Genetic Alliance

Annual Report 2017

About Genetic Alliance

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.

Founded in 1986, Genetic Alliance has pioneered the concept that individuals, families, and communities are partners in health research and care , long before it was fashionable.

Genetic Alliance is a national network of thousands of health organizations; 1,200 of which are disease advocacy organizations (AO) representing both common and rare conditions. Genetic Alliance was originally founded to give voice to people affected by genetic conditions, but over the years, has evolved our mission to comprise health more broadly. Our primary partners are individuals, families, and communities. We are dedicated to responding to the needs of people through the transformation of health systems. Collaboration and partnership are core model since all stakeholders must work together to transform health. We complement other national health advocacy organizations because of our unique commitment to the application and implementation of policies and concepts; using lean-start-up style projects to pilot and test tools and technology solutions. Genetic Alliance has a demonstrated commitment to scientific research and dissemination, through an independent publication record including scientific, peer-reviewed articles, as well as freely disseminated educational materials.

IN THIS REPORT

Welcome from CEO

This was a great year of celebration and planning for Genetic Alliance. When marking anniversary milestones, it is obvious that organizations celebrate their successes. However, Genetic Alliance ever in search of how to increase our impact, took this year as a time to ask: "*Should we continue on as an organization or is our job done? How have we contributed to changing the world of health and health research? How do we want to focus our considerable strengths in the future?*"

You'll read below about our process and outcomes in this year-long foray. I want to state simply: YES, we will continue on with great vigor. The last 30 years of ploughing the ground and disrupting the biomedical research ecosystem, is starting to pay off. Many more entities are singing our song. There is finally recognition that people must be partners in the work of discovering interventions to health problems.

And so, Genetic Alliance was able this year to focus on engaging individuals, families, and communities in really meaningful ways such that we are answering the critical questions with our limited resources.

Let's be bold, let's risk together, as those who suffer risk. "The best time to do this was 20 years ago, the second best time is now." ~Chinese Proverb

Best,
Sharon

COUNCIL

Kemp Battle–Secretary
Managing Director, Tucker Capital Corporation
Catalytic Change Agent

Kelly Edwards, PhD
Associate Professor
University of Washington School of Medicine

Shantanu Gaur, MD–Treasurer
Physician, Entrepreneur
Co-founder, Allurion Technologies

Usama Malik, MBA
Founder and Managing Director
InnoAction Advisory Services

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Executive Director, PXE International, Inc.
Ashoka Fellow

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Chief Strategy Officer

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Program Assistant, PCORnet Coordinating Center

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Program Coordinator, PCORnet Coordinating Center

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Director of Engagement

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Office Manager

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Assistant Director, Maternal and Child Health Programs

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Communications & Outreach Coordinator

Matthew Smith
Project Manager, CENA

Sharon Terry, MA
Chief Executive Officer

Amanda-T Schlichte, MA
Communications and Operations Coordinator

Tamara Wurst, MS
Research Manager

Genetic Alliance 30th Anniversary

CO-CREATING A HEALTHY FUTURE

On March 9-10, 2017, together with peers and friends from diverse backgrounds in healthcare, medical research, and patient advocacy, Genetic Alliance planned for a future that prioritizes the health of individuals, families, and communities.

For two days, we took a breath together, slowing down to ponder 30 years of glorious work by our community in advocacy, policy, technology, and education. We jointly asked hard questions. Not resting on our laurels, at every major anniversary Genetic Alliance brings our community together to ask, "*Does the world still need us?*" "*How can we be most effective, most compassionate, most disruptive?*" "*To what are we called as the world of health, healthcare, genetics, biomedical research, and bioethics evolve?*" We invested our comfort, moving beyond what is familiar, to experiment with how we can alleviate suffering, support health, and further well-being. We united as a community of diverse stakeholders. We did this with very real urgency, for those who cannot take the steps we can—sometimes quite literally.

With more than 200 individuals in attendance representing many viewpoints and experiences within the participant, patient, caregiver and healthcare sectors, Genetic Alliance set out to create an atmosphere of open heart and open mind. The body of the meeting offered four unique work streams:

1. Engagement: national and local
2. People-centered design in health
3. High touch and high tech
4. Radical innovation and/or iterative improvement

Participants were invited to leave all biases at the door and engage with one another in openness. Over the course of two days, using these four focus areas and an option to step out into a free-form session, participants discussed, debated, and defined opportunities and challenges for individuals to take charge of their health and catalyze the answers they seek. Mindful of the marching orders to bring solutions, meeting participants did not focus on plowing old ground or griping about the problems. Each stream came up with projects that had legs well beyond the conference.

In addition to "Co-creating a Healthy Future," Genetic Alliance and guests spent the first evening of the conference celebrating 30 years of excellence and the individuals who made that possible. No organization reaches such a milestone without strong leadership. Genetic Alliance has been graced with three incredibly strong leaders over the decades: Joan Weiss, Mary Davidson, and Sharon Terry.

Celebrations included toasts to these leaders and the community who helped guide Genetic Alliance through its 30 years; a formal dinner; and special presentations. One such special guest was founder of Positive Exposure, Rick Guidotti, who shared his experiences photographing individuals with rare genetic conditions and how the simple act of taking someone's picture can help instill confidence. Rick spoke passionately about replacing the lens through which we see genetic conditions— instead of looking at a person and seeing their condition, the beauty of the individual is what we see.

Regina Holliday, founder of the Walking Wall, is an activist, artist, speaker, and author. She is part of the movement known as participatory medicine. While participating in the conference, Regina created an original piece of artwork telling the story of our gathering. Her personal story and her paintings did more than just move the packed room to tears; they have become part of the national debate on healthcare reform and are helping guide public policy. In his keynote address, Dr. Reed Tuckson delivered a strong message,

> *"We must create a shared vision for health and it begins inside of us."*

His remarks hammered home the impact of the conference – the fight for humanistic, holistic, equitable, and quality health and medical care. Dr. Tuckson asked those in attendance to be the change we wish to see. Reminding us it is the individual that we are meant to help – that we must ask them about their goals and their definition of success.

You can find the full conference report here.

Sharon Terry's TEDMED Talk

In June 2017, Sharon Terry's TEDMED talk, "Science Didn't Understand my Kids' Rare Disease Until I Decided to Study It," was publicly released on the TED website. In less than three months the video was viewed more than one million times!

The TEDMED talk details how Sharon and her husband, Patrick, took the bull by the horns and researched their children's rare condition. As citizen scientists, gathering thousands of similarly affected people around the world, they discovered the causative gene, developed a genetic test, and initiated studies and clinical trials. Her message:"citizen scientists, activists using do-it-yourself science and crowdsourcing, are changing the game."

Dr. Francis Collins, director of the National Institutes of Health, said, "The Terrys have been pioneers in bringing patients and their loved ones to the front lines of medical research, becoming active participants in the search for cures. All of us involved in the pursuit of health progress should take Sharon Terry's talk to heart and continually re-evaluate the true meaning of patient engagement and patient-centric research."

In a statement reflecting on the milestone, Sharon said, "This interest is a testimony to the heart of people, as we all seek to come into meaningful community."

COMMUNITY AND PARTNER ENGAGEMENT

The National Patient-Centered Outcomes Research Network Coordinating Center

Genetic Alliance continued to play a critical role for the National Patient-Centered Outcomes Research Network (PCORnet) in 2017, as it enhanced activities around co-production, novel methods of participant-led research, and communicated with hundreds of partners to elevate success of this innovative network and accelerate participant-centered research for the nation.

Genetic Alliance's core values of transparency, inclusivity, collectivity—among others—support advanced facilitation and sharing for the Network and more broadly in the field of clinical research.

Over the year, the Genetic Alliance Coordinating Center (CC) hosted 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. The CC coordinated all 21 Phase II and affiliate Patient Powered Research Networks (PPRNs) for the first-ever, multi-network study among the PPRNs in PCORnet.

62 Calls

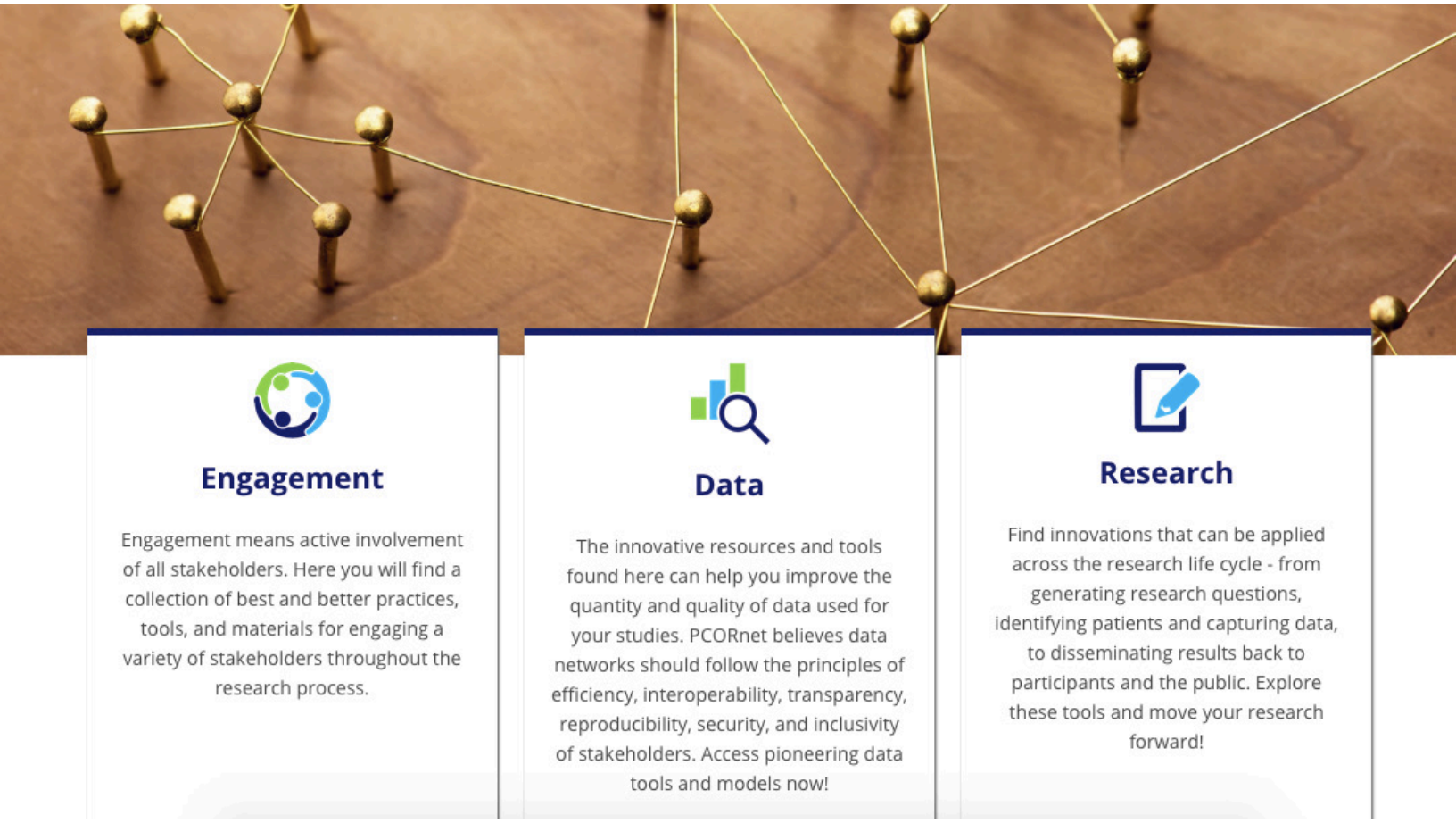
14 PPRN PI Monthly Cross-PPRN
10 EASAG monthly calls
7 Engagement Committee
5 EHR
5 Seal of Approval WG
3 PCRF Transition Office Hours calls
2 Monthly DCRI/GA/PCORI
2 Clinician Engagement WG
2 PCORnet Commons training
1 NewCo
1 BPSS

11 Meetings

5 Engagement Committee
2 PCORnet Network
2 PCORnet PI
1 DCRI/GA/PCORI meeting

This year we launched a new website, called the Commons, to enable PCORnet collaboration; advance PPRN data strategy and capacity by exploring connections to mHealth and EHR data; and worked with communities and studies to elevate the voice of participants and challenge the status quo around what it means for research outcomes to suit community needs.

Some of the many notable materials this year include a nationally-distributed tool to plan for and assess engagement processes, various research-ready resources and tools developed and posted on the Commons; and a project to explore and expand methods of community activation among research organizations.



In its role as facilitator of the parent and stakeholder leaders (the "EASAG") for PCORnet's Short and Long-term Effects of Antibiotics on Childhood Growth" study, Genetic Alliance routinely convened stakeholders for routine updates about the study and to gather feedback on specific topics or projects. A stakeholder survey disseminated for quality improvement and ongoing learning, with a 100% response rate, illustrated that stakeholders generally felt as if they had opportunities to find feedback and participate in decisions; felt respected; and learned from the process. The survey results were shared through an academic poster and Genetic Alliance is guiding the EASAG through drafting a stakeholder-led publication based on the work during the study. This work has contributed to the overall understanding of patient engagement in practice and will lead to improved stakeholder leadership roles in the future.

PCORnet Ladder of Engagement

Genetic Alliance's team worked closely with the PCORnet Engagement Committee to publish the Engagement Assessment Tool. One of the major projects the team accomplished this past year was its project with 270 Strategies. Genetic Alliance teamed up with 270 Strategies to distribute a PCORnet-wide survey regarding community building in the network. 270 Strategies surveyed 20 PPRNs, conducted interviews, and crafted engagement recommendations for PCORnet. The team then created an abstract on the process and results. The poster was showcased at the PCORI Annual Meeting.

To address a variety of challenges associated with the diversity of human participant research oversight experience and infrastructure among the PPRNs, the Coordinating Center provided technical assistance to PPRN sites to support the use of a single IRB (SMART IRB) for multi-site research projects. The team compiled an entire SMART IRB Guide to assist the network through the SMART IRB process. Specifically, the CC supported all PPRN research sites through the process of signing on to and using SMART IRB for the cross-PPRN study, Healthy Mind Healthy You. Additionally, given its expertise with participant-led research projects, the Genetic Alliance IRB was selected to be the reviewing IRB for this study. The PCORnet Coordinating Center team worked with all 21 PPRN networks and the Genetic Alliance IRB to develop resources and monitor successes and challenges with SMART IRB implementation; streamline the SMART IRB process for cross-network PCORnet studies; and facilitate the adoption of SMART IRB by PCORnet.

UNC Catalyst

Open lab notebooks? Freely sharing discoveries? This year, Genetic Alliance, with the University of North Carolina and the International Structural Genomics Consortium, launched UNC Catalyst to recruit, train, and fund research scientists. These scientists who create and use tools needed to study the physical effects genetic mutations have on the body and create a framework for designing a new treatment. To magnify and accelerate the impact of this initiative, researchers across the globe will have unrestricted access to the research tools generated by UNC Catalyst. Genetic Alliance brings the urgency of people who long to have their suffering alleviated. We are delighted to work with these partners to change the paradigm of science.

International Rare Disease Research Consortium (IRDiRC)

Genetic Alliance was among the founders of the International Rare Disease Research Consortium (IRDiRC) more than 7 years ago. The Consortium set out to achieve two main objectives by the year 2020, namely to deliver 200 new therapies for rare diseases and the means to diagnose most rare diseases. Remarkably, IRDiRC achieved its goals this year, and has established new ones.

The new goals are:

1. All patients coming to medical attention with a suspected rare disease will be diagnosed within one year if their disorder is known in the medical literature; all currently undiagnosable individuals will enter a globally coordinated diagnostic and research pipeline.

2. 1,000 new therapies for rare diseases will be approved, the majority of which will focus on diseases without approved options.

3. Methodologies will be developed to assess the impact of diagnoses and therapies on rare disease patients.

The group of funders, industry, researchers, and individuals with a lived experience of disease are working relentlessly to figure out how to achieve these new audacious goals. Sharon Terry is the chair of the Patient Constituent Committee, leading the other national and regional advocacy organization in creating tangible steps to these goals. She also serves on the Operating (formerly Executive) Committee.

Beyond the Bloodspot: Newborn Screening Education and Engagement Summit

The Beyond the Bloodspot: Education and Engagement Summit, hosted by Baby's First Test, brought together nearly one hundred attendees including families, healthcare professionals, newborn screening and public health professionals, national organizations, and experts in health communication and policy. Attendees spent two days identifying the need for an approach to reach priority populations, forming partnerships with health educators, and improving health professionals' understanding of newborn screening, among many others. Many noted that, though they work with families and are responsible for educating citizens on newborn screening, they had never been part of a training and meeting completely devoted to this critical topic. The success of the meeting was highlighted by attendees meeting new people in the newborn screening community, learning about strategies used by other organizations and agencies, and engaging with others in maternal and child health interested in implementing and evaluating educational initiatives.

"This was, hands down, one of the best conferences that I have attended – breadth, depth, expertise."

– Summit attendee

Perinatal Nutrition Collaborative

To further expand the impact of Expecting Health's nutrition initiative, the Perinatal Nutrition Collaborative was formed in 2017, stemming from the academic-focused Perinatal Nutrition Working Group, to bring together critical thought leaders and dissemination partners in perinatal nutrition. The Collaborative has representation from 12 national organizations spanning obstetrics, pediatrics, maternal health, and nutrition. During the year, the advisors and Collaborative members convened in person and received ongoing updates on new research regarding prenatal and lactation nutrition. This comes during a time with increased focus on the wellbeing of mothers and mothers-to-be, and an opportunity to connect consumers with science-based, actionable information.

TOOLS AND TRAININGS

Community Engaged Network for All (CENA)

For Genetic Alliance, "community-led research" isn't just a buzzword. The concept of research participants as partners is core to our identity and has been since our establishment in 1986. What started as a way to give voice to people affected by genetic conditions has evolved to include health more broadly, and today we represent a network of more than 10,000 health organizations whose primary partners are individuals, families, and communities. Together we respond to people's needs through the transformation of health systems. Collaboration and partnership are integral to our model, and we work with our partners to pilot and test a variety of new methods, tools, and technology solutions. The Community Engaged Network for All (CENA) is one such testing ground.

CENA is a collaborative, cross-disciplinary team of advocacy organizations and their research partners, led by Genetic Alliance. The Patient-Centered Outcomes Research Institute funds CENA as a Patient-Powered Research Network (PPRN) within the National Patient-Centered Clinical Research Network (PCORnet). 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 network uses a federated model in which distinct communities utilize unique skills in outreach, recruitment, and retention to engage a cadre of trusted researchers, while still sharing lessons learned. Communities participating in CENA have established registries and other research initiatives using Genetic Alliance's Platform for Engaging Everyone Responsibly, and have also developed and piloted the use of Mosaic to prioritize research questions, publicly build protocols, and carry out studies. Mosaic is an open-source, transparent, crowdsourcing platform for developing research studies with input from all stakeholders.

This year, CENA organizations led a variety of research activities in and out of Mosaic and PEER. PXE International used the Mosaic platform as a community forum for generating research questions of interest to the community, before doing a deep dive with their members on the topic of PXE and nutrition. The organization now plans to release survey on vegan and vegetarian diets to their community in 2018. Two other organizations, AliveAndKickn and International Breast Cancer Research Foundation, submitted abstracts about their registries to domestic and international conferences. Several foundations have also used their PEER registries to develop partnerships in the biopharma and biotech spaces and connect community members to relevant clinical trials.

In addition, 10 out of 13 CENA organizations signed on to the Streamlined, Multisite, Accelerated Resources for Trials IRB Reliance platform (SMART IRB) promulgated by the National Center for Advancing Translational Sciences at NIH. Three of these organizations – AliveAndKickn, Celiac Disease Foundation, and PXE International – are using SMART IRB to participate in the PCORnet cross-PPRN demonstration project, Healthy Mind, Healthy You: A Study of Mindfulness. SMART IRB is designed to harmonize and streamline the IRB review process for multisite studies while ensuring a high level of protection for research participants. As human participant research oversight experience and infrastructure differ substantially across the different CENA sites, participation with SMART IRB creates new opportunities for collaboration on community-led research projects.

Going into 2018, CENA's previously tested tools and methods will empower community-based, people-centered research across our network. Despite the growing movement towards community-led research, people's expertise about their own health is still grossly underutilized. In 2018, we will unleash that power by catalyzing and supporting communities in leading all aspects of research, from prioritizing research questions, to protocol development, through to analysis and implementation.

13 organizations participated in CENA in 2017

AliveAndKickn
Alström Syndrome International
Association for X and Y Chromosome Variations
Asthma and Allergy Foundation of America
Celiac Disease Foundation
Dyskeratosis Congenita Outreach
Hepatitis Foundation International
Inflammatory Breast Cancer Research Foundation
Joubert Syndrome and Related Disorders Foundation
Metachromatic Leukodystrophy Foundation
Pancreatic Cancer Action Network
Pseudoxanthoma Elasticum International
The Fibrolamellar Registry

Number of peer-reviewed publications: 30

Platform for Engaging Everyone Responsibly (PEER)

The culture of health research is evolving. In the past, academic and industry investigators were its primary stewards, but today communities of people can, and do, drive their own research. Genetic Alliance's signature research tool – the Platform for Engaging Everyone Responsibly (PEER) – enables individuals, families, and communities to drive research priorities by creating customizable, dynamic, and accessible community research portals. Participants in PEER contribute their patient-reported outcomes and other health-related data for research using the platform's award-winning tools for data sharing. These tools place control in the hands of participants, empowering them to broadly share their data with a variety of researchers while still addressing individual concerns about privacy and access.

To date, more than 45 communities have onboarded 25,613 individual users who used PEER to develop and conduct community-based research projects. These projects exemplify the diversity of communities' participation in biomedical research, from registry and cohort development to conduct of natural history, family history, observational, and patient-reported outcome studies. In 2017, nine PEER communities launched new research initiatives on a variety of subjects, including rare cancers, bleeding disorders, experiences with genetic testing, the community health impacts of fracking, and more. To help support these and future initiatives, Genetic Alliance also launched a companion wiki for PEER in 2017. The wiki contains documentation for using the platform to set up registries and collect data, and for conducting related activities such as registry planning and community development of research questions.

This year, Genetic Alliance also announced a plan to launch the PEER Consortium: a partnership built around PEER where communities using the platform can set priorities for its development roadmap and receive training and support to enhance their registry activities. Launching in 2018, the Consortium will establish PEER as a sustainable, community-centered software for research and engagement that empowers communities to not only take ownership over their research activities but also over the tools they use to drive research.

Baby's First Test: Nation's Newborn Screening Clearinghouse

Baby's First Test continues to grow both in online presence and in support of newborn screening efforts on the community level, with over 1 million page views and countless requests for organizational support in consumer engagement. In addition to running the Beyond the Bloodspot: Education and Engagement Summit (page 13) the program expanded its work for Spanish speaking communities. The program team convened a community meeting with representatives from local and national organizations that serve the Latino community, as well as conducted focus groups with families and healthcare providers. Out of these efforts, a program plan is being developed to showcase how to authentically engage this community in newborn screening beyond providing translated materials. This work reinforces the program's commitment to authentic family engagement and the importance of adapting modules to the technological needs and preferences of priority audiences.

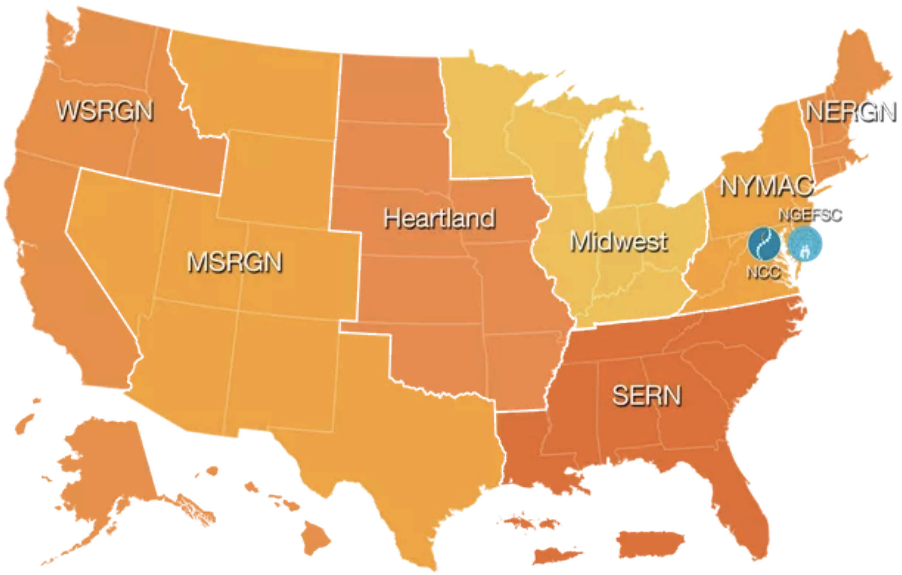
Two new modules, Ask an Expert and The Public Square, helped expand the capacity of this program by providing more direct engagement with families and other stakeholders.

Ask an Expert exceeded expectations after launch, with more than 130 questions from parents, healthcare professionals, and other members of the public, seeking information on the screening process, the meaning of specific results, as well as alternatives to state-mandates screening. These questions provide a direct roadmap of where newborn screening efforts should focus for the nation. The Public Square hosted four discussion forums on a range of topics. Not only did this lead to more dialogue on emerging issues in newborn screening, it provided another federally funded program with a new avenue to gain feedback on recommendations. The discussion from the Assessing Ethical and Social Challenges in Newborn Screening Research Public Square influenced topics and the structure of a paper written by collaborators of the National Institute of Child Health and Human Development-funded program, the Newborn Screening Translational Research Network (NBSTRN).

Genetics Education and Family Support

Genetic Alliance continued its work to support individuals and families navigating the complex ecosystem of care for genetic conditions. The HRSA-funded National Genetics Education and Consumer Network (NGECN) magnified the voice of those living with genetic conditions through an Advocates Leader Program, needs assessment data, and perspective pieces. The Center released an article based upon a 34-question national needs assessment entitled, Understanding Access to and Quality of Genetic Services: The Individual/Family Perspective, nine articles and perspective pieces in national publications; and a monograph titled, Next Steps for Patient Navigation: Perspectives from Partners in Care. The monograph was based on 18 semi-structured interviews with hospitals, advocacy networks, and community health centers.

Genetic Alliance launched a new program in 2017, the National Genetics Education and Family Support Center (NGEFSC). NGEFSC is a companion project to the HRSA-funded Regional Genetics Networks (RGN) and is led by three organizations working in collaboration: Genetic Alliance, Family Voices, and Parent to Parent USA. RGNs link medically underserved populations to quality genetic services and provide resources to genetic service providers, public health officials, and families. In many cases though, linking isn't enough. Individuals and families need direct support and assistance. Through this Center, Genetic Alliance offered education and resources through its online presence, GenesInLife.org, a source of comprehensive, easy-to-understand, vetted information about genetics and health, which was expanded in 2017 with new content. This year, Genes in Life was visited by more than 100,000 unique users.



- 7 Regional Genetics Networks
- National Coordinating Center
  - *Housed at ACMG*
- National Genetics Education and Family Support Center
  - *Housed at Genetic Alliance*
  - *Partnered with Family Voices*

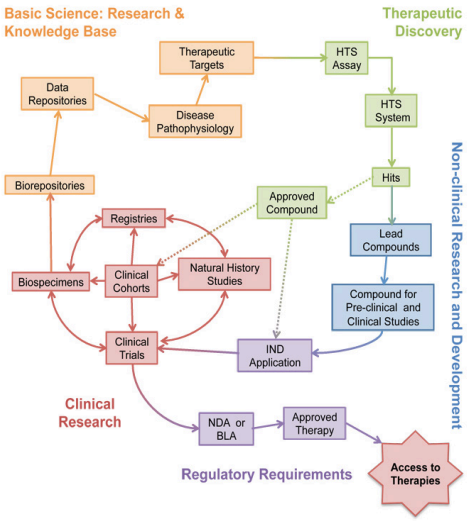
Disease InfoSearch (DIS)

Genetic Alliance's web tool, Disease InfoSearch.org, helps individuals and families navigate services and support by bringing credible information to one place and helping individuals find and compare online sources on more than 10,000 conditions. Most importantly, it aims to help families avoid a broad Internet search containing high literacy, poorly contextualized information about the condition. This year saw increased interest in the site, with more than 210,000 unique visitors.

Genetic Alliance BioBank

Biobank was founded in 2003 as a cooperative to decrease costs by increasing the "buying power" of a collective of communities. Individual communities manage an account under the Genetic Alliance's agreement with biobanks, cell banks, and other specialty repositories for greatly reduced cost and simple online management. In 2017, we stored more than 50,000 samples across a dozen diseases in the Biobank.

Navigating the Ecosystem of Translational Science (NETS)



NETS is a map of the process for engaging as communities in discovery of pathways to better health. Established in 2011 as an interactive map of "neighborhoods" with associated resources, and subsequently published in 2013, this navigational tool guides communities in planning and executing on studies of all kinds. The National Academies of Medicine Drug Forum recently collaborated with Genetic Alliance to revise the concept and post the map to the National Academy of Medicine and NCATS websites.

Genetic Alliance Institutional Review Board (IRB)

BENEFICIENCE RESPECT FOR PERSONS JUSTICE

IRB

INSTITUTIONAL REVIEW BOARD
GENETIC ALLIANCE

Genetic Alliance IRB was founded in 2003 and is comprised of leading experts in human research protections. Genetic Alliance has Federal Wide Assurance # FWA00017292.

Genetic Alliance IRB is now one of 355 institutions nationwide that has joined SMART IRB, a platform designed to ease common challenges and burdens associated with initiating multi-site research. SMART IRB will help Genetic Alliance advocacy researchers involved in multi-site, NIH-funded studies streamline human subjects research, while ensuring robust protections for study participants. This IRB is the reviewing IRB upon which 20 organizations rely for a large multisite PCORnet study, Healthy Mind Healthy You, using SMART IRB, since it 1) understands community-based research, and 2) is fast and efficient. With organizations now relying on Genetic Alliance IRB for single review, the IRB Chair has spent time updating the Genetic Alliance Policies and Procedures (GAPP). GAPP will serve as a regulatory reference and working document for institutions that rely on the Genetic Alliance IRB.

In addition to serving as the IRB of record on this large, multisite study, Genetic Alliance IRB has conducted 18 initial reviews, 23 continuing reviews, and 1 protocol closure.

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.

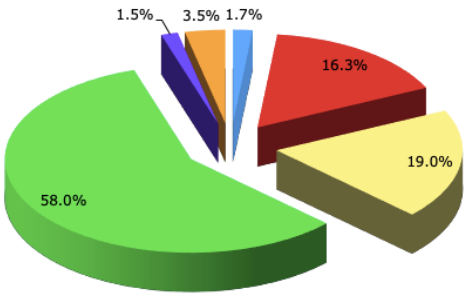
We continually diversify our funding sources, with a diversification plan to secure strategic, fee-for-service partnerships that leverage our expertise, serve the needs of the field and community, and bring greater financial sustainability to the organization.

Genetic Alliance
Condensed Financial Information

Statement of Activities and Changes in Net Assets
as of September 30, 2017

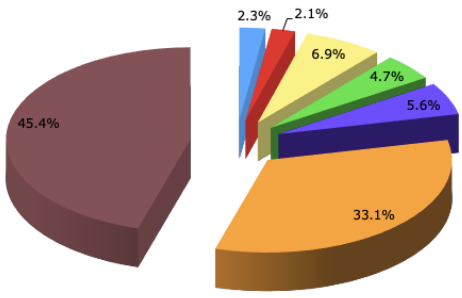
Revenue and Other Support	**2017**	**2016**
Contracts and Grants	$909,843	$1,238,293
Foundation Contracts	2,693,521	1,690,792
Corporate Contracts	731,815	587,013
Biobank Revenue	78,778	69,944
Contributions	67,492	38,967
Other Revenue	162,750	53,555
Total Revenue and Other Support	$4,644,199	$3,678,564
Expenses		
Program Services		
General Programs	$3,643,987	$3,220,127
Supporting Services		
General and Administrative	704,787	607,405
Fundraising		2,034
Total Expenses	$4,348,774	$3,829,566
Net Increase (Decrease) in Net Assets	295,425	-151,002
Net Assets, Beginning of Year	$157,623	$308,625
Net Assets, End of Year	$453,048	$157,623

2017 Revenue



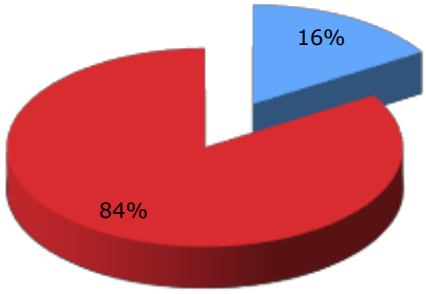
- BioBank & Other
- Corporate Contracts
- Gov't Contracts & Grants
- Foundation Contracts
- Contributions
- Other

2017 Expense



- Office Expenses
- Professional Fees & Other
- Travel and Meetings
- Rent & Depreciation
- IT & Communications
- Partner Organizations & Consultants
- Salaries and Benefits

2017 Fund Spending



- General & Admin
- Programs

Genetic Alliance
Condensed Financial Information

Statement of Financial Position
as of September 30, 2017

Assets	2017	2016
Cash and Cash Equivalents	$239,781	$24,848
Accounts Receivable	530,418	281,909
Grants Receivable	0	59,277
Prepaid Expenses	49,364	49,288
Deposits	7,176	6,595
Furniture and Equipment	1,240	1,360
Total Assets	$827,979	$423,277
Current Liabilities		
Accounts Payable and Accrued Expense	$323,774	$178,361
Long-term Liabilities		
Deferred Rent		3,185
Deferred Revenue	51,157	84,108
Total Current Liabilities	374,931	265,654
Net Assets		
Unrestricted	453,048	157,623
Total Net Assets	453,048	157,623
Total Liabilities and Net Assets	$827,979	$423,277

Giving Back

Wanting to give back on a more intimate scale and make a direct impact in our local community, we chose to partner with the Capital Area Food Bank for one of our service projects this past year. The Capital Area Food Bank is the largest organization in the Washington metro area working to solve hunger and its companion problems: chronic undernutrition, heart disease, and obesity. During our service, Genetic Alliance helped put together more than 400 packages of food supplies to be delivered to families in need in the D.C. Metro area. In addition to the work done for Capital Area Food Bank, our staff pooled together a large collection of brand new toys to donate to the local nonprofit, La Clinica Del Pueblo.

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