



Genetic Alliance

Annual Report 2018



IN THIS REPORT

Ponderings from the CEO	3
Staff and Council	4
Engagement	5
Research Done Differently	14
Expecting Health	25
Financials	31

PONDERINGS



Dear Friends,

We usually call this part of the annual report the introduction or welcome from the CEO. I have renamed it ponderings this year for a couple of reasons.

The first reason is wondering about why I get to write an introduction? Any other Genetic Alliance staff should have the right to do this, we are all equal members of the body. Sure, I am supposed to have some bird's eye view, but in working with my colleagues I notice they hold an important piece of our whole, and I do not have a handle on all of it. Their voices and vision actually create Genetic Alliance, and so they should be recognized and applauded. It is my great fortune in this life that I get to work with these amazing individuals.

The second reason is about where we are as an organization in this world right now. It is never easy to be a nonprofit in any climate. I am most reflective about what it has meant for us to push so many cutting-edge elements of participant inclusion in biomedical research and services. We have pushed hard, risking our human and other capital, to effect change. We often say that we should risk as much as those who through their suffering risk every minute. I do not believe, that while we have made great advances, we have actually transformed these systems to produce outcomes that benefit people as much as is possible. And so, we continue to review, revise, and deploy new tools.

As you read about what we focus on for 2018, and our plans for 2019, I hope you will continue to partner with us, challenge us, and above all strive for the change we have seen in other industries in our own field.

Sincerely,

Sharon Terry

COUNCIL

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

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

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Physician, Entrepreneur
Co-founder, Allurion Technologies

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Founder and Managing Director
InnoAction Advisory Services

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Executive Director, PXE International, Inc.
Ashoka Fellow

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Program Assistant, Expecting Health

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Deputy Director of Engagement

Tetyana Murza, MES
Managing Director

James O'Leary, MBA
Chief Innovation Officer

Mary Peckiconis, MA
Office Manager

Jaclyn Seisman, MPH
Assistant Director, Maternal and Child Health Programs

Sharon Terry
Chief Executive Officer

Tamara Wurst, MS
Research Manager



ENGAGEMENT

Genetic Alliance is committed to a vision whereby nothing happens for or to a group of stakeholders without meaningful engagement. This is the starting place for any activity or project. Therefore, because we have worked for 32 years as grassroots community leaders from the ground up with diverse stakeholders, we have excellent expertise in engaging communities and organizations. We provide that expertise in and through our projects, and offer as a core service to other entities.



National Patient–Centered Clinical Research Network: Coordinating Center

Genetic Alliance leads multiple efforts for engagement of people in research, programs, and systems, most notably through the National Patient- Centered Outcomes Research Network (PCORnet). As a key part of PCORnet’s Coordinating Center, and through initiatives and consortia around the world, Genetic Alliance brings expertise from the perspective of the community and elevates learning; co-production of tools; monitoring and assessment of participant-driven research; and establishing methods to make it easier for people in the healthcare system to access and share their data.

PCORnet’s Evolution

In line with PCORnet’s mission to accelerate people-driven research, Genetic Alliance supported the founding and launch of the People-Centered Research Foundation, the Central Office for PCORnet, which was established to sustain and expand this Network. Over the course of 2018, Genetic Alliance contributed to strategy, processes, policies, and engagement planning for the Network.

Facilitating People-Powered Research

This year, the Genetic Alliance Coordinating Center conducted a variety of activities to support the Participant-Powered Research Networks (PPRN) of PCORnet, including:



- Partnering with the PPRNs and various external partners to grow collective people-centered research power and further understand the role and value of the advocacy community in the larger research ecosystem.



- Increasing PPRN capacity to integrate data from participants into registries through an EHR extraction pilot project.

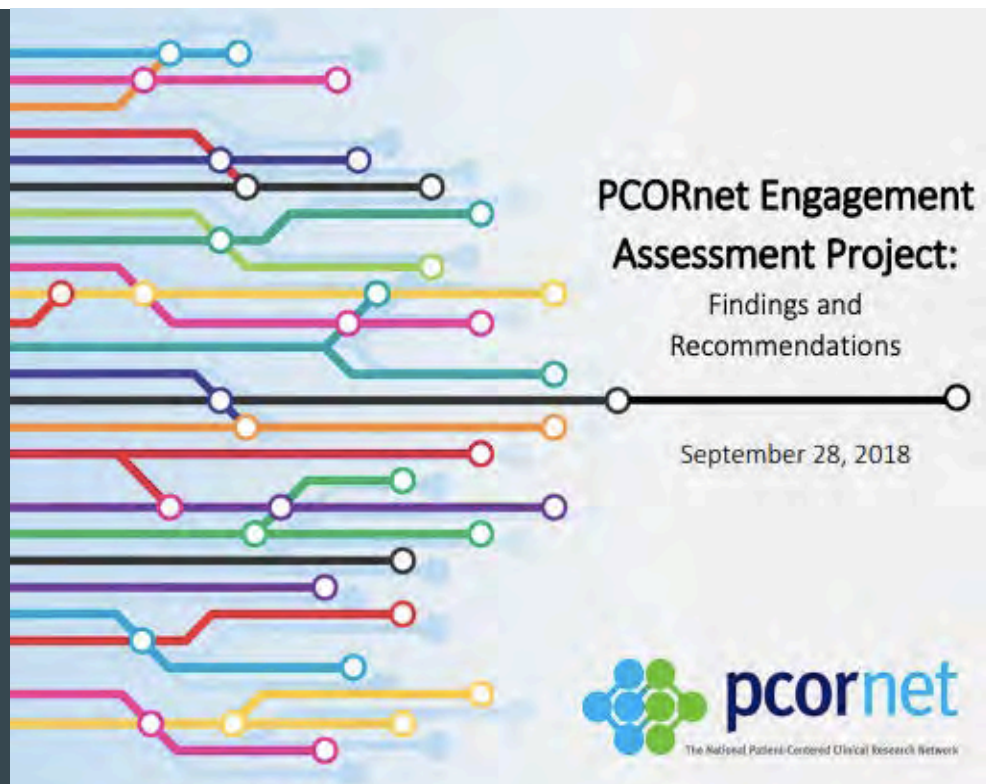


- Facilitating the process for all 20 PPRNs to join and execute a single-IRB model using the NIH SMART IRB platform.
- Hosting dozens of phone calls, webinars, and meetings.

Engagement Tools

In its role as the Coordinating Center, Genetic Alliance supported collaborative engagement activities in PCORnet by convening the PCORnet Engagement Committee, a multidisciplinary group charged with advocating for, embedding, and facilitating people-centered research across the Network. In collaboration with this Committee, the Coordinating Center developed a suite of tools to enable communities to better define, plan, implement, and measure engagement activities.

Additionally, Genetic Alliance conducted a robust engagement assessment to analyze engagement strategies and activities being utilized across PCORnet. Through this project, the team surveyed and interviewed all 35 PCORnet networks to identify best practices, challenges, and lessons learned, as well as a compilation of products and tools.





THE COMMONS IS A SPACE FOR PEOPLE INVOLVED, INVESTED, AND INTERESTED IN HEALTH RESEARCH TO COLLABORATE, SHARE, AND LEARN.

Become a member

The Commons for PCORnet

more than
500
registered users

over
290
resources shared

44
active groups

90
forum topics

In 2018, the Genetic Alliance Coordinating Center team embarked on a user experience research process to enhance the Commons for PCORnet, an interactive website designed to provide researchers with opportunities to share resources, engage in dialogue, and learn from one another. Using the user experience framework, the team distributed a survey and conducted interviews with site users to inform the development and refinement of user-journey maps and wireframes.

The goal of this process was to identify ways to make the site more valuable to the Network and simpler to use. Findings from a Network-wide survey and one-on-one stakeholder interviews resulted in site enhancements to improve Commons content, features, and functionality, including:

- a refreshed homepage design with clearer calls to action;
- a straightforward way to submit resources that
- integrates with common tools (e.g., Dropbox and Google Drive); and,
- improved content organization and presentation.

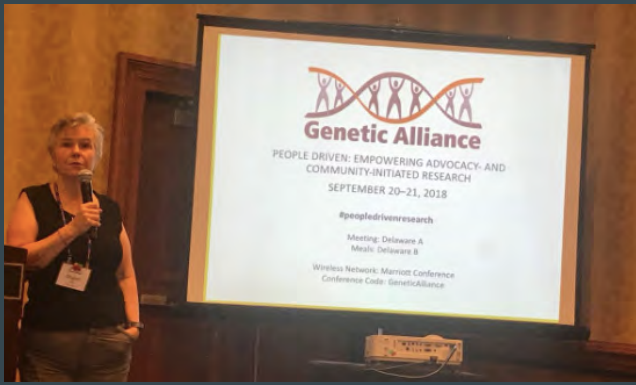
People Driven: Empowering Advocacy- and Community-Initiated Research Workshop

In this two-day meeting, 70 advocates, investigators, and innovators explored the current state of community-led research, in the continuum from those led by health advocacy organizations to communities interested in advancing health.

Much of the effort in biomedical research is centered around a medical model, often held by academic medical centers. In this workshop, we envisioned solutions outside of the current paradigm. This is not an easy task within the very system we wish to challenge. Or, to put this more positively, we set out to understand how we would support the development of a new paradigm in a system that at present is focused on clinics, hospitals, and/or clinicians.

Before there
was data,
there were
PEOPLE





The meeting focused on high-level concepts and the infrastructure that empowers communities. By first reviewing existing evidence for this approach, we were able to make some recommendations on eight areas of interest and concern:

1. Create a coalition, or alliance, of organizations that support people-driven research.
2. Create and support a common repository for all of the resources and tools.
3. Stand up a “marketplace” for skill, expertise, and tool sharing.
4. Create a forum for discussion to share best practices.
5. Spend time and resources on solving the problem of reaching underserved individuals and those who do not access care.
6. Stop talking and start collaborating.
7. Partner where possible; otherwise create new working groups.
8. Balance each organization’s needs/objectives with the more general needs that can be answered for many groups (collectively vs. individually).
9. Create a side-by-side comparison of different tools (e.g., Invitae, PEER, NORD registries):
 - NCATS information available on what registries and technologies exist
 - AHRQ survey of all of the registries (also in the NCATS toolkit)
 - Genetic Alliance tools to help advocacy groups that want to start a registry
10. Fund a National Academy of Medicine roundtable on patient-driven research created by lay people, with lay people as speakers (about \$100,000).
11. Create a tool detailing registry use and value for both participants and funders.
12. Get a commitment from a small group to share and work together and build from there. Stop the “Not Invented Here” cycle.
13. Make the collaboration so good that another group doesn’t try to fill a “gap” left.
14. Use and refine existing resources, including a method for efficiently gathering information, reviews, and current user feedback on existing registries and tools.
15. Come together as a community and demand funding.
16. Make this process “frictionless” for smaller organizations so that they can put in less effort and get more out of collaborations.
17. Use Genetic Alliance as a convener and to serve its original purpose—to share information and resources that benefit the community; refine Alliance role-based on a sharing model that works and looking at when things need to be owned by the individuals.

The National Genetics Education and Family Support Center

The National Genetics Education and Family Support Center is a companion project to the Regional Genetics Networks (RGNs) and is led by three organizations working together: Genetic Alliance, Family Voices, and Parent to Parent USA.

In this first year of the project, the National Genetics Education and Family Support Center focused on understanding the needs and plans of the RGNs while updating and expanding educational and support materials and resources for families. This national center connected each region to state Family to Family Health Information Centers, Parent to Parent Affiliates, disease advocacy organizations, and community groups and helped the RGNs form concrete partnerships. In addition, through individual calls and working groups, the center generated specific collaborative projects with each RGNs to support their target populations. Finally, the center offered multiple in-person opportunities to train program staff and families from the RGNs through two innovative offerings from Family Voices, Leading through Convening and Serving on Groups.



The goals of the Family Center are to support the RGNs in promoting health equity and reducing barriers to accessing care. The Family Center does this by collaborating on educational materials that help the RGNs learn to partner with community and family-led organizations to better understand and meet the needs of their respective populations. The Family Center also provides trainings, technical assistance, education and resources directly to families.

The Family Center showed measurable success in reaching families through robust online resources:

Disease InfoSearch

A resource created 32 years ago to help individuals and families navigate services and support by bringing together credible information in one place and helping individuals find and compare online sources on over 10,000 conditions. Most importantly, it aims to help families avoid a broad internet search containing high literacy, poorly contextualized information about the condition.

GenesInLife.org

A source of comprehensive, easy to understand, vetted information about genetics and health, was expanded with new content. GenesInLife.org is a place to learn about all the ways genetics is a part of life, with a specific focus on genetics services, including genetic testing and working with genetics professionals.

Advocacy ATLAS

A web-based toolkit specifically designed to provide individuals with special healthcare needs and their families tools and strategies to advocate for whatever they may need.

more than

330,000

users accessed online resources over the project's first year





RESEARCH DONE DIFFERENTLY

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. 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.

Platform for Engaging Everyone Responsibly (PEER)

Genetic Alliance's signature research tool - PEER - enables individuals, families, and communities to drive research priorities by creating customizable, dynamic, and accessible community research portals.

Participants in PEER contribute 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 variety of researchers while still addressing individual concerns about privacy and access.

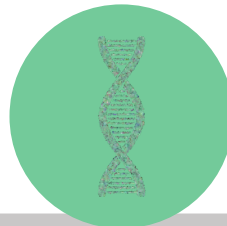
NO ONE SIZE FITS ALL!



Organizational sponsors create and manage their own registries



People govern their data with dynamic and granular privacy settings



Backend linkage of registries enables cross-disease learning potential



Shared features and documentation address a common set of needs



PEER Consortium

more than
45
communities
onboarded

30,000
users enrolled

PEER empowers communities to work collectively to generate knowledge and gather real world evidence to advocate for critical needs. Using PEER, individuals 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.

This year, Genetic Alliance launched the PEER Consortium: a partnership where communities using the platform can set priorities for its development roadmap, receive training and support to enhance their registry activities. 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 over the tools they use to drive research as well.

Community Engaged Network for all (CENA)

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

CENA 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 (PEER). CENA has also developed and piloted the use of Mosaic to prioritize research questions, publicly build protocols, and execute on studies. Mosaic is an open-source, transparent crowdsourcing platform for developing research studies with input from all stakeholders.



CENA has made considerable progress in 2018. We continue to work within our communities to conduct research prioritization. This year we embarked on an assessment of impact, which included in-depth interviews with each of the CENA networks and analysis of previously administered surveys and documentation. In fall 2018, we produced a report “Disease Advocacy Organizations and the Research Ecosystem: An Impact Assessment” ([view full report](#)). We confirmed that CENA organizations participate and lead research activities with varying roles and intensities across all phases of the research process.

Three core areas emerged for advocacy organization impact on research:



1. Shifting Cultures

A powerful role in shifting the culture of research from a traditional model to patient-centered and participant-driven approach:

- Inclusion of Participant Voice
- Participant Driven
- Changed Worldview of Disease



2. Connecting Communities

History in and knowledge of connecting communities to each other and the research process:

- Community Building and Convening
- Connection to Participants
- Promoting Research Readiness



3. Tools and Approaches

Expertise in developing or influencing the tools and approaches used to conduct research:

- Registries & Databases
- Biobanking
- Participant Reported Outcomes
- Conducting Research



Genetic Alliance Biobank

The Biobank was founded in 2003 as a cooperative venture to decrease cost by increasing the “buying power” of a collective of communities. Individual communities, mostly disease advocacy communities, manage their own biobank under Genetic Alliance agreement with biobanks, cell banks, and other specialty repositories.

Individual organizations collect, store, and disseminate blood, saliva, buccal cells, DNA, and tissue of all types. An online digital portal allows the organization to manage collection kits sent by their members, bulk orders of such kits for conferences, accessioning of samples, extraction of DNA or other preparation, inventory, and distribution of samples. At this time more than a dozen communities are storing samples in Genetic Alliance BioBank.

more than

50,000

samples

20,000

clinical records stored



Genetic Alliance Institutional Review Board (IRB)

Genetic Alliance IRB (IORG0003358) was founded in 2003 and is comprised of leading experts in human research protections. Genetic Alliance has Federal Wide Assurance (# FWA00017292).

Smart IRB Implementation

Genetic Alliance IRB is now one of 476 institutions nationwide that have 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 multi-site PCORnet study, Healthy Mind Healthy You, using SMART IRB, since it:

- 1) understands community-based research, and
- 2) is fast and efficient.



The Genetic Alliance IRB serves as the reviewing IRB for a large whole genome sequencing (WGS) study. This is a landmark study for the Genetic Alliance IRB and provides an opportunity to develop best practices and standards for reviewing WGS studies to ensure participant centrality when conducting research with whole genomes. This study also includes protocol for returning results to participants.

In light of new policies from the Office of Human Research Protections, the Genetic Alliance Policies and Procedures (GAPP) have been updated. GAPP serves as a regulatory reference and working document for institutions that rely on the Genetic Alliance IRB.

In addition as the IRB of record on two large studies, the Genetic Alliance IRB has:

27

**initial reviews
conducted**

39

**continuing
reviews**

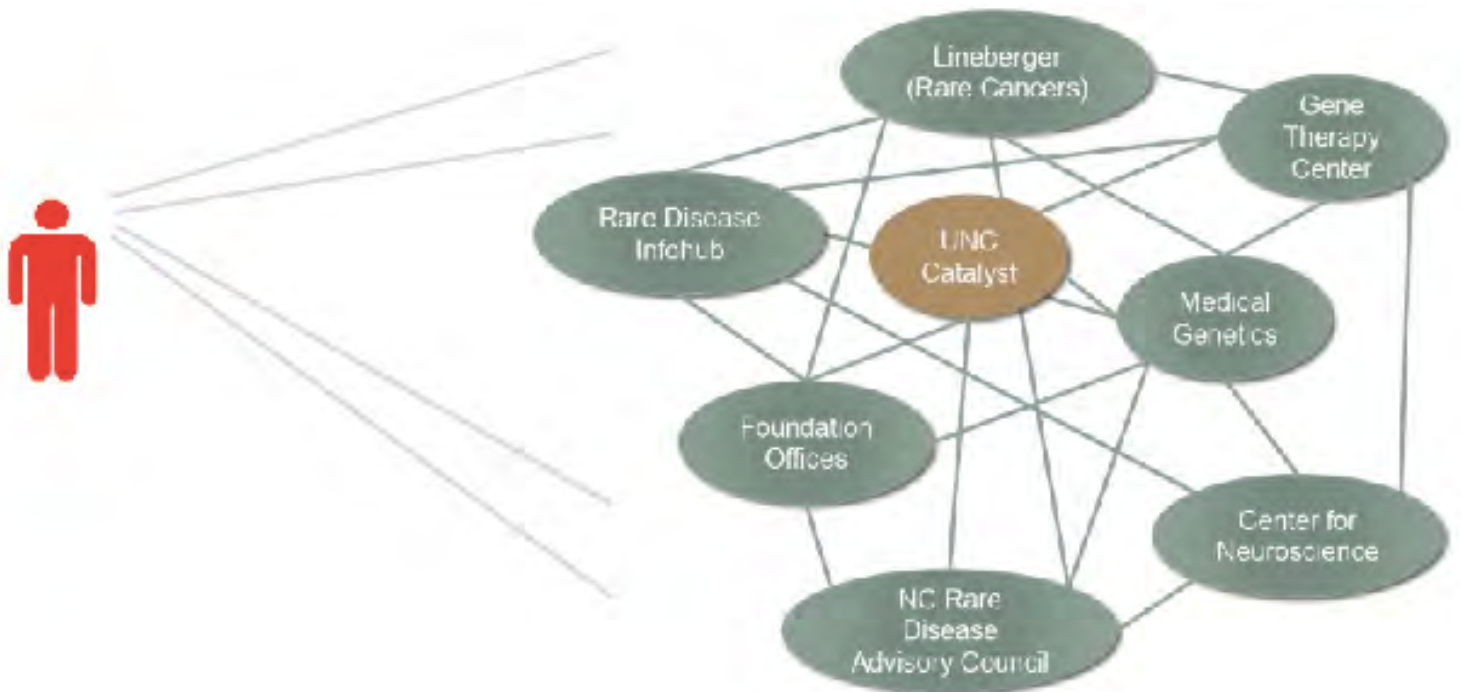
66

**total open
protocols**

UNC Catalyst

Genetic Alliance partners with the University of North Carolina and the international Structural Genomics Consortium, in UNC Catalyst. Genetic Alliance demands we focus on the urgency of people who need their suffering alleviated.

What if research was conducted collaboratively and in the open? What if the investigators, academic institutions, and industry partners relinquished any claim to IP? Particularly in the rare disease realm, it is about time. A safe harbor to conduct critical research on the 7000 rare diseases should include free and open sharing. UNC Catalyst endeavors to support and accelerate research that answers the significant questions of communities and does so in a way that remodels the research paradigm. To magnify and accelerate this paradigm shift, researchers working in UNC Catalyst will have unrestricted access to the research tools as collaborators in this endeavor.



time

IRDiRC's new goals:

- Goal 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.
- Goal 2:** 1,000 new therapies for rare diseases will be approved, the majority of which will focus on diseases without approved options.
- Goal 3:** Methodologies will be developed to assess the impact of diagnoses and therapies on rare disease patients.

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

[illegible]

Disease InfoSearch (DIS)

Disease InfoSearch was first published in print in 1988. It was called the Directory of Genetic Support Groups. In 2001, we put the resource online and began to expand its capacity to provide information about support, research, policies and other important aspects of living with a disease for affected individuals, their families, and their clinicians.

Subject matter experts from disease advocacy organizations populate information directly, ensuring that it is as credible, complete, and as current as possible. We curate the information. In addition, DIS has a web service connection with National Center for Biotechnology Information databases, as well as the Genetics and Rare Disease Information Center, Online Mendelian Inheritance in Man (OMIM), and the European Union resource Orphanet, to permit greater integration and “one-stop-shopping”. Researchers find DIS useful because it catalogs many essential attributes a research will consider in choosing a focus, for both the disease and the advocacy group.

resources for more than

10,000

diseases

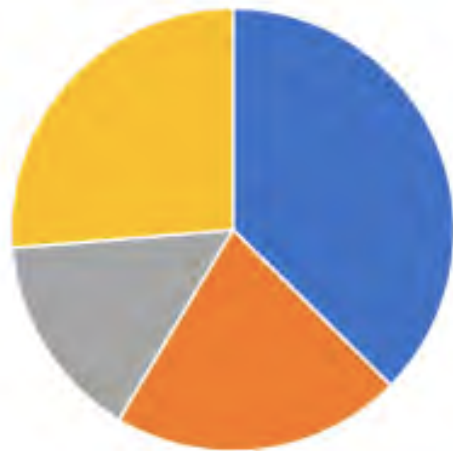
346,186

pages viewed

over

225,000

new visitors to the site



Most needed:

- Help understanding the condition
- Emotional support and guidance
- Recommendations for local provider
- Other



EXPECTING HEALTH

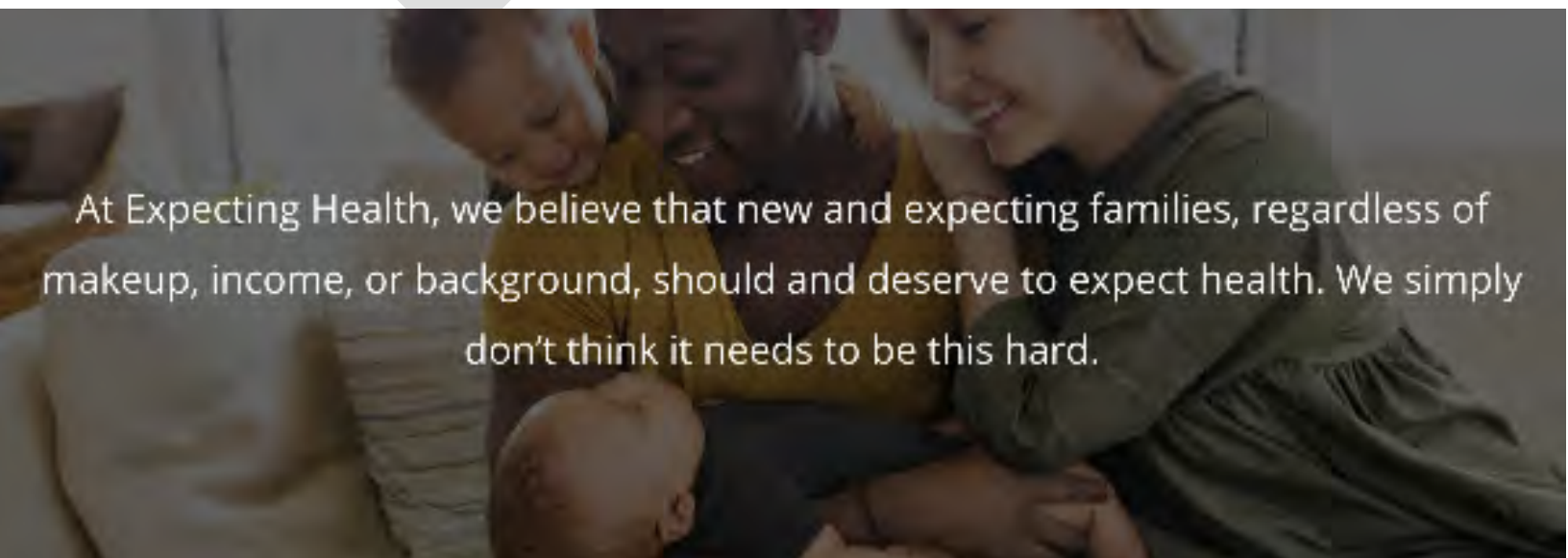
Expecting Health shares science-based and policy-informed information that reflects the lived experiences of individuals and their families. With a focus on pregnancy and newborn health, we utilize principles of community engagement and user driven design to reach diverse audiences. We do this through the power of relationships; convening the top experts; working with key leaders in health; and engaging with families at the center of the conversation.



Expecting Health

A New Phase Begins

The maternal and child health focused initiative, Expecting Health, gained visibility and impact this year as it continues to incubate new programs and opportunities.



At Expecting Health, we believe that new and expecting families, regardless of makeup, income, or background, should and deserve to expect health. We simply don't think it needs to be this hard.

over

60,000

resources disseminated since 2016

more than

3 million

reached on social media

In September, we announced that Expecting Health was **awarded \$2 million** from the Health Resources and Services Administration, a 5-year cooperative agreement **to create and implement new family-oriented training programs on newborn screening**, with a focus on medically underserved communities. This bolsters our ability to build innovative approaches to educating expectant parents about critical health services they and their children will encounter, giving families the tools to actively engage early in a newborn's healthcare.

We know that there are proven ways to increase awareness and empower families to make healthy, informed decisions, and we are thrilled to embark on this project as a means to keep families central to the newborn screening system.

NATASHA BONHOMME

Founder of Expecting Health and Genetic Alliance's Chief Strategy Officer





THE PREGNANT WOMAN'S GUIDE TO EATING SEAFOOD

A new edition of the popular *The Pregnant Woman's Guide to Eating Seafood* was published with a focus on easy to incorporate strategies that benefit the health of new and expecting moms as well as infants. This work was shared with, and supported by, the Perinatal Nutrition Collaborative represented by 12 national nutrition, maternal, and child health related organizations. Representatives met in the fall to discuss the latest nutrition science, opportunities for healthcare provider education, and upcoming policy decisions.

shared with more than

500

health care professionals

Why We Should Promote Breastfeeding

In August, the Breastfeeding Awareness month, Natasha Bonhomme's message on the importance of continued promotion on science-based breastfeeding was published in *RealClear Health*.

With continued medical advances, it can be easy to forget one of the most basic activities that can support the health of moms and babies — breastfeeding. Breastfeeding is the best source of nutrition for most infants and research shows that breastfeeding is linked to fewer infant infections, a reduction in Sudden Infant Death Syndrome, and higher IQ scores.

The American Academy of Pediatrics (AAP) recommends that infants be exclusively breastfed for about the first 6 months.

Baby's First Test: The Nation's Newborn Screening Education Center

Baby's First Test brings together the latest information and resources to help guide parents, families, loved ones, and their health professionals throughout the newborn screening process.

The Baby's First Test team, in collaboration with its workgroups, drafted multiple tools to drive family-centered newborn screening practices from ideation to implementation. *The Newborn Screening Education Best Practice Framework* was developed with multi-stakeholder input as a resource to fill the gaps identified in the 2017 Education and Engagement Summit, with a focus on helping people who want to implement an education program determine the potential impact and scalability of their efforts. This work will be published in 2019.



INFORMS. SUPPORTS. EMPOWERS.

| WWW.BABYSFIRSTTEST.ORG

Why does
*newborn
screening*
matter to you?



Community Outreach

65%

learned something new
from visiting the website

5.3M

impressions
on social media

Baby's First Test continued the tradition of leading Newborn Screening Awareness efforts with an updated social media tool kit: Twitter Chat with March of Dimes, Texas Children's Hospital, and many other stakeholders.

Through this year's *IgniteNBS* campaign we had nearly 5 million impressions to spread awareness about newborn screening to families, health professionals, policymakers, and the public.



WHERE DOES OUR SUPPORT COME FROM?

Genetic Alliance's work is supported by government grants and contracts, industry and corporate support, individual donations, and fees generated by services.

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 our organization.

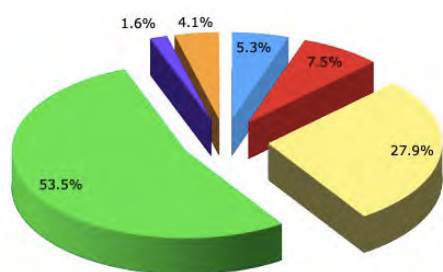
Genetic Alliance

Condensed Financial Information

Statement of Activities and Changes in Net Assets as of September 30th 2018

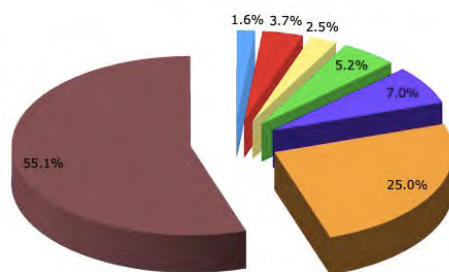
Revenue and Other Support	2018	2017
Contracts and Grants	\$1,143,421	\$909,843
Foundation Contracts	2,155,458	2,693,521
Corporate Contracts	303,023	731,815
Biobank Revenue	212,397	78,778
Contributions	64,829	67,492
Other Revenue	146,064	162,750
Total Revenue and Other Support	\$4,025,193	\$4,644,199
Expenses		
Program Services		
General Programs	\$3,143,835	\$3,643,987
Supporting Services		
General and Administrative	774,384	704,787
Total Expenses	\$3,918,219	\$4,348,774
Net Increase (Decrease) in Net Asset	106,974	295,425
Net Assets, Beginning of Year	\$453,048	\$157,623
Net Assets, End of Year	\$560,022	\$453,048

2018 Revenue



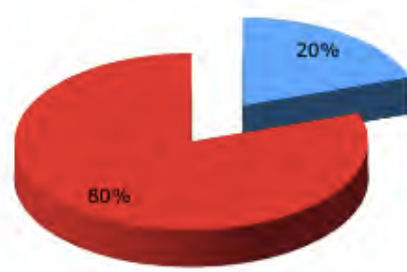
- Foundation Contracts
- Gov't Contracts & Grants
- Corporate Contracts
- PEER & BioBank
- Other
- Contributions

2018 Expense



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

2018 Fund Spending



- Programs
- General & Admin

Genetic Alliance

Condensed Financial Information

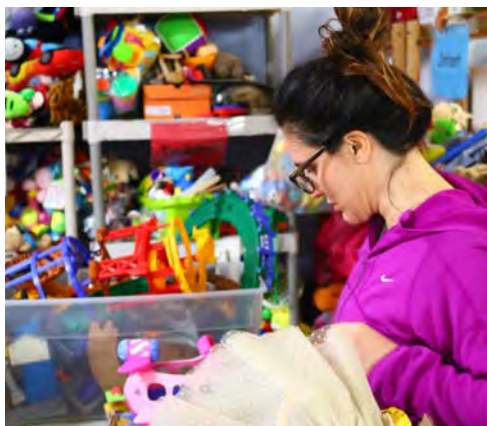
Statement of Financial Position as of September 30th 2018

	2018	2017	and
Assets			
Cash And CashEquivalents	\$584,891	\$239,781	
Accounts Receivable	322,304	530,418	
Prepaid Expenses	46,477	49,364	
Deposits	7,922	7,176	
Furniture and Equipment	0	1,240	
Total Assets	\$961,593	\$827,979	
Current Liabilities			
Accounts Payable and Accrued Expense	\$352,496	\$323,774	
Long-term Liabilities			
Deferred Revenue	49,074	51,157	
Total Liabilities	401,570	374,931	
Net Assets			
Unrestricted	560,023	453,048	
Total Net Assets	560,023	453,048	
Total Liabilities and Net Assets	\$961,593	\$827,979	



GIVING BACK

Genetic Alliance staff are the heart and soul of the organization. We know that we must embody our values at home and in the community. Every year we find ways to meaningfully contribute to our community. This year we spent one afternoon volunteering at A Wider Circle assisting with the North Pole program and helping families secure essential items for their home.





facebook.com/GeneticAlliance



youtube.com/GeneticAlliance



twitter.com/GeneticAlliance



linkedin.com/company/Genetic-Alliance



Genetic Alliance

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