GENETIC ALLIANCE ANNUAL REPORT

2012

In this report:

Background

Genetic Alliance improves health through the authentic engagement of communities and individuals.

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 empowers individuals to take charge of their health by using genetic and genomic tools. We bring together diverse stakeholders to create novel partnerships in advocacy; we integrate individual, family, and community perspectives to improve health systems; we revolutionize access to information to enable translation of research into services and individualized decision making.

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.

Dear Friends,

Advocacy in the 21st century requires new definitions and new focus. We must develop and engage informed consumers and disrupt tired models that no longer serve. We must foster dialogue that includes the perspectives of all stakeholders: from industry professionals, researchers, healthcare providers, and public policy leaders to individuals, families, and communities.

As technology enables more dynamic interchange of diverse perspectives, individuals often self-aggregate around issues they find compelling. Genetic Alliance is dedicated to enabling consumers to remember they are the center of the healthcare system and to take charge accordingly. New methods for individuals to collaborate and participate in research greatly augment the traditional function of nonprofit advocacy organizations.

To best serve our network, in 2012 Genetic Alliance structured our programs into three complementary Enterprises: BioTrust, Genes in Life, and Maternal and Child Health. Through the activities and products of these Enterprises, we are committed to helping systems identify new solutions and pathways for the common good.

Sincerely,
Sharon F. Terry, President & CEO

BioTrust

Genetic Alliance believes that individuals (aka consumers, citizens, the public) are rightful participants in their own health, including in the translational science necessary to catalyze the therapies and diagnostics that individuals, and the communities they are part of, need today and in the future. BioTrust was formed as an organic response to evolving needs as Disease Advocacy Organizations (DAOs) and affected individuals begin to engage differently in the networked information age. This program is a living laboratory, a learning system, for accelerating the amazing theories while applying lessons learned.

Genetic Alliance Registry and BioBank (GARB)

For years Genetic Alliance has encouraged individuals to donate DNA and tissue and offer clinical data through DAOs affiliated with the Genetic Alliance Registry and BioBank (GARB), the only lay-run, cross-disease biobank and registry. GARB serves six DAOs and holds collections of biological samples and clinical information for seven diseases. It provides state-of-the-art biobanking capacity and a registry solution. Through BioTrust, GARB will expand to interact with affected and not-yet-affected individuals directly, not just through DAOs, using Disease InfoSearch.

Disease InfoSearch (DIS)

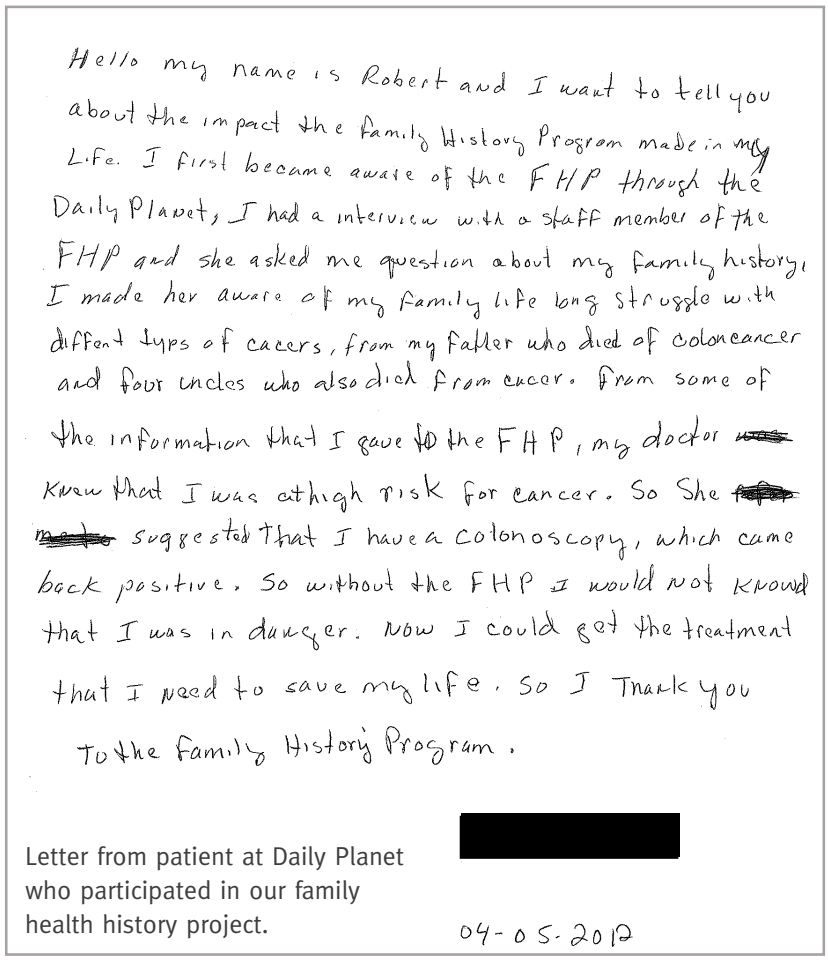
Twenty years ago, Disease InfoSearch was a simple listing of DAO contact information in a sprial-bound book. Today, it includes more than 13,000 conditions, with information contributed by DAOs and pulled from entities that produce nomenclature for genetic diseases, including NCBI, GARD, Genetic Testing Registry, Orphanet, SNOMED-CT, UMLS, ICD-9, and MeSH.

In August 2012 Disease InfoSearch soft launched as an independent website (DiseaseInfoSearch.org) with a new interface and improved usability. We are continually reaching out to new organizations to increase the number of conditions in our database with associated DAOs, and we plan to publicly launch the site and disseminate widely in the first quarter of 2013.

Ethics Team

The Biotrust Ethics Team works in partnership with Genetic Alliance's efforts to integrate and inform business and management decisions with ethical principles and practices throughout all of our translational science experiences. The team is comprised of world-renowned experts who strive to accelerate research in a culture of respect and trust.

Nick Anderson, PhD, Kemp Battle, Greg Biggers, Kelly Edwards, PhD, Leila Jamal, PhD, ScM, CGC, Jane Kaye, DPhil, LLB, Kieran O'Doherty, PhD, Suzanne Vernon, PhD, David Winickoff, JD, MA



Hello my name is Robert and I want to tell you about the impact the family History Program made in my Life. I first became aware of the FHP through the Daily Planet, I had a interview with a staff member of the FHP and she asked me question about my family history, I made her aware of my family life long struggle with diffent types of cacers, from my father who died of coloncancer and four uncles who also dich from cucer. From some of the information that I gave to the FHP, my doctor knew that I was athigh risk for cancer. So She suggested that I have a colonoscopy, which came back positive. So without the FHP I would not knowd that I was in dunger. Now I could get the treatment that I need to save my life. So I Thank you To the family History Program.

[redacted]

04-05-2012

Letter from patient at Daily Planet who participated in our family health history project.

Genes in Life

When Genetic Alliance was founded, conditions classified as "genetic" were primarily caused by a mutation in a single gene, and "genetics services" largely consisted of methods for diagnosing those disorders. As the science has progressed, so has our understanding of both rare and common, complex conditions. With that came realization of the immense contributions of genetics and genomics to overall health. In addition, a wide range of services has sprung up in the genetics arena, from testing and screening to risk assessment and targeted therapeutics. In response to this evolution, Genetic Alliance has developed a variety of tools and resources to help individuals identify and access quality information, services, and support. We fill the gaps that exist in patient education.

Education and Empowerment

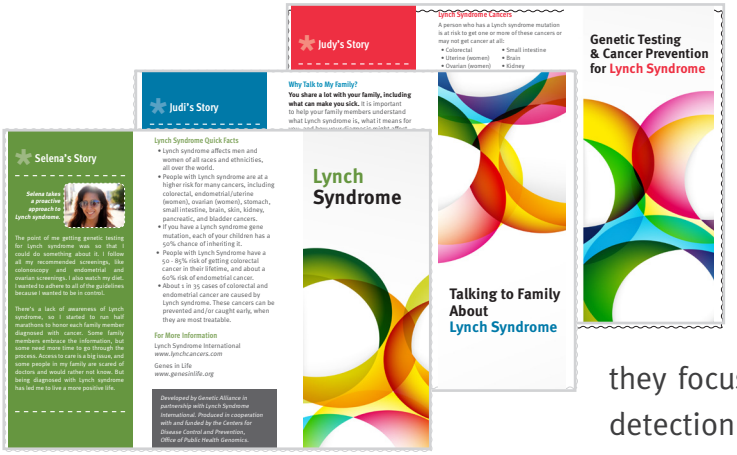
National Genetics Education and Consumer Network

Genetic Alliance is now the National Genetics Education and Consumer Network, part of the National Coordinating Center for the Regional Genetic and Newborn Screening Services Collaboratives. As such, we will collect and disseminate advocacy resources in partnership with Family Voices and Parent to Parent USA, expand and strengthen the network of patient-focused organizations (see Disease InfoSearch), and fund expansion of existing consumer-focused projects that have been shown to be effective in the states.

How Do I Talk to My Family about My Genetic Condition?

It is not only important to collect family health history from your relatives; it is similarly important to tell them what you know about your own health. For this reason, in collaboration with Genzyme, we created resources on how to share a diagnosis of a genetic condition with your family. The booklets are specifically about Gaucher, Fabry, and Pompe diseases, but the strategies for sharing health information with family can be applied to many conditions.

> *Before [the materials on Fabry] felt very scientific, throwing all these great big words around. We have a lot to absorb already. [This booklet] just felt very user-friendly, it brings it down to a common language.* - Debra, Fabry patient



We also worked with the CDC Office of Public Health Genomics to create three complementary pamphlets on talking to family about Lynch syndrome. The brochures can be read together or individually, depending on how much information a patient is ready for, and they focus on the importance of screening for early detection and disease prevention.

Patient- and Family-Centered Medicine

Genetic Alliance strives to ensure that individuals can play an important role in their own medical care. In 2012, we continued our partnership with the National Coalition for Health Professional Education in Genetics (NCHPEG), March of Dimes, Harvard Partners, and the Health Resources and Services Administration to make it easy for patients to contribute medical and family health history information to their medical record and enable providers to use that information to improve care through targeted clinical decision support. The Pregnancy & Health Profile is a tablet PC-based tool that a woman uses in the waiting room before her first prenatal appointment. It is designed to replace all of the paper forms that women normally fill out, streamlining the patient intake process and providing both patient and provider education . The tool was pilot-tested in four clinics across the country and was well-received by both patients and providers.

It is also important to change the practice of medicine from the top down. Therefore, we partnered with El Camino Hospital and NCHPEG to develop a genetics/genomics curriculum for practicing doctors. A hallmark of the curriculum was the use of patient videos to frame each session, giving voice to the experiences of individuals and families.

In addition, we continued our work with six federally-funded health centers to promote better collection and use of family health history (FHH) information in risk assessment and disease management. FHH is an important component of a primary care visit, but it is inconsistently collected. Our national evaluation found increases in provider and staff self-reported understanding of FHH and confidence with FHH skills, and these gains were sustained throughout the course of the yearlong project.

Maternal and Child Health

In the year since its debut, Baby's First Test has become the main form of newborn screening education on a number of public health education sites including HealthyWomen.org and WhatToExpect.com. We continue to engage the community through social media and attendance at professional conferences. We focused on expanding our work in newborn screening and further exploring the educational and decision-making needs of families and providers during the prenatal period. As prenatal screening becomes more available to the public, Genetic Alliance is well-positioned to provide the tools that will help families make the best-informed decisions.

Newborn Screening

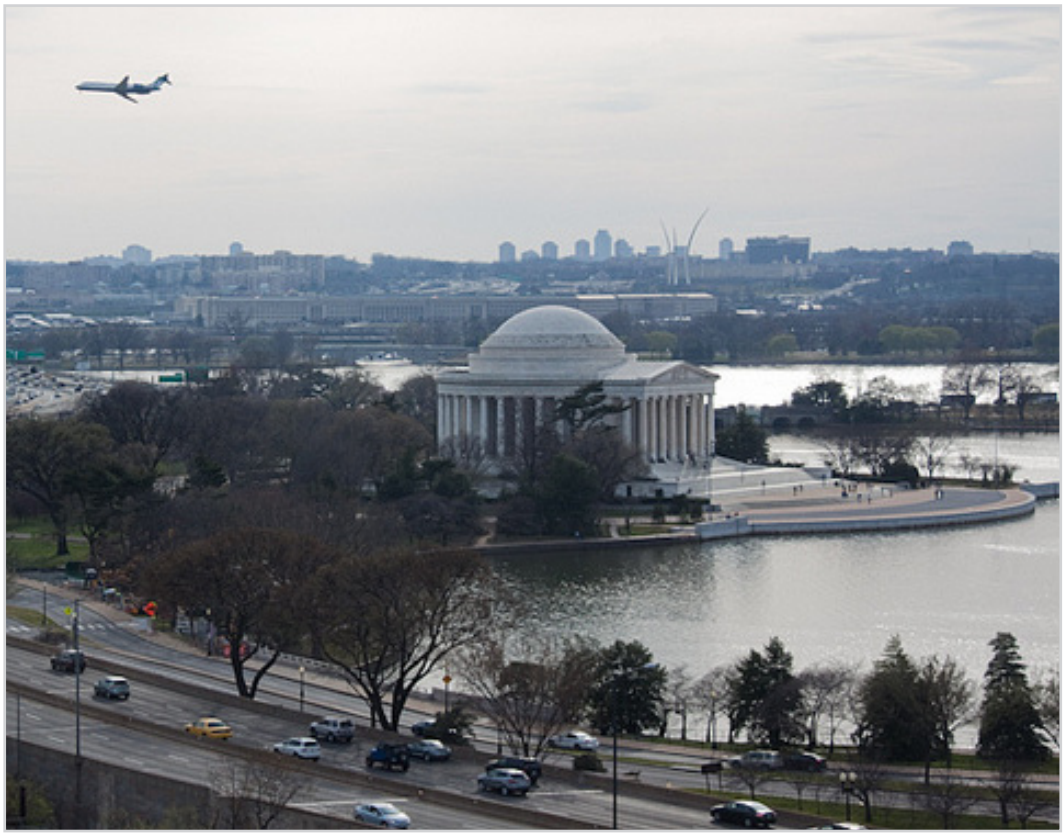
Consumer Task Force

In 2012 we re-launched our Consumer Task Force, and it was the a competitive year, with more than twice the number of applications as spots available. Ten parents and health professionals - many of whom were not previously involved in state or regional newborn screening and genetics advisory groups or programs - completed a training program, attended a meeting in Washington, DC, and executed individual awareness projects in their communities. We gave this group the tools and networking opportunities to start health-related campaigns in their communities.

Top Row: Amanda Beard, Kee Chan, PhD, Ruth Caruthers, Willa Doswell, Mark Engman
Bottom Row: Stacy Hines-Dowell, Julie Miller, William Morris, Chantel Murray, Kristi Wees

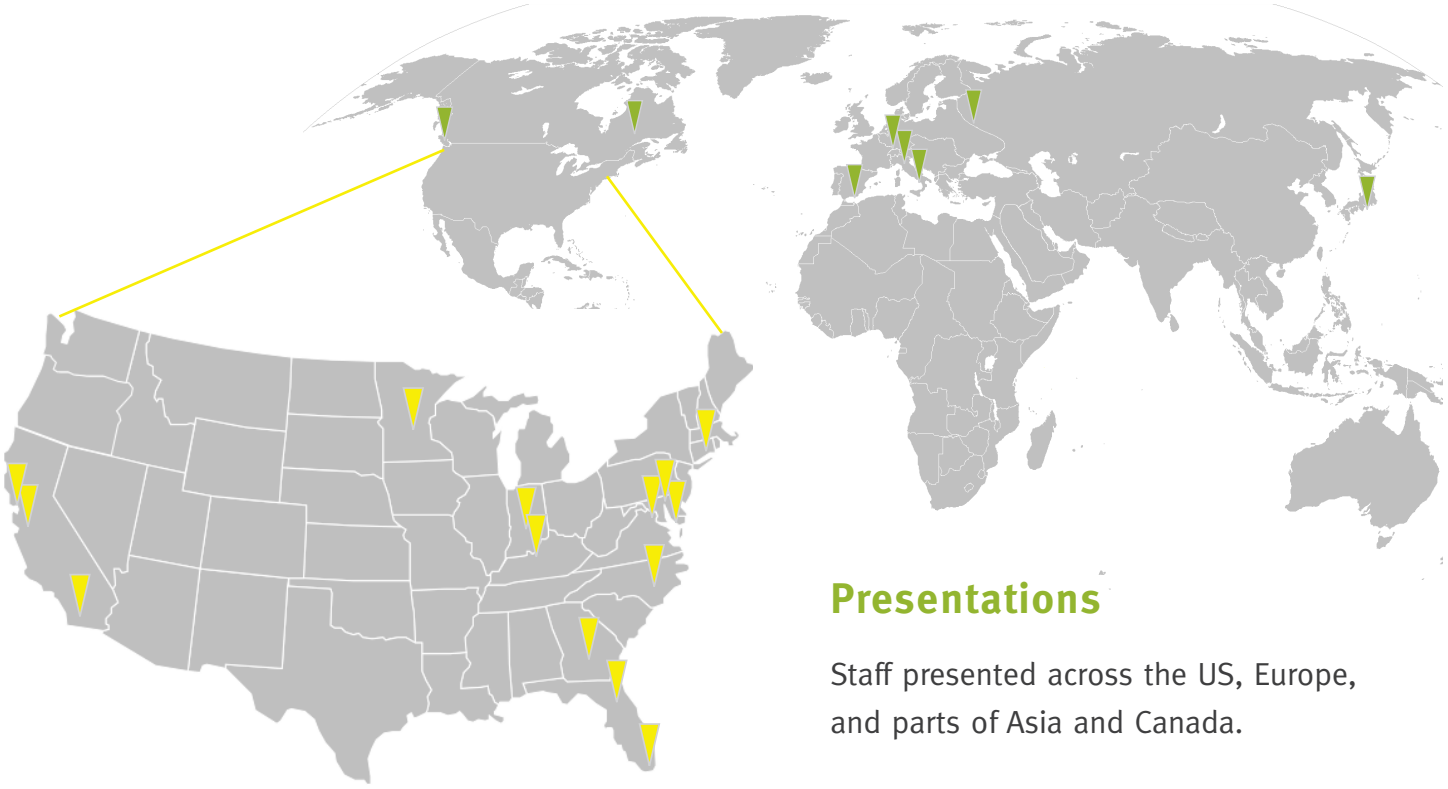
Challenge Awards

In addition to our Consumer Task Foce, we distributed six Challenge Awards to organizations pursuing innovative, impactful solutions for the newborn screening community. Projects produced and evaluated videos, web-based applications, and educational materials on NBS.



Out and About

Every year, Genetic Alliance staff travel the country and the globe to present to our collegaues in the genetics, health, and advocacy community. To reach those professionals not attending meetings and conferences, we publish in magazines and journals. Finally, while most of our work is on the national or international level, we recognize the value of promoting health in our local community. For example, in July, Baby's First Test attended a "baby shower" hosted by United Health to educate new and expectant parents about newborn screening.



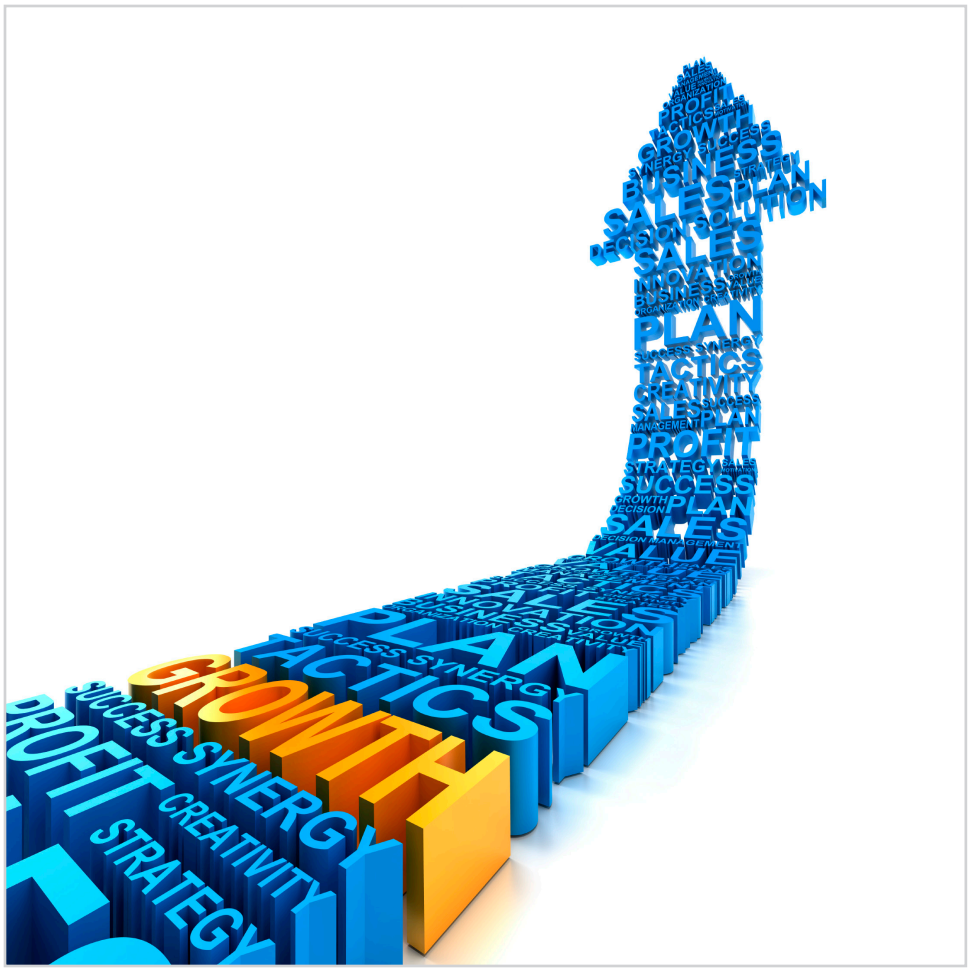
Presentations

Staff presented across the US, Europe, and parts of Asia and Canada.

Conferences

In 2012 we retired our annual conference, which had become unsustainable with federal funding cuts. We still believe the face-to-face experience has value, so instead we began hosting daylong summits on emerging issues. We had a sold-out crowd in March for the Genetic Testing and Data Management Summit: Improving Health Outcomes, Disease Management, and Accountable Care Delivery. Meeting participants outlined elements of a rational patient-centered system, mapped challenges, analyzed best practices (e.g., cancer management), and identified key entities to guide system improvements. We also hosted a Registry and Biobank Boot Camp in August.

These smaller events demonstrated our ability to convene diverse stakeholders and our capacity to facilitate difficult conversations and engage with the real issues. Our work is focused on improving people's lives, not anyone's ego, and each meeting is action-oriented: participants leave with a plan.



Financials

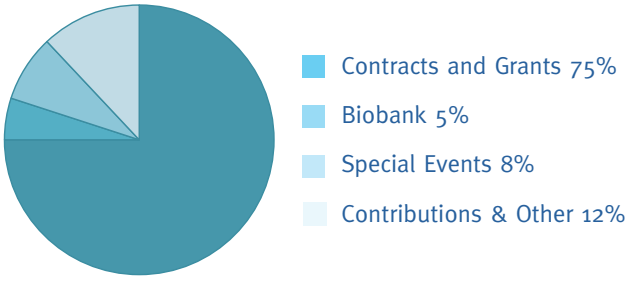
Genetic Alliance's work is supported by a blend of funding from government grants and contracts, industry and corporate support, individual donations, and fees generated by services and events. We continually work to diversify our funding sources. A key part of this diversification plan is to secure 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	2012 Total	2011 Total
Government Contracts and Grants	$2,196,518	$3,273,580
Biobank Program Revenue	156,438	351,340
Special Events	227,152	441,347
Contributions	149,340	89,275
Listserv Income	2,000	5,400
In-Kind Contributions	-	1,141
Interest Income	54	31
Other Revenue	60,594	46,978
Total Revenue and Other Support	2,792,096	4,209,092
Net Assets Released from Restrictions	-	-
Total Revenue and Other Support	**$2,792,096**	**$4,209,092**
Expenses		
Program Services		
General Programs	$2,683,107	$3,400,452
Policy	1,516	1,550
Supporting Services		
General and Administrative	38,923	20,186
Fundraising	74,228	24,582
Total Expenses	**$2,797,774**	**$3,446,770**
Net Increase (Decrease) in Net Assets	(5,678)	68,736
Net Assets, Beginning of Year	1,286,963	$524,641
Net Assets, End of Year	$1,281,285	$1,286,693

Operating Fund Sources

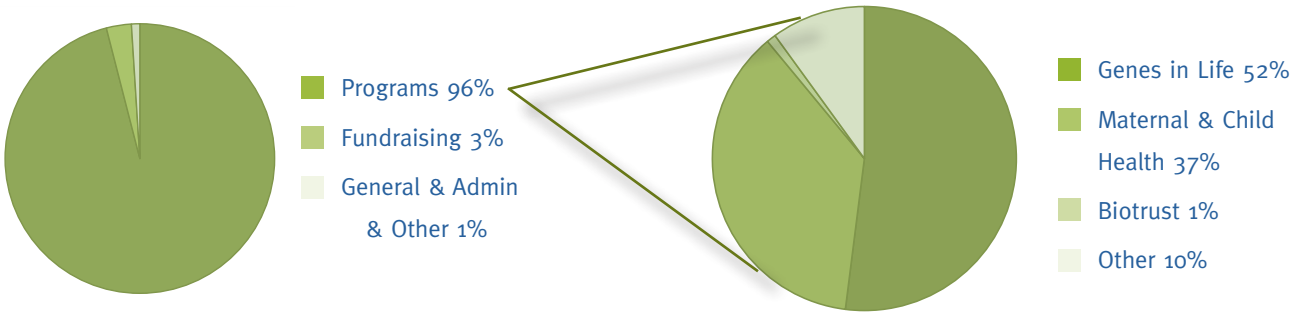


Statement of Financial Position

as of September 30th of each year

Assets	2012	2011
Cash and Cash Equivalents	$55,973	$65,007
Accounts Receivable	84,765	399,578
Grants Receivable	586,763	425,663
Prepaid Expenses	31,130	29,536
Deposits	6,595	12,718
Furniture & Equipment	676,349	732,967
Total Assets	$1,441,575	$1,665,469
Current Liabilities		
Accounts Payable and Accrued Expense	$105,144	$310,764
Capital Lease Obligation, current portion	-	6,609
Long-term Liabilities		
Deferred Rent	55,146	59,783
Security Deposits	-	1,350
Capital Lease Obligation, net of current portion	-	-
Total Current Liabilities	160,290	378,506
Net Assets		
Unrestricted	1,085,031	937,613
Temporarily Restricted	196,254	349,350
Total Net Assets	1,281,285	1,286,963
Total Liabilities and Net Assets	$1,441,575	$1,665,469

Fund Spending



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