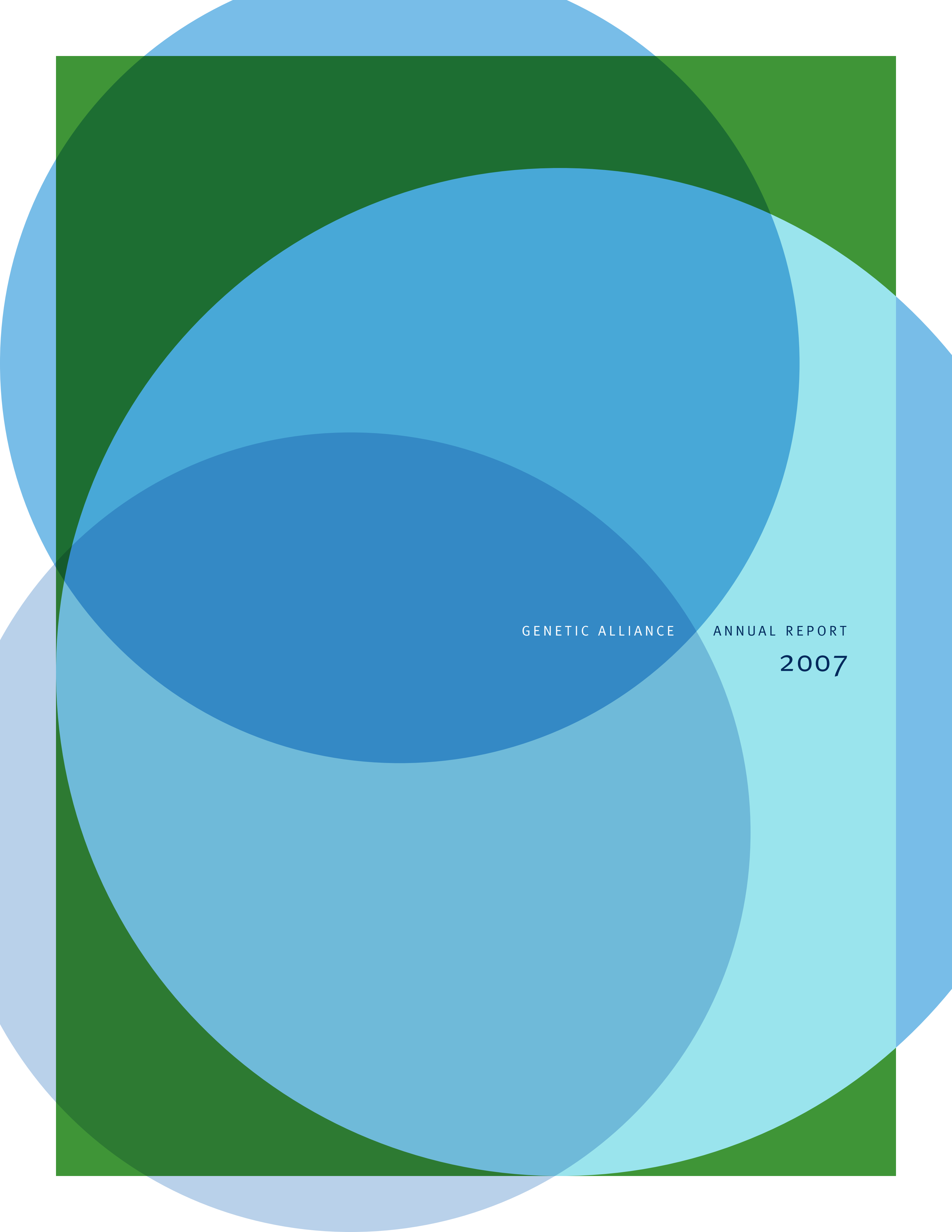


GENETIC ALLIANCE ANNUAL REPORT

2007

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.

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.

Genetic Alliance's network includes more than 1,000 disease-specific advocacy organizations as well as thousands of 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.

Over the past 21 years, Genetic Alliance has been the voice of advocacy in genetics. Advocacy in the 21st century, however, requires new definitions and new focus. Healthcare, from basic research to services, is in need of transformation. We use genetics and advocacy as disruptors to drive innovation. We revolutionize access, decision-making, and partnerships.

Dear Friends,

Genetic Alliance took bold steps in 2007, engaging in profound transformation. We support and empower the genetics community and the systems that surround it, impede it, and support it. In this context, we are all leaders, and most importantly, agents of change. Together, we discovered how we hold open space to transform systems.

There are many wonderful examples of systems in our world radically re-tooling themselves to be superbly functional and effective. We seek to understand those systems and improve on them – as such we are students of transformation and invite our network to join us.

At the Genetic Alliance conference this summer, Newt Gingrich spoke of the need for us to be both patient and visionary – for we are on the brink of numerous new worlds. The vivid picture he painted remains in our mind as a template: the pace of science has quickened to such a degree that as we envision the future today, we are akin to Isaac Newton trying to invent the iPhone. This is the leap we must take.

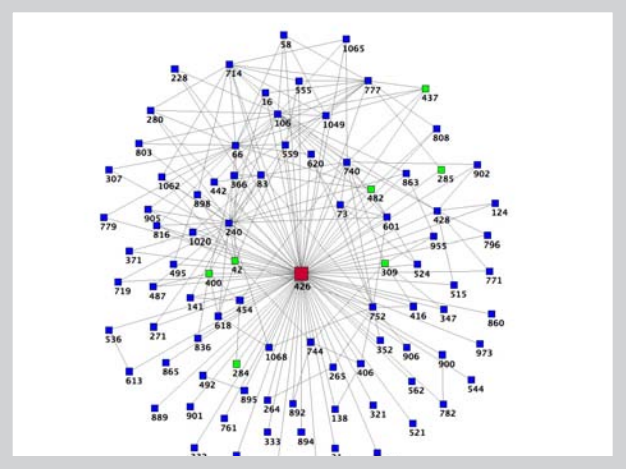
We come from multiple perspectives, but ultimately one goal unifies us all – we seek the prize of better health and excellent quality of life for our loved ones and ourselves. Let's celebrate our successes and challenge ourselves to go beyond!

Sincerely,
Sharon F. Terry, President & CEO, Genetic Alliance

Transform Systems

Networks that Transform

Social network analysis visualizes energy and pathways for resource flow within and between organizations. We liberate the potential energy of the genetics community by connecting the broad network to facilitate interaction and resource sharing.



National Consumer Center for Genetics Resources and Services

In 2007, Genetic Alliance opened the National Consumer Center for Genetics Resources and Services (NCCGRS). The major purpose of this five-year project is to mitigate the substantial information and resource deficit for consumers of genetic services. The Center offers open access resources developed by Genetic Alliance to meet the needs of consumers and stakeholders: Disease InfoSearch, Resource Repository, Understanding Genetics, the Interactive Guide, Strategies for Success, the customizable Family Health History Guide, and two new resources, WikiGenetics and WikiAdvocacy.

Further, NCCGRS aims to bring the voices of consumers and their concerns to the attention of policymakers and government agencies. NCCGRS works proactively to focus the future of the field on the issues that matter most to consumers and make sure genetics services are accessible, affordable, and of high quality.

“Genetic Alliance has tracked the difficulties in obtaining credible information and quality services. We’ve built substantial systems to alleviate the burden caused by these issues. Now it is time to explode the dysfunctional systems and enable the community to accelerate the development of solutions and resources.” – Sharon Terry, President and CEO, Genetic Alliance

COUNCIL

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Alyson Krokosky
Genetic Counseling Fellow

Promoting Access to Accurate and Affordable Genetic Tests

2007 marked another year in Genetic Alliance's leadership as a consumer advocate for genetic testing oversight. Our work, both independently and with partners, raised the profile of genetic testing regulation, and we have taken a lead role in influencing dialogue and debate around this issue.

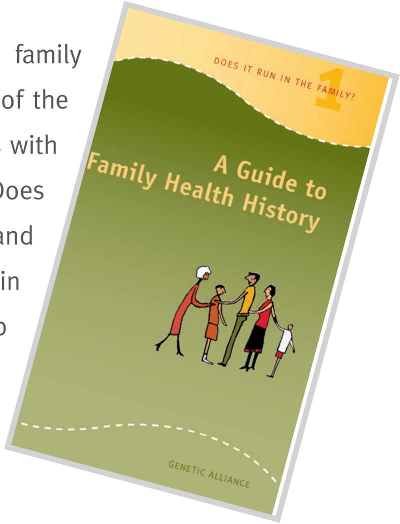
In the spring of 2007, Genetic Alliance joined the Genetics and Public Policy Center and Public Citizen in petition to the Centers for Medicare and Medicaid Services to create the genetics specialty. It was denied, and as a result Genetic Alliance convened a summit on genetic testing.

Genetic Alliance was actively involved in discussions with key stakeholders concerning the Food and Drug Administration's (FDA) draft guidances on in vitro diagnostic multivariate index assays (IVDMIAs) and analyte specific reagents (ASRs). During the year, Genetic Alliance offered public comment, drafted comments on both guidances, and submitted them to the FDA docket, including more than 40 signatures from organizations in the genetics community. We also developed a model for genetic testing oversight with the Coalition for 21st Century Medicine.

Genetic Alliance served as a sounding board for members of Congress as they considered legislation on genetic testing. Genetic Alliance continues to monitor the progress of this legislation and provide guidance on the effect of genetic testing regulation on consumers.

Engaging Families in Health

Genetic Alliance partnered with diverse communities to create customized family health history tools. In 2007, Genetic Alliance created the template version of the "Does It Run In the Family?" toolkit and developed thorough evaluation plans with each of our partners. Each community involved in the project adapted the "Does It Run In the Family?" toolkit with stories, interview questions, resources, and condition information. Partners disseminated the toolkit to 25 families within each community to evaluate its usefulness through baseline and follow-up surveys.



"This is outstanding work, vital for helping those working with distinct communities." – Genetic Alliance 2007 Annual Conference participant

Newborn Screening Models

As newborn screening expands nationwide, it becomes a model for successful genetic services and the integration of genetics into public health. Genetic Alliance successfully competed for two cooperative agreements from the Health Resources and Services Administration's Genetic Services Branch of the Maternal and Child Health Bureau to establish the Consumer Focused Newborn Screening projects. These three-year projects are regionally and nationally significant. They will develop models to maximize the benefits of the newborn screening system for newborns and their families.

In partnership with the University of Maryland School of Medicine, one project focuses on the effects on families and the newborn screening system of false positive screen results and carrier identification. The other project, in partnership with the Genetics and Public Policy Center, will evaluate public perceptions of newborn screening and develop public education models on the topic.

"Newborn screening projects that include consumers as integral contributors to the discussion close the loop with regard to the system of delivery. This well rounded approach is extremely important considering the rapid advancements taking place."

– Andrea Williams, Executive Director, Children's Sickle Cell Foundation

Creating Quality Information

The Access to Credible Genetics Resources Network (ATCG RN) developed a Toolbox for Quality Information. The Toolbox is comprised of quality, content, and usability scales. The Centers for Disease Control and Prevention funds this project with special emphasis on Duchene Becker Muscular Dystrophy and Fragile X Syndrome. Our partners in this project are the University of Maryland School of Medicine, National Coalition of Health Professional Education in Genetics, Parent Project Muscular Dystrophy, Fragile X Research Foundation, National Council of La Raza, and GeneTests.

"The ATCG project has the exciting potential to improve the lives of people affected by a broad range of genetic diseases."

– Katie Clapp, President, Fragile X Research Foundation

"ATCG will enable us to make informed decisions that positively impact quality of life and in many cases, the lifespan, giving us more time with those we love."

– Patricia Furlong, President, Parent Project Muscular Dystrophy

Ending Genetic Discrimination

Genetic Alliance's top policy priority in 2007 was genetic nondiscrimination. As chair of the Coalition for Genetic Fairness, Genetic Alliance worked relentlessly to educate the nation's top decision-makers about the Genetic Information Nondiscrimination Act (GINA).

GINA saw swift action in the House of Representatives: on April 25, GINA passed the House by an impressive 420-3 vote.

GINA's Senate sponsors, Senator Olympia Snowe (R-ME), Senator Edward Kennedy (D-MA), and Senator Mike Enzi (R-WY) introduced companion legislation on January 22. The bill was reported favorably from the Health, Education, Labor, and Pensions Committee and was poised for consideration but was not brought to the floor for a full vote.

"GINA provides protections from genetic discrimination that Americans want and would allow genetic research to move forward in this country so we can all have healthier lives."

– Representative Louise Slaughter (D-NY)

"It is my hope that we shall see this bill again receive the unanimous support of the Senate."

– Senator Olympia Snowe (R-ME)

Advocates as Test Developers

As steering committee member and co-founder of Collaboration, Education, Test Translation (CETT) Program, Genetic Alliance worked in 2007 to strengthen the Advocate Mentor Program. The CETT Program, sponsored by the National Institutes of Health Office of Rare Diseases, helps bring new tests to patients while requiring collaborations between advocates, clinical laboratories, and clinicians or researchers.

"The CETT program has helped our Molecular Genetics Laboratory to focus more on new test development and has funded five new tests in the last year. It has also been an amazing experience for me to collaborate with researchers, experts, patient advocates, and advocacy groups."

– Melissa Dempsey, Genetic Counselor, The University of Chicago

Global Outreach

In 2007, we joined the Brazilian Genetic Alliance, which we helped found, in the inaugural advocates meeting at the Third International Conference on Birth Defects and Disabilities in the Developing World, setting a trend for this conference in the future. The conference inspired the Rio Declaration, which summarizes goals for the future of birth defects and disabilities in the developing world with an emphasis on the importance of advocacy.

Building on work that commenced in 2006 at the Strengthening Newborn Screening in the Middle East and North Africa conference in Morocco, Genetic Alliance actively engaged with representatives from the Arab world who are working to establish variations of Genetic Alliance throughout the region. In 2007, Genetic Alliance attended the Second Pan Arab Human Genetics Conference and met with individuals at the Centre for Arab Genomic Studies as well as representatives of the Dubai city government and related health-based foundations about issues related to patient and family advocacy.

Building Opportunities Through Our Programs

In 2007, the Fellows Program, established by Genetic Alliance in 2005, grew to 21 participants, an 80 percent increase since 2006. This program supports up-and-coming community and health advocates who aspire to become more involved in the fields of genetics advocacy and community-based health. Genetic Alliance partners nominated fellows, each of whom received free registration and travel and hotel expense reimbursement.

"[The fellows] deeply appreciated the opportunity given and felt empowered by the experience as it further fed their passion for community work and enhanced their advocacy and leadership skills."

– Alejandra Gepp, Institute for Hispanic Health, National Council of La Raza

Connecting Advocates with Professionals

In its third year, the Advocates Partnership Program collaborated again with the American Society of Human Genetics to bring advocates to San Diego, CA for its annual conference. The American College of Medical Genetics and the National Society of Genetic Counselors also partnered with us to provide the program at their annual meetings in Nashville, TN, and Kansas City, MO, respectively.

"We were recognized and valued as the critical link between the scientists and doctors and the affected patients and families." – Dean Suhr, President, MLD Foundation

Contributing to Growing the Genetics Workforce

This year, Genetic Alliance continued its partnership with the National Human Genome Research Institute and Johns Hopkins University genetic counseling program and launched a new partnership with the University of Maryland program, mentoring and supervising genetic counseling graduate students in working with advocacy organizations.

"The project with Genetic Alliance is a unique educational experience allowing students to develop skills necessary to work with advocacy partners." – Shannan Dixon, Assistant Professor, University of Maryland School of Medicine

Take Action

Eyes on the Prize: Truth Telling about Genetic Testing

As systems are stressed by the advent of personalized medicine, genetic testing requires that we seek the truth – about the systems that surround it, impede it, and support it. September 20-21 Genetic Alliance convened a summit, Eyes on the Prize: Truth Telling about Genetic Testing, in Washington, DC. The summit successfully fostered honest, stimulating discussions about genetic testing and initiated the transformation of the genetic testing system as it relates to the ultimate outcome – health. Participants hailed from every sector of the genetics community – government, biotechnology companies, academia, advocacy organizations, laboratories, law/consulting firms, and professional organizations – and addressed issues pertaining to the whole genetic testing pipeline, from research and development to the practice of medicine.

Interactive discussion and a debate dinner the first evening resulted in a lively, open dialogue that characterized the proceedings. Several consensus points were reached along with action steps to effect the desired change. Genetic Alliance is producing journal articles, a monograph, and a comprehensive report of the event to publicize the Summit outcomes.

"Genetic testing is one of the preeminent scientific and ethical issues of the 21st century, and the people in this room today will be at the forefront of our effort to harness the power of this extraordinary new scientific tool and do so responsibly." – Senator Edward Kennedy (D-MA)

Connecting Leadership

The Genetic Alliance 2007 Annual Conference, The Year of the Advocate, brought together more than 200 leaders from all stakeholder groups. The conference kicked off with the Institute for Advocacy, which focused on empowering consumer advocates through community and organization building, leadership development, and coalition building in three concurrent daylong symposia — Organizations in Action, Transformational Leadership, and Research in Action.

Thirty cutting edge workshops covered critical issues, including genetic testing, personalized medicine, newborn screening, outreach and advocacy, race and genetics, evidence-based information, and family history. The event concluded with a passionate keynote address by former Speaker of the US House of Representatives, Newt Gingrich. Patience and vision as agents for change and innovation framed his speech — a fitting capstone to an empowering event.

"I was very honored to have been able to speak at the most energetic and impassioned conference I have ever attended!" – Susan Fernbach, Genetic Counselor, Baylor College of Medicine

"Genetic Alliance means strength, empowerment and generosity. Thank all of you, again, for a marvelous experience." – Sandy Gordon, Co-founder, Trimethylaminuria Foundation

Genetics Day on the Hill

Genetic Alliance held the second annual Genetics Day on the Hill on July 26. More than 100 advocates, medical professionals, and scientists participated in the event. Grouped by region, participants took to the Hill, and by the end of the day, 100 Senate offices understood genetic diseases, genetic testing, and the importance of GINA and witnessed the strength of the genetics community.

"We made a big difference by being there."

"The whole process was new to me —any skills I have now were newly attained. I feel confident that I can now easily carry on a conversation or hold a meeting with Congressional staff."

– Genetics Day 2007 participants

Genetic Alliance celebrates outstanding members of its community at our annual conference. In 2007, we had four exceptional honorees:

The Art of Listening Award honors a health professional who models the importance of caring, receptive professionals in the lives of individuals and families living with genetic conditions.

Dr. Ronald M. Zuker
The Hospital for Sick Kids
Toronto, CN

The Art of Reporting Award honors a reporter or journalist who models the special responsibility to report fairly and impartially about developments in genetics and the impact of these discoveries on people's lives.

Amy Marcus,
Wall Street Journal

The Art of Advocacy Award pays tribute to a visionary grassroots leader who is harnessing his or her knowledge and experience to improve the quality of research, healthcare, information and support services for a specific condition or for a coalition of grassroots organizations.

Abbey Meyers,
National Organization for
Rare Disorders

The Art of Industry Award honors a for-profit biotechnology, pharmaceutical, or genetics company whose track record models the benefits of creative partnerships between consumer advocates and industry to advance understanding and treatment of genetic conditions, disorders, and diseases.

Affymetrix

Celebrating Our Community

Genetic Alliance celebrated the passage of the Genetic Information Nondiscrimination Act (GINA) in the US House of Representatives at a Gala on July 25. Two hundred Genetic Alliance friends and supporters paid tribute to the achievements of two important figures in the advancement of GINA: Kathy Hudson, founder and Director of the Genetics and Public Policy Center, and Frank Swain, Senior Vice President of B&D Consulting. Attendees also saw an exhibit of new photos from photographer Rick Guidotti's Positive Exposure exhibit, a celebration of people living with genetic, physical, and mental health conditions.

Create Tools

Committed to Quality Information

Genetic Alliance expanded Disease InfoSearch, our online directory of genetic conditions, support groups and resources, in 2007. In collaboration with the National Center for Biotechnology Information (NCBI), we created a portal linking Disease InfoSearch's advocacy organization-supported catalog of information to a filtered subset of information available from the National Library of Medicine (NLM), a part of the National Institutes of Health.

The portal provides an automatic search for each specific condition, and using a series of filters calibrated to consumer interests, links to a wide range of information for patients and caregivers, from basic descriptions of a disease and its symptoms to the most current scientific research.

Connecting the Community

Strategies for Success (SfS), Genetic Alliance's training and educational series, continues to grow in content and attendance. Boasting 17 sessions throughout the year, SfS covered topics ranging from wikis to genetic testing.

With registration exceeding 500 participants in 2007, the audience and networking opportunities are larger than ever. Streaming audio, podcasting, and downloadable resources create on-demand resources.

"Informative and highly relevant to the health systems situation today."

"I truly appreciate the webinars Genetic Alliance has hosted. It makes a huge difference given our program's distance from DC. Policy discussions and information from Genetic Alliance are excellent!"

– 2007 SfS participants

Harnessing New Technology

With the emergence of crowd-sourcing and open access resources, Genetic Alliance launched WikiGenetics [wikigenetics.org] and WikiAdvocacy [wikiadvocacy.org]. WikiGenetics provides an open-source, user-generated encyclopedia on human genetics for the public. Due to the contributions of countless volunteers, it provides credible and up-to-date information on human genetics that anyone, including people with no scientific background, can understand. A professional advisory board and an editorial board comprised of experts in genetics, genomics, services, policy, and education work to maintain its quality and keep its literacy level appropriate for the public. Based on the Interactive Guide to Advocacy, WikiAdvocacy is a compilation of the wisdom of the advocacy community. Users continually add and refine tips and tools on maintaining and growing advocacy groups.

WikiADVOCACY

WikiGENETICS

"Wikigenetics?! Brilliant. Go with the flow, take hold of it. Bravo."

– Angela E. Lin, Medical Geneticist

Sharing Resources for Mutual Benefit

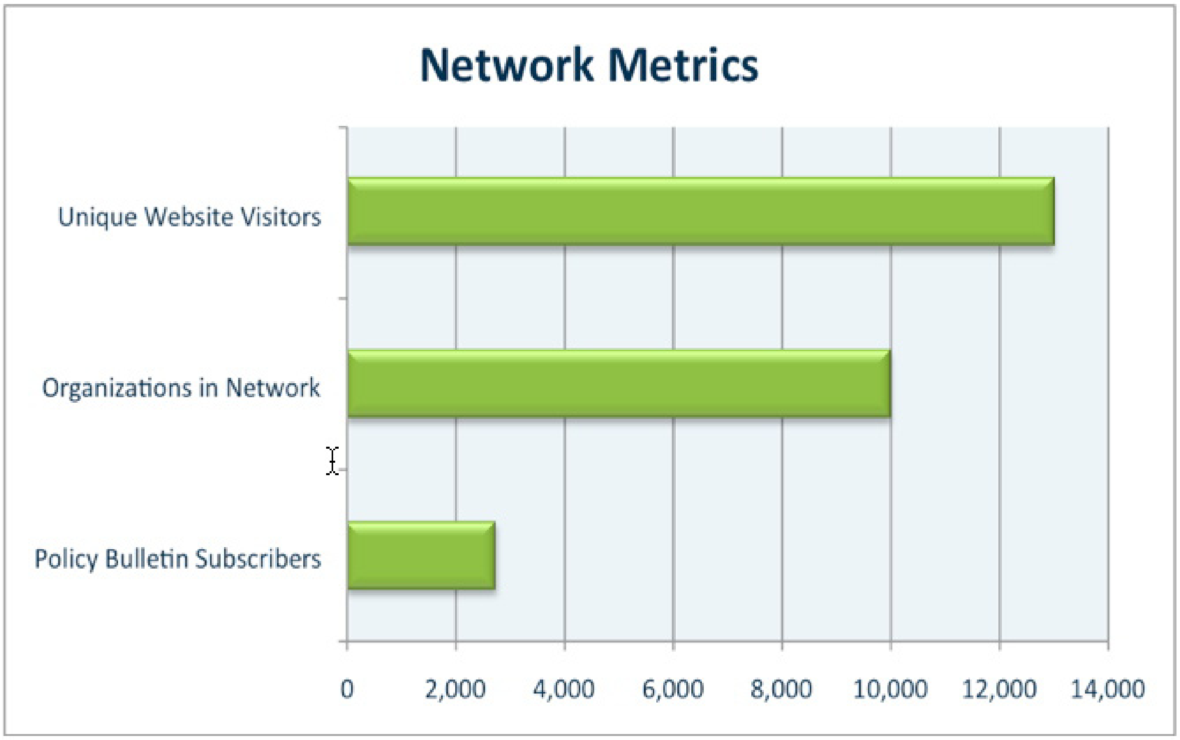
Genetic Alliance's Resource Repository is a robust document collection service that aggregates the combined resources of advocates, healthcare professionals, government agencies, think tanks, and other contributors. The Resource Repository [resourcerepository.org], features state of the art technology, allowing visitors to search full text using keywords, or browse collections by categories, author, or upload date.

"The Resource Repository is a dynamic digital library, created by the community, for the community, giving everyone access to a vast knowledge network. We are excited to offer this nexus that will enable everyone to leverage communal resources!"

– Sharon Terry, President and CEO, Genetic Alliance

Network Communications

Information flows through the Genetic Alliance network via more than 100 listservs that include tens of thousands of subscribers. As a common link between members of the genetics community, Genetic Alliance serves as a conduit for cutting edge news and information.



"Every time I get an email message from Genetic Alliance, I'm reminded of the terrific job Genetic Alliance has done and is doing for its member organizations."

– Mervyn L. Tano, President, International Institute for Indigenous Resource Management

Financials

2007 marked a year of overall fiscal health and organizational growth. 2007 revenues grew by 13.6 percent and we will move into 2008 with a budget of nearly $3,000,000, the largest operating budget in the 21-year history of Genetic Alliance.

Programs, collaborative projects, research, publications, and content are made possible through a blend of government grants, small foundations, corporate contributions, generous individual donors, fee–for-service efforts, and events. In 2007, Genetic Alliance competed successfully for three new grants from the Health Resources and Services Administration. The National Center for Genetics Resources and Services is funded for $500,000 per year for five years. Two, three-year grants for newborn screening programs were awarded $250,000 and $350,000, respectively. Genetic Alliance is in its third year of receiving $850,000 from CDC for the Access to Credible Genetics Resources Network. Thus, government funding is predominant, and in 2008 we will work to create a balance between government, foundation, and industry funding.

Genetic Alliance events also increased revenues in 2007. Continuing to build on prior year models, the successful Genetic Alliance Annual Conference, Gala, and Genetic Testing Summit created unique opportunities for corporate sponsorship. Genetic Alliance will continue to invest in the transformation of systems through public engagement and open space dialogue.

Genetic Alliance also proudly reports that each board and staff member contributed to the organization financially in fiscal year ’07.

Strack Stanfield LLC executed the audit of fiscal year 2006 financials and, consistent with past years, found the organization to have completed all fiduciary responsibilities without any concerns. The audit of fiscal year 2007 was available in early 2008.

Statement of Activities and Changes in Net Assets

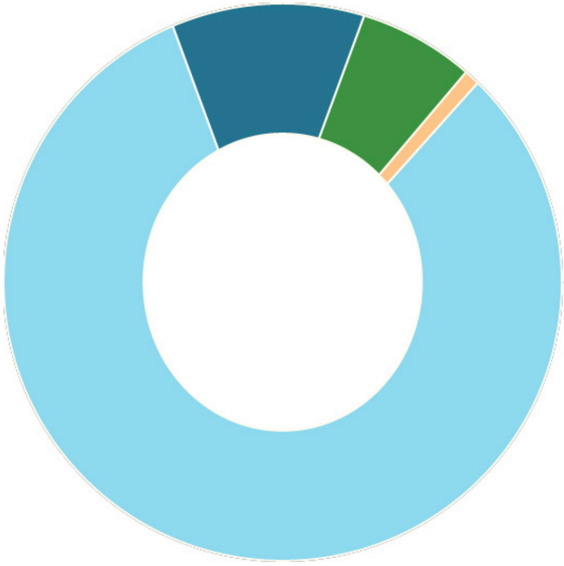
as of September 30th of each year

	Unrestricted	Temporarily Restricted	2007 Total	2006 Total
Revenue and Other Support				
Contracts and Grants	$1,801,096	$267,818	$2,068,914	$1,663,916
Employee Services Revenue	6,050	-	6,050	-
Contributions	121,670	-	121,670	101,315
In-Kind Contributions	3,796	-	3,796	52,360
Listserv Income	2,770	-	2,770	2,150
Interest Income	11,113	-	11,113	3,433
Special Events	167,298	-	167,298	207,146
Member Services	4,492	-	4,492	1,245
Total Revenue and Other Support	2,118,285	267,818	2,386,103	2,031,565
Net Assets Released from Restrictions	275,936	275,936	-	-
Total Revenue and Other Support	$2,394,221	$(8,118)	$2,386,103	$2,031,565
Expenses				
Program Services				
Membership	$2,088,465	$ -	$2,088,465	$1,704,111
Policy	218,041	-	218,041	131,366
Total Program Services	2,306,506	-	2,306,506	1,835,477
Supporting Services				
General and Administrative	2,937	-	2,937	30,997
Fundraising	837	-	837	5,751
Total Supporting Services	3,774	-	3,774	36,748
Total Expenses	$2,310,280	$ -	$2,310,280	$1,872,225
Increase (Decrease) in Net Assets	83,941	(8,118)	75,823	159,340
Increase from Net Assets Transfer	-	-	-	-
Net Increase (Decrease) in Net Assets	$83,941	$(8,118)	$75,823	$159,340
Net Assets, Beginning of Year	$322,200	$52,422	$374,622	$215,282
Net Assets, End of Year	$406,141	$44,304	$450,445	$374,622

Statement of Financial Position

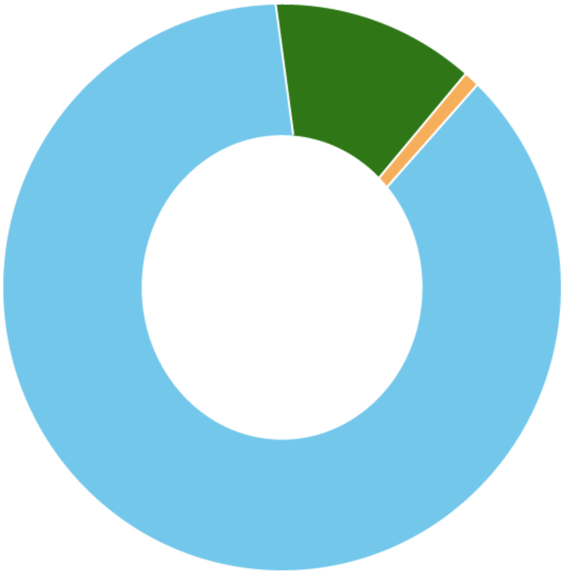
as of September 30th of each year

Assets	2008	2007
Cash and Cash Equivalents	$452,684	$314,810
Accounts Receivable	13,723	42,277
Grants Receivable	109,500	173,961
Prepaid Expenses	15,029	16,712
Furniture and Equipment, Net	64,722	11,244
Other	8,394	8,394
Total Assets	$664,052	$567,398
Liabilities and Net Assets		
Accounts Payable and Accrued Expense	$ 137,040	$176,073
Capital Lease Obligation	32,128	8,976
Deferred Rent	44,439	7,727
Total Liabilities	213,607	192,776
Net Assets		
Unrestricted	406,141	322,200
Temporarily Restricted	44,304	52,422
Total Net Assets	450,445	374,622
Total Liabilities and Net Assets	$664,052	$567,398



Operating Fund Sources

- ● Contracts and Grants 87%
- ● Special Events 7%
- ● Contributions & Other 5%
- ● Biobank Membership 1%



Fund Spending

- ● Membership 90.4%
- ● Policy 9.4%
- ● G & A 0.2%

Genetic Alliance

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