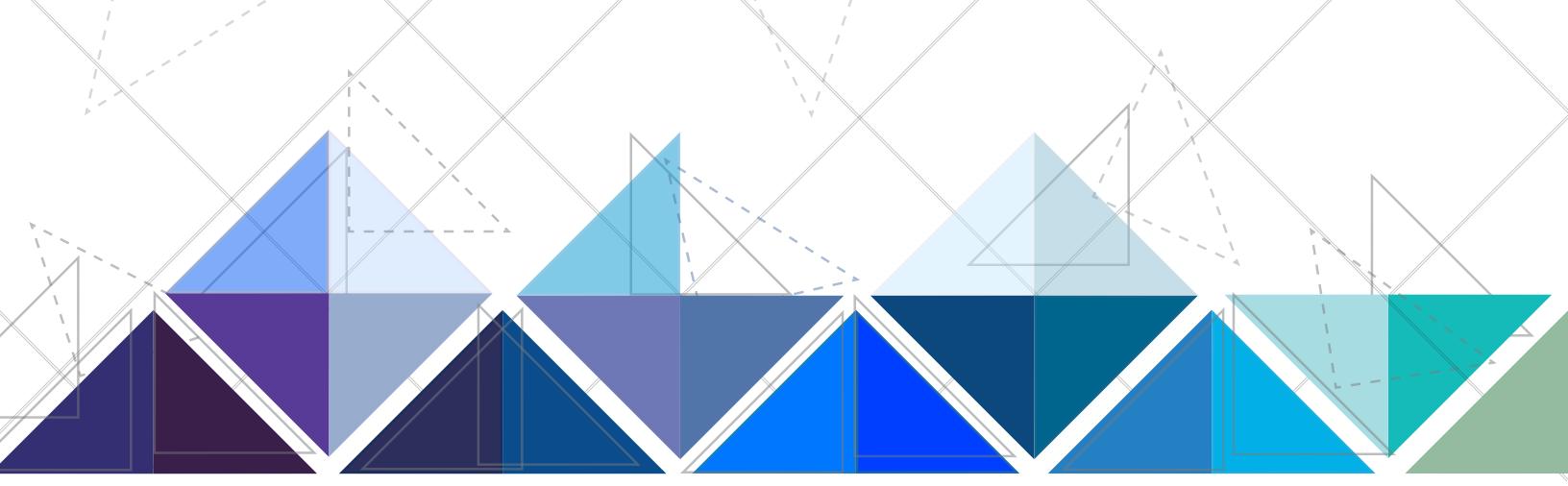




# Genetic Alliance

## Annual Report 2016





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

Individuals and families need and deserve opportunities to be active participants in health, from services in traditional health settings to groundbreaking research endeavors.

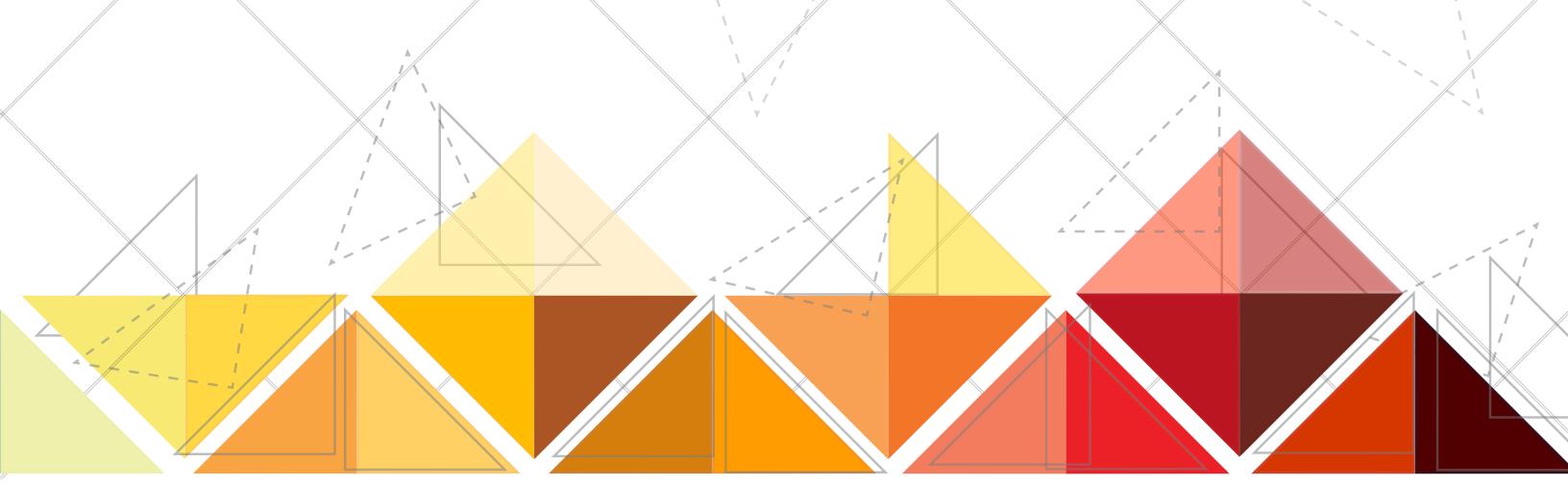
Genetic Alliance is resolute that people come first. We partner with individuals and communities to transform health systems to respond to what people most need.

We convene powerful networks, deliver actionable information, build intuitive tools, and drive policy decisions.

## About Genetic Alliance

Genetic Alliance, Inc. (Genetic Alliance) was incorporated as a non-stock, nonprofit organization on October 31, 1986 within the laws of the State of Maryland.

Genetic Alliance's network includes more than 1,200 disease-specific advocacy organizations as well as approximately ten thousand universities, private companies, government agencies, and public policy organizations. The network is a dynamic and growing open space for shared resources, creative tools and innovative programs.



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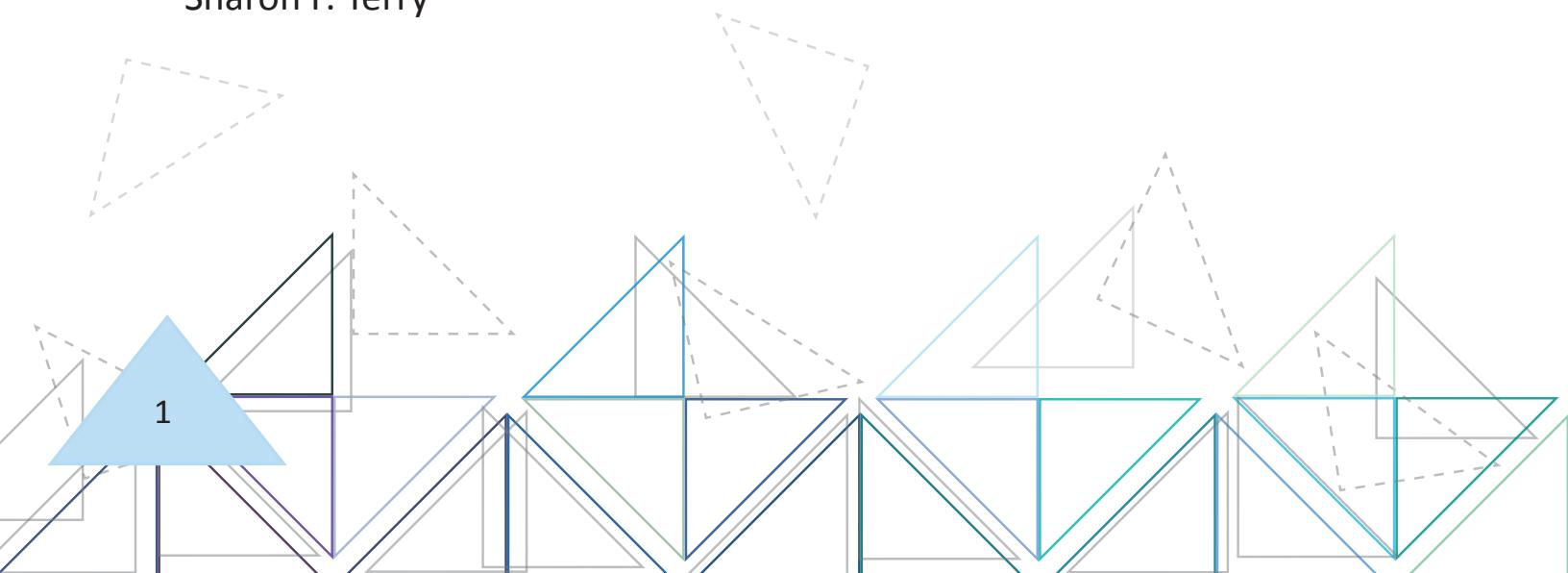
# Dear Friends,

Genetic Alliance is 30 years old! In this report, we describe several of our exciting programs – programs that herald in a new age in which genetics and health and medicine are so much more integrated than when we began. Genetic Alliance strives to work without boundaries, and though that sounds abstract, we are experimenting regularly with how to break down silos that are impeding the advances we all know are possible.



We know there is still a long way to go, and we are ready to meet the needs of individuals, families, and communities as they grapple with health, wellness, and disease. Our programs in this past year provided services to thousands of individuals, offered expertise to dozens of committees, including the Precision Medicine Initiative and the Cancer Moonshot, and we were instrumental in coordination of meaningful national initiatives like PCORnet. We look forward to moving into the next phase! Thanks to all of our partners, we could not do this work except in collaboration with you. Let's make meaningful change together!

Best,  
Sharon F. Terry



## COUNCIL

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Managing Director, Tucker Capital Corporation  
Catalytic Change Agent

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InnoAction Advisory Services

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Executive Director, PXE International, Inc.  
Ashoka Fellow

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Vice President of Strategic  
Development

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Program Assistant

**Ruth Child**  
Chief Financial Officer

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Director of Network Activities

**Yuliya Ilchyk**  
Executive Assistant

**Cyan James**, PhD  
Program Manager

**Alyson Krokosky**, MS, CGC  
Assistant Director of Genetics  
Resources and Services

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Program Manager

**KyungSun Lee**  
Program Assistant - PEER & CENA

**Claire Mena**  
Online Engagement &  
Outreach Assistant

**Amelia Mulford**  
Program Assistant

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Associate Director, PCORnet  
Coordinating Center

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**Ugonnah Nwokedi**  
Events Coordinator

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**Sarah Roth**, MFA  
Program Coordinator

**Bri Sanders**  
Program Assistant

**Anastasia Sissamis**  
Communications &  
Outreach Coordinator

**Matthew Smith**  
Project Manager, CENA

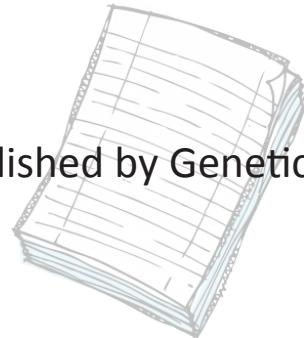
**Sharon Terry**  
CEO

**Amanda-T Schlichte**  
Communications and  
Operations Coordinator

**Alexandra White**  
HIT Program Assistant

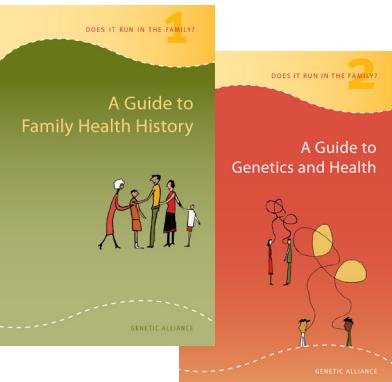
**Tamara Wurst**, MS  
Research Manager

# 2016 by the numbers



**21** papers published by Genetic Alliance staff

**16** presentations by staff in North America, Asia and Europe



**\$3,678,562** in funding secured



**1,197** *Does it Run in the Family?* toolkits to families and organizations through two national E-Card campaigns (for Thanksgiving and New Years)

Family-friendly Guide to Genetic Counseling integrated into genetics training workshop for 100 nurses



## Platform for Engaging Everyone Responsibly (PEER)

PEER empowers individuals and families to safely share health information by providing them with tools to choose how much, and with whom, they'd like to share.

- 45 community-specific PEER portals
- 15,300 users on the platform
- 861,000 questions answered, on topics ranging from diagnoses and quality of life to interest in participating in research
- 6 PEER registries launched in 2016: G-PACT, HEROIC, PanCAN, Turner Syndrome Research Registry, AAFA (Allergy), Fibromellar Registry.

## Baby's First Test

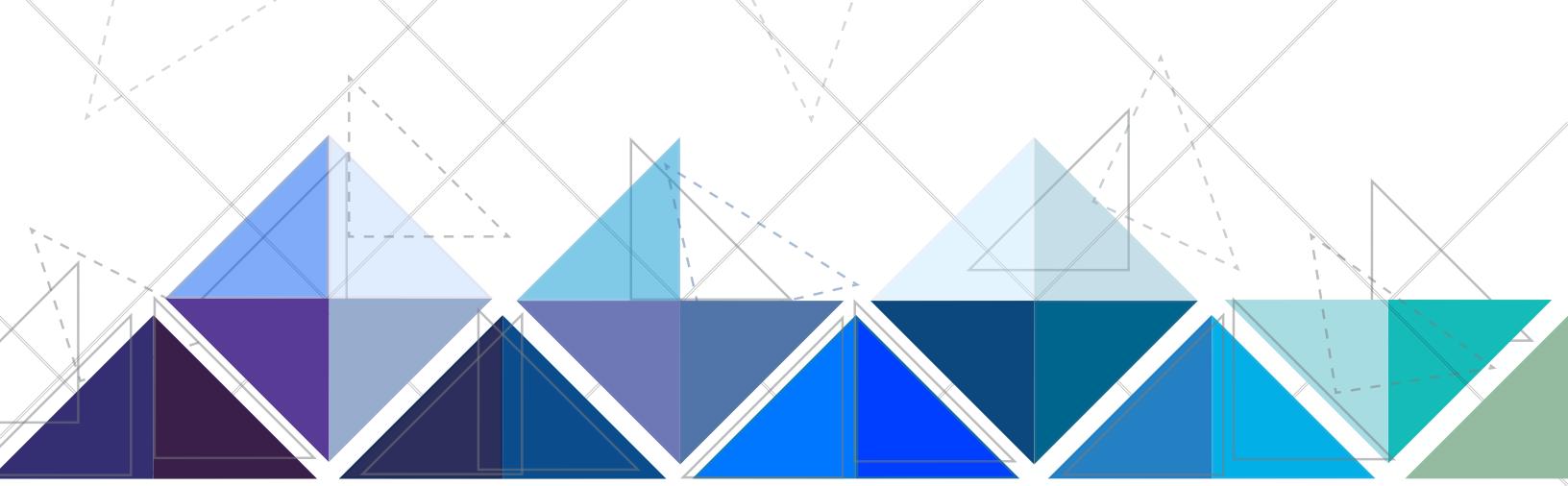
As the nation's newborn screening educational resource center, BabysFirstTest.org provides parents, healthcare professionals, and the public access to reliable, up-to-date information and resources on the newborn screening process.

- Of the 3.3 million page views to date, more than 56% of users access BabysFirstTest.org through mobile devices
- 775,000 visits (from more than 647,000 users – 25% increase in visits since last year), adding to the 1.9 million sessions on BabysFirstTest.org since its launch in 2011.
- Since 2012, Baby's First Test has trained 37 Consumer Task Force members across 18 states to channel their passion for baby screenings into tangible, outcomes-based actions

## Disease Info Search

DiseaseInfoSearch.org collects quality health information from across the internet, including support groups, resources, journal articles, and clinical trials for over 10,000 conditions.

- 326,000 visits (from more than 268,000 users) found accessible and clinically accurate condition information on DiseaseInfoSearch.org
- Nearly 7,000 site visitors accessed links to support groups
- Added 1,663 curated, patient-centered, and low-literacy condition descriptions and 125 new updated support groups to DiseaseInfoSearch.org



## Key Trends In Health

Genetic Alliance is now at the nexus of many core markets and movements, all of which seek to catalyze improvements in health, including consumer advocacy, health information technology, translation research, genomics, and many more. To achieve the greatest positive impact in these areas, stakeholders – individuals, families, and communities – must be fully engaged. We are committed to thinking, planning, and acting in a participant-centric manner and envisioning tools and systems that will empower consumers to create change.

## Expecting Health

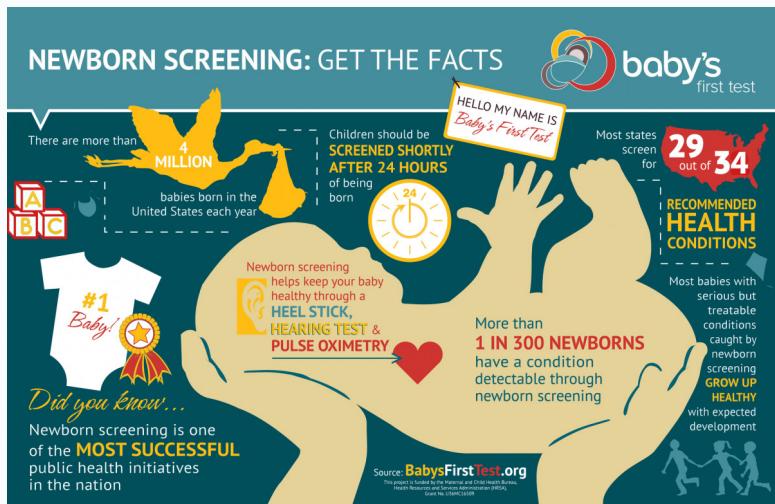
This year, the Expecting Health initiative simultaneously grew its established programs and further solidified its future direction. Through focused data gathering [in-depth stakeholder interviews with 10 maternal and child health education experts] and extensive market research, the team identified gaps in needs and impactful solutions, resulting in a report for developing a comprehensive resource for mothers and families.

With this initial data, the team developed and launched a splash site, ExpectingHealth.org, as a starting point for content creation, reaching out to partners, and establishing a more formal presence as an inclusive platform for the broader maternal and child health arena.

## Baby's First Test

This past year, the Newborn Screening Clearinghouse continued to build, expand, and maintain BabysFirstTest.org. This led to more than 1.9 million sessions on the site by nearly 1.6 million users. To evaluate the Clearinghouse's impact, an online survey on BabysFirstTest.org from October 2015-February 2016 informed the Clearinghouse's understanding of the types of users visiting the site, the reason for users visiting the

site, and to evaluate whether BabysFirstTest.org was meeting the expectations and needs of its visitors. Of its 713 respondents, 85% found the information they were looking for on the site, and 65% reported learning something new. The Clearinghouse is using the survey findings to inform education strategies and outreach. A full summary report can be found [here](#).



## Facilitating Data and Information Sharing

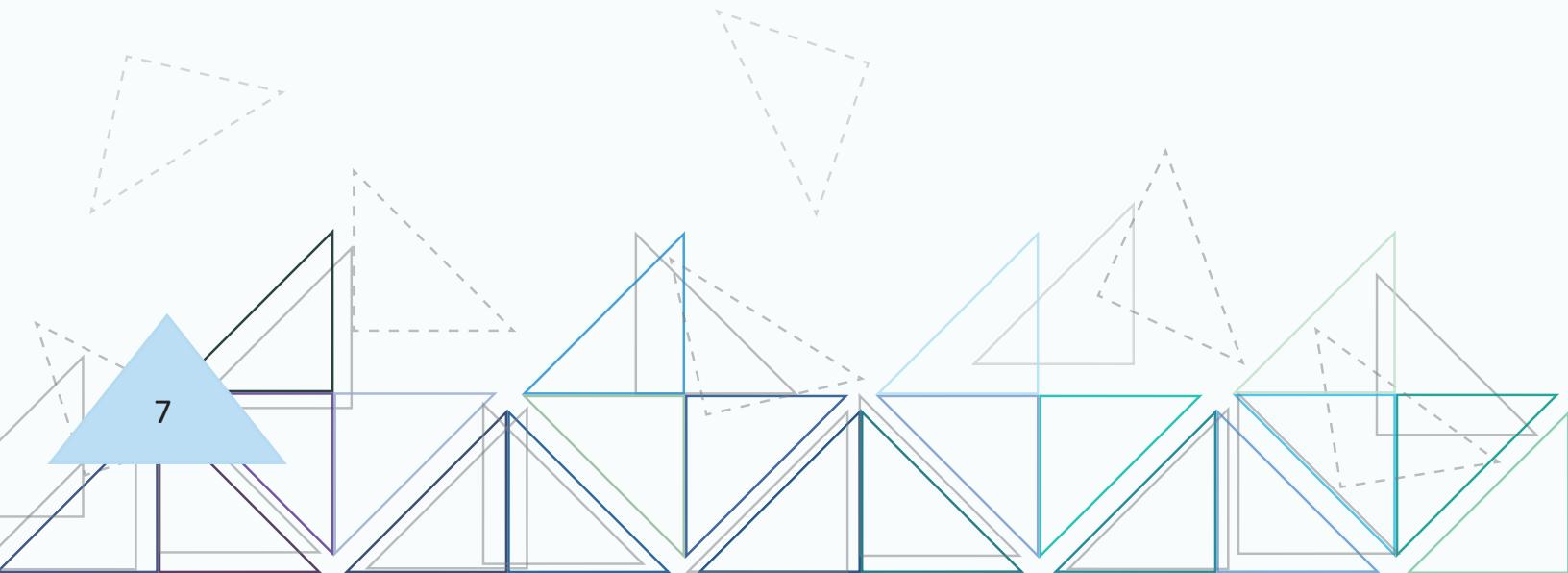
From 2015-2016, BabysFirstTest.org had a 25% increase in visits, with more than 775,000 visits by more than 647,000 users. This growth is due to broader education and outreach efforts as well as increased information sharing through diverse partners and platforms. As part of an effort to increase information and resource sharing, Baby's First Test launched the Newborn Screening Resource Center. While the site has always linked to a range of educational materials, Baby's First Test received several requests for a centralized location on the site for educational and training materials. As a result, the resource center features factsheets, videos, trainings, and educational tools from states and organizations across the United States. Users are able to filter by resource type or audience or search by keyword to find and download resources that match their interest.

Additionally, Baby's First Test developed a national interactive map focusing on the National Recommended Uniform Screening Panel (RUSP) conditions. By aggregating state and condition-level information, users are able to stay up-to-date on what RUSP conditions states screen for in a central location.

## Engaging with Communities and Stakeholders

Throughout the year, Baby's First Test focused on engaging with families and communities, along with members of the newborn screening community, to increase awareness and scale educational efforts around newborn screening. We did this in myriad ways using both in-person and online engagement.

Throughout the month of September 2016, Baby's First Test continued to be a prime leader for Newborn Screening Awareness Month. We maximized leverage on social media – Twitter, Facebook, Instagram and Pinterest – by sharing unique stories from families, individuals, and organizations about their experience with newborn screening as well as graphics and infographics with key facts and information about newborn screening. Our graphics and stories on social media reached nearly half a million people.



We also engaged with more than 25 key partners throughout the month and co-hosted a Twitter chat about newborn screening, where we reached more than 136,000 people and left more than 1.5 million impressions. Furthermore, to help families and communities with newborn screening awareness efforts in their own community, Baby's First Test updated its Newborn Screening Awareness Toolkit, which included social media messaging and sample tweets. The Baby's First Test team sent the toolkit to more than 1,000 newborn screening supporters and stakeholders.

One new approach for Baby's First Test engagement across stakeholders is the development of the Newborn Screening Public Square, a new open space dedicated to ongoing conversations about newborn screening. Baby's First Test launched its first public square in September 2016 in honor of Newborn Screening Awareness Month, as 1) a platform for knowledge contribution and dialogue building and 2) a space to bring together a range of communities within newborn screening to improve education and awareness through experience sharing. It consists of a series of online discussions and webinars on different newborn screening topics. Each public square is moderated and open for comments for a certain time period, ranging from two weeks to a month.

Lastly, Baby's First Test relaunched its Challenge Awards program this year, a program supporting and funding proposals highlighting innovative solutions to challenges within the newborn screening community. The 2016 Challenge Awards focused on scaling Connecting the Dots, a leading newborn screening education module for Neonatal Intensive Care Unit (NICU) nurses in tertiary care facilities and for NICU families. Originally created in 2013 with support from that year's Challenge Awards, Stacy Hines Dowell, DNP, AGN-BC launched Connecting the Dots to address NICU nurses' knowledge and barriers regarding newborn screening. As part of the Challenge Awards program, Albany Medical Center in New York and Saint Peter's University Hospital in New Jersey implemented Connecting the Dots over a six-month period. Preliminary findings support its effectiveness, validating the importance of an evidence-based standardized and comprehensive education module specific to NICU nursing practice.



## Perinatal Nutrition Working Group

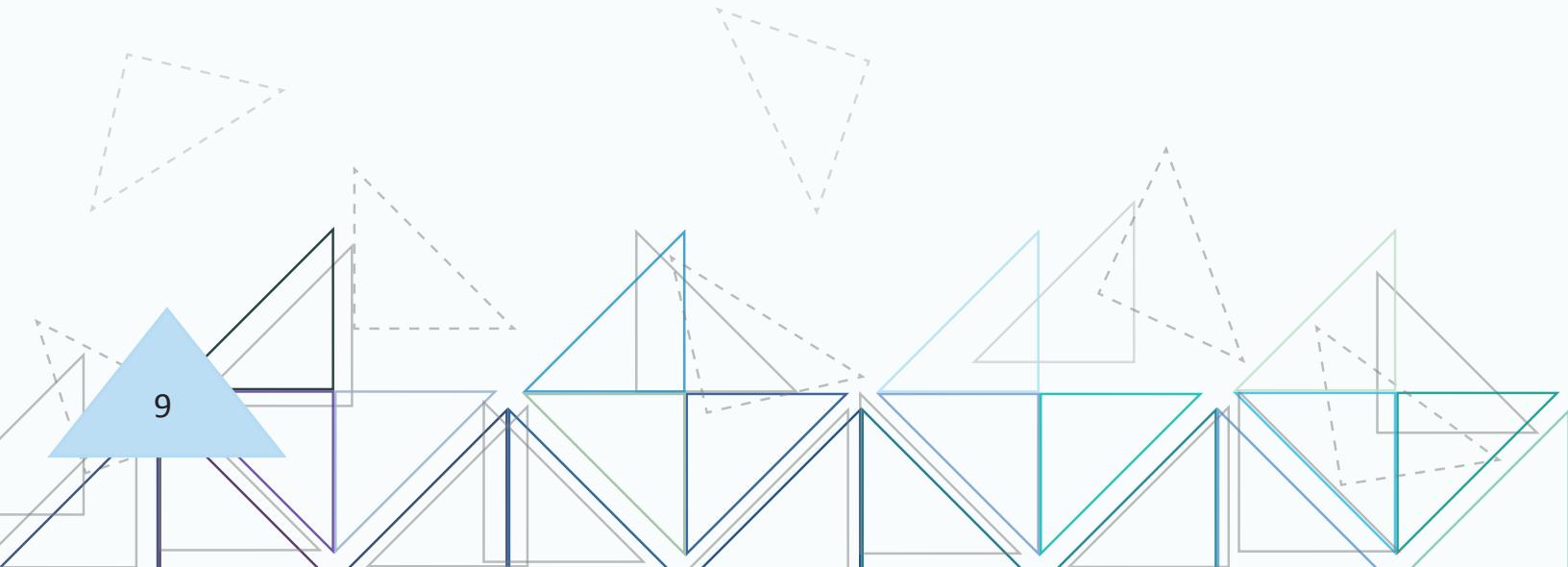


### Perinatal Nutrition Working Group

Genetic Alliance's Perinatal Nutrition Working Group (PNWG)—a coalition of experts dedicated to educating pregnant and breastfeeding women about the science behind healthy food choices—was focused on evolution this year, with new Food and Drug Administration (FDA) guidance pending and numerous new partners for collaboration on improved education and strong advocacy efforts.

In February 2016, the team convened the Perinatal Nutrition Working Group for a face-to-face working session during Society for Maternal-Fetal Medicine (SMFM)'s Annual Meeting. Out of the session emerged passion and commitment to finalize the new fish and seafood advice for pregnant women, and streamline public information about perinatal nutrition so that all pregnant women and parents are informed and confident about making healthy food decisions.

The Genetic Alliance team focused efforts on encouraging improved fish and seafood guidance from the FDA this year by educating key stakeholders on the latest nutrition and communications science. With new guidance imminent, the team plans to shift towards a Collaborative model in the near future, with a focus on dissemination, communicating with providers as well as direct-to-consumer, and expanding to broader nutrition topics for all pregnant, postpartum and parenting women.



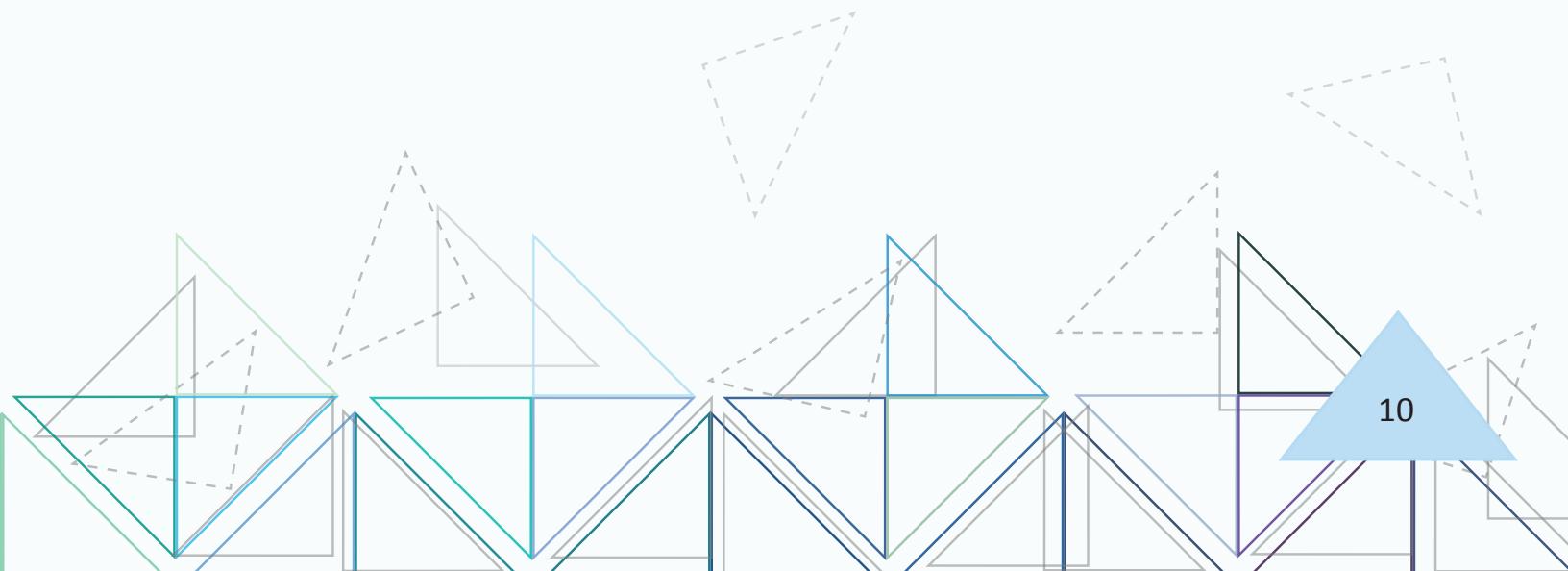
# Understand Consumer Experiences in Healthcare

## Genetic Services Needs Assessment

In its role as the National Genetics Education and Consumer Network (NGECN), Genetic Alliance worked closely with families and family support groups this year to develop and disseminate a national needs assessment to gather actionable data on needs related to access and quality. The 34-question survey, titled Understanding Access to and Quality of Genetic Services: The Individual/Family Perspective, resulted in 1,355 responses from affected individuals/parents. In addition, we hosted two community engagement webinars with consumers (202 total attendees) on genetic services needs, and facilitated discussions with 49 advocates/advocate leaders across HRSA-funded programs (RCs, LEND, Title V) in Genetic Alliance's Family Advocates Network.

## Patient Navigation

To explore the role of patient navigation for individuals with complex care needs, Genetic Alliance conducted a field survey of a cross-site sample of programs and interventions. Semi-structured interviews were conducted with representatives from hospitals, advocacy networks, and community health centers (n=18), including multiple site visits. From these interviews, eight scalable models were developed, core themes and approaches were distilled, and evidence of impact was assessed. In March 2016, Genetic Alliance composed and submitted a set of policy recommendations to the federal government and is preparing a monograph for release on the topic.



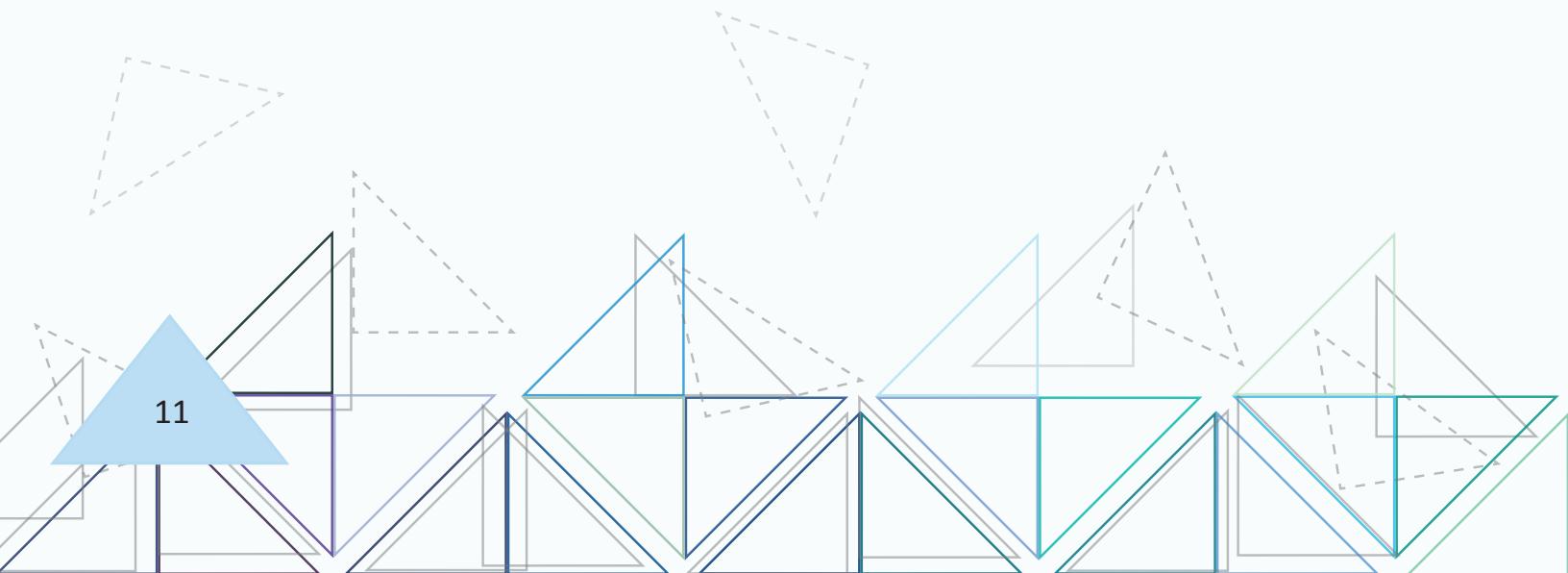
## Platform for Engaging Everyone Responsibly (PEER)

The Platform for Engaging Everyone Responsibly (PEER) is a dynamic patient registry solution designed to support data sharing across a variety of stakeholders, while simultaneously providing registry sponsors with a customizable data collection tool that meets their communities' needs. The platform is offered using a "software as a service" model, and allows registry sponsors to develop custom content for data collection and registry branding. Once deployed, the platform empowers individual participants — together with their families and caregivers—to share clinical information, medical records, and more, in a trusted environment.

In 2016, we expanded on our work to develop resources supporting easy customization and installation of PEER by registry sponsors.

With support from the Robert Wood Johnson Foundation, we awarded PEER registries to ten organizations with an interest in health and a desire to engage their communities in building registries and conducting research. These organizations built on the efforts of the fourteen organizations selected the previous year, and have contributed feedback regarding existing documentation suites, content management tools, and more. Their efforts have culminated in the creation of a PEER documentation wiki, which will be fully launched to the PEER community in 2017.

As PEER has matured as a "software as a service" product we have also become aware of several key areas for future growth and development around both data collection and participant engagement. We have thus made the strategic decision to migrate PEER to an open source software (OSS) system. While we will continue to offer PEER under a "software as a service" model, in the fall of 2016 we began the process of developing a separate, self-supported PEER initiative with a committed community of sponsors, users, and software developers. This community is united in its belief that PEER can support participant-centric research on a variety of topics, and we look forward to working with them to enhance PEER's reach and capacity.



## Community Engaged Network for All (CENA)

The Community Engaged Network for All (CENA) is a collaborative, cross-disciplinary team led by Genetic Alliance. Since 2014, CENA has been dedicated to engaging communities and building participant-led research cohorts to better understand and treat the more than 30 common and rare conditions it represents. The Patient-Centered Outcomes Research Institute (PCORI) funded CENA during the first phase of PCORnet, the National Patient-Centered Clinical Research Network. PCORnet is a community of patients, their families and caregivers, researchers, scientists, clinicians, health system leaders, and other committed individuals and organizations dedicated to the common purpose of accelerating patient-centered outcomes research (PCOR).

By supporting a broadly-accessible online environment where communities and researchers have equal voice in the development of research hypotheses, CENA is piloting new methods of facilitating collaboration among researchers and participants. In PCORnet, CENA is developing systematic approaches to engagement, recruitment, retention, and people-driven research efforts with templates, models, resources and technology to the network.

In FY 2016, CENA was approved for a three-year, \$1.2 million funding award by PCORI as part of the second phase of PCORnet. As one of 34 health networks comprising this national clinical research resource in Phase II, CENA is unique among the Patient Powered Research Networks: 1) it is itself a network of eleven organizations; 2) it empowers people to set (and change) their own health data sharing, privacy, and access preferences; and 3) it has refined a scalable system for prioritizing and conducting research with these communities. CENA welcomed two new disease advocacy organizations (DAOs) to its network — the Asthma and Allergy Association of America (AAFA) and The Fibrolamellar Registry (TFR). CENA has enrolled approximately 3,900 participants using Genetic Alliance's Platform for Engaging Everyone Responsibly (PEER) since its inception.

This year two CENA groups have utilized Mosaic, an online system developed by partners at the University of California, San Francisco, which creatively manages crowdsourcing research questions from multi-stakeholder communities to design, implement, and disseminate relevant research studies. The Joubert Syndrome and Related Disorders Foundation (JSRDF) conducted PCOR under a protocol developed using Mosaic; a research abstract was accepted to the Western Society for Pediatric Research annual meeting; a manuscript is in preparation entitled "A Patient-Centered Study of the Diagnosis and Clinical Characteristics of Joubert Syndrome". The Celiac Disease Foundation determined research priorities using Mosaic around a specific research topic of arsenic in the gluten-free diet, moving celiac disease and gluten sensitivity research forward by identifying key questions and prioritizing areas of research.

Additional CENA activities have focused on ways to further align CENA's data infrastructure with other models to allow for seamless integration in larger networks, as part of a partnership with the University of California, Davis. CENA has also worked with other PCORnet partners to develop best practices for engagement and recruitment, and to identify strategies for continued sustainability of the network and its model for participant centricity.



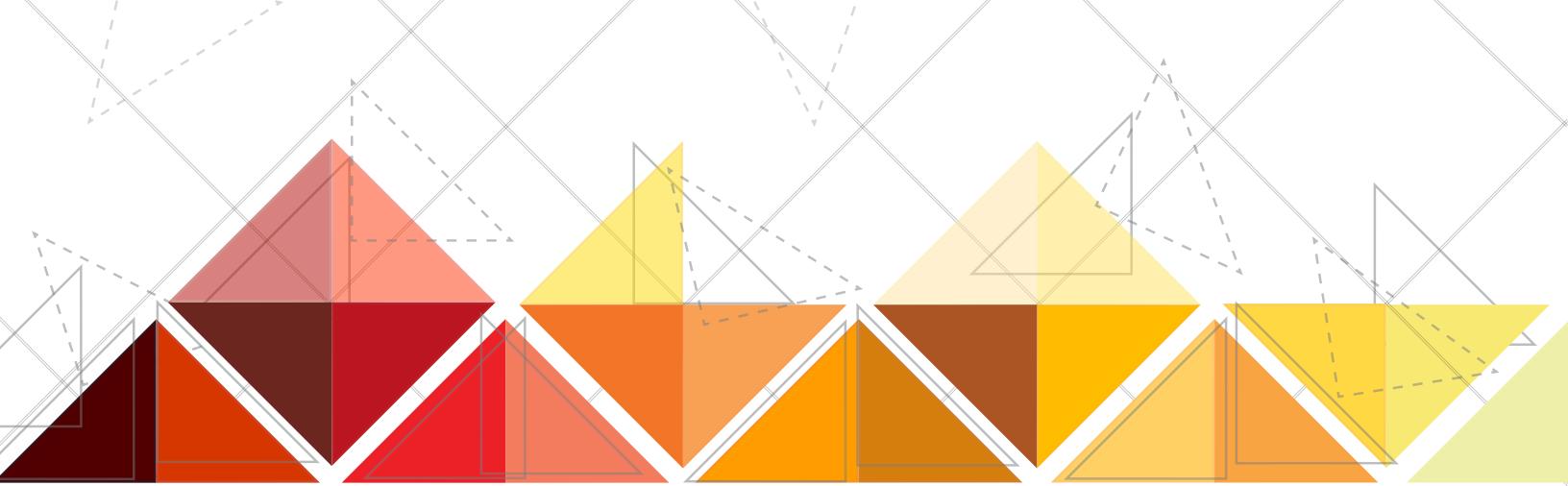
## PCORnet

In 2016, Genetic Alliance took on an expanded and critical role for PCORnet as a leading institution of its Coordinating Center— coordinating activities, developing resources and platforms, and communicating with hundreds of partners to elevate success of this innovative network and accelerate participant-centered research for the nation.

Genetic Alliance's focus on seamless coordination transparency and people-centricity offers the propensity to facilitate the advancement of and between PCORnet's Clinical Data Research Networks (CDRNs) and Patient Powered Research Networks (PPRNs). The year focused on enabling sharing through a new Commons website, advancing data strategy and capacity for the PPRNs, and elevating the voice of participants to challenge the status quo around what it means for research outcomes to suit community needs.

Over the year, the GA Coordinating Center hosted over 50 collaborative meetings, webinars, and conference calls; developed guidance documents and synthesized reports for the Network and to shape their participation in the national research landscape; and shared public-facing, consumer-appropriate lay materials to improve the capacity of real people understanding and contributing to the research ecosystem.

Some of the many notable achievements include a nationally-distributed glossary of engagement terms and definitions; the development and nurturing of several stakeholder collaboratives to guide research interests and projects; the analysis and recommendations around PPRN data dictionaries and synergy of participant-reported outcomes; and hosting a vibrant and dynamic Building Trustworthiness in PCORnet two-day meeting. Diverse stakeholders— with 45 presenters, 166 attendees, and 357 webcast viewers — came together from PCORnet networks and other communities, including individuals and patients; parents and caregivers; clinicians; advocates and activists; citizen scientists; and experts in research, policy, public health, community outreach, and engagement. After two days of productive dialogue, meeting participants developed seminal recommendations for PCORnet, including that the network should: learn from best practices in other research and community engagement efforts; inculcate cultural humility; be transparent; provide substantial budget for engagement and dissemination activities; and recognize and engage diversity.



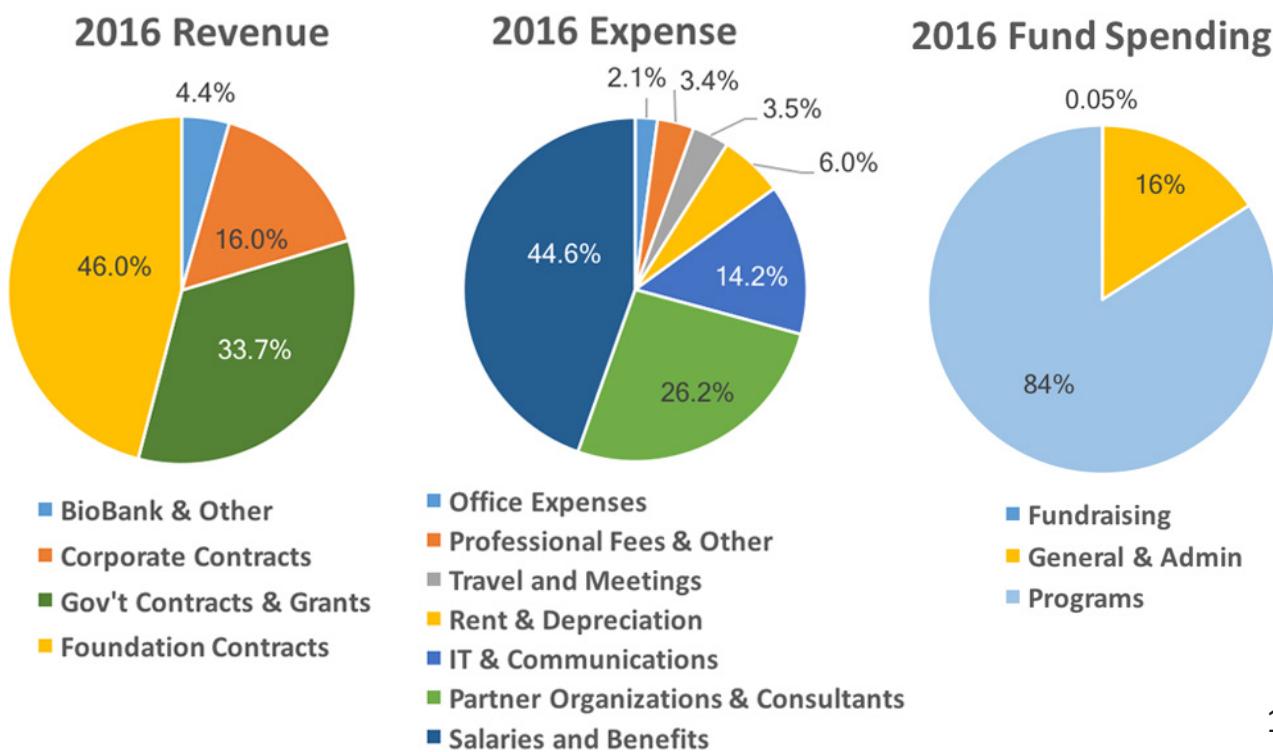
## Financials

Genetic Alliance's work is supported by a blend of funding from government grants and contracts, industry and corporate support, individual donations, and fees generated by services and events.

We continually work to diversify our funding sources. A key part of this diversification plan is to secure strategic, fee-for-service partnerships that leverage our expertise, serve the needs of the field and community, and bring greater financial sustainability to the organization.

## Statement of Activities and Changes in Net Assets as of September 30th of each year

Revenue and Other Support	2015	2016
Contracts and Grants	\$1,238,293	\$1,078,724
Foundation Contracts	1,690,792	1,341,937
Corporate Contracts	587,013	1,053,096
Biobank Revenue	69,944	76,044
Contributions	38,967	22,464
Other Revenue	53,555	40,501
<b>Total Revenue and Other Support</b>	<b>\$3,678,564</b>	<b>\$3,612,766</b>
<b>Expenses</b>		
<b>Program Services</b>		
General Programs	\$3,220,127	\$3,230,045
<b>Supporting Services</b>		
General and Administrative	607,405	504,090
Fundraising	2,034	3,648
<b>Total Expenses</b>	<b>\$3,829,566</b>	<b>\$3,737,783</b>
Net Increase (Decrease) in Net Assets	-151,002	-125,017
Net Assets, Beginning of Year	\$308,625	\$433,642
Net Assets, End of Year	\$157,623	\$308,625



## Statement of Financial Position as of September 30th of each year

<b>Assets</b>	<b>2016</b>	<b>2015</b>
Cash and Cash Equivalents	\$24,848	\$110,526
Accounts Receivable	281,909	426,988
Grants Receivable	59,277	136,686
Prepaid Expenses	49,288	13,634
Deposits	6,595	6,595
Furniture and Equipment	1,360	54,874
<b>Total Assets</b>	<b>\$423,277</b>	<b>\$749,303</b>
<b>Current Liabilities</b>		
Accounts Payable and Accrued Expense	\$178,361	\$343,545
<b>Long-term Liabilities</b>		
Deferred Rent	3,185	21,671
Deferred Revenue	84,108	75,462
<b>Total Current Liabilities</b>	<b>265,654</b>	<b>440,678</b>
<b>Net Assets</b>		
Unrestricted	157,623	308,625
Total Net Assets	157,623	308,625
<b>Total Liabilities and Net Assets</b>	<b>\$423,277</b>	<b>\$749,303</b>



WWW.GENETICALLIANCE.ORG

T: 202.966.5557

F: 202.966.8553



info@geneticalliance.org  
4301 Connecticut Ave., NW  
Suite 404  
Washington, DC 20008-2369