GENETIC ALLIANCE

ANNUAL REPORT 2010

Genetic Alliance

Background

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.

Over the past 24 years, Genetic Alliance systematically built a world-class disease advocacy platform and transformed from a basic advocacy organization to a leading network of key stakeholders determined to transform health through genetics. Today, we represent over 1,000 disease advocacy groups and 10,000 organizations that serve some aspect of our national health.

Genetic Alliance transforms health through genetics. 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.

We believe that system transformation demands innovation, disruption and collaboration. Our methodologies have been resourcefully crafted from lessons learned as advocates. We engage an array of stakeholders in national and international presentations, webinars, coalition building initiatives, the creation of research repositories, film festivals, listservs, peer-reviewed publications, wikis, multi-day conferences with dedicated sessions, and more. Whether fostering intense, open dialogue between adversaries, convening meetings where disparate stakeholders identify common purpose, or sharing resources typically considered proprietary, we are committed to helping systems identify new solutions and pathways for the common good.

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Dear Friends,

Our focus for 2010 was partnership, and, in openness, we let its promise be our driver. Building on our decision to engage the community without boundaries, we pursued new partnerships while strengthening and diversifying existing partnerships. All our initiatives reflect the high value we place on relationship building, in the service of those who need information and resources.

In 2010, we chose, with great intentionality, to open the phenomenal culture we have forged to all of our partners. Operating as though there were no walls between us, we offered our resources, skills and talents in novel and innovative ways. We advanced programs in policy, translational research, information and support, all infused with the Genetic Alliance culture, from our office dog to our CEO.

We seek new perspectives and relationships; through them we continue our transformation. We hope you will join us on this path. Novel partnerships will fuel our success as a community!

Sincerely,
Sharon F. Terry, President & CEO

COUNCIL

STAFF

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Health Information Systems Coordinator

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Vice President of Strategic Development

Molly Brenner
Executive Assistant

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Manager of Finance and Administration

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BioBank Director

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Grants Administration Director

Sharon Terry, MA
President and CEO

Lisa Wise, MA
Chief Operating Officer

Kristi Zonno, MS, CGC
Director of Genetics and Health Policy

Suite 404 and Beyond

For Fun and Fitness

Every month, Genetic Alliance staff engage in a different Health Club challenge. Challenges can be individual—for every hour you sit at your desk, get up and do a short activity (stretch, lunge, etc.)—or in teams—which group can walk and run the most miles this month; sometimes the challenges are competitive—who can walk up the five flights of stairs to our office the most times in a month—and sometimes social—once a day, blast music over the intercom, and everyone has to get up and dance. Whatever the challenge, we recognize that both fun and fitness lead to better overall health.

Open House

In November 2009 and May 2010, we invited partners, friends, family, and neighbors to check out our renovated offices and enjoy an evening of mixing and mingling.

In Our Community

Genetic Alliance is a primarily national organization with international reach; given this scope, it is easy to focus on the big picture of partnerships with hundreds of other organizations across the country and the globe, rather than hone in on the community in our own backyard. Washington, DC, is a hotbed of health activism—with scores of health-focused nonprofits, not to mention the federal government, which recently passed a little bill called the Patient Protection and Affordable Care Act—but it is also a city with many pressing health concerns.

This year, Genetic Alliance made it a point to reach out to our local community to promote healthy living. We participated in health fairs, including the 25th annual National Council of Negro Women Black Family Reunion Celebration and the DC Family Expo. We hosted the 2nd annual Gene Screen: A Night of Film on Health and Genetics, which aims to make health and genetics more palatable to the general public through film. Finally, the staff and Council volunteered at a local farm, investing in the health of our environment, and its people.

GeneDx Art Show

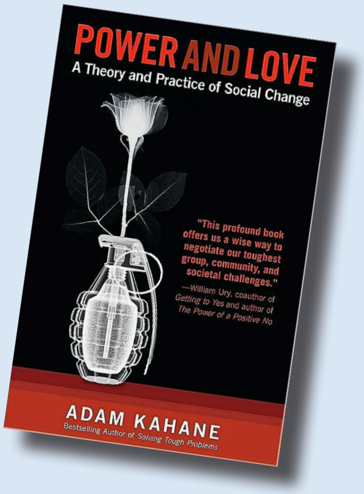
On June 17, 2010, GeneDx, a genetic testing and diagnosis company and Genetic Alliance partner, hosted an art show and sale to benefit Genetic Alliance in the space that has since become their new laboratory. A $5 entry fee bought guests cocktails and hors d'oeuvres, and 14 artists donated at least 10% of all proceeds from sales to Genetic Alliance.

Recognition

Sharon Terry was selected as an Ashoka Fellow, a distinguished lifelong position attained after a vigorous search and selection process. Ashoka Fellows are leading social entrepreneurs with innovative solutions to social problems. Working in over 60 countries around the globe in every area of human need, Ashoka Fellows demonstrate an unrivaled commitment to bold new ideas through a combination of compassion, creativity and collaboration. Other Ashoka Fellows working in the health field focus on securing much needed medicines, developing mechanisms for knowledge transfer, building robust public health systems, delivering a holistic approach to health, and more.

Sharon said: “Being named as an Ashoka Fellow is both humbling and empowering. It calls me to live entrepreneurship very personally, and thereby align and focus my energy on deep personal and organizational transformation. I am thrilled to collaborate with some of the best minds in the world to address serious global health issues. I will approach this task with the same dedication I have put into advancing the understanding of genetic disease over the past 15 years.”

Staff Book Club

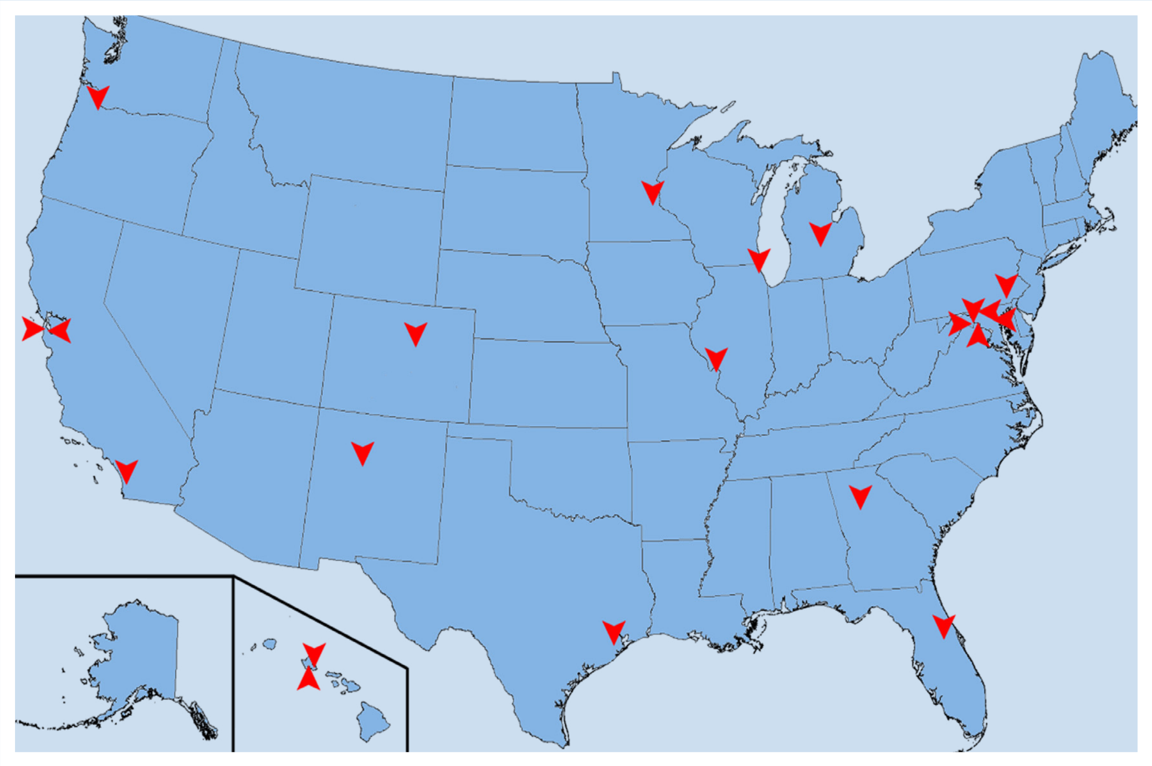


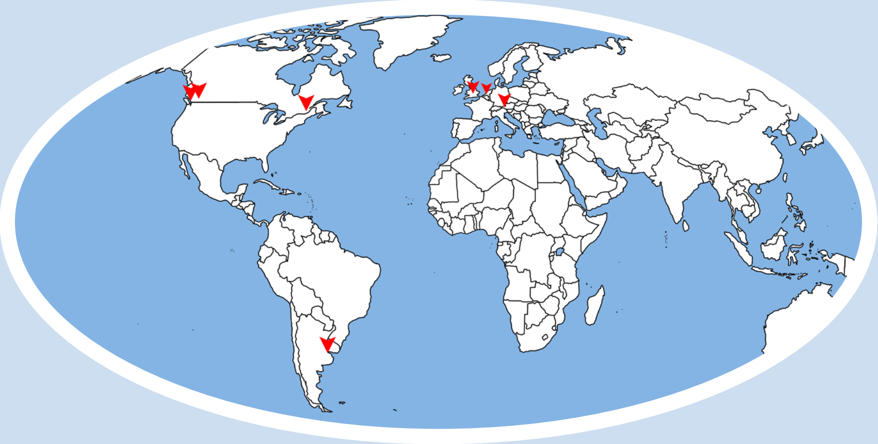
Sharon and Council member Gene Early read and were powerfully moved by this book, which presents a new approach for making progress on our most important and difficult collective challenges. Based on the author’s own experiences working with teams of business, government, and civil society leaders around the world, it argues that the two main ways that people try to solve their toughest group, community, and societal problems are fundamentally flawed.

Staff were asked to read the book and reflect on the passages that were most meaningful to them.

How is Genetic Alliance an experiment? What experiment in social change is it? What are our reagents? In what areas can we play? How does it feel safe? How does it feel unsafe? Do we model change, do we create change, do we inspire change?

Presentations





Genetic Alliance staff regularly give presentations around the country and the globe. These maps represent our presentations in 2010.

Name the most important value or leadership attribute that represents Genetic Alliance:

Balance. Genetic Alliance is not about winning or grabbing a piece of the pie, it's about doing the right thing. It is the least ego-driven and the most truth-seeking organization I've ever seen.

-- external partner

Public Policy

Genetic Alliance engages diverse stakeholders to bring about meaningful change in genetics and health policy. In 2010, Sharon testified before the following committees:

- House Appropriations Committee
- House Committee on Science and Technology
- House Committee on Oversight and Government Reform
- National Committee on Vital and Health Statistics
- Food and Drug Administration Committee for Rare Diseases

Additionally, Natasha Bonhomme, Vice President of Strategic Development, presented public comments before the HHS Office of the National Coordinator's Health Information Technology (HIT) Policy Committee to advocate for the inclusion of newborn screening as a focus for meaningful use of HIT in 2013:

"A child's electronic health record should begin with newborn screening results."

Public Health

Genetic Alliance's work and mission embody the goals of public health: prevention, prolonging life, and promoting health.

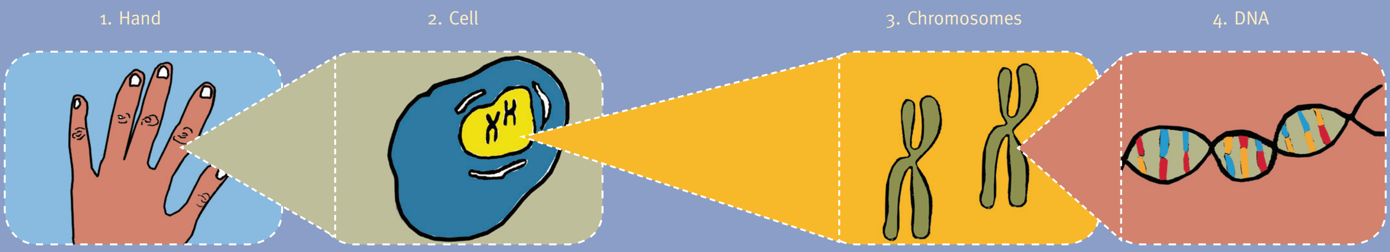
Genetic Alliance works to improve the health of individuals, families, and communities. We employ a broad interpretation of "community," the most important part being that community is self-defined. Each individual selects to which communities he or she belongs; this can be based on geography, culture, race, ethnicity, age, gender, sexual orientation, disability or other health condition, or common interest or cause.

The field of genetics has expanded rapidly, and Genetic Alliance has kept pace. With this growth, and with our focus on openness, we now take a more holistic view of health.

Many of our programs and resources provide genetics and health education at the individual and organizational or community level, which is integral to increasing public awareness about genetics and improving public health. In addition to these educational and informational initiatives, we are changing the context of genetics within our health system, working to integrate the benefits of genomics into healthcare and public health programming.

Disease Detection and Prevention

Genetic Alliance developed a close partnership with the CDC's Office of Public Health Genomics. We provide outreach, support, and expertise for the Genetics for Early Disease Detection and Intervention (GEDDI) initiative and the Genomic Applications in Practice and Prevention Network (GAPPNet). These programs are shaping the landscape for translation science and research and are taking a public health approach to increase the number of lives saved by genetic tests and applications.



Newborn Screening

Newborn screening (NBS) is touted as one of the most important and successful public health initiatives in genetics. At Genetic Alliance, we provide a variety of resources to educate the community on newborn screening. The Newborn Screening Clearinghouse and newsletter are an invaluable source of information for consumers and organizations. Our Consumer Focused Newborn Screening programs actively engage consumers in the NBS system. Likewise, we continually engage the broader health community in open and proactive dialogue on policy development for dried blood spot storage to facilitate improvements in newborn screening tests and procedures.

Family Health History

Family health history (FHH) is often called the most basic genetic test. Knowing your FHH – and taking action based on what you find – is one of the best preventive measures individuals and families can take to safeguard their health. Genetic Alliance produced a monograph based on the Community Centered Family Health History (CCFHH) project, which will serve as a resource for organizations interested in starting their own FHH initiatives. CCFHH was unique in the field of community-based participatory research, as it explored the impact of a FHH intervention across diverse communities. The monograph, fourth in the Genetic Alliance Monograph Series, describes partners' varied approaches to FHH integration in their communities and provides a comprehensive picture, including successes and challenges, of carrying out a national research project at the community level.

GENETIC ALLIANCE
MONOGRAPH
SERIES #4

COMMUNITY CENTERED
FAMILY HEALTH HISTORY
Collaboration Across Communities:
How Do You Make Research
Community-Specific
and Universally-Relevant?

PUBLISHED BY GENETIC ALLIANCE

Genetic Alliance: Vaughn Edelson, Sharon Terry, James O'Leary • **American Folklife Center of the Library of Congress:** Ilana Harlow, Margaret Kruesi • **Alpha-1 Foundation:** Dawn McGee, Charlie Strange • **Health Resources and Services Administration:** Penny Kyler • **Institute for Cultural Partnerships:** Claudia Petruccio • **Intermountain Healthcare:** Marc Williams, Janet Williams • **Iona College:** Penelope Moore, William Gratzer, Caroline Lieber • **National Council of La Raza:** Alejandra Gepp • **National Psoriasis Foundation:** Nicora Gardner • **Office of Justice and Peace/St. Mary's Health Wagon:** Karen O'Quinn, Teresa Gardner • **Seattle Indian Health Board:** Meghan Jernigan, Alice Park, Ralph Forquera

Advocacy

Advocacy has always been central to the achievement of our mission, though over time our definition of what it means to be an advocate has evolved and expanded. Our own advocacy and consumer engagement now ranges from newborn screening and family health history to policymaking, drug development, clinical care, and more.

Advocates at the November 2009 ASHG Partnership Program

> In the past year, we have not only continued our commitment to enhancing advocate involvement in diverse systems, but also asked for this commitment from our partners.

Genetic Alliance co-hosts Advocates Partnership Programs at the annual meetings of the National Society of Genetic Counselors, the American Society of Human Genetics, and the American College of Medical Genetics. The Programs are designed to foster collaborations between the advocacy community (disease-specific and community organization leaders, individuals and families affected by genetic conditions, and students/youth) and health professionals. Up to ten advocates attend each conference and participate in exclusive meetings with leaders in the fields of clinical genetics, scientific research, drug and test development, and government. The success of all three programs, as measured by the new collaborations formed both among the advocates and within the professional community, can be attributed to the diversity of the participants selected and the eagerness of genetics professionals to work more closely with families.

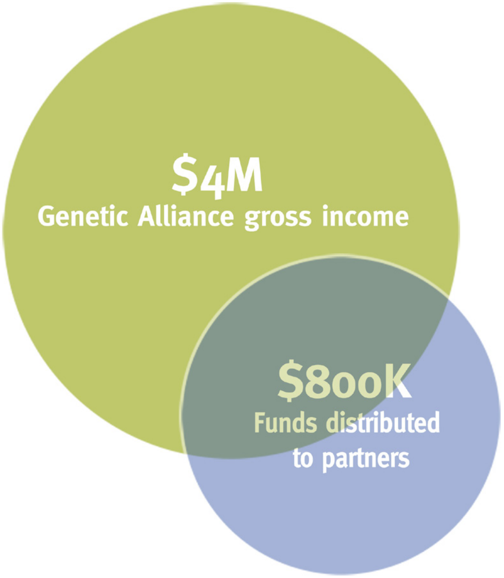
> “The question I had hoped to answer in respect to attending and participating in the 2010 ACMG Annual Clinical Genetics Meeting was, “Will the current study of genetics make a difference in my consumer advocacy work and the cause I serve?” I found the answer to be a resounding YES. ... Thanks for the opportunity to enter your world, learn from your scholars, and to take that enthusiasm and knowledge back to the community I serve.”
>
> -- Darla Stuart, Arc of Aurora

Collaboration

"You have to remember that most of the time, when a group of stakeholder leaders enter a dialogue, every one of them believes that if only the other ones would change what they were thinking and doing, then the problem would be solved... The real innovation here is that we are inviting stakeholder leaders to reflect on how they might need to change what they themselves are thinking and doing."

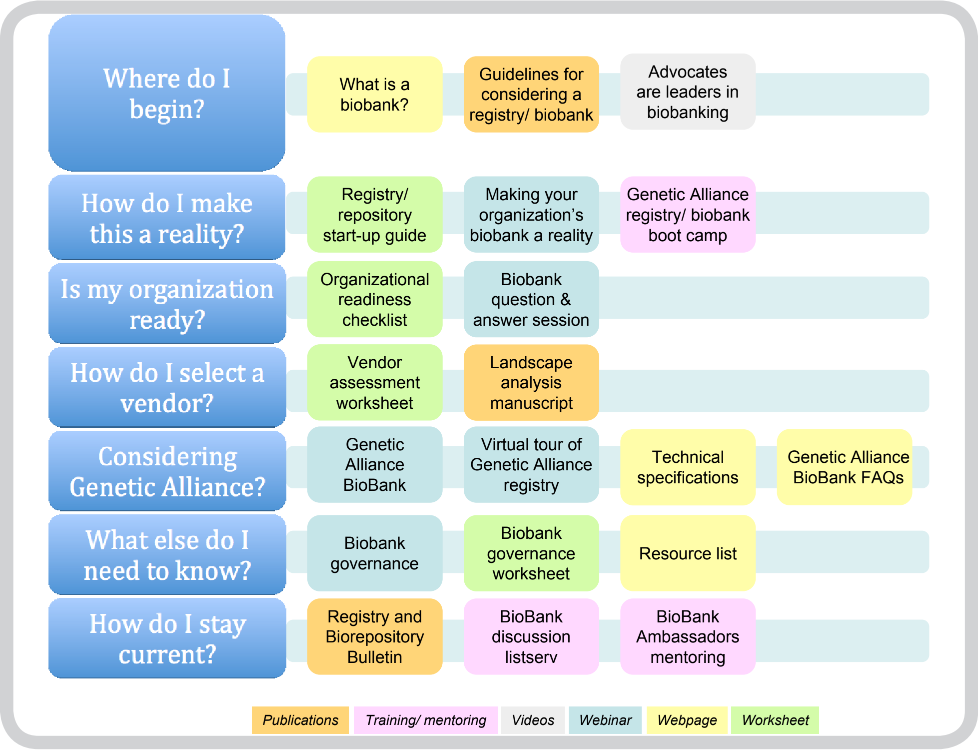
Genetic Alliance values collaboration as an essential ingredient for success. Innovation is a collaborative endeavor, so we promote collaboration among staff members, among Genetic Alliance and other organizations, and among all the organizations in our extensive network.

In 2010, we had formal, contractual relationships with almost 50 organizations, more than 100 informal project partners, and a network of thousands (above). Though these collaborations are invaluable, their importance can be seen if you open our financial books: almost a quarter of the money that came into Genetic Alliance in 2010 went right back out to partners (right) to support ground-breaking work in genetics, health, and advocacy.



Genetic Alliance BioBank

In 2010, we welcomed CFIDS Association of America and Children's Tumor Foundation as new members. We also increased our commitment to developing tools and resources to educate the advocacy community about registries and biobanks.



Where do I begin?	What is a biobank?	Guidelines for considering a registry/ biobank	Advocates are leaders in biobanking	
How do I make this a reality?	Registry/ repository start-up guide	Making your organization's biobank a reality	Genetic Alliance registry/ biobank boot camp	
Is my organization ready?	Organizational readiness checklist	Biobank question & answer session		
How do I select a vendor?	Vendor assessment worksheet	Landscape analysis manuscript		
Considering Genetic Alliance?	Genetic Alliance BioBank	Virtual tour of Genetic Alliance registry	Technical specifications	Genetic Alliance BioBank FAQs
What else do I need to know?	Biobank governance	Biobank governance worksheet	Resource list	
How do I stay current?	Registry and Biorepository Bulletin	BioBank discussion listserv	BioBank Ambassadors mentoring	

Publications *Training/ mentoring* *Videos* *Webinar* *Webpage* *Worksheet*

- In January, in collaboration with GRANDRx, we held our first BioBank Boot Camp, a hands-on, in person training session about establishing a registry or biobank.
- In March, we introduced the Registry and Repository Bulletin, a monthly newsletter about current trends and developments in the biobanking field.
- In July, we created the BioBank Ambassadors mentoring and networking group to connect organizations interested in registries and biobanks.
- Throughout the year, we held a series of webinars focused on registries and biobanks.

Name the most important value or leadership attribute that represents Genetic Alliance:

Integrity, confidentiality, wisdom, sincerity, compassion... honesty, credibility, political savvy, commitment and dedication to rare disease...Genetic Alliance is "you-centric" and on your side.

-- external partners

Genetics Day on the Hill

Genetics Day on the Hill unites individuals with diverse perspectives to learn from one another and form lasting partnerships; it enables the empowering, gratifying, and often exhilarating experience of participating in the policymaking process; and above all, it demonstrates to Congress our collective energy and vision for advancing the path to better health. At the fifth annual Genetics Day on the Hill, participants shared personal and corporate stories about the importance of the following:

- Genetic testing oversight
- Public access to federally-funded research results
- Public engagement in clinical research

Gene Screen

The second annual Gene Screen was divided into three screenings to showcase a range of films. Q&A sessions with filmmakers followed each screening, including one via Skype!

6:00 p.m.
In My Hands

7:30 p.m.
The Power of Two
Mito-Kids
Jewish Genetic Diseases
On Beauty

9:00 p.m.
Darius Goes West:
The Roll of His Life

Annual Conference

The 2010 Genetic Alliance Annual Conference took place July 16-18, 2010, and brought attendees two new modes of engagement. On Friday, participants enjoyed a new format for dinner, and chose from two simultaneous debates: each debate offered a unique opportunity for cutting-edge discourse relevant to the genetics community. Sunday, participants were invited to explore free-form "Open Innovation" sessions, which allowed them to create their own workshops.

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

	Unrestricted	2010 Total	2009 Total
REVENUE AND OTHER SUPPORT			
Government Contracts and Grants	$2,170,431	$2,670,431	$2,918,510
Corporate/Private Contracts & Grants	684,190	684,190	0
Individual Contributions	22,256	22,256	36,391
Corporate Contributions	23,000	23,000	93,500
Biobank Program Revenue	482,673	482,673	213,627
In-Kind Contributions	491	491	2,076
Listserv Income	0	0	3,000
Interest Income	424	424	979
Special Events	149,540	149,540	116,755
Fees	0	0	75
Miscellaneous Income	2,019	2,019	0
Rental Income	3,050	3,050	0
Total Revenue	3,538,075	4,038,075	3,384,913
Net Assets Released from Restrictions	117,823	-	-
Total Revenue and Other Support	$3,655,898	$4,038,075	$3,384,913
EXPENSES			
Program Services			
Education, Research, & Services	$3,842,792	$3,842,792	$3,253,071
Policy	65,030	65,030	24,812
Supporting Services			
General and Administrative	28,058	28,058	108,700
Fundraising	33,460	33,460	0
Total Expenses	$3,969,940	$4,032,801	$3,386,583
Increase (Decrease) in Net Assets	(313,442)	68,735	(1,670)
Increase from Net Assets Transfer	-	-	-
Net Increase (Decrease) in Net Assets	($313,442)	$68,735	$(1,670)
Net Assets, Beginning of Year	$430,599	$455,905	$457,575
Net Assets, End of Year	$117,157	$524,640	$455,905

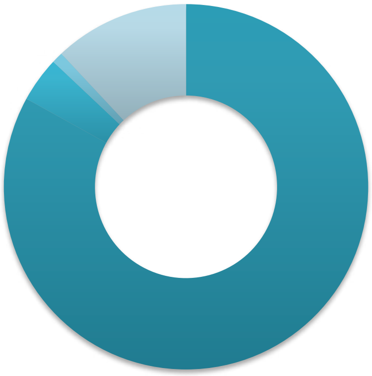
Statement of Financial Position

as of September 30th of each year

Assets	2010	2009
Cash and Cash Equivalents	$123,498	$361,191
Accounts Receivable	397,134	140,296
Grants Receivable	380,786	225,286
Prepaid Expenses	31,811	37,057
Fixed Assets, Net	144,964	43,539
Other	12,718	8,394
Total Assets	$1,090,871	$815,763
Liabilities and Net Assets		
Accounts Payable and Accrued Expense	$490,832	$279,872
Capital Lease Obligation	13,896	20,541
Deferred Rent	61,502	59,445
Total Liabilities	566,230	359,858
Net Assets		
Unrestricted	117,158	430,599
Temporarily Restricted	407,483	25,306
Total Net Assets	524,681	455,905
Total Liabilities and Net Assets	$1,090,871	$815,763

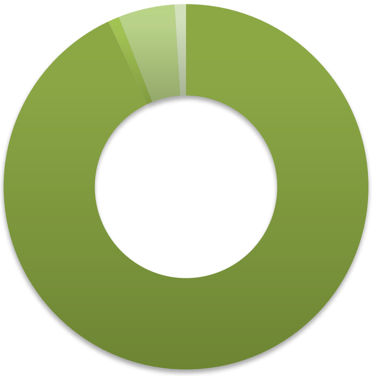
Operating Fund Sources

- Contracts and Grants 83%
- Special Events 4%
- Contributions & Other 1%
- Biobank 12%



Fund Spending

- Programs 93%
- Policy 1%
- G & A 5%
- Fundraising 1%



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