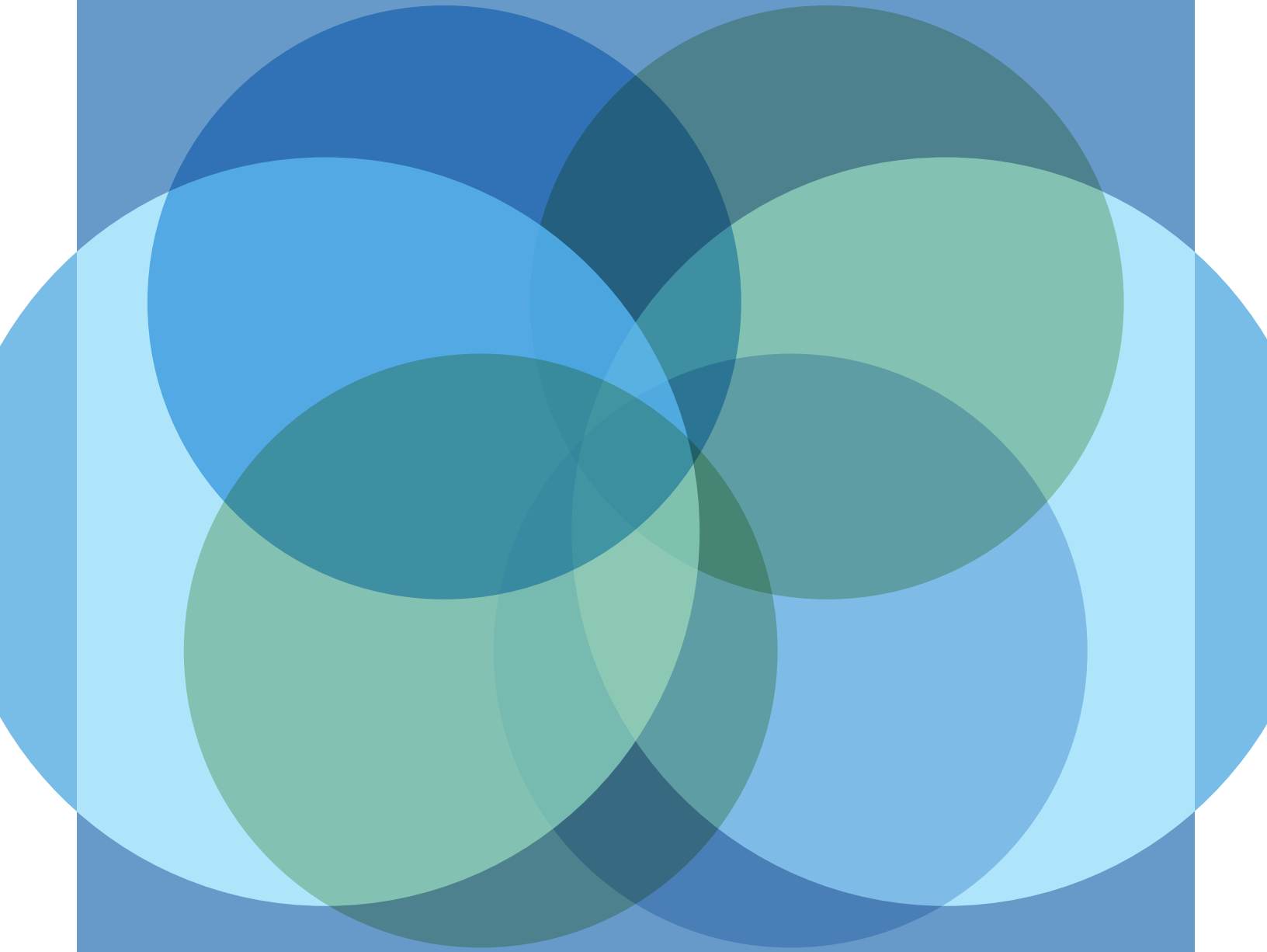


GENETIC ALLIANCE

ANNUAL REPORT

2009





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 is the world's leading nonprofit advocacy organization committed to transforming 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 10,000 organizations, including disease-specific advocacy organizations as well as 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 23 years, Genetic Alliance has been the voice of advocacy in genetics. Advocacy in the 21st century, however, requires new definitions and new focus. We dissolve boundaries to foster dialogue that includes the perspectives of all stakeholders: from industry professionals, researchers, healthcare providers, and public policy leaders to individuals, families, and communities. In a rapidly changing world, Genetic Alliance understands that nothing short of the transformation of our mission, our goals, even our Board of Directors will suffice to transform health..

Table of Contents

Welcome from the President 2

Council and Staff 2

Organizational Culture 3

Novel Partnerships 4

Informed Decision Making 10

Individual, Family, and Community Perspectives 14

Financials 20



Dear Friends,

When Genetic Alliance began to explore openness about two years ago, we did so because it was clear to us that to accelerate our mission we must dissolve boundaries. By opening ourselves and the flow of information and resources around us, we release energy that transforms systems. Now, there are more than 9.5 million “openness” entries on the Internet, and many organizations and individuals have adopted openness, even the President of the United States. What a different world we live in this year!

In addition to openness, we explored the meaning of advocacy. In salons throughout the country, this exploration always leads us to health. As we grapple with the word, we have come to wonderfully whole realizations. Health is justice. Health is better expressed as well-being. In all of these discussions the realization is that we no longer define it in a medical sense as “lack of disease.” In fact, when health is holistic, it can contain disease. We are ready now for a more whole integration of all aspects of life as an expression of health.

Each of these things – openness, advocacy, health – is both personal and universal. We add discovery to this list. We are familiar with scientific discovery, but if discovery is personal, familial, and communal and cuts across all systems, then it is far more dynamic. If we commit to understanding the enormous disruption of informatics colliding with genomics, we will be both surprised and delighted.

2009 was a year of celebration, refocus, dedication, explosion – we are doing more than simply taking systems to the next level. We are blowing them up, re-envisioning what success looks like, and using the lens of genetics to bring us to a focus on health itself.

Sincerely,

Sharon F. Terry, President & CEO, Genetic Alliance

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,
Tucker Capitol Corporation
Folklorist and Writer

Natasha Bonhomme
Vice President of Strategic
Development, Genetic Alliance

Gene Early
Consultant, Early Leadership
Solutions, LLC

Sharon Kardia, PhD
Director, Public Health Genetics
Program, University of Michigan

Susan King, D.Min
Associate Director, Life Science
and Society Program, University of
Michigan

Organizational Culture

Over the last six years, we have transformed our organization and our culture. As an organization with a central goal of incorporating a range of health consumer perspectives, it is vital that a similar diversity of thought, experience and background exists within the organization, including staff, volunteers, network and board. 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 passion leads to dynamic conversations and multifaceted approaches to the work at hand. Our staff has an appetite for pushing the limits of engagement.

Another fundamental philosophy of the organization is that there is no division between the personal and professional. On one hand, this means that people should apply their whole selves to the work they do. On the other hand, it allows staff to share their extracurricular passions within the workplace.

For example, Genetic Alliance incorporates the range of backgrounds and interests within the office through Staff Appreciation Days. Periodically, one staff member organizes a day for staff to “appreciate” a particular interest, hobby, or topic. The topics are drawn from culture or ethnicity, past experiences, and passions. This is a way for everyone to share something about their personality and engage all coworkers in activities together. Examples over the past year include: sleepover appreciation day, “green” appreciation day, and friendly competition appreciation day.

Another example, new in 2009, that satisfies the stomachs, and often the souls, of participating staff, is Lunch Club. Every Monday, someone cooks a meal for the office, giving everyone a taste of their home kitchen and a delicious start to the week.



STAFF

Jim Bialick

Health Information Systems
Coordinator

Natasha Bonhomme

Vice President of Strategic
Development

Rhianna Campbell

Manager of Finance and
Administration

Amelia Chappelle, MA, MS

Associate Director of Genetics
Resources and Services

Andria Cornell

Advocacy and Health Policy
Coordinator

Vaughn Edelson

Programs Manager

Liz Horn, PhD, MBI

BioBank Director

Alyson Krokosky

Genetic Information Coordinator

Tetyana Murza, MES

Programs and Events Coordinator

Tam Nguyen

Electronic Communications Assistant

James O'Leary

Chief Innovation Officer

Mary Peckiconis, MA

Office Manager

Hanaa Rifaey, MA

International Outreach Liaison

Kristen Queen Shaffer

Grants Administration Director

Laura Silver

Executive Assistant

Sharon Terry, MA

President and CEO

Helen Travers, MS, CGC

Genetic Resource
Specialist

Tiphané Turpin, MA

Communications Manager

Lisa Wise, MA

Chief Operating Officer

Kristi Zonno

Director of Genetics and Health
Policy

Novel Partnerships

Genetic Alliance convenes diverse stakeholders - including disease-specific advocacy organizations, universities, companies, government agencies, and policy organizations - to explore and create novel partnerships in advocacy. Our network of thousands of organizations provides an open space for shared resources, creative tools, and dozens of timely programs.

We bring together diverse stakeholders that create novel partnerships in advocacy.



Access to Credible Genetics Resources Network

In its fourth year, the Access to Credible Genetics Resources Network launched the Trust It Or Trash It? online tool and hosted a daylong meeting on creating and assessing genetic health information. Thinking critically about the credibility of information is essential in all areas of health, and genetics in particular. Instead of filling an information gap with new materials, ATCG RN gives individuals – parents and family of newly diagnosed children as well as healthcare providers – the tools they need to fill those gaps on their own by deciding for themselves what constitutes quality information.

ATCG PARTNERS

- FRAXA Research Foundation
- Gene Tests/Gene Clinics
- National Center on Birth Defects and Disabilities, CDC
- National Coalition for Health Professional Education in Genetics
- National Council of La Raza
- National Fragile X Foundation
- Parent Project Muscular Dystrophy
- University of Maryland School of Medicine

BioBank

Genetic Alliance BioBank is a centralized, advocacy-owned, biological sample repository and registry that enables translational genomic research. We provide registry and repository solutions and infrastructure for disease advocacy organizations to pursue sophisticated, novel research collaborations with academia and industry to accelerate research, develop new diagnostics and therapeutics, and better understand and treat disease.

In 2009, we welcomed Hereditary Angioedema Association (HAEA) as a new member. We also added new datamining software, GENESIS, to our registry and repository tools. GENESIS is a robust data mining software that allows queries of any field in the TRIMS database, both standard TRIMS and customizable fields. BioBank members will benefit from this new functionality.

BioBank members receive:



- Training and mentoring by experts in BioBanking and templates for all necessary documents and protocols.
- Tools to recruit participants to the BioBank using methods that emphasize trust, privacy protections, data security, empowerment of participants and the member advocacy groups, and ongoing education.
- State-of-the-art storage facility and systems for collection, processing, archiving and distributing biological samples, with à la carte genetic and genomic analysis.
- Clinical data collection system with customizable, web-based interface for participant data entry.
- Web-applications for ease of sample and data management.
- Robust data-mining tool for samples and clinical information.

Condition	Biological Samples
Cardio-Facio-Cutaneous Syndrome	158
Hereditary Angioedema	490
Infammatory Breast Cancer	286
Joubert Syndrome	456
Neurodegeneration with Brain Iron Accumulation Disorders	216
Noonan Syndrome	72
Pseudoxanthoma elasticum	2,100
Psoriasis	2,652

Community Centered Family Health History



CCFHH promotes conversations about health in the family to reduce stigma and encourage healthy lifestyle choices. Genetic Alliance distributed 10 CCFHH Program Awards for organizations to customize the Does It Run In the Family? toolkit and use it within existing programs and initiatives to seamlessly integrate conversations about family health history into diverse communities across the country. In 2009, using Awardees' final reports, Genetic Alliance created an interactive model project database, housed in WikiAdvocacy, as a resource for individuals and organizations interested in launching their own family health history initiatives.

New Family Health History Projects

It is not only important to collect family health history information from your relatives; it is similarly important to tell them what you know about your own health. Genetic Alliance began creating information on how to share a disease diagnosis with your family, particularly around Gaucher disease.

The National Coalition for Health Professional Education in Genetics, March of Dimes, Genetic Alliance, and Harvard Partners began a three-year cooperative agreement with HRSA to develop an electronic tool to gather a woman's consistent family history information and analyze it immediately to improve patient care. The new tool, to be used in the healthcare provider's office waiting area, will put family medical history at doctors' fingertips, alerting them to a patient's increased risk for birth defects or pregnancy complications.

Consumer Focused Newborn Screening

With the Genetics and Public Policy Center, Genetic Alliance continued to explore public perceptions of newborn screening and develop public education models on the topic. To increase the accessibility of newborn screening for the public, we are working to aggregate quality information on YouTube and establish a newborn screening channel. Along with the University of Maryland, we conducted semi-structured interviews and focus groups that generated significant discussion around the importance of timing when receiving information about screening and the impact of a difficult pregnancy on the ability to process newborn screening information.

On September 25, 2009, the CTF-NBS presented comments to the Advisory Committee on Heritable Disorders in Newborns and Children on a vision for long-term follow-up care in newborn screening, examining the roles of players in the newborn screening system; key features of a family-centered solution that address the psychosocial impact of conditions on the family unit; and integration of long-term follow-up into the health reform dialogue.

CCFHH PROGRAM AWARDEES

- Angioma Alliance
- Brookdale University Hospital and Medical Center
- Duke Institute for Genome Sciences & Policy
- Ferre Institute
- The Genomedical Connection
- The Heredity Project
- Progreso Latino
- Southern Missouri Telehealth Genetics Services
- University of Oklahoma College of Medicine

CF-NBS PARTNERS

- Genetics and Public Policy Center
- University of Maryland School of Medicine
- Consumer Task Force on Newborn Screening (CTF-NBS)

New Newborn Screening Projects

Building on the success of CF-NBS, Genetic Alliance received two additional grants from HRSA's Genetic Services Branch this year: the Quality Assessment of Newborn Screening System (NBS Clearinghouse) and Translating Medical Genetics into Services (Congenital Conditions). These multi-year, nationally focused programs will improve the quality of screening materials and resources available to expectant and new parents, health professionals, industry representatives and advocates; increase decision-making capacity; and develop robust tools that will serve the newborn screening community and the public for years to come.

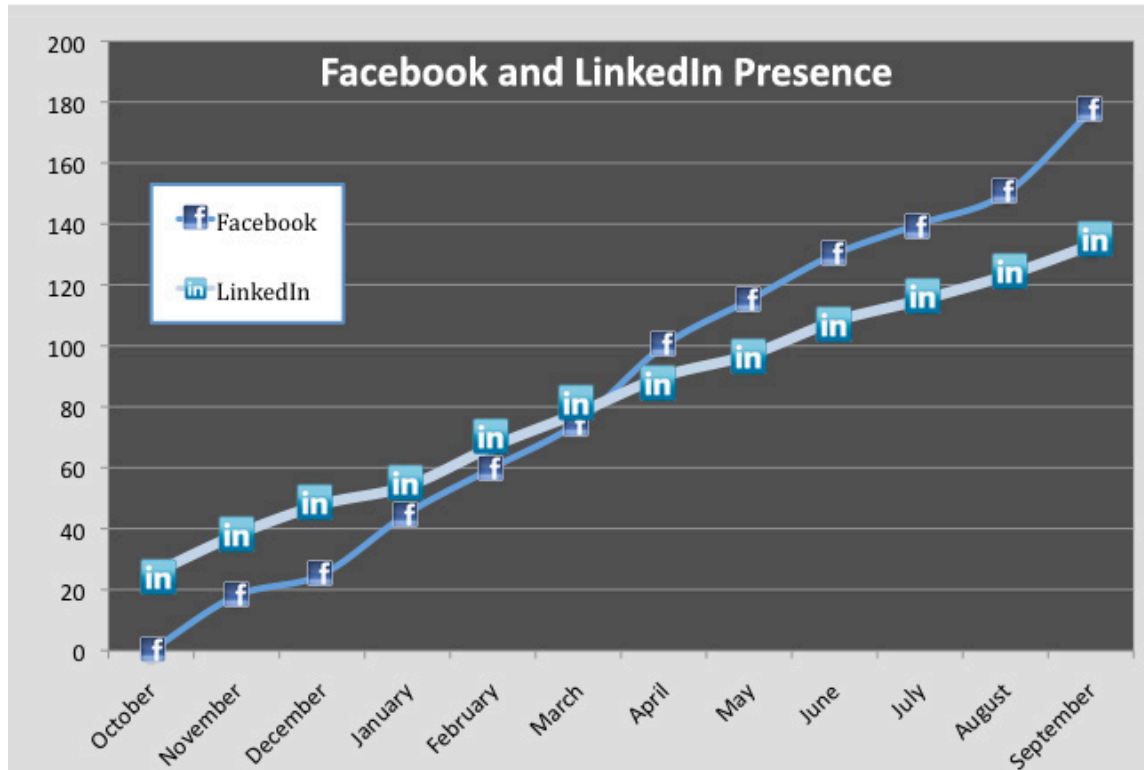
- The nation's first Newborn Screening Clearinghouse (NBSC) will connect millions of parents and healthcare providers with resources and information relevant to more than four million newborns screened annually. Over the course of five years, Genetic Alliance, together with our NBSC partners, will develop the electronic and outreach components of the NBSC balancing privacy concerns and the informational needs of the public and providers.
- The goal of the Congenital Conditions Program is to collect and disseminate evidence-based information, while coordinating the availability of supportive services for parents whose child receives a diagnosis prenatally, at birth, or up to one year after birth. Partnering initially with the Down syndrome, spina bifida and dwarfism communities, we will develop awareness and educational models for healthcare providers who are responsible for delivering and interpreting confirmatory diagnosis results for parents. These models will be replicable, sustainable mechanisms for patient and provider education that can be adapted and applied to other conditions.

GEDDI

Millions of individuals with genetic diseases could benefit from early detection and intervention through a closer partnership between clinical medicine and public health. Genetics for Early Disease Detection and Intervention to Improve Health Outcomes (GEDDI) is a collaborative initiative funded by the Office of Public Health Genomics, CDC, that will analyze and initiate a systematic approach for detection and intervention using clinical, genetic, and family health history information. GEDDI aims to enhance existing healthcare practices, improve provider and public education, and increase referral to appropriate services using interviews, salons, webinars, white papers, workshops, and WikiGenetics.

Social Media

In 2009, Genetic Alliance increased our virtual presence, fostering thousands of connections with individuals and organizations across the World Wide Web.



RT @NIHforHealth Missed it live? The recording of this morning's speech by President Obama at NIH is now available. <http://bit.ly/sELtK>
9:31 AM Sep 30th, 2009 from web

See @cnn <http://bit.ly/3w0QTJ> for more information on the \$5 billion in grants announced by Pres. Obama in the meeting. @NIHforHealth
9:27 AM Sep 30th, 2009 from web

Collins welcomes Sibelius and President Obama to NIH. [http://bit.ly/3w0QTJ](#)
8:02 AM Sep 30th, 2009 from Tweetie

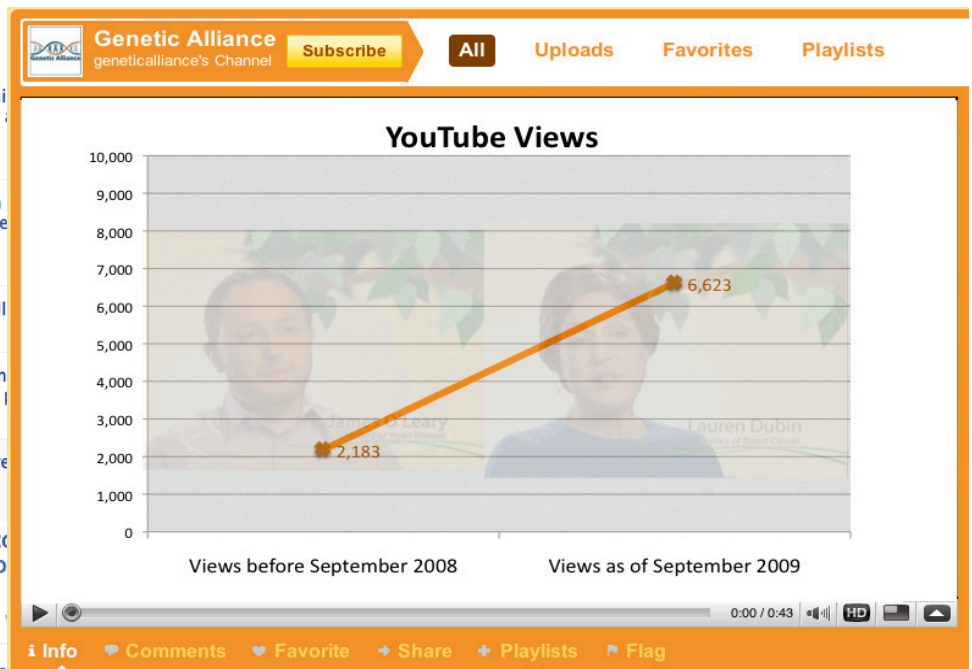
Francis Collins just announced that as of today NIH has awarded 5 billion dollars in ARRA grants. New brave new world.
8:00 AM Sep 30th, 2009 from Tweetie

@geneticalliance's Sharon Terry is waiting for the President to announce the NIH Clinical Center.
6:21 AM Sep 30th, 2009 from Tweetie

At NIH state-of-the-science conference, Genetic Alliance announced the launch of our new history. @geneticalliance announced the launch of our new tool this week.
5:30 AM Aug 24th, 2009 from mobile

Private Access Announces Commercial Data Release of Privacy-Enhanced Search Technology <http://bit.ly/3Z1zhX>
12:03 PM Aug 19th, 2009 from web

Final question from #bloodspots forum: Where/when in the birth process should consent for residual use be requested?
6:03 PM Sep 23rd, 2009 from web



GRANDRx

Launched at the Genetic Alliance Annual Conference in July 2009, GRANDRx will catalyze the development of treatments for rare and neglected diseases. By implementing novel solutions throughout the research and healthcare system, it will transform the current “pipeline” into an

integrated network. Established through the efforts of advocates, academia, industry, federal health agencies and other stakeholders, GRANDRx requires a culture shift in all these areas. Focus on single diseases and issues must be transferred to focus on commonalities, collaborations and system-wide change through an open and transparent process that will benefit all stakeholders. The Human Genome Project demonstrated that open access to information, cross-disease focus, and transformed systems lead to greater success. A substantial part of the effort will be dedicated to improving systems through sharing methodology leading to both successes and failures.



Genomics Forum

Chief Innovation Officer James O’Leary spearheaded Genetic Alliance’s expansion into public health genomics work as co-chair of the American Public Health Association Genomics Forum, an interdisciplinary group within APHA committed to engaging public health and healthcare communities in projects and activities that increase the awareness, knowledge, and skills of genetic services. Other staff played key roles leading Genomics Forum subcommittees on healthcare policy and communications.



HEALTH INFORMATION TECHNOLOGY STANDARDS COMMITTEE

In May 2009, Sharon Terry was appointed to the Health IT Standards Committee, charged with making recommendations to the National Coordinator for Health IT on standards, implementation specifications, and certification criteria for the electronic exchange and use of health information. Her colleagues on the Committee reflect a broad range of stakeholders, including providers, ancillary healthcare workers, consumers, purchasers, health plans, technology vendors, researchers, relevant federal agencies, and individuals with technical expertise on health care quality, privacy and security, and on the electronic exchange and use of health information.

Informed Decision Making

Genetic Alliance revolutionizes access to information to enable translation of research into services and individualized decision making. We offer technical assistance to organizations, build and sustain robust information systems, and actively work for public policies that promote the advancement of healthcare for the common good.

We revolutionize access to information to enable transformation of research into services and individualized decision making.



Does It Run In the Family?

Communication is the key to unlocking your family health history. The Does It Run In the Family? online tool (www.familyhealthhistory.org) helps individuals create tailored family health history materials for their families, organizations, and communities. The tool allows you to customize two booklets, “A Guide to Family Health History” and “A Guide for Understanding Genetics and Health”, with:

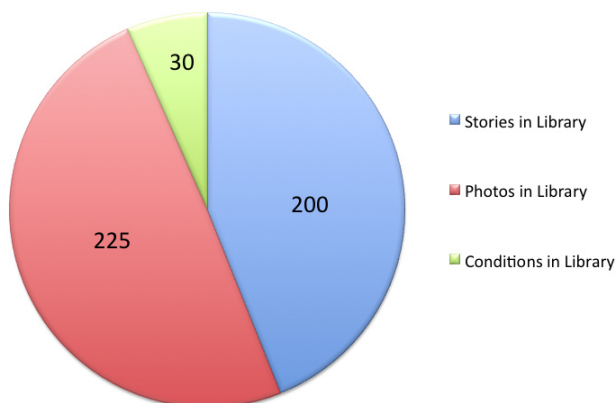
- Personal health stories
- Photographs
- Family health history quotes
- Interview questions
- Disease information
- Health resources



The tool was created to facilitate proactive conversations about health with your family, healthcare provider, and community. Together, the booklets explain the importance of knowing and talking about health within the family as well as basics

about how conditions are passed down through generations. They provide suggestions and resources to help people not only talk about the health conditions affecting their families but also to use that information to maintain and improve their health.

Genetic Alliance engaged community members in the planning and implementation of the tool (funded in part by a cooperative agreement from HRSA), maximizing the accessibility of family health history through its customizable nature. By developing an effective model of community engagement, the guides can be disseminated to more diverse segments of communities and in turn, reach a larger segment of the population.



« CUSTOMIZABLE ELEMENTS

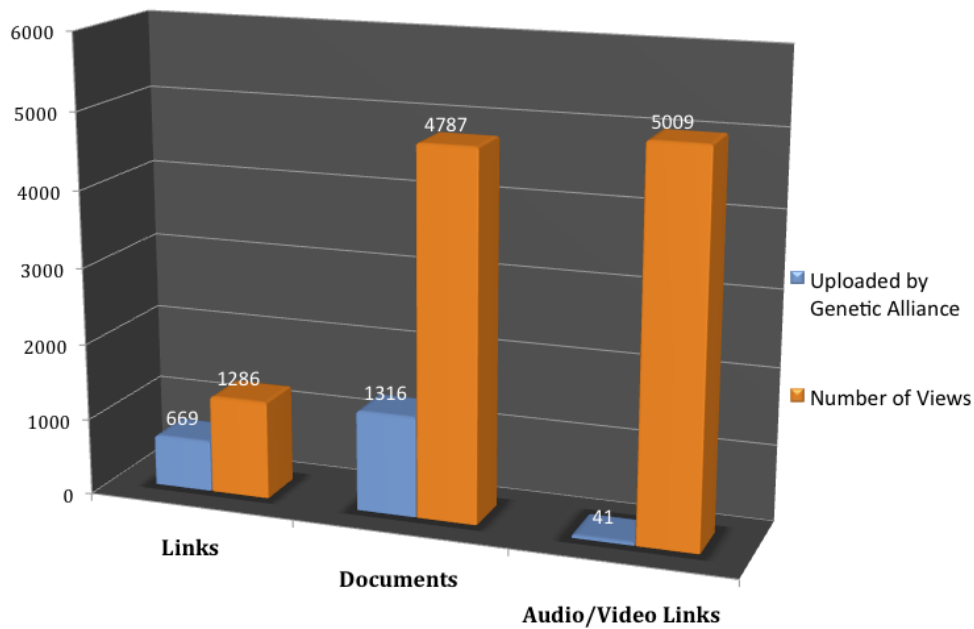
USERS: ~400
BOOKLET DOWNLOADS: ~150

Resource Repository

After undergoing extensive renovation in 2008, the Genetic Alliance Resource Repository (RR) re-launched this year as a state-of-the-art digital commons for the global health community. This electronic collection of documents, links, and audio and video files is home to “how to” guides, best practices, conference presentations, podcasts, and more covering topic areas such as newborn screening, family health history, genetic testing, reimbursement, research, drug development, community engagement, and organizational development. Experts from every corner of the genetics and health community contribute resources, enhancing the already customized user experience to empower individuals and communities. The Resource Repository will soon reside on other websites so that a more diverse population can search and download the vast array of information. The RR experienced a nearly 400% growth in resources over the past year, and will continue to expand and thrive.



Resource Repository Activity



DISEASE INFOSEARCH



Disease InfoSearch is an online search tool and database of information about genetic conditions provided and vetted by disease-specific advocacy organizations, with a portal to National Library of Medicine resources. Genetic Alliance seeks to expand its capacity by capturing phenotypic data as well as information on gene identification for each condition. Disease InfoSearch is an invaluable resource to the community. In the future, allowing cross-disease searches will accelerate research to the benefit of the communities that have helped it grow.

Trust It or Trash It?

Launched in April 2009, the Trust It or Trash It? tool is an online resource to help individuals evaluate health information (www.trustortrash.org) and create quality educational materials (www.trustortrash.org/developer). As we encounter health information in our daily lives, in print or online, we need a systematic way to decide whether or not to trust a resource. This tool gives people specific guides to help them decide whether to “trust” or “trash” what they read. The developers’ version of the Trust It or Trash It? tool contains in-depth information on content, quality, and usability to help someone creating health information think about what to include and how to present content. The tool will soon be a widget that can be hosted on websites. It will link to the tool and remain on-screen

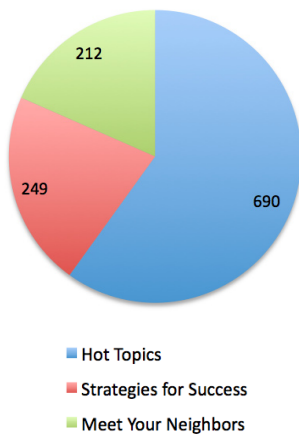
Who said it? When did they say it? How do they know?

as a user evaluates content on the web. The Access to Credible Genetics Resources Network developed this tool with grant funds from the Centers for Disease Control & Prevention.

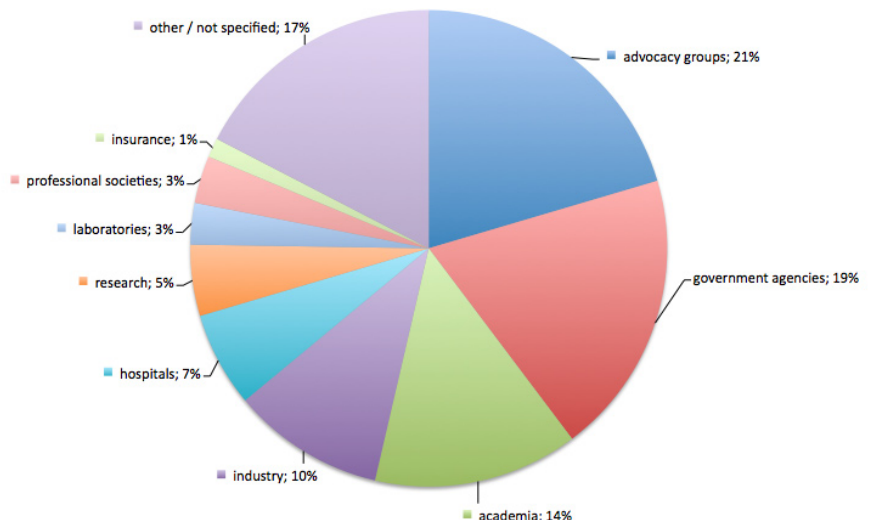
Genetic Alliance Webinars

In 2009, Genetic Alliance hosted 33 webinars in three series: Hot Topics in Genetics and Advocacy (14), Strategies for Success (13), and Meet Your Neighbors (6). Our webinars serve a dual purpose: they provide education and training and encourage collaboration among members of the Genetic Alliance network.

PARTICIPANTS BY SERIES



OVERALL WEBINAR PARTICIPATION BY SECTOR



Individual, Family, and Community Perspectives

Genetic Alliance identifies solutions to emerging problems and reduces obstacles to rapid and effective translation of research into accessible technologies and services that improve human health. In all we do, we integrate individual, family, and community perspectives to improve health systems.

We integrate individual, family, and community perspectives to improve health systems.



Genetics Day on the Hill

At Genetics Day 2009, we tackled five key issues: healthcare reform, health information technology, comparative effectiveness research, genetic testing, and public access. Participants visited the offices of their elected officials to discuss what is important to them and their families, work, and communities. Individuals representing a cross-section of the health community—disease-specific organizations, researchers, healthcare providers, industry, policy organizations, individuals and families, and more—participated in the event. In a keynote address, Congressman Patrick Kennedy (D-RI), discussed health reform, the Genomics and Personalized Medicine Act, and the importance of the advocacy community engaging in the policymaking process.



Gene Screen

After the success of our screenings of *In the Family* in 2008, Genetic Alliance decided to host a mini-film festival, the first annual Gene Screen: A Night of Film on Health and Genetics. After a competitive

Genetic Alliance presents

A NIGHT OF FILM ON HEALTH AND GENETICS

Gene Screen
FIRST ANNUAL

OUR DREAM COME TRUE?
GENOME:
THE FUTURE IS NOW
GENETICS 101
USING FAMILY HISTORY
TO IMPROVE HEALTH
INCLUDING
SAMUEL

Thursday, July 16, 2009
6:30pm
E St Cinema, Washington, DC
Theater 4

Q&A with filmmakers after the screening

Sponsored by:

BCM
MGL
Genetic Alliance

selection process, five films were chosen for screening:

- A Dream Come True?
- Genomics: The Future is Now
- Genetics 101
- Using Family History to Improve Health
- Including Samuel

From the basics of biology taught by cartoon characters to the latest advancements in science at Harvard to poignant personal accounts of people struggling with medical conditions, these films are entertaining, emotional, and informative for everyone.

Annual Conference

Openness forms both the product and the process of Genetic Alliance. We believe that an environment of openness is essential to the health of all individuals, families, and communities. The Genetic Alliance 2009 Annual Conference, Discovering Openness in Health Systems, was a celebration of openness and an invitation to the community at large to abandon turf so that we can achieve truly productive



transformation, of the health system and health itself. July 17-19, 2009, more than 300 advocates, health professionals, policymakers, industry professionals, and community leaders engaged in open discussion and debate on a range of relevant topics in genetics and advocacy.

"This is my many-ith Genetic Alliance Conference. Each time I come I'm impressed by how much it's grown, both intellectually and in attendance. The topics were targeted and timely, and the company was stimulating, motivating and enjoyable." – Lisa Forman Neall, NCBI

This year's Leadership daylong symposium was the most powerful yet; participants focused on getting "BIG" and sharing bigness with their friends, families, and colleagues. Later in the weekend, two panel discussions, alternately contentious and convivial—Harmonizing Privacy and Access in Healthcare and Creating Open Systems for Drug Development—concluded the conference on a high note, focusing everyone on what ultimately matters: health.

"This is our first year attending and exhibiting at the conference. It was a wonderful experience for me personally and professionally. I feel the best part of the weekend was meeting and speaking with such a diverse group of people. I not only enjoyed listening to their personal stories and journeys, but I learned so much about myself and my leadership style. It was also a great place to network with many people working in the field of genetics or whose lives have been changed somehow by genetics."

– Dawn Bergquist, PKS Kids



ATCG Meeting

Trust It or Trash It? Creating and Assessing Genetic Health Information

On September 22, 2009, the Access to Credible Genetics Resources Network (ATCG) hosted a daylong meeting entitled, Trust It or Trash It? Creating and Assessing Genetic Health Information. The evolution of Web 2.0 to Web 3.0 has critical implications for how information is disseminated. Accelerating technology and research allow increasingly rapid information flow, which leads to problems with quality control. This influx of information paired with new ways to communicate and disseminate

it leads to parents, families, and providers with more information than they can reasonably handle. The ATCG project seeks to both increase the amount of credible genetic health information available while simultaneously giving individuals the tools to evaluate the quality of information.

Four panel discussions were held throughout the day on how we assess quality of information; what constitutes being an expert; the content of information; and what makes the presentation of information relevant, appealing, and user-friendly. Speakers represented multiple perspectives, including the theoretical, practical, and visionary.

We used *The Wisdom of Crowds: Foolhardy or Brilliant?* as a starting point for a lively dinner debate to conclude the day. Three speakers representing the “visioning” perspectives from the day’s panels engaged conference participants and highlighted the importance of dialogue around the role the genetics community should play in this deluge of information. The debate reinforced the need for work in this area and the potential for increased access to information.



@ednfstaff thanks for your post about the #geneticalliance Annual Awards <http://bit.ly/1F5lo7>. Great nominations are coming in already!

3:13 PM Sep 22nd, 2009 from web in reply to ednfstaff

RT @mielldog: Curious what conditions affect your favorite celebrities? Heard about www.celebritydiagnosis.com at #trustortrash

2:04 PM Sep 22nd, 2009 from Tweetie

RT @mielldog: Check out our tool for creating and assessing genetic health information at www.trustortrash.org #trustortrash

2:01 PM Sep 22nd, 2009 from Tweetie

Ben Heywood is on tonight's panel re: wisdom of the crowds (via @patientslikeme) #trustortrash

1:41 PM Sep 22nd, 2009 from web

How do you assess the quality of educational materials?*

- Ask colleagues
- Compare to other publications
- Date
- Evidence-based research
- Government websites
- Literature review
- My own knowledge/analysis/gut feeling
- Peer-review/Systematic Review
- Personal investigation
- Potential users
- Presentation
- Qualification and experience of authors
- Readability/Reading level
- Recent literature
- References
- Reputation of source
- Wikipedia background check

*From meeting evaluation

Recognition

In 2009, Genetic Alliance was featured in more than 100 stories in national media outlets as well as local publications. A few highlights:

Date	Article	Source
October 23, 2008	Private Access seeks experimental treatments for patients without giving up privacy	The New York Times
March 23, 2009	Protect our access to medical research	The Boston Globe
May 20, 2009	NIH Rare Disease Program Leans on 'Omics	GenomeWeb
June 11, 2009	Genetic Anti-Discrimination Law Starts Thursday	Associated Press, ABC News
June 25, 2009	The Life-Saving Secrets in Your Family Tree	The Wall Street Journal
June 30, 2009	Blood Samples Raise Questions of Privacy	The Washington Post
July 23	A Heartbreaking Choice	Pasadena Weekly
August 7	Collins Confirmed	Nature
September 4	Should You Get Genetic Testing?	Consumer Affairs
September 27	Stomping the Hill for Health Care Reform with Genetic Alliance	Health Dame



Research!America Advocacy Award

On March 24, 2009, Genetic Alliance received Research!America's Paul G. Rogers Distinguished Organization Advocacy Award recognizing our exemplary advocacy on behalf of people with genetic diseases, particularly our leadership role in advocacy for the Genetic Information Nondiscrimination Act of 2008 (GINA). The award was named in 2007 for the former Congressman and renowned advocate for health, The Honorable Paul G. Rogers. Rogers was Research!America's chair emeritus until his death in October 2008.

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	2009 Total	2008 Total
Revenue and Other Support			
Contracts and Grants	\$2,918,511	\$2,918,511	\$2,695,249
Employee Services Revenue	-	-	5,162
Contributions	36,391	36,391	53,123
Biobank Membership Revenue	213,627	213,627	42,069
In-Kind Contributions	2,076	2,076	7,533
Listserv Income	3,000	3,000	2,350
Interest Income	979	979	7,229
Special Events	210,255	210,255	243,466
Member Services	75	75	75
Total Revenue and Other Support	3,384,914	3,384,914	3,056,256
Net Assets Released from Restrictions	12,341	-	-
Total Revenue and Other Support	\$3,397,255	\$3,384,914	\$3,056,256
Expenses			
Program Services			
Membership	\$3,253,071	\$3,253,071	\$2,989,195
Policy	24,812	24,812	78,029
Total Program Services	3,277,884	3,277,884	3,067,224
Supporting Services			
General and Administrative	108,700	108,700	44,626
Fundraising	-	-	68
Total Supporting Services	108,700	108,700	44,694
Total Expenses	\$3,386,584	\$3,386,584	\$3,111,918
Increase (Decrease) in Net Assets	10,671	(1,670)	(55,662)
Increase from Net Assets Transfer	-	-	62,792
Net Increase (Decrease) in Net Assets	\$10,671	\$(1,670)	\$7,130
Net Assets, Beginning of Year	\$419,928	\$457,575	\$450,445
Net Assets, End of Year	\$430,599	\$455,905	\$457,575

Statement of Financial Position

as of September 30th of each year

Assets	2009	2008
Cash and Cash Equivalents	\$361,191	\$347,948
Accounts Receivable	140,296	9,908
Grants Receivable	225,286	171,354
Prepaid Expenses	37,057	22,584
Furniture and Equipment, Net	43,539	53,605
Other	8,394	8,394
Total Assets	\$815,763	\$613,793

Liabilities and Net Assets

Accounts Payable and Accrued Expense	\$ 279,872	\$ 75,896
Capital Lease Obligation	20,541	26,600
Deferred Rent	59,445	53,722
Total Liabilities	359,858	156,218

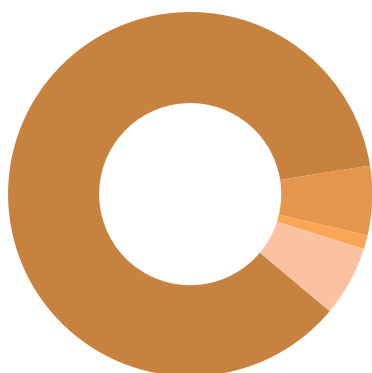
Net Assets

Unrestricted	430,599	419,928
Temporarily Restricted	25,306	37,647
Total Net Assets	455,905	457,575

Total Liabilities and Net Assets	\$815,763	\$613,793
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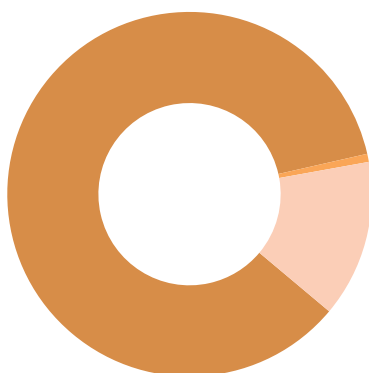
Operating Fund Sources

- Contracts and Grants 87%
- Special Events 6%
- Contributions & Other 3%
- Biobank Membership 6%



Fund Spending

- Membership 85%
- Policy 1%
- G & A 14%





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