Genetic Alliance
2021 Annual Report

Ponderings

EVERY ORGANIZATION THOUGHT that 2021 might signal a restoration to normalcy. Instead, the year continued the virulent pandemic and brought many organizations to a halt. Genetic Alliance continued to fare well, despite the challenges. While we witnessed many organizations falter amidst staff changes, and general burnout rampant, we held strong.

I believe that an organization is an organism, and as such, it is made up of its members. Each person contributes to what we are in the world. I recall a retreat we conducted at the end of 2020. We each named our north star: When we answered the question - how do you want to show up in the world before you die? Things became clear for each of us. Some of us decided to do something different, some of us sought ever more meaningful ways to work within Genetic Alliance.

We ask how we can show up, turn toward suffering and offer time and space to those who suffer?

Genetic Alliance always seeks to live vibrantly in the world. This requires that we risk everything. Hardly a "safe" position for a nonprofit. We go to bed every night knowing that millions depend on us. How can we play it safe? We ask how we can show up, turn toward suffering and offer time and space to those who suffer? We can only do this if we take care of ourselves as individuals and as an organization if we put our own oxygen masks on first.

Significantly, we decided to close our physical office in DC this fiscal year. We love being with each other. In the pandemic lockdown, we began to see each person blossom in a new way so they could be with their families more fully. It became even more clear that this is a family organization. We are a family. We support each of us being with our family and community more fully. The world's mores are catching up with ours!

Personally, since that is all we each have anyway, I share that I have become bicoastal - living with my daughter and her wife in Maryland some of the year and in San Diego near my son, his wife, and their daughter, most of the time. Most of you know I started on this path because of them. And now, quite remarkably, I have each of them as partners in so many aspects of my life and work. Their support buoys me up. Their perspectives challenge me. I am astounded at their capacity. Their love so fills me. I am happy to have them by my side. And, I am clear that the locus is beginning to shift - I am by their side.

Pause. Breathe. Take a look around you. What do you need? Really - deep in your marrow - what cries for attention? Let us know. Genetic Alliance continues to be facile, available, and ready to slay the monsters.

Much love,
Sharon

Sharon F. Terry, MA
CEO, Genetic Alliance

Introduction

GENETIC ALLIANCE RECOGNIZES PEOPLE as experts in their own health. We provide services and tools to unleash the power of people who both desperately need access to better health and have the focus and energy to keep the health systems, researchers, and clinicians focused on what matters most to people. We do this in partnership with disease advocacy and other communities since they are the best stewards of the needs of their members. Communities, particularly disease advocacy communities, have decades of policies, tools, and resources that have catalyzed research, advanced care and resulted in better outcomes for their members. These communities are the hidden, unsung heroes of biomedical research in the United States and internationally. A great deal of federally funded research is seeded by these communities working with academic and industry researchers. Depending on "bake sales and car washes" takes a tremendous toll on these organizations. They not only do vital work in the world, but they also have to find a way to sustain that work. Double duty. It is time to activate and support communities to participate in all aspects of research, from prioritizing research questions to protocol development, analysis, and implementation of findings. Each community can solicit research priorities from its members, be responsive to those identified priority areas, and empower their community to find solutions.

Genetic Alliance has extensive experience in supporting organizations through this process with decades of knowledge, a suite of customizable, crowd-sourced training, and technologies designed to liberate the potential of individuals and communities. Recognizing that the people and their trusted partners are the quintessential experts, Genetic Alliance uses a federated model that allows each community to capitalize on unique skills in outreach, recruitment, and retention; and engage a cadre of trusted researchers. This system results in effective research processes and projects, community trust and long-term relationships with potential participants, shared learning, tool development, cross-condition research, and methods to free data from research silos.

BALANCING NEEDS

Harnessing the power of a research network or community requires balancing the goals of each stakeholder group and prioritizing shared opportunities for success among communities, researchers, and participants. We know that doing this effectively means real, positive change and better outcomes for people. For example, trusted advocacy and community organizations can actively coalesce, engage, recruit, retain, and activate a community of disease- or issue-specific participants. When organizations have the requisite infrastructure, they work to benefit the whole to advance issues of interest. Organizations are responsive to the opportunity to access resources and fulfill roles specific to their interests, therefore generalizing learning capitalizing on the power of community-based research.

Genetic Alliance offers many services and programs ranging from the Promise for Engaging Everyone Responsibly (PEER), the Genetic Alliance BioBank and Genetic Alliance IRB, Disease InfoSearch, Registry Bootcamp, Expecting Health, and more.

Our Team

Staff

Sharon Terry, MA
Chief Executive Officer

Natasha Bonhomme
Chief Strategy Officer

Ruth Child
Chief Financial Officer

Susan McClure
Vice President, Outreach and Growth

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Council

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

Kelly Edwards, PhD
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Shantanu Gaur, MD
Treasurer
Physician, Entrepreneur
Co-founder, SGL Medical

Usama Malik, MBA
Founder and Managing Director, InnoAction Advisory Services

Sharon Terry, MA
President
Executive Director, PXE International, Inc.
Ashoka Fellow

PEER

Delivering on a Promise for Engaging Everyone Responsibly

THE PROMISE FOR ENGAGING EVERYONE RESPONSIBLY (PEER) is communities' collective commitment to work together on a shared registry system and resulting research. Since 2019, PEER has used the Luna platform for managing patient-reported outcomes, longitudinal natural history, electronic health records, and genomic/genetic information. This provides participants with granular and dynamic data, sharing, privacy, and access controls. PEER is governed by a Consortium of advocacy and community leaders drawn from the 45 active communities utilizing the platform.

The PEER Consortium members determine and implement policy, define the product roadmap, co-create new features, and access training and support. Under-resourced communities receive free access to the consortium. This illustrates both collaborations capitalizing on these organizations' issue-specific motivation and their capacity to sustain a grassroots research network with sophisticated technology. It also demonstrates our capacity to run a diverse community-based research network.

45

active communities utilizing the platform

Genetic Alliance Biobank

THE GENETIC ALLIANCE BIOBANK was established in 2003 to provide a shared and affordable infrastructure for disease advocacy organizations to collect and archive biological samples. The co-op nature of the bank – discrete organizations, working together to sustain the infrastructure – allows this inexpensive solution to flourish. The bank collects, indexes, and archives every type of sample, including but not limited to saliva and blood for DNA, tissue from any organ, and whole-body donation.

The BioBank provides kits for single donations sent to and from the donor's home and multiple kits for large meetings and conferences. In addition, using an online dashboard, communities can distribute samples to researchers they approve.

The Genetic Alliance Institutional Review Board, also founded in 2003, oversees the BioBank's programs). Almost 100,000 samples are banked here. Members share the cost of the infrastructure, bringing it to a very affordable quarterly price. Currently, nine communities are storing 92,688 samples in the Genetic Alliance BioBank.

92,688

samples currently in the Genetic Alliance BioBank

Genetic Alliance Institutional Review Board (IRB)

FOUNDED IN 2003, Genetic Alliance IRB consists of leading experts in human research protections. IRB Applications are accepted via a unique online web form that guides applicants through the process of describing their study in a manner that is ready to be received by the Genetic Alliance IRB. We have experience reviewing protocols for large-scale and multi-institutional studies with specific expertise in privacy review, registry management, survey-based studies, genomics, genetic testing, and the return of results. The Genetic Alliance IRB is substantially less expensive than any private IRB and close to 15 times faster than many academic IRBs. In 2021, the Genetic Alliance IRB reviewed or processed 60 submissions (amendment applications, initial protocols, progress reports), has 70 active and 100 completed protocols.

70
active protocols

100
completed protocols

Disease InfoSearch

IN ITS 36TH YEAR, Disease InfoSearch (DIS) is an online directory of more than 10,000 diseases and their subtypes, populated by over 900 disease advocacy organizations supporting individuals affected by diseases. It was built to make the dissemination of information more straightforward and more accessible to all people.

DIS provides up-to-date, accurate information about:

- Support opportunities for affected individuals and their families through a directory of all of the specific-condition support groups and resources they offer
- Resources for clinicians with patient information about support and research
- Organized information for researchers, including which diseases have registries, biobanks, well-characterized cohorts, assays, biomarkers, funding, and other resources

10,000+

diseases and their subtypes

900+

participating disease advocacy organizations

2021 Outreach Campaign

WITH THE HELP of our army of summer interns, we contacted 700 advocacy organizations to update and add new listings and fields to DIS, resulting in 537 updates to both organizational and disease information. In addition, we added 462 new conditions. We wrote descriptions for all of them, either with parents/patients who directly contacted us to get these added or through our genetic counseling internship program. Some of these new diseases come through our partnerships with Global Genes and the NIH Genetics and Rare Diseases Information Center. A number of these were brought to us by parents who needed support organizations, registries, and biobanks. We have helped to establish several dozen nonprofits this year. As a result, something we have done often over the years. During the campaign, we learned from the advocacy leaders what changes in DIS would make it easier to update their entries every six months.

We conducted an audit of the fields we capture, don't capture, and those which we display to the public. There are 90 fields, of which 50 are publicly displayed. The public fields are helpful to newly diagnosed individuals. They provide information on the current understanding of the condition, from simple descriptions of symptoms to more detailed descriptions of various phenotypes. In addition, individuals receive information from three APIs we have developed to filter and make more relevant information in public databases such as the National Institutes of Health Clinical Trials site, their biomedical publications (PubMed), and their Genetic and Rare Disease resource site. About 40 fields are technically specific to research and will be used when we launch GaugeRx in 2022.

The system is crowdsourced, long-tail, and sustainable. This will be entirely rebuilt in 2022.

900+
disease support organizations listed

63,447
unique visits to the site in 2021

164,260
disease and condition pages viewed in 2021

35,871
PubMed articles accessed in 2021

Registry Bootcamp

IN FEBRUARY OF 2021, Genetic Alliance announced Registry Bootcamp – a new program designed to help advocacy organizations launch a successful registry. We offered our first three Registry Bootcamp courses in Spring, Fall, and Winter 2021 and will provide additional courses in 2022.

Registry Bootcamp offers communities a deep dive into the world of registries. Resources provided in the course are wide-ranging and guide communities through the steps necessary to begin designing and developing their own registries. Each group accepted to Registry Bootcamp receives the guidance and support required to plan and launch a registry or study.

Communities using Genetic Alliance's registry solution, Promise for Engaging Everyone Responsibly (PEER), receive access to the required infrastructure to set up a registry, including IRB application writing assistance, in-house IRB review, the data platform, and EHR connectivity. However, the use of PEER is not required to participate in Registry Bootcamp.

30

participants enrolled

20

communities impacted

Expecting Health

Sustainability Through Steady Growth

EXPECTING HEALTH SHARES science-based information that reflects the lived experiences of individuals and their families. We utilize principles of community engagement and collaborative partnerships to reach diverse audiences. This year provided more opportunities for virtual convenings and new partnerships.

COMMITMENT

We are health communicators committed to providing actionable, relatable science-based information. During this year of changing health information and uncertainty, we continued our work of educating and supporting new and expecting families. To alleviate any anxiety or confusion related to COVID-19, we created a variety of timely COVID-19 materials to meet families where they are:

- Developed and Launched digital Center for Genetics Education and Family Support with companion social media presence.
- 85 parents and families reporting increased knowledge about NBS and 87 parents and families reporting increased self-efficacy to talk to a healthcare provider about newborn screening after going through our NavigateNBS program

We are maternal health advocates committed to fighting for equitable healthcare and accessible health education. Rooted in social justice, our programs aim to provide access to important health information throughout the prenatal and early motherhood years.

- We piloted a social media campaign to increase outreach to medically underserved individuals which resulted in 2,766,047 impressions
- Engaged 143 pregnant women at a clinic that serves a medically underserved community.
- The NBS Family Education Program increased awareness of NBS in 3,665 medically underserved individuals.
- Through the National Genetic Education and Family Support Center (The Family Center) family leaders from across the country conveyed multiple times a year as part of the Workgroup on Inclusion
- The Family Center Community of Practice on Diversity, Equity, and Inclusion was formed as a result of the overwhelming response of applications from the Family Center work group on Inclusion. 10 Family Leaders meet every other month and discusses an article/trends and its meaning to family leaders.

COLLABORATION

With the tenet of nothing about us without us at our core, we know collaboration is the key to meaningful success. With our expertise in elevating the family experience in the rare disease and newborn screening communities, we collaborate with advocacy and professional organizations across the nation.

- We revamped content on 2 federally-funded programs focused on newborn screening and family support with input and direction from those with lived experiences.
- We joined 3 additional national initiatives looking to modernize and improve healthcare systems by focusing on the day-to-day experiences of families and other stakeholders.

We support the work of organizations to ensure multiple opportunities for new and expecting families to get actionable, digestible information to feel empowered in their healthcare decisions.

- 8 new partners have joined the NBS Family Education Program for a total of 19 organizations working to increase awareness of newborn screening.
- Highlighted the work of 18 different organizations and agencies, exposing their work and successes to new audiences.

12

NBS Ambassadors recruited and trained to join local systems change initiatives.

670+

individuals participated on our online learning sessions

6

office hours held to provide a safe place for genetics providers and families to learn more about healthcare system and get tangible strategies to improve care

Support

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 vital 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

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