GENETIC ALLIANCE ANNUAL REPORT

2008

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 22 years, Genetic Alliance has been the voice of advocacy in genetics. Advocacy in the 21st century, however, 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. Today, as technology enables more dynamic interchange of diverse perspectives, individuals often self-aggregate around issues they find compelling. New methods for individuals to collaborate and participate in research greatly augment the traditional function of nonprofit advocacy organizations. Given this rapidly changing environment, Genetic Alliance understands that nothing short of the transformation of our mission, our goals, even our Board of Directors will suffice to transform health.

Dear Friends,

This is our moment! We are transforming leadership in a new age, and the change is palpable! The old paradigms are tired, and they are unable to move us forward in this age of connectivity and openness. Every one of us must be authentically open—to partnership, to change, and to all the risks this sea change will bring. Gandhi taught that we must be the change we want to see in the world. If we are truly committed to improved health, to transforming systems, then each of us is an advocate.

In our major events this year, we both celebrated and challenged leadership. We applaud the passage of the Genetic Information Nondiscrimination Act. GINA is only the first milestone on the long road to the transformation of health through genetics. We released a powerful energy by transforming a stagnant bill into an empowering law, and now we must learn as a community how to sustain and amplify that energy. We know that genetics is a wonderfully disruptive innovation, and we can make it a vibrant catalyst in the creation of a health system that faithfully serves all of us.

We welcome partnership and collaboration as we move forward toward continued transformation. Join us as deeply as you can, set aside your agendas, don't worry about turf —open yourself to transformation.

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

Transforming Systems by Transforming Genetic Alliance

Genetic Alliance's mission is to transform health through genetics. In order to realize our ambitious mission, we need to fully understand how to transform systems, dissolve boundaries between traditional adversaries, convene and sustain space for meaningful dialogue, and promote processes that are marked by transparency and openness. Creating our own organizational transparency is the first step toward actively seeking it from a broader community. We know that to transform systems, we must start with our own. Nurturing this kind of working environment calls us, both personally and professionally, to explore the deepest truths about ourselves and the systems we impact.

The historical function of our Board of Directors, for example, is no longer sufficient for the work our organization is called upon to do. Historically, the Board limited itself to general oversight of activities, and its own activity was detached from the day-to-day organization. Our expanded mission demands a shift in scope and responsibility from staff and Board alike. The leadership body of Genetic Alliance, in particular, must go beyond simple oversight and develop responsibilities that go deeper than annual reviews. The leadership must be able to convene space that supports and manifests visioning at the deepest level. We must be willing to constantly ask ourselves the hardest questions about how we model our mission and pursue transformation in the community. In addition, Genetic Alliance demands a governance structure that serves the transparency we promote and supports the rigorous process of self-discovery (awareness) required during our internal decision-making. In order to fulfill our mission, we need to demonstrate the internal process by which decisions are explored and how we collectively discern in openness and clarity the highest good for all concerned. And so, we transformed "Genetic Alliance Board" into "Genetic Alliance Council." The Council is a discerning body drawn from a committed community determined to transform health through genetics. Expectations of full Council involvement are high. The procedures and processes of the Council actively build our capacity to explore disagreements, weigh nuanced issues, and listen to one another with great resolve and care. The members, drawn from very different quarters of our community (nonprofit, for-profit, academia, publishing, ministry, etc.), consistently create and sustain an environment of openness in order to continue learning how to promote transparency in our wider community. These individuals are committed to undertaking personal transformation to realize the collective transformation of health we seek.

COUNCIL

Sharon Terry, MA, President
and CEO
Executive Director,
PXE International, Inc.

Diane Baker, MS, CGC, Secretary
Past President, National Society
of Genetic Counselors

Kemp Battle, Treasurer
Managing Director,
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STAFF

Natasha Bonhomme
Program Manager

Rhianna Campbell
Manager of Finance and
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Amelia Chappelle, MA, MS
Associate Director of Genetics
Resources and Services

Andria Cornell
Public Policy Program Assistant

Vaughn Edelson
Program Coordinator

Liz Horn, PhD, MBI
BioBank Director

Tetyana Murza, MES
Programs and Events Coordinator

Tam Nguyen
Electronic Communications Assistant

James O'Leary
Chief Operating Officer

Mary Peckiconis, MA
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International Outreach Liaison

Laura Silver
Executive Assistant

Sharon Terry, MA
President and CEO

Helen Travers, MS, CGC
Genetic Resource
Specialist

Tiphané Turpin, MA
Communications Manager

Sim Wimbush
Program Assistant

Lisa Wise, MA
Vice President

Strategic Visioning

As part of revolutionizing advocacy, Genetic Alliance engages in strategic visioning, "brown bag lunches," and openness meetings that continually engage the office in the same way the organization seeks to impact the world. Through these meetings, specific tools have been developed as part of the strategic plan of Genetic Alliance, including: a 'phenotype filter' for characterizing project ideas, organizational and genetics history timelines, a glossary of terms related to the visioning process, and teams that focus on social trends and blueprints of the organization. The phenotype filter, for example, allows the Genetic Alliance staff to deeply analyze a project or topic in order to discern whether it is a priority for the organization. Most Genetic Alliance projects are staff-initiated, so the layers of the filter ask, "What is the purpose of the program, project, or concept?" "What is the landscape or environment?" and "What resources are needed in terms of money, staff, sustainability, and existing infrastructure?" Finally, the question is asked, "How does this project exemplify and bring about the openness we seek to promote in the wider community?" This last question is key to bringing the entire process into a space of openness where perspectives can be fully and honestly debated. Through this tool, among others, the Genetic Alliance staff is able to focus on openness not only in meetings, but also in every organizational product and program.

SALONS

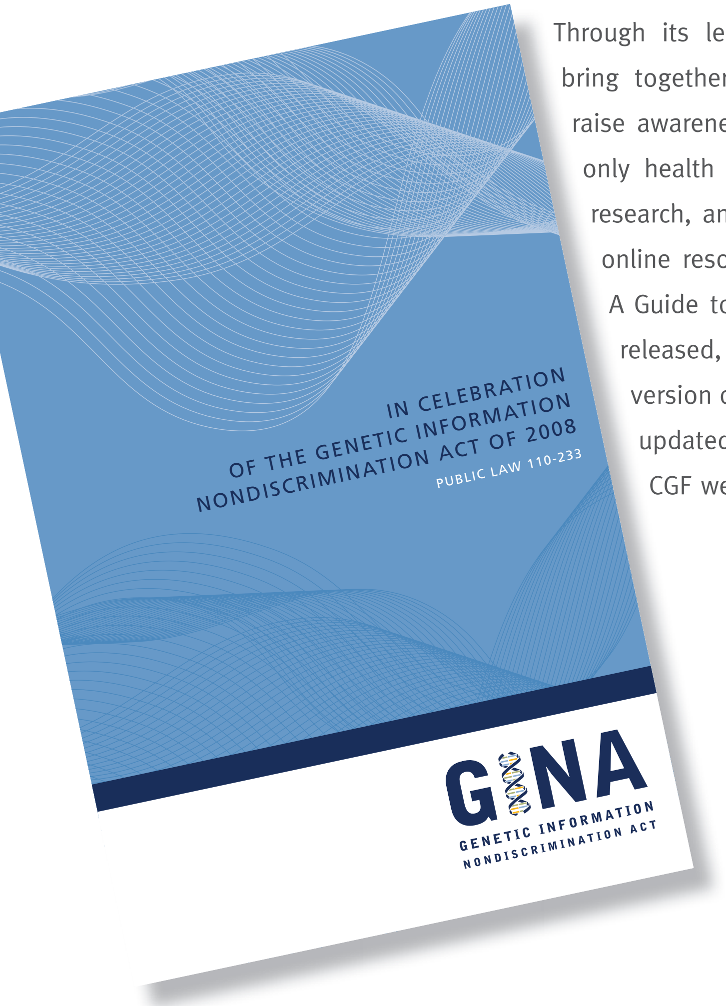
In another example of transformative visioning, Genetic Alliance regularly holds salons, similar to the 17th – 19th century gatherings of intellectuals and other eminent individuals. In our case, individuals are not chosen for their expertise or the expansiveness of their resumes, but for their characters and their reputations as open-minded, curious, and willing to explore all sides of a given issue. Salons are fueled by the mechanism of open space, allowing unfettered thought and discussion; we leave our certitude and intellectual property at the door. Through our conversation, we realize more than any one of us could have done alone. This is our chief aim: transformative knowledge through conversation with others. We have held several of these salons, including one with thought leaders in health in Silicon Valley, and one with individuals in Washington, D.C., who interact with the genetic testing regulatory environment. In another case, we brought together individuals to inform a committee of the U.S. House of Representatives about analytic validity. The salons are a useful way to practice openness and transformation; dynamic interaction around rigorous topics inevitably leads to disruptive and exciting solutions.

Ending Genetic Discrimination

Genetic Alliance's top policy priority in 2008 was genetic nondiscrimination. As Chair of the Coalition for Genetic Fairness (CGF), Genetic Alliance worked to educate the nation's top decision-makers about the Genetic Information Nondiscrimination Act (GINA), a bill that would prohibit the misuse of individuals' genetic information in both health insurance and employment. The Coalition's efforts in 2007 led to the House of Representatives passing GINA on April 25 (DNA Day) by a vote of 414-1, and in 2008, the Coalition pushed onward to the passage of the bill in the Senate on April 24 by a vote of 95-0. GINA was signed into law on May 21, 2008, marking the completion of an effort spanning more than 12 years.

The health insurance provisions of the law, Title I, take effect on May 21, 2009, and the employment provisions of the law, Title II, take effect on November 21, 2009. Genetic Alliance leads the Coalition's efforts to proactively engage in the regulatory process. Our greatest goal is to ensure the resulting regulations are clear, transparent, and accurately reflect the intent of the broad group of stakeholders that supported the legislation. In general, the Coalition for Genetic Fairness encourages the agencies with regulatory responsibility to be open in their process and clear in the regulatory product.

Through its leadership of the CGF, Genetic Alliance continues to bring together the health community to educate the public and raise awareness of GINA, its meaning, and how it will impact not only health insurance and employment, but healthcare delivery, research, and emerging technologies. On September 8, 2008, an online resource for the public entitled "What Does GINA Mean? A Guide to the Genetic Information Nondiscrimination Act" was released, and later that month, by popular demand, a print version of the tool was created. These resources are continually updated and available on both the Genetic Alliance and the CGF websites.



IN CELEBRATION
OF THE GENETIC INFORMATION
NONDISCRIMINATION ACT OF 2008
PUBLIC LAW 110-233

GINA
GENETIC INFORMATION
NONDISCRIMINATION ACT

Programs

National Consumer Center for Genetics Resources and Services

In 2008, Genetic Alliance continued to operate 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 of genetic services for consumers. The Center offers open access to the following resources developed by Genetic Alliance to meet the needs of consumers and stakeholders: Disease InfoSearch, the customizable *Does It Run In the Family?* toolkit, the Resource Repository, *Understanding Genetics: A Guide for Patients and Professionals*, WikiAdvocacy, WikiGenetics, and Genetic Alliance Webinars in three series: Strategies for Success, Hot Topics in Genetics and Advocacy, and Meet Your Neighbors.

Further, NCCGRS brings the voices and concerns of consumers to policymakers and government agencies. NCCGRS works proactively on the issues that matter most to consumers and makes sure genetics services are accessible, affordable, and of high quality. NCCGRS is funded through a cooperative agreement (U33MC07945-02) with the Health Resources and Services Administration (HRSA).

Community Centered Family Health History

Significant stigma exists in communities and families surrounding health information. Privacy concerns and fears of discrimination can make it difficult to discuss health within the family, let alone with a healthcare provider. However, an individual's family health history (FHH) is an important predictor of his/her health today and in the future. In fact, FHH can be more predictive of diseases than genetic variants. The Community Centered Family Health History (CCFHH) project began with the idea that accessible tools produced by the community, for the community, would promote conversations among family members about health within the family and would translate knowledge of FHH into healthy lifestyle choices. Genetic Alliance has partnered with 20 diverse communities, and continually engages new partners, to customize the *Does It Run In the Family?* toolkit: a set of two booklets created to explain the importance of FHH and how to collect it, as well as explain basic genetics concepts and introduce readers to various conditions that can run in families. In 2008, Genetic Alliance completed eight community versions of the toolkit and began 12 more. All community partners adapted the toolkit to include personal health stories, photographs, interview questions, resources, community quotes, and health condition information, including local statistics. Genetic Alliance worked with seven of the original eight communities to customize and measure the utility of the *Does It Run In the Family?* toolkit. Each community partner recruited at least 25 families, consisting of two or more family members related by blood, to use the toolkit for three months, discuss it among their family members, and consider the implications of the information. Before and after using the toolkit, participants completed surveys measuring family communication about family history and disease risk and the use of family history information in provider interactions. An online customizable version of the toolkit is in development. CCFHH is also funded by HRSA. CCFHH is also funded through a cooperative agreement (U33MC06836-02) with HRSA.

Consumer Focused Newborn Screening

As newborn screening expands nationwide, it is a model for successful genetic service delivery and the integration of genetics into public health. There are, however, concerns that this integration be meaningful and appropriate for families as they navigate pregnancy and birth. Genetic Alliance successfully competed for two cooperative agreements (U33MC07951-02 and U33MC07952-02) from HRSA's Genetic Services Branch of the Maternal and child Health Bureau to establish the consumer Focused newborn Screening projects. These three-year, regionally and nationally significant projects will develop models to maximize the benefits of the newborn screening system for newborns and their families. The overarching purpose of these projects is to incorporate a range of consumer perspectives in the ongoing dialogue about genetic services. These projects increased the participation of consumers and advocates in the national discussion on newborn screening by providing access to federal meetings and planning free educational webinars for the public, among other activities. Through these projects, a Consumer Taskforce on Newborn screening was established.

In partnership with the University of Maryland School of Medicine, one project focuses on the effects of false positive screen results and carrier identification on families and the newborn screening system. The perspectives of more than 500 parents will be collected to better understand the impact of newborn screening on families. 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. In 2008, more than 2,000 women completed surveys about their current understanding of newborn screening and shared their expectations of this public health system.

Access to Credible Genetics Resources Network

Critical thinking and informed decision making are crucial to a productive and robust healthcare system. Access to quality information and the skills to think critically about the credibility of information are extremely important in all areas of health, but are especially pressing in the realm of genetic conditions. Families and healthcare providers may have trouble locating quality and accurate information on rare genetic disorders, because of their complexity or because the conditions are not common and therefore lack an ample evidence base. In addition, no healthcare provider can be an expert on every condition, so providers also need access to quality information on genetic disorders in order to deliver appropriate care. The Access to Credible Genetics Resources Network is solving this problem in two ways: contributing high quality information to the pool of available educational materials, and giving individuals, be it a parent of a newly diagnosed child or a healthcare provider, the power to decide for themselves what constitutes quality information. Genetic Alliance partnered with organizations focused on two specific genetic conditions – Duchenne/Becker Muscular Dystrophy and Fragile X Syndrome – to create the Quality Assessment Toolbox, which guides the creation and critical evaluation of educational material. Although the Toolbox was created with genetic conditions in mind, it is easily applicable to the creation and evaluation of educational material on any health condition, rare or common, genetic or infectious. This grant (5U10DD525036-03) is funded by the Centers for Disease Control and Prevention (CDC).

Promoting Access to Accurate and Affordable Genetic Tests

This year marked another milestone in Genetic Alliance's leadership as a consumer advocate for genetic testing oversight. As a result of the organization's work, both independently and with partners, Genetic Alliance has raised the profile of genetic testing regulation and taken a leading role in influencing dialogue and debate around this issue.

Genetic Alliance initiated and led 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). Furthermore, Genetic Alliance convened the Consumer Taskforce on Genetic Testing (CTGT), which made great strides in determining the next steps for consumer participation in these emerging technologies. The CTGT met throughout the year to address several requests for information and comments, and collaborated with the Coalition for 21st Century Medicine, on which Genetic Alliance holds a board seat, and other coalitions working on genetic testing oversight. Genetic Alliance also participates in the Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Stakeholders Group.

Genetic Alliance served as a resource for members of Congress as they considered legislation on genetic testing and continues to monitor the progress of this legislation and provide guidance on the effect of genetic testing regulation on consumers. For example, Genetic Alliance staff meet regularly with all stakeholders to discuss issues related to the transparency of tests, their clinical utility, and their relationship to personalized medicine and pharmacogenomics.

Advocates as Test Developers

As a steering committee member and co-founder of the Collaboration, Education, Test Translation (CETT) Program, Genetic Alliance worked to strengthen the Advocate Mentor Program for CETT in 2008. The CETT Program, sponsored by the National Institutes of Health Office of Rare Diseases, helps to create new tests for rare and neglected diseases. It requires collaborations between advocates, clinical laboratories, clinicians, and researchers. Genetic Alliance helped to establish an MTC8 disease foundation, and aided in the development of the foundation website. Genetic Alliance was also instrumental in the development of a test for pseudoxanthoma elasticum (PXE).

Contributing to Growing the Genetics Workforce

This year, Genetic Alliance continued its partnership with the National Human Genome Research Institute and the Johns Hopkins University genetic counseling program. A major output of their work was *A Guide to Genetic Counseling,* a consumer-friendly introduction to genetic counseling and its application. The guide includes information on preparing for a genetic counseling session and the different specialties in the field. We also renewed a partnership with the University of Maryland genetic counseling program, mentoring and supervising genetic counseling graduate students in working with advocacy organizations. Continuing the tradition of preparing students for future careers in health and/or genetics, Genetic Alliance provided a focused and collaborative project experience to eight genetic counseling students, four fellows, 15 interns, and nine work-study students during 2008.

Collaborating Among Regions

Genetic Alliance promotes consumer engagement and empowerment and infuses the consumer perspective in HRSA's seven Genetics and Newborn Screening Regional Collaborative Groups. Genetic Alliance staff held multiple visioning meetings about its role among the regions and attended each of the regions' annual meetings held nationwide. A staff member has been assigned to each region in order to increase consistent interaction with the regions.

Global Outreach

In 2008, Genetic Alliance continued its international work through global partnerships with rare disease, genetics, and health organizations. Staff presented at conferences around the world, on six of seven continents. In addition, Genetic Alliance worked to translate materials, including the *Does It Run In the Family?* toolkit, into additional languages, such as Spanish and Chinese. A landscape analysis of genetic services in China laid the groundwork for successfully adapting materials for that population.

Taking Action

Genetic Alliance hosted the third annual Genetics Day on the Hill on July 10. This gathering brought together the largest and most diverse group of participants to date. More than 100 individuals representing all areas of genetics, including disease-specific organizations, researchers, healthcare providers, industry representatives, and individuals and families affected by genetic conditions, came together to advocate for the public policy changes necessary to improve health. Grouped by region, participants visited the offices of key policymakers in both the U.S. House of Representatives and the Senate to celebrate the passage of GINA and educate Congressional staff members about genetic testing oversight and health information technology, among other topics. Joining us as speakers for the event were Dr. Dora Hughes, MD, MPH, Health Policy Advisor to then Senator Barack Obama and Congresswomen Louise Slaughter (D-NY) and Judy Biggert (R-IL). By the end of the day, House and Senate offices witnessed the strength and dedication of the genetics community, and the event participants were empowered and excited about the future of genetics and health.

Uniting Science and the Arts

a film by Joanna Rudnick

IN THE FAMILY

At 31, Joanna Rudnick — faces an impossible decision

remove her breasts and ovaries

or risk incredible odds of developing cancer.

Genetic Alliance Presents
Sneak Preview: *In The Family*
Thursday, July 10th 6:00pm & 8:30pm
E St. Cinema, Washington, DC

In The Family is a co-production of Joanna Rudnick, Kartemquin Film, and the Independent Television Service (ITVS). Coming to PBS On P.O.V. Fall 2008

Immediately following Genetics Day on the Hill, Genetic Alliance hosted back-to-back screenings of *In the Family,* a documentary chronicling one woman's exploration of the unpredictable world of predictive genetic testing for breast cancer. More than 300 people attended the screenings, including Genetic Alliance Annual Conference and Genetics Day on the Hill participants, as well as Genetic Alliance partners and interested residents of Washington, D.C. Question and answer sessions after each screening with Joanna Rudnick, director and star of the film; Sharon Terry, President and CEO of Genetic Alliance; and Sue Friedman, founder of FORCE (Facing Our Risk of Cancer Empowered) generated thoughtful discussion about cancer, genetic testing, family health history, privacy, and more.

Transforming Leadership

Genetic Alliance Annual Conference

July 11-13, 2008, the Annual Conference, *Transformational Leadership*, brought together more than 300 participants from all stakeholder groups: advocates, health professionals, policymakers, industry professionals, and community leaders. The conference began with four concurrent daylong symposia focused on Organizations, Leadership, Policy, and Research.

The second day of the conference featured 20 workshops, all of which highlighted cutting edge and internationally significant topics, including clinical research, delivery of services, family health history, health disparities, health information technology, and newborn screening. The 2008 conference featured Genetic Alliance's signature awards banquet, an annual celebration of outstanding individuals and organizations in advocacy, reporting, industry, and healthcare. Conference attendees also celebrated the passage of the Genetic Information Nondiscrimination Act with a ceremony honoring the bill's champions in the U.S. House of Representatives and the Senate.

The conference concluded with a day of thought-provoking panels addressing issues of race, ethnicity, and gender in the context of health; genetics and novel partnerships; and direct-to-consumer genetic testing. These panels, as well as the workshops, symposia, celebratory events, and other conference activities, such as morning walks, emphasize a unique aspect of the Genetic Alliance Annual Conference: the dynamic interaction, in various settings, of diverse stakeholders across the health community.

Advocates Partnership Program

Annually, Genetic Alliance partners with the American Society of Human Genetics (ASHG), the American College of Medical Genetics (ACMG), and the National Society of Genetic Counselors (NSGC) to offer an Advocates Partnership Program in conjunction with each organization's annual meeting. The programs aim to foster new connections among members of the genetics community. Up to 12 advocates attend each conference and have the opportunity to participate in exclusive meetings with genetics professionals – including representatives from industry, academia, research, and government —organized by Genetic Alliance and the professional societies.

In 2008, the Advocates Partnership Program was not limited to disease-specific advocates, as had been the case in the past, but was open to the entire genetics community, based on the belief that anyone can be an advocate for a cause. The Advocates Partnership Program provides participants with waived, full registration to the meetings and a partial reimbursement for transportation, hotel room, or airfare.

Creating Tools

Connecting the Community

Genetic Alliance's webinars continue to grow, both in breadth of content and in attendance. Boasting 25 sessions throughout the year, the 2008 webinars offered rich discussions and presented the work of experts in a variety of health-related fields. These webinars were held in three distinct series: Hot Topics in Genetics and Advocacy, Meet Your Neighbors, and Strategies for Success. In 2008, registration reached 140, 220, and 560 unique attendees respectively for these three series. In addition, many individuals attend multiple webinars per year and still more stream audio or download the podcasts that Genetic Alliance offers on its website following each webinar.

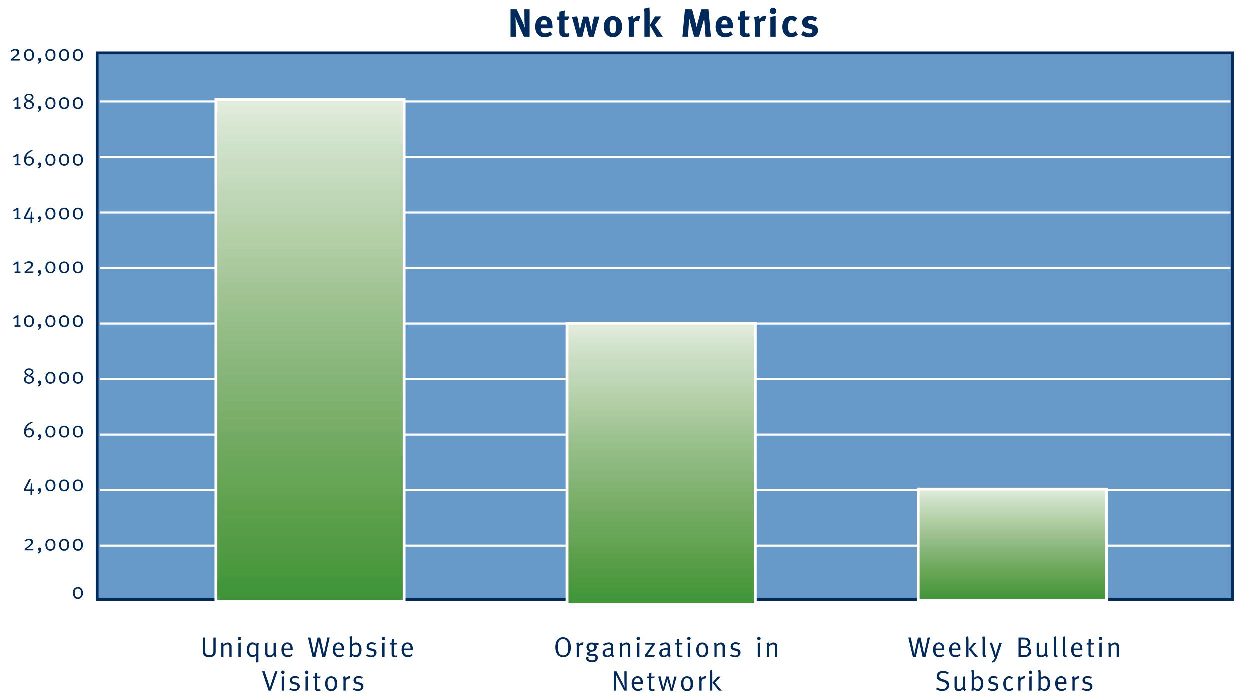
Hot Topics in Genetics and Advocacy highlights exciting new programs and policies, ranging from newborn screening to genetic testing regulation. Meet Your Neighbors showcases the work of particular organizations and encourages collaboration to achieve success. In 2008, this series featured clinical laboratories, professional societies, venture capitalists, parent advocacy groups, and multiple organizations that use innovative technologies, to name a few. Strategies for Success provides useful tips about cutting edge resources and best practices to help organizations in their development and growth. Streaming audio, podcasting, and downloadable resources create on-demand resources from these webinars.

Network Communications

Genetic Alliance promotes open access to information and serves as a vehicle for the genetics community to share materials and resources. In 2008, www.geneticalliance.org had over 14.5 million hits with an average of 18,000 unique visitors each month, a 35 percent increase from 2007. In addition, Genetic Alliance reaches stakeholders in the genetics and health community through a variety of regular publications. Advocacy in Genetics, our seasonal electronic newsletter, highlights new Genetic Alliance programs, resources, and partnerships.

The Genetic Alliance Weekly Policy Bulletin provides a unique platform for engaging our network in the policymaking process. The publication covers international, federal, and regional policy news to provide readers with the most up-to-date information on genetics and health public policy: it covers legislative updates, Congressional and regulatory agency activity, newly released publications and reports, and opportunities for involvement. In 2008, we saw a significant increase both in requests for joining the listserv and in the number of public policy and research organizations submitting requests to us to highlight their activities in the Weekly Policy Bulletin, signifying its broadening reach within the genetics community.

During 2008, Genetic Alliance continued to build novel partnerships in advocacy by launching the Genetic Alliance Weekly Bulletin, a snapshot of organizations, events, and publications from Genetic Alliance and organizations in its network, presented in an interactive web-based format. The Weekly Bulletin features a Meet Your Neighbors spotlight, mirrored on the Genetic Alliance homepage, to introduce organizations to each other in order to promote awareness and facilitate new partnerships. This bulletin is a welcome addition to existing information channels, including more than 100 listservs with more than 50,000 subscribers. As a common link between members of the genetics community, Genetic Alliance serves as a conduit for cutting edge news and information



HARNESSING NEW TECHNOLOGY

Capturing the power of crowd-sourcing and open access resources, Genetic Alliance created and launched WikiGenetics (www.wikigenetics.org) and WikiAdvocacy (www.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. WikiGenetics currently has a total of 1,401 pages in the database, and 171 files have been uploaded. There have been a total of 342,463 page views and 2,932 page edits since WikiGenetics was formally launched. That comprises an average of 2.81 average edits per page and 87.10 views per edit. There are 232 unique registered users.

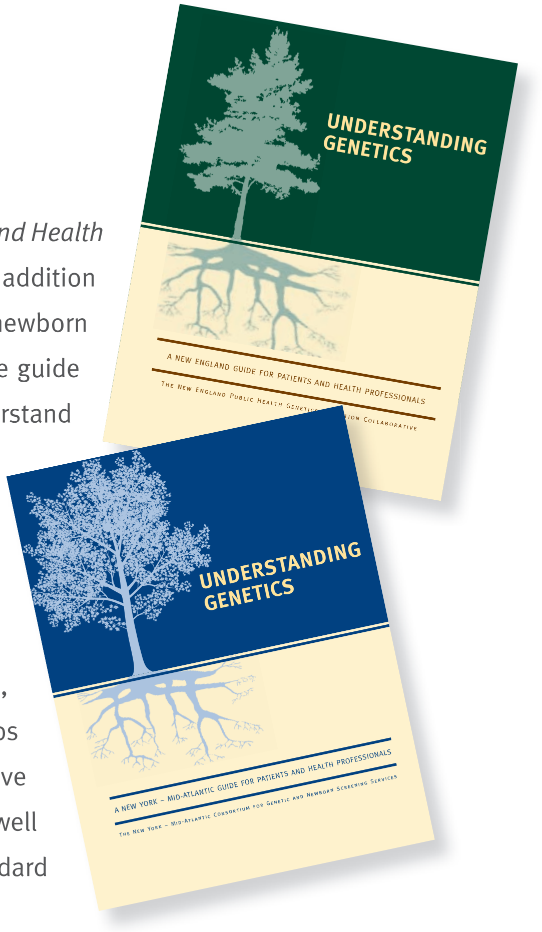
WikiAdvocacy grew out of the Interactive Guide to Starting and Sustaining an Advocacy Organization, a manual that contains articles, templates, stories, and experiential knowledge on everything needed to begin, maintain, and grow an advocacy organization. This wiki is a compilation of the wisdom of the advocacy community and contains regular updates from key leaders, all the while benefiting from advisory and editorial board oversight. Members of the advocacy community continually add and refine the tips and tools offered through this resource. WikiAdvocacy currently has 285 total pages in the database and 45 files have been uploaded to date. There have been a total of 146,278 page views and 3,216 page edits since WikiAdvocacy's inception. That comprises an average of 11.28 edits per page and 45.48 views per edit. There are 514 unique registered users.

SHARING RESOURCES FOR MUTUAL BENEFIT

Genetic Alliance's Resource Repository is a robust electronic repository for documents, multimedia files, and links that aggregates the combined resources of advocates, healthcare professionals, government agencies, think tanks, and other contributors. The Resource Repository (www.resourcerepository.org) features state of the art technology, allowing visitors to track new content tailored to the user's interests and view the most recently uploaded and most often downloaded content. The upload and download processes are user-friendly and free, allowing this tool to grow in strength with every contribution from the genetics and health community. The Resource Repository was undergoing renovation for much of 2008 in order to allow the free flow of even more advanced content, including audio files, video files, and links.

Priming the Literacy Pipeline

Genetic Alliance's publication *Understanding Genetics: A Guide for Patients and Health Professionals* is an intuitive guide that elucidates basic genetics concepts in addition to in-depth information about receiving a diagnosis of a genetic condition, newborn screening, family health history, genetic counseling, and genetic testing. The guide is written so that readers at every level of genetics literacy can easily understand the text. Resources in the guide are customizable to geographic region. In 2007, Genetic Alliance partnered with the New England Regional Genetics Group to customize the guide for Maine, Vermont, New Hampshire, Massachusetts, Rhode Island, and Connecticut. In 2008, Genetic Alliance partnered with the New York Mid-Atlantic Consortium for Genetics and Newborn Screening Services to produce a guide for New York, Pennsylvania, New Jersey, the District of Columbia, West Virginia, and Virginia. Next steps for this publication are to create customized versions for the remaining five HRSA Newborn Screening and Genetics Regional Collaborative Groups, as well as a general version that will be translated into Spanish and Modern Standard Arabic.



Seizing Marketing Opportunities

Genetic Alliance explored and tested various marketing tactics with multiple stakeholders in the public and private sectors to educate and inform the general population in order to revolutionize decision-making as well as position our organization as a resource for members of the public in need of more information. We employed traditional media relations tactics such as press releases, opinion editorials, and reporter outreach. We also explored new media tactics such as blog posting, blogger relations, and various social media platforms (Facebook, LinkedIn, Twitter, etc.) to educate new publics about health and genetics resources and increase visibility for our organization. Also, we planned and oversaw the production of a public service announcement (PSA). The campaign, which was initiated in June 2008 and ran on the local ABC affiliate in December 2008 and January 2009, successfully raised awareness about the importance of family health history and easy steps people can take to collect and use family health history. Genetic Alliance partnered with the American Society of Human Genetics (ASHG), FORCE (Facing Our Risk of Cancer Empowered), and Aetna in a dynamic partnership that benefited the Washington, D.C., community. This partnership will serve as a model to facilitate new partnerships between health organizations around the country that can air the PSA in their own markets.

Conclusion

Sparked by the mutual discoveries of the Council and staff, in 2008 we renewed our commitment to consumer health, while recognizing the need to focus on health at a systems level. Using these guiding principles, we discerned four goals that could promote systems transformation:

- **Diffusion** of the best attributes of advocacy into communities, professional societies, and beyond to enable more effective work by all members of the network, including shared infrastructure to allow freeing of resources to focus on content work;
- **Increased literacy** levels for consumers to make better decisions about their own healthcare, and for other stakeholders to make better decisions about the systems that sustain the research and services enterprise;
- **Open access** to resources and sharing information, with an understanding of the importance of pervasive open access, and moving the pre-competitive line back;
- **Innovative Partnerships** that build on these new paradigms and release tremendous potential energy to accelerate the development of more functional systems.

As a result of our visioning we reassessed core elements of our identity including:

- **Who we serve.** The systems we wish to impact require interaction with many types of organizations (rather than disease-specific advocacy organizations only), such as parent and family groups, community organizations, professional societies, for-profit corporations, and government agencies.
- **How we see ourselves.** As we widen our community we must enhance our skills to dialogue with it. We need to reinvigorate and broaden the power of active advocacy.
- **Aligning and streamlining infrastructure.** The hundreds of disease-specific advocacy organizations currently operating will not achieve their missions if their resources continue to be used predominantly for infrastructure. Our energy and resources would be better spent commoditizing the common aspects of these groups' infrastructure and allowing the brilliant leadership in this community and others to focus on the creative and unique aspects of each organization.
- **Leadership.** The leadership of advocacy organizations is aging and is primarily composed of parents of affected children now in their late teens and twenties. The parents, in their 50s and above, will not achieve their goals at the current rate, despite the speed and creativity with which they have worked to this point. We must model new tools that will serve a new generation of leaders. The next generation of leaders needs to be in place now! Recruitment, support, and empowerment have all become static and need to be brought back to vital form.

- **Development.** We can animate money both negatively and positively, so where does purposeful openness fit in with the animation of money? We believe that money follows the energy, and energy is stimulated by vision. We do not start by asking how much money we need to be effective; we begin by fleshing out what efficacy looks like, by asking ourselves, “What is at stake?” If the truth of what we are trying to accomplish is clear and real, we believe the money to support that truth will follow

Finally, as an organization with a central goal of incorporating a range of health consumer perspectives, it is vital that we maintain a great diversity of thought, experience, and background within the organization, including staff, volunteers, network, and Council. When engaging staff to join this organization, the focus is more on resonance with the mission rather than specific experiences and expertise. The mixture of backgrounds and personal passions leads to dynamic conversations and multifaceted approaches to the work at hand.

We also see these benefits when working with a range of partners on different subjects. A crucial element to our partnerships is our focus on working with groups that may not have previously been engaged in genetics or health. These perspectives are needed because they have not been incorporated in the past, and all stakeholder voices must engage together to bring about real systems transformation.

Financials

The fiscal year was immensely successful for Genetic Alliance. We continued to work on five federal grants: (1) the National Consumer Center for Genetics Resources and Services (a $500,000 value, in year 2 of 5); (2) Consumer Focused Newborn Screening – A Qualitative Approach (a $350,000 value, in year 2 of 3); (3) Consumer Focused Newborn Screening – A Quantitative Approach (a $250,000 value, in year 2 of 3); (4) Community Centered Family Health History (a $600,000 value, in year 3 of 3); and (5) the Access To Credible Genetics Resources Network (valued at $850,000, in year 4 of 5). Genetic Alliance’s work is supported by a blend of funding from government grants, industry and corporate support, individual donations, and fees generated by services and events.

Genetic Alliance is financially well grounded and actively diversifies its funding sources. A key part of our diversification plan is to secure foundation funds, which requires creating tangible products as evidence of our capacity. Further, we continue to build relationships within the for-profit sector and are increasing industry and corporate contributions.

Statement of Activities and Changes in Net Assets

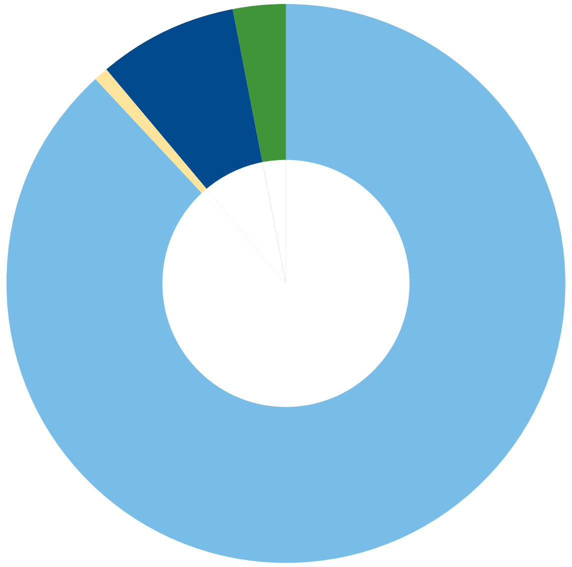
as of September 30th of each year

	Unrestricted	Temporarily Restricted	2008 Total	2007 Total
REVENUE AND OTHER SUPPORT				
Contracts and Grants	$2,695,249	$ -	$2,695,249	$2,068,914
Employee Services Revenue	5,162	-	5,162	6,050
Contributions	53,123	-	53,123	121,670
Biobank Membership Revenue	42,069	-	42,069	-
In-Kind Contributions	7,533	-	7,533	3,796
Listserv Income	2,350	-	2,350	2,770
Interest Income	7,229	-	7,229	11,113
Special Events	243,466	-	243,466	167,298
Member Services	75	-	75	4,492
Total Revenue and Other Support	3,056,256	-	3,056,256	2,386,103
Net Assets Released from Restrictions	6,657	6,657	-	-
Total Revenue and Other Support	$3,062,913	$(6,657)	$3,056,256	$2,386,103
EXPENSES				
Program Services				
Membership	$2,989,195	$ -	$2,989,195	$2,088,465
Policy	78,029	-	78,029	218,041
Total Program Services	3,067,224	-	3,067,224	2,306,506
Supporting Services				
General and Administrative	44,626	-	44,626	2,937
Fundraising	68	-	68	837
Total Supporting Services	44,694	-	44,694	3,774
Total Expenses	$3,111,918	$ -	$3,111,918	$2,310,280
Increase (Decrease) in Net Assets	(49,005)	(6,657)	(55,662)	75,823
Increase from Net Assets Transfer	62,792	-	62,792	-
Net Increase (Decrease) in Net Assets	$13,787	$(6,657)	$7,130	$75,823
Net Assets, Beginning of Year	$406,141	$44,304	$450,445	$374,622
Net Assets, End of Year	$419,928	$37,647	$457,575	$450,445

Statement of Financial Position

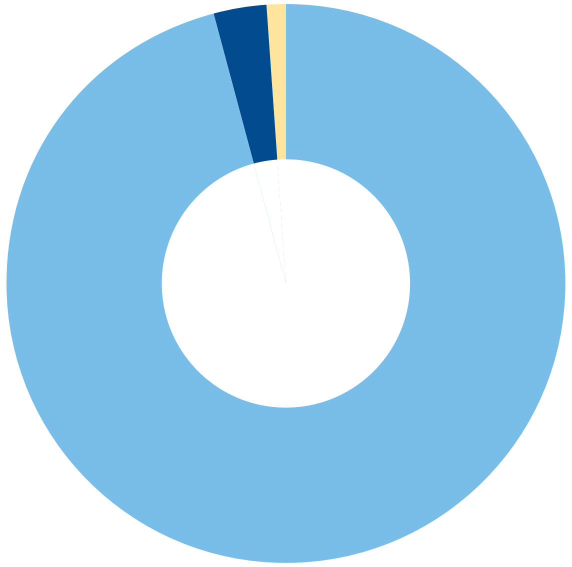
as of September 30th of each year

ASSETS	2008	2007
Cash and Cash Equivalents	$347,948	$452,684
Accounts Receivable	9,908	13,723
Grants Receivable	171,354	109,500
Prepaid Expenses	22,584	15,029
Furniture and Equipment, Net	53,605	64,722
Other	8,394	8,394
Total Assets	$613,793	$664,052
LIABILITIES AND NET ASSETS		
Accounts Payable and Accrued Expense	$75,896	$137,040
Capital Lease Obligation	26,600	32,128
Deferred Rent	53,722	44,439
Total Liabilities	156,218	213,607
NET ASSETS		
Unrestricted	419,928	406,141
Temporarily Restricted	37,647	44,304
Total Net Assets	457,575	450,445
TOTAL LIABILITIES AND NET ASSETS	$613,793	$664,052



Operating Fund Sources

- Contracts and Grants 88%
- Special Events 8%
- Contributions & Other 3%
- Biobank Membership 1%



Fund Spending

- Membership 96%
- Policy 3%
- G & A 1%

Genetic Alliance

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