GENETIC ALLIANCE

ANNUAL REPORT

2015

Genetic Alliance empowers individuals, families, and communities to reclaim their health and THRIVE.

Individuals and families need resources and tools to participate in their own health, from everyday life, to services in traditional health settings and groundbreaking biomedical research endeavors. Genetic Alliance is resolute that all of these activities should be centered on the very people who will benefit from these activities.

We partner with individuals, families, and communities to transform health systems and respond to what people need most. 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.

IN THIS REPORT

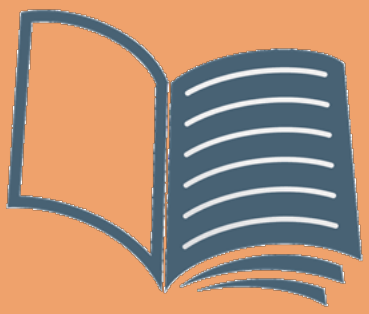
DEAR FRIENDS,

Fiscal year 2015 saw many of our programs and tools mature. We have, for all of our almost 30 years, come from the point of view of the consumer, the patients, the participant. We have long held that when health – all aspects from day to day living through healthcare services to the biomedical research needed to effect appropriate change – is centered on the individual, family, and their community, it will improve immensely for all.

We were particularly proud to be present early in 2015 at the White House to hear this sentiment from President Obama. On January 29, he said that people should be partners in the research process. As you will see below, our work has expanded to hundreds of communities and hundreds of thousands of individuals. We look forward to collaborating with many more communities in growing the cohorts that will be true partners through FY2016.

Best,
Sharon F. Terry, President & CEO

2015 by the numbers

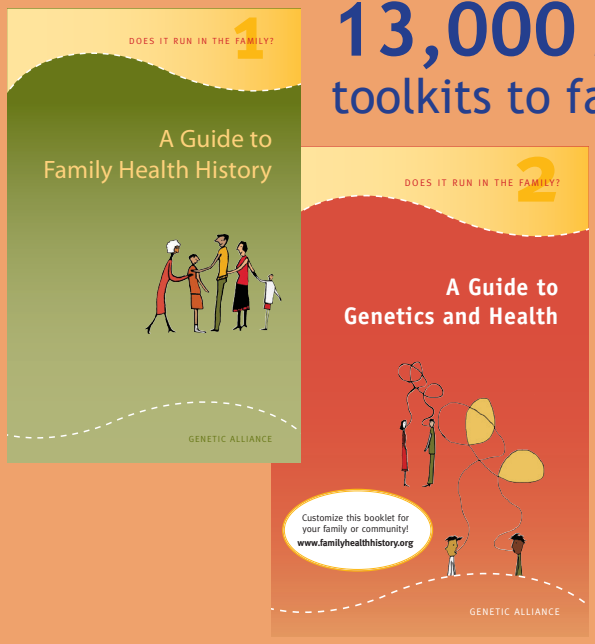


16 scholarly articles

32 presentations

$3,200,000 in funding secured

11,197 patient-centered educational materials on genetics and genetic counseling disseminated to over healthcare providers, interdisciplinary training programs, and consumer-focused health organizations



13,000 *Does It Run in the Family?* toolkits to families and organizations through two national e-card campaigns (for Thanksgiving and New Years), encouraging individuals to "give the gift of family health history."

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.

- 20 community-specific portals through which to enter PEER
- 8,279 PEER users
- 93,860 questions answered, on topics ranging from diagnoses and quality of life to interest in participating in research

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.

- 1.5 million page views to date, more than 50% of users accessing BabysFirstTest.org through mobile devices
- 622,000 visits from more than 520,000 users (over 100% increase in visits since last year)
- Adding to the 1 million sessions on Baby's First Test since launch in 2011

Disease InfoSearch

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

- 273,746 individuals visited DiseaseInfoSearch.org
- 4,126 individuals linked to support groups
- 10,000+ conditions
- 732 support and advocacy group

Key Trends in Health

Genetic Alliance is at the nexus of many markets and movements, all of which seek to catalyze improvements in health, including consumer advocacy, health information technology, translational research, genomics, and many more. To achieve the greatest positive impact in these areas, stakeholders must fully engage individuals, families, and communities. We must think in a participant-centric manner and envision tools and systems that will empower consumers to create change.

EMPOWER PEOPLE TO SHARE DATA WHILE PROTECTING PRIVACY

Privacy can be defined as freedom from unauthorized intrusion. The key word here is unauthorized. We have devised a system in which individuals can share health information when they want to, and with whom they wish. With people at the center, it is possible to protect privacy and share at the same time.

Platform for Engaging Everyone Responsibly (PEER)

PEER, from partners Genetic Alliance and Private Access, enables participants and their caregivers to share clinical information, medical records, and even genomic information – all within an environment that provides the look and feel of familiar, trusted communities, under access-permission rules defined by the participants themselves. PEER provides data-entry, data-query, and privacy-management services that are accessed through standard application programming interfaces (APIs).

In 2015 we sought to increase the platform's ease of use for a variety of communities, by introducing the resources needed to support easy customization and installation of the system.

With support from the Robert Wood Johnson Foundation, we have gone on to put these resources to the test: we awarded PEER registries to fourteen different organizations and programs with an interest in health, and a desire to engage their communities in building registries and conducting research. These organizations are working to launch their registries while simultaneously assessing the platform for ease of use – both from the perspective of a community customizing and launching a PEER registry, and from the perspective of the community's participants, who will make decisions about data sharing using the registry. This assessment is an ongoing process, taking place over two years and utilizing both qualitative and quantitative methods. Between this project, PCORnet, and a number of other partners, there are now 39 communities using PEER.

Community Engaged Network for All

The Community Engaged Network for All (CENA) is one of 29 networks in PCORnet, the National Patient-Centered Clinical Research Network. CENA comprises 10 disease-specific communities working together with Genetic Alliance and other partners,to pilot new technologies and methods for facilitating collaboration among researchers and participants.

In 2015, the five remaining CENA communities established and launched PEER registries, enabling participants to safely share information about their conditions in accordance with individualized sharing, privacy and data access preferences.

This year also marked the launch of the Mosaic platform, a University of California San Francisco tool, as a means of prioritizing research agendas within a community context. Mosaic allows CENA community members to reflect on aggregate data generated in PEER, and work together to design, implement, and disseminate research studies. The first CENA member to launch on Mosaic, the Joubert Syndrome and Related Disorders Foundation (JSRDF), has used the tool to initiate active discussions on a variety of topics, and to both define and refine the JSRDF community's needs, interests, and priorities related to diagnosis, therapeutic interventions, and medical treatments.

UNDERSTAND CONSUMER EXPERIENCES IN HEALTHCARE

In the information age, big data is king. It drives multi-billion dollar business, predicts the rise and fall of political leaders, and tracks our every movement, purchase, and click. But data can only track existing behavior where services exist. To address needs and gaps, we frequently need to go one step farther and ask individuals, families, and communities about their lived experience. This year, Genetic Alliance continued and expanded our efforts to collect quantitative and qualitative data and understand what challenges individuals and families face when accessing healthcare services.

Survey on Genetic Services

In its role as the National Genetics Education and Consumer Network (NGECN), Genetic Alliance continues to strive towards improved access and quality of genetic services for individuals and families. Beginning in 2013, Genetic Alliance, in partnership with the American College of Medical Genetics (ACMG) and with funding from the Health Resources and Services Administration (HRSA), led NGECN efforts around consumer engagement and public education. As part of this effort, we engaged individuals and families in a number of formal and informal dialogues to better understand what barriers and gaps exist for genetic services. In 2013, we collected national data, the first of its kind, through the Genetic Alliance network concerning access to care and the care experience for individuals affected by genetic conditions (1,895 respondents).

- This year, the 2013 data was published in manuscript form in the Journal of Maternal and Child Health, establishing benchmark data on access to care, care coordination, and transition for individuals with genetic conditions across the lifespan in the US.
- In 2015, we reached back out to a segment of 2013 survey respondents (1,015 respondents) to see if access to care had changed and to hone in on causative factors. First-time national data was gathered on information and resource needs, the types of questions consumers have about genetic services, and where support organizations refer individuals for credible information on genetics and genetic services.

National Genetics Education and Consumer Network

Genetic Alliance worked closely with the NGECN Consumer Advisory Group, a group of eight passionate consumers from across the United States, to develop tools and trainings that amplify the voices of consumers and strengthen consumer participation in genetics programs. We continued to collaborate with the Regional Genetics and Newborn Screening Collaboratives, hosting in-person and virtual opportunities for family advocates across the regions and leaders from Parent to Parent and Family Voices to collaborate around what families need in order to better understand, access, and utilize services and support.

- Gathered best practices for orienting and engaging consumers from the 7 RCs; released Bringing Your Voice to the Table: Maximizing the Individual and Family Perspective in the Regional Genetics Collaborative, an activity of the NGECN Consumer Advisory Group
- Hosted collaborative networking session on Strengthening Family Partnerships (84 attendees from 33 states, across HRSA-funded MCH programs)
- Collaborated across HRSA-funded MCH programs on the importance of meaningful consumer engagement allowed NGECN to create an active listserv for ongoing engagement that will inform and advise future genetic services programs.

Genetics Education and Referral Advisory Group

This past year we reached out to 17 genetic counselors in the metropolitan DC area in an effort to understand resource needs at different points within the referral and diagnosis process. We hosted two group conference calls and one in-person networking event in DC to strengthen the community of local genetics providers and continue the conversation around patient needs.

BRING PUBLIC HEALTH TO INDIVIDUALS AND COMMUNITIES

In the information age, big data is king. It drives multi-billion dollar business, predicts the rise and fall of political leaders, and tracks our every movement, purchase, and click. But data can only track existing behavior where services exist. To address needs and gaps, we frequently need to go one step farther and ask individuals, families, and communities about their lived experience.

Baby's First Test

This past year, Baby's First Test relaunched both of its English and Spanish language sites (BabysFirstTest.org and Spanish.BabysFirstTest.org). Both sites offer training videos and other educational resources for healthcare providers supporting families throughout the newborn screening process as well as information at the local, state, and national levels for new and expectant parents. Due to the high demand for state and condition specific information, each page of the site has a section dedicated to bringing users directly to their state and/or condition of choice.

Another key piece of the relaunch was to integrate responsive web design (RWD) for both sites. Whether users are coming from a desktop, smartphone, or tablet, the site will automatically display in the most user-friendly mode. This is critical, as the number of users coming from mobile or tablet devices has increased by tenfold since BabysFirstTest.org's initial launch in 2011.

With 100% increase in visits since 2014, this year brought nearly 622,000 visits from more than 520,000 users, adding to the 1 million sessions on Baby's First Test since our launch in 2011. This is growth is due to broader education and outreach efforts as well as increased information sharing with diverse partners.

Newborn Screening Engagement

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 a myriad of ways, including creating an animated video for expecting parents called "What to Expect from your Baby's First Test" and continuing to be a prime leader for Newborn Screening Awarness Month in September.

Throughout the month of September, we shared unique stories from families, individuals, and organizations about their experience with newborn screening as well as graphics with key facts and information about newborn screening. Our graphics and stories reached nearly 75,000 people. We also engaged with more than 30 key partners throughout the month and hosted a Twitter chat about newborn screening with March of Dimes, where we reached more than 174,000 people and left more than 3 million impressions. Finally, in order to help families and communities with newborn screening awareness efforts in their own community, Baby's First Test produced a Newborn Screening Awareness Toolkit, which included social media messaging and sample tweets, graphics to share, and educational videos about newborn screening. The Baby's First Test team sent the toolkit to more than 900 newborn screening supporter and stakeholders.

Cascade Screening

Genetic Alliance partnered with the Center for Disease Control and Prevention's Office of Public Health Genomics to champion multiple state and consumer-focused initiatives during the year. We worked with advocates and experts in the genetics/genomics field to create several new, accessible education materials, including patient brochures, template letters, and provider training materials on clinical guidelines for Lynch Syndrome and Hereditary Breast and Ovarian Cancer Syndrome. We worked closely with CDC OPHG to create three educational videos on Hereditary Breast and Ovarian Cancer Syndrome and Lynch Syndrome and public health screening techniques.

Genetic Alliance also created a summary report designed to inform OPHG on the views and needs of potential stakeholders regarding accelerating genomics applications into practice. The report discussed tier 1 applications as case studies to cover different issues in the landscape implementation while evaluating emerging data and evidence. We also conducted key informant interviews and produce a report detailing barriers to effective cascade screening in the states and key approaches to overcome those challenges. The report discussed the value proposition for different models of cascade screening, including impact, cost, and legal, and regulatory issues. These materials are all available on the Tier 1 Genomic Applications Toolkit for Public Health Departments.

GROUNDBREAKING PROGRAMS

In addition to driving key trends in research and healthcare, Genetic Alliance was an integral player in launching new movements and initiatives. From national programs, such as the President's Precision Medicine Initative, to the scaling of local efforts with promise to change the way people interact with their health, Genetic Alliance and its powerful network were front and center.

PCORnet

In early 2015, Genetic Alliance joined Harvard Pilgrim Health Care Institute and Duke Clinical Research Institute to become an integral part of the PCORnet Coordinating Center. PCORnet, the national clinical research network, is made up of more than 1,000 institutions and is funded by the Patient Centered Outcomes Research Institute (PCORI). The Coordinating Center leads systems management and operations for this innovative network in order to accelerate participant-centered outcomes research in the nation.

Genetic Alliance's focus on facile and cutting-edge methods, in a culture of openness and transparency, offers excellent resources to facilitate the coordination and collaboration of all of PCORnet's Clinical Data Research Networks (CDRNs) and Patient Powered Research Networks (PPRNs). To meet the growing and critical needs of the network, Genetic Alliance develops resources and tools on an ongoing basis to catalyze comparative effectiveness research. To date, this includes enabling digital sharing and archiving of information; a comparison of data elements of interest to the networks; and strengthening collaborations between and among CDRNs and PPRNs. Due to emerging interests and need, Genetic Alliance shapes and serves PCORnet within three main areas: network science, engagement, and the PCORnet Commons. We are building methods and processes for each of these areas that will accelerate PCORnet's mission and deliver benefit to those who are in need.

NETS

Drug development is often illustrated as a linear process, proceeding from basic research on up through translational science and clinical trials. This model fails to recognize the richness and complexity of this process, in which many functions occur simultaneously and partners in advocacy, academia, and industry fulfill ever-changing roles. Our NETS (Navigating the Ecosystem of Translational Science) map, originally released in 2007, seeks to illustrate this complexity in an approachable way by presenting a networked model of drug development within the context of an educational toolkit.

In 2015 NETS served a new purpose, by bringing stakeholders together at the Institute of Medicine's Forum on Drug Discovery, Development and Translation. The Forum identified the map as a tool for building common ground beween different parties in drug development and translation, which could define a common understanding of various processes and terms, irregardless of role. As part of this work, the map was updated to illustrate two paths to drug development – small molecules and biologics – with patient need acting as an ever-present compass. We look forward to exploring the NETS's map renewed use as a policy making tool, and will release updated images and resources in the coming year.

Perinatal Nutrition Working Group

In June 2015, Genetic Alliance assumed the already-established Perinatal Nutrition Working Group (PNWG), a coalition of healthcare professionals dedicated to educating pregnant and breastfeeding women about the science behind healthy food choices, and particularly the role of eating seafood in a healthy pregnancy. Previously a program of the National Healthy Mothers, Healthy Babies Coalition-- a trusted organization with a 33-year history of reaching pregnant women and key constituents-- the PNWG was moved to Genetic Alliance with the goal of optimizing the potential for growth and impact in coming years.

With a mission of advocating and educating about optimal nutrition in pregnancy and postpartum, the PNWG has made incredible strides in shifting legislative and public perception; developing provider, patient, and community tools; and empowering women and families to make positive decisions for infant health.

Impact Awards

In addition to consumer engagement, Genetic Alliance sought to promote expansion of evidence-based programs that increase access to genetic services. We funded seven Impact Awards for the period of May 2014-April 2015. Project descriptions and highlights include:

- The Center for Jewish Genetics developed a model for accessible, effective, at-home screening/education that reached 349 high-risk individuals (177; 51% were found to be carriers) during the project period
- The Hali Project trained and placed 2 additional parent partners in Wyoming, serving an additional 100 families and demonstrated cost effectiveness and increased patient provider satisfaction
- Nemours Al Dupont Hospital produced two videos with and for indivdiuals with genetic conditions on planning a family and transition
- Boston University School of Public Health incorporated genetic testing information into existing autism support program for families, trained 6 new Autism Resource Specialists for 6 Boston area hospitals
- Michigan Public Health Institute developed and implemented a “Train the Facilitator” model for improving access to a medical home for children with genetic conditions and their families through care coordination training; 16 new individuals in 6 states were trained as facilitators, reaching 68 families
- University of Wisconsin hosted several educational events to train 170 community members and 60 midwives/plain birth attendants on newborn screening
- Gallaudet University developed and disseminated culturally competent educational materials on family health history and cancer genetics in American Sign Language for the Deaf community reaching 68 families to date.
  Development of this curriculum led to 24 facilitators being trained in 6 additional states in the Heartland region
- University of Wisconsin’s “Genetics Education and Outreach to Plain Communities in Northwestern Wisconsin” hosted several educational events to train 170 community members and 60 midwives/plain birth attendants on newborn screening; educational events have already demonstrated an increase in newborn screening by ~60% in communities where midwives and birth attendants have been trained to complete the newborn screening and provided with equipment to do so.

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.

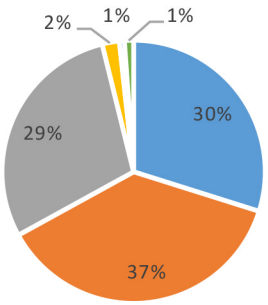
We continually work to diversify our funding sources. A key part of this diversification plan is to secure strategic, fee-for-service partnerships that leverage our expertise, serve the needs of the field and community, and bring greater financial sustainability to the organization.

Statement of Activities and Changes in Net Assets

as of September 30th of each year

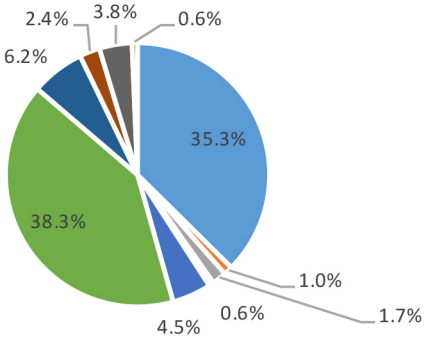
Revenue and Other Support	2015 Total	2014 Total
Contracts and Grants	$1,078,724	$1,469,988
Foundation Contracts	$1,341,937	$452,933
Corporate Contracts	$1,053,096	$546,659
Biobank Revenue	76,044	75,598
Special Events	-	34,750
Contributions	22,464	13,631
Other Revenue	40,501	35,976
Total Revenue and Other Support	$3,612,766	$2,629,535
Expenses		
Program Services		
General Programs	$3,732,734	$3,124,096
Supporting Services		
General and Administrative	33	-
Fundraising	5,016	2,843
Total Expenses	$3,737,783	$3,126,939
Net Increase (Decrease) in Net Assets	(125,017)	(497,404)
Net Assets, Beginning of Year	$ 433,642	$ 931,046
Net Assets, End of Year	$ 308,625	$ 433,642

Genetic Alliance 2015 Revenue



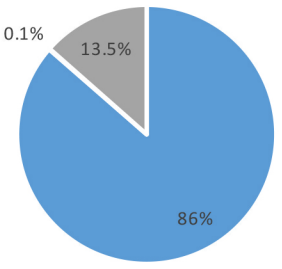
- Gov't Contracts & Grants
- Foundation Contracts
- Corporate Contracts
- BioBank & Registry
- Contributions
- Other

Genetic Alliance 2007 Expense



- Salaries and Benefits
- Internship Program
- Professional Fees
- Consumer Stipends
- Rent
- Partner Organizations & Consultants
- IT & Communications
- Office Expenses
- Travel and Meetings
- Insurance

2015 FUND SPENDING



- Programs
- Fundraising
- General & Admin

Statement of Financial Position

as of September 30th of each year

Assets	2015	2014
Cash and Cash Equivalents	$110,526	$86,771
Accounts Receivable	426,988	114,792
Grants Receivable	136,686	146,586
Prepaid Expenses	13,634	32,934
Deposits	6,595	6,595
Furniture and Equipment	54,874	222,760
Total Assets	$749,303	$610,438
Current Liabilities		
Accounts Payable and Accrued Expense	$343,545	$140,375
Long-term Liabilities		
Deferred Rent	21,671	36,421
Deferred Revenue	75,462	-
Total Current Liabilities	$440,678	$176,796
Net Assets		
Unrestricted	308,625	433,642
Total Liabilities and Net Assets	$749,303	$610,438

COUNCIL

Sharon F. Terry, MA - President and CEO
Exdecutive Director, PXE International
Ashoka Fellow

Kemp Battle - Secretary
Managing Director, Tucker Capital Corporation
Folklorist and Writer

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