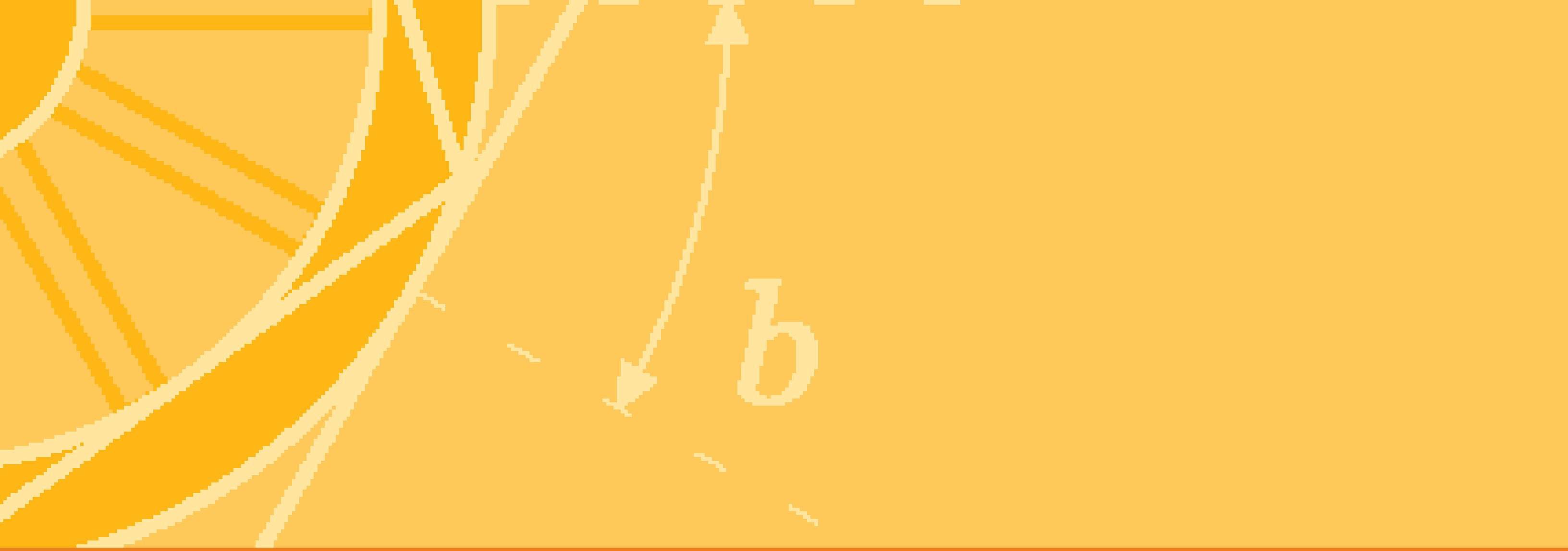
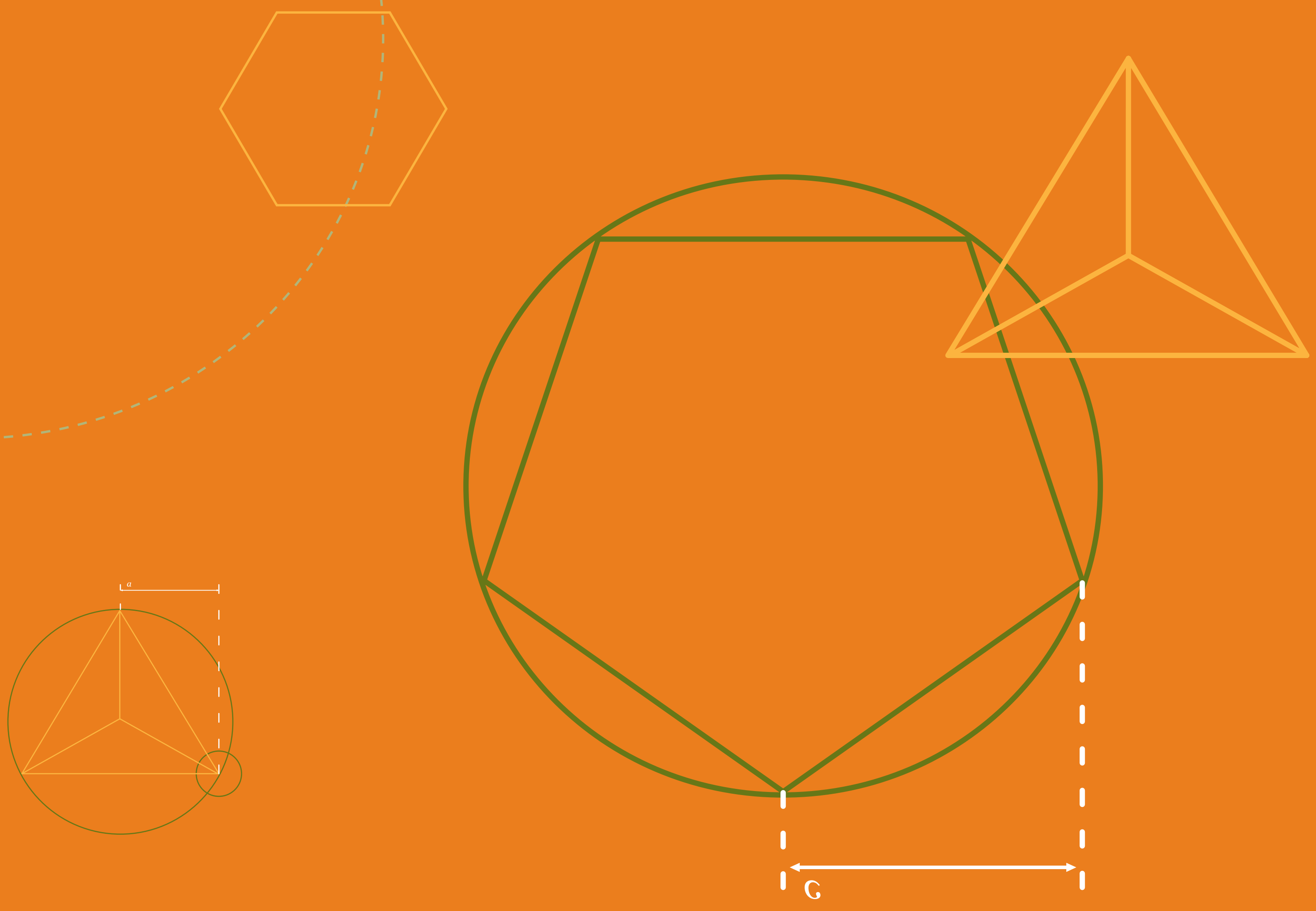


GENETIC ALLIANCE ANNUAL REPORT

2011



Background

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

Genetic Alliance, Inc. (Genetic Alliance) was incorporated as a non-stock, nonprofit organization on October 31, 1986 within the laws of the State of Maryland.

Over the past 25 years, Genetic Alliance systematically built a world-class disease advocacy platform and transformed from a basic advocacy organization to a leading network of key stakeholders determined to transform health through genetics. Today, our network includes more than 1,000 disease advocacy organizations as well as thousands of universities, private companies, government agencies, and public policy organizations that serve some aspect of our national health. The network is a dynamic and growing open space for shared resources, creative tools, and innovative programs.

In this, our 25th year, we celebrate innovation on our journey toward novel partnerships, connected consumers, and smart services.

In this report:

Dear Friends,

Twenty-five years is an important anniversary for any organization; it is a milestone of stability, a testament to perseverance. And yet, in this age of accelerating change, longevity does not guarantee relevance and perseverance is wasted without a commitment to grow and develop. That is why, throughout our 25th year, we celebrated the power and promise of innovation.

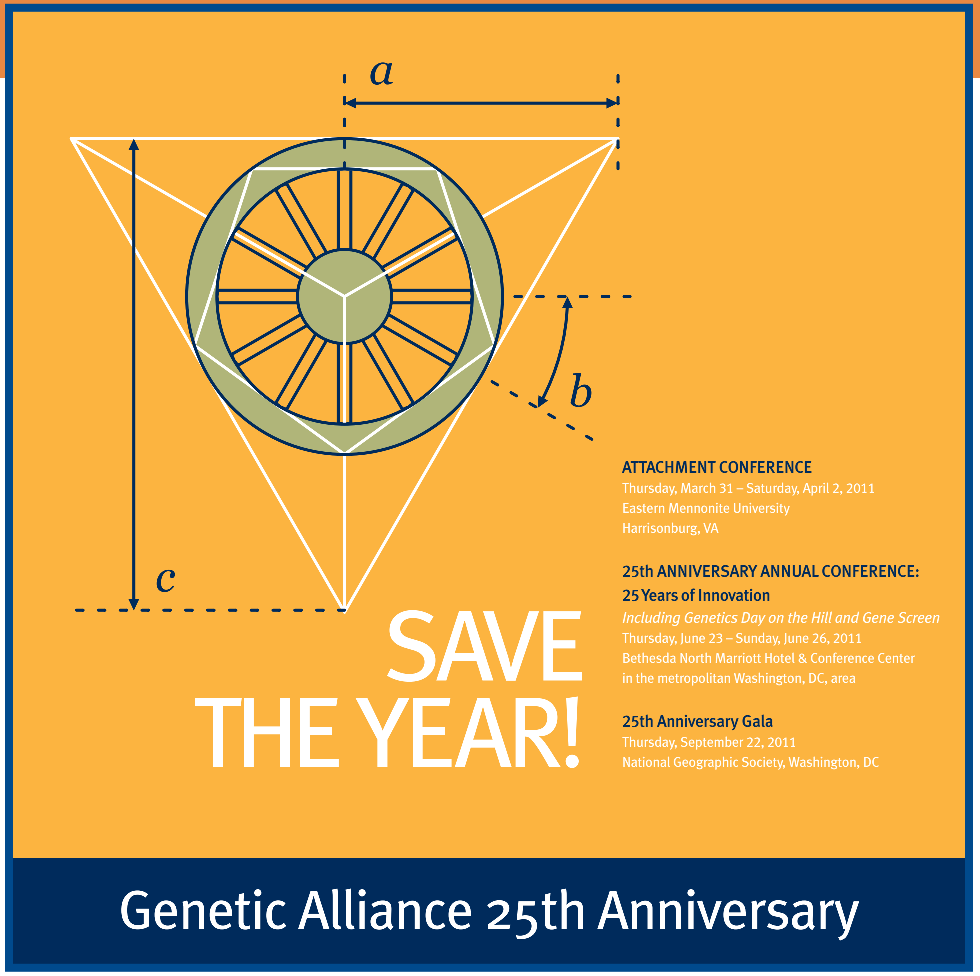
We live in an age in which innovation abounds. We experience its promise in the vast array of products that all of us use daily. It influences our travel, health, education, and even entertainment. And so it must be if we are to revolutionize translational research, information, and services.

Our determination to transform our health system is at once corporate, communal, and individual. We will succeed because we will marshal within our community the formidable intuition, creativity, and imagination that sustains true innovation.

Our 25th year is not about us—it is about you: our partners, colleagues, funders, family, and friends. We invite you to reflect on your own personal experience of innovation. Explore how it is that you are an innovator. What dreams do you have for bettering the systems around you? What are you willing to risk to bring your idea to fruition?

Join us this year and beyond as we continue to innovate and explore how we can and must transform healthcare together!

Sincerely,
Sharon F. Terry, President & CEO



ATTACHMENT CONFERENCE
Thursday, March 31 – Saturday, April 2, 2011
Eastern Mennonite University
Harrisonburg, VA

25th ANNIVERSARY ANNUAL CONFERENCE:
25 Years of Innovation
Including Genetics Day on the Hill and Gene Screen
Thursday, June 23 – Sunday, June 26, 2011
Bethesda North Marriott Hotel & Conference Center
in the metropolitan Washington, DC, area

25th Anniversary Gala
Thursday, September 22, 2011
National Geographic Society, Washington, DC

Genetic Alliance 25th Anniversary

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 Capital Corporation; Folklorist and Writer

Natasha Bonhomme VP of Strategic Development, Genetic Alliance

Gene Early Consultant, Early Leadership Solutions, LLC

Stephen Friend, MD, PhD President, Sage Bionetworks

Shantanu Gaur MD Candidate, Harvard Medical School

STAFF

Kristin Baxter, PhD Assistant Director of Translational Research and Policy

Tara Biagi, MS Maternal and Child Health Program Coordinator

Natasha Bonhomme Vice President of Strategic Development

Rhianna Campbell Manager of Finance and Administration

Andria Cornell Advocacy and Health Policy Manager

Vaughn Edelson Programs Manager

Amanda Field, MPH Public Health Programs Manager

Liz Horn, PhD, MBI BioBank Director

Mallory Kilfoyle Executive Assistant

Alyson Krokosky, MS, CGC Asst. Director of Genetics Resources and Services

James Lightner Bookkeeper

Scott McDaniel Web Development Director

Tetyana Murza, MES Programs and Events Coordinator

Tam Nguyen Electronic Communications Assistant

James O'Leary Chief Innovation Officer

MaryPeckiconis, MA Office Manager

Mark Petruniak New Media Coordinator

Elizabeth Stark, MS, MA, CGC Maternal and Child Health Program Manager

Sharon Terry, MA President and CEO

Lisa Wise, MA Chief Operating Officer

Lauren Youngborg, MS Maternal and Child Health Program Assistant

25th Anniversary Events

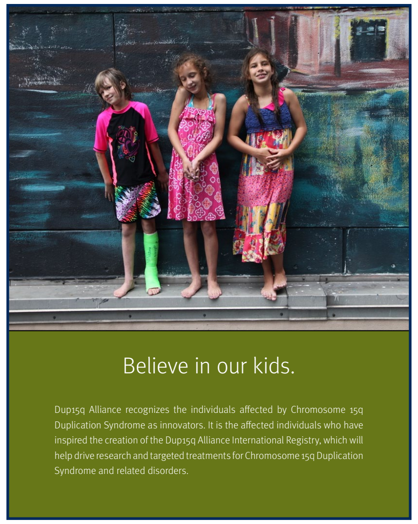
Over the past quarter century, Genetic Alliance has dissolved boundaries to foster dialogue among all stakeholders in the genetics, health, and advocacy community: industry professionals, researchers, healthcare providers, and public policy leaders as well as individuals, families, and communities. We marked our 25th anniversary with a Celebration on September 22, 2011, at the National Geographic Society in Washington, DC. The Celebration applauded individuals that exemplify advocacy, passion, partnership, and innovation.

We featured a museum-quality Innovators Exhibit that highlighted almost 100 founders of advocacy organizations, board, staff, members, volunteers, researchers, policymakers, and others who have transformed their communities:

Ana and Isa demonstrate the power of storytelling for global change around critical health issues.

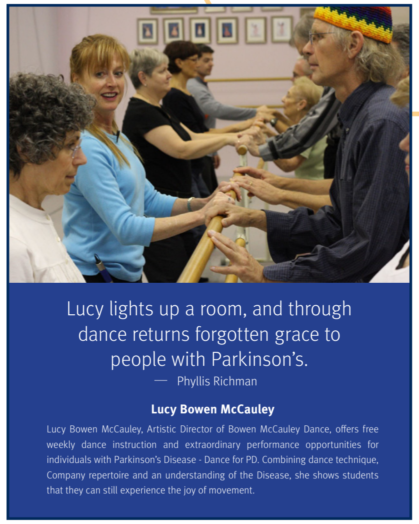
Anabel Stenzel & Isabel Stenzel Byrnes

Twin sisters Anabel Stenzel and Isabel Stenzel Byrnes, centerpiece characters of the documentary "The Power Of Two," survived a lifelong battle with cystic fibrosis through miraculous double lung transplants and have emerged as authors, athletes and advocates for organ donation and those with CF in the U.S. and Japan.



Believe in our kids.

Dup15q Alliance recognizes the individuals affected by Chromosome 15q Duplication Syndrome as innovators. It is the affected individuals who have inspired the creation of the Dup15q Alliance International Registry, which will help drive research and targeted treatments for Chromosome 15q Duplication Syndrome and related disorders.



Lucy lights up a room, and through dance returns forgotten grace to people with Parkinson's.

— Phyllis Richman

Lucy Bowen McCauley

Lucy Bowen McCauley, Artistic Director of Bowen McCauley Dance, offers free weekly dance instruction and extraordinary performance opportunities for individuals with Parkinson's Disease - Dance for PD. Combining dance technique, Company repertoire and an understanding of the Disease, she shows students that they can still experience the joy of movement.

Annual Conference

June 24-26, we celebrated 25 years of innovation in the genetics and health community as a whole. Our goal was for our diverse attendees to engage in cutting-edge discourse, networking, and fun, and to use the conference as an innovation platform for the next quarter century and beyond.

We achieved this goal!

> "Thanks again for welcoming me into the Genetic Alliance family. I learned a lot, and met great people at the conference. It was my pleasure to spend time with a community of such hard-working and passionate people. I look forward to the next sing-a-long."
>
> - Rebecca Marci (Brown) Goodwin,
> Annual Conference participant

> "I am so glad that I was given the opportunity to attend. Everything was so organized and professional, and provided an unparalleled opportunity to network with such influential members in our field."
>
> - Neely Gal-Edd,
> Genetic Alliance intern

Genetics Day on the Hill

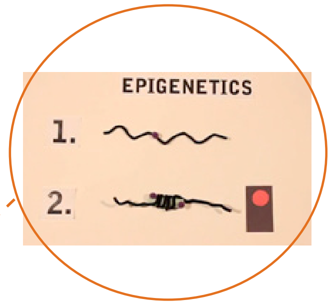
The sixth annual Genetics Day on the Hill brought together disease advocates, health professionals, researchers, industry representatives, families, students, and other members of the genetics community. Members of our diverse network gave input on what issues to bring to the Hill, and decided on three important topics:

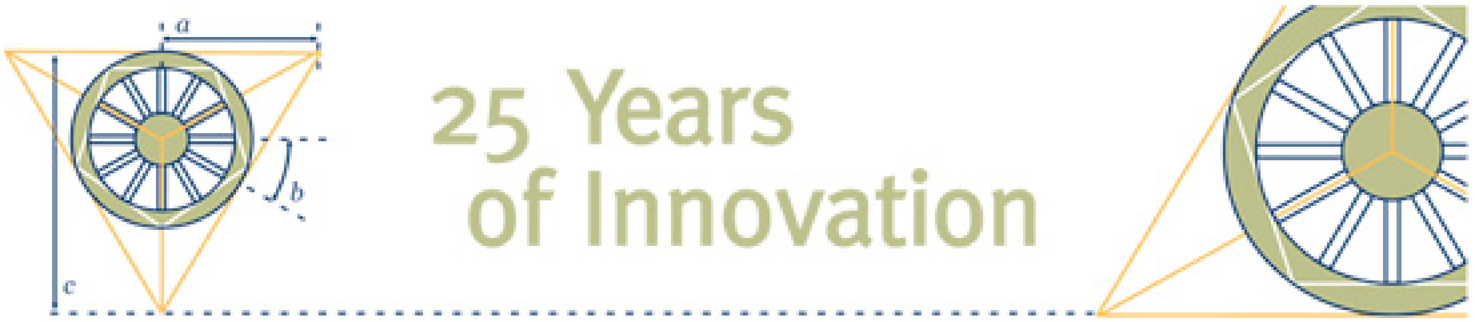
- Supporting our nation's most vulnerable populations, specifically through advancing the work of the Maternal and Child Health Bureau, Health Resources and Services Administration—particularly the Title V Block Grant program
- Incentivizing translational research, particularly through the National Center for Accelerating Translational Sciences, a new Center at the NIH
- Providing crucial initiatives that protect and support the health and well-being of individuals through the lifespan, particularly through the CDC programs for birth defects, disabilities, and public health

Gene Screen: A Night of Film on Health and Genetics

For the 3rd Annual Gene Screen, we screened a series of short films followed by a Q&A session with several filmmakers. A second screening took place as a conference workshop for those who were unable to attend Thursday night's event.

Me and Antoine B.
Broken Dreams
No More Hand-Me-Downs:
Research Designed for Children
Aiden's Journey: Awareness and Hope
If I Can't Dance
One Little Difference
Epigenetic Landscapes





Program Accomplishments

Access to Credible Genetics Resources Network

The Access to Credible Genetics Resources Network (ATCG) wraps up after five years, plus a one-year extension for evaluation activities. Genetic Alliance teamed up with eight partners to provide accurate information for families and healthcare providers about rare genetic disorders, specifically Duchenne/Becker muscular dystrophy and fragile X syndrome. Though project activities focused on these two genetic conditions, many project activities and products are applicable to other rare genetic conditions and more common health conditions.

What is Trust It or Trash It?

This is a tool to help you think critically about the quality of health information (including websites, handouts, booklets, etc.). Click on *Who said it? When did they say it?* and *How did they know?* to guide you through the process.

Have questions, comments or suggestions? Send us a note.
Click here for a printer friendly version.
The Quality Assessment Toolbox is for educational purposes only. Read our disclaimer language.
Creating a resource? Click here for the developer version.
How has the "*Trust It or Trash It?*" tool worked for you? Take this short survey and let us know.

Except where otherwise noted, content on this site is licensed under a Creative Commons Attribution 3.0 License. This tool is for educational purposes only.
:: DESIGN & DEVELOPMENT BY - WWW.PROJECTMISO.NET ::

Project Partners

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

Trust It or Trash It?

Trust It or Trash It? is an online tool that serves two purposes: to encourage critical thinking as people encounter health information and to add to the existing volume of high quality genetics education materials. It is available in both English and Spanish for healthcare consumers (trustortrash.org) as well as developers of health educational materials (trustortrash.org/developer).

baby's first test

In honor of Newborn Screening Awareness Month, on September 7, 2011, Genetic Alliance launched www.BabysFirstTest.org. The website, funded by the Health Resources and Services Administration (HRSA), is the national clearinghouse of newborn screening information. It is an objective resource for expecting and new parents to learn about newborn screening and a place for families and health professionals to share their questions and experiences.

Baby's First Test brings together stakeholders and provides easy access to newborn screening resources from community groups, government agencies, and public organizations. BabysFirstTest.org features condition-specific information, state information, family videos, and a Community Corner section, where visitors can learn about reliable sources of information related to maternal and child health.

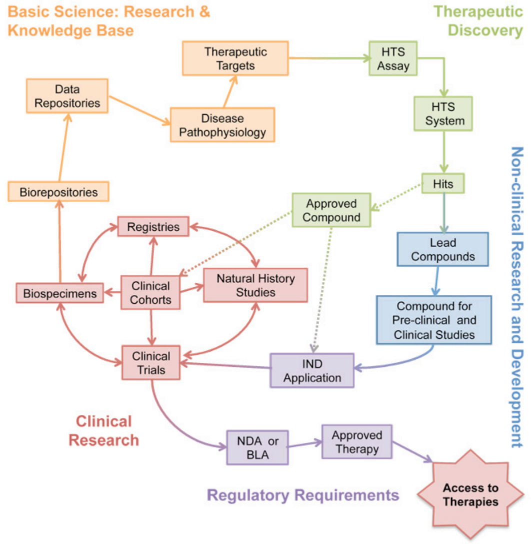
Genetic Alliance Registry and BioBank

2011 was a productive year for the Genetic Alliance Registry and BioBank (GARB):

- 12 issues of Registry and Biorepository bulletin
- 5 months of weekly tips on establishing and managing a registry and biobank
- Updated website content at biobank.org
- Launch of GARB toolbox, a resource for registry and biobank infomation
- Biobank and Registry Bootcamp help at Annual Conference

Navigating the Research Enterprise

NETS, Navigating the Ecosystem of Translational Science, is an interactive model of drug development intended to educate and empower individuals to get involved in translational science. Designed by Genetic Alliance, the model offers a more realistic and nuanced view of drug development than the traditional pipeline model. By grouping related processes into five different "neighborhoods," NETS shows the general order of drug development while demonstrating its flexibility. NETS also provides toolkits of definitions, resources, and educational materials to disease advocacy organizations and basic researchers who want to become more involved in the drug development process.



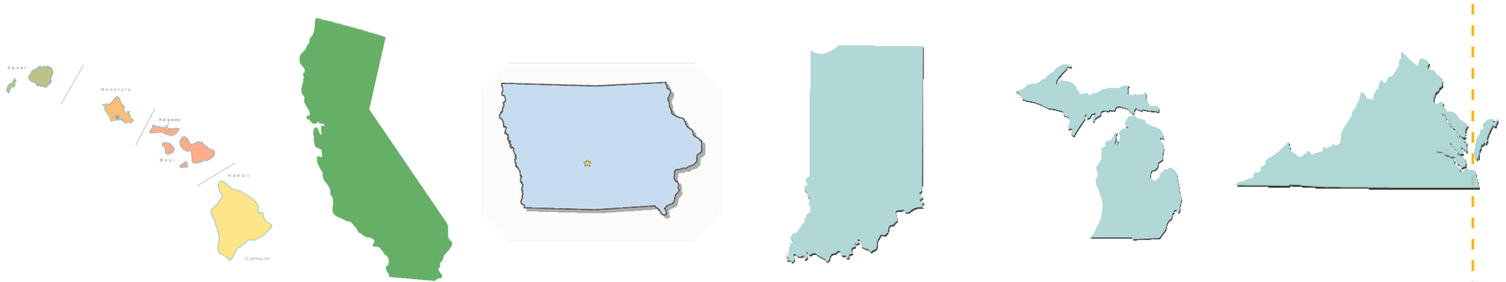
Disease Detection and Intervention

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, to analyze and initiate a systematic approach for detection and intervention using clinical, genetic, and family health history information. In 2011, Genetic Alliance conducted interviews with key stakeholders in the genetics, public health, and technology arenas and hosted two salons on early disease detection and intervention to allow open thought, unfettered discussion, and dynamic interaction between individuals around these topics.

Family Health History in Health Centers

After years working with community-based and disease-specific organizations on family health history education and outreach, Genetic Alliance and HRSA decided it was time to try the patient-focused model in the clinical setting. The Family Health History Integration into Federally-funded Health Centers project, supported by HRSA, kicked off in October 2010 to create and sustain family health history awareness and discussion in the healthcare setting among health center providers, staff, and patients.

An advisory committee comprised of experts in family health history, provider education, and health information technology helped select six partner health centers to customize and disseminate the *Does It Run In the Family?* toolkit. Each center designed their own implementation strategy – wellness visits, health education classes, and new patient orientations were all venues for FHH education – and various staff and providers championed the cause, from physicians to case managers, health educators, nurses, and administrators. Partner centers serve diverse populations and are located in both urban and rural areas across the country. They customized toolkits in English, Spanish, Ilocano, and Tagalog.

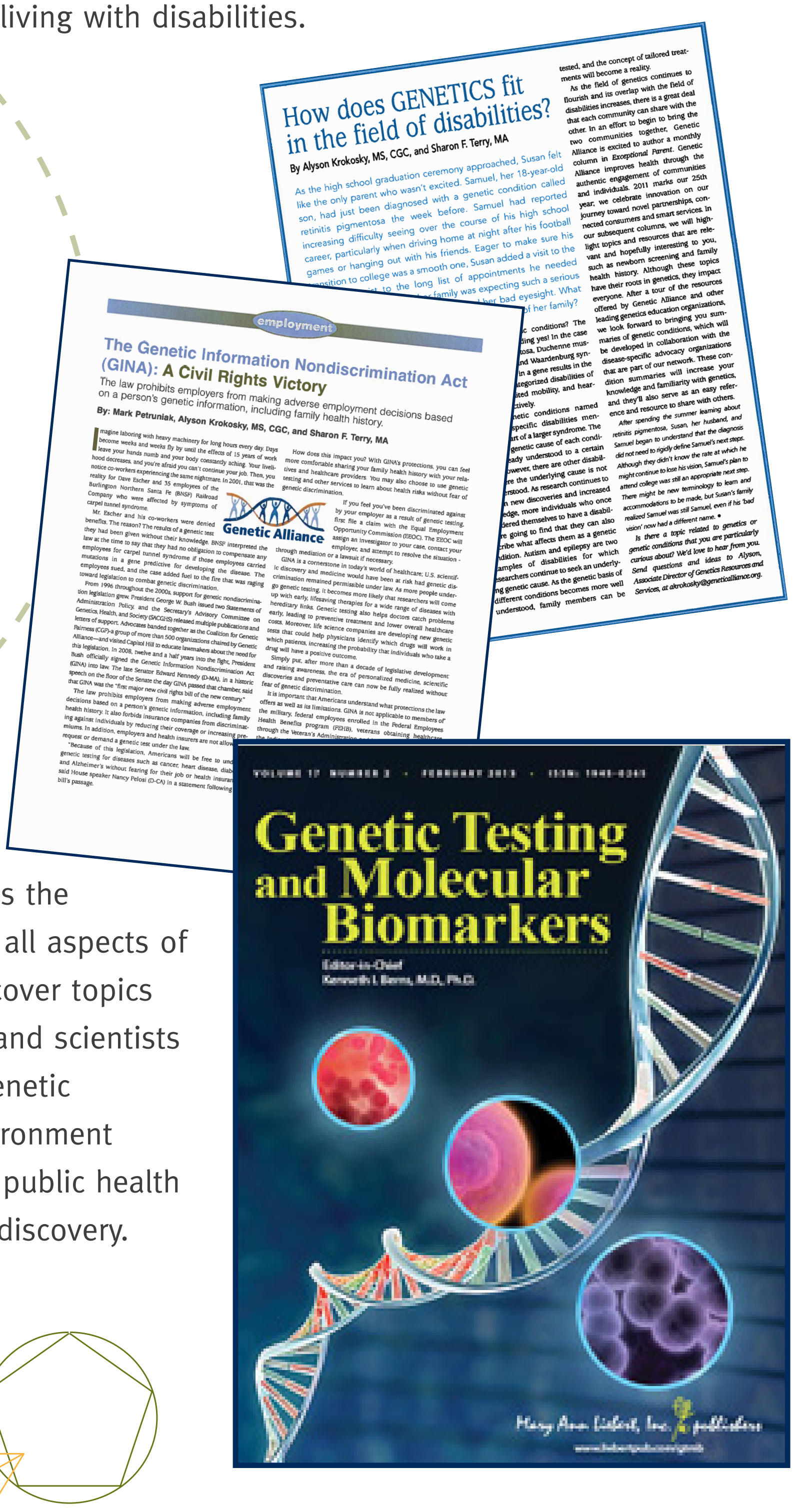


In Press

Exceptional Parent

In April 2011, we wrote our first column for Exceptional Parent e-magazine, “How does genetics fit in the field of disabilities?” Since then, every month Genetic Alliance highlights resources, programs, and tools that make life easier for individuals, families, and communities living with disabilities.

> "With the simultaneous growth of scientific knowledge and testing capability, we are continuously learning that there is tremendous overlap between the disability and genetics communities. As an individual with disabilities as well as professional training in genetics, I have a foot in both communities and see the commonalities firsthand."
>
> - Alyson Krokosky, Asst. Dir. of Genetics Resources and Services



How does GENETICS fit in the field of disabilities?

By Alyson Krokosky, MS, CGC, and Sharon F. Terry, MA

employment

The Genetic Information Nondiscrimination Act (GINA): A Civil Rights Victory

The law prohibits employers from making adverse employment decisions based on a person's genetic information, including family health history.

By: Mark Petruniak, Alyson Krokosky, MS, CGC, and Sharon F. Terry, MA

Genetic Testing and Molecular Biomarkers

Editor-in-Chief
Kenneth I. Berns, M.D., Ph.D.

Genetic Testing and Molecular Biomarkers

The official journal of Genetic Alliance is the leading peer-reviewed journal covering all aspects of genetic testing. Our monthly columns cover topics relevant to the researchers, clinicians, and scientists who develop, perform, and interpret genetic tests and their results—from gene-environment interactions to barriers to realizing the public health and clinical promise of basic scientific discovery.

Financials

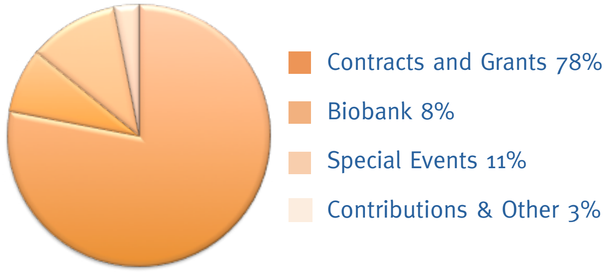
Genetic Alliance’s work is supported by a blend of funding from government grants and contracts, industry and corporate support, individual donations, and fees generated by services and events. We continually work to diversify our funding sources. A key part of this diversification plan is to secure strategic, fee-for-service partnerships that leverage our expertise, serve the needs of the field and community and bring greater financial sustainability to the organization.

Statement of Activities and Changes in Net Assets

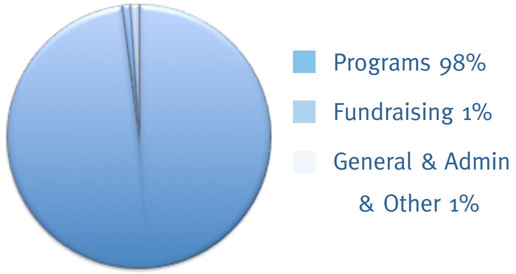
as of September 30th of each year

	Unrestricted	2011 Total	2010 Total
REVENUE AND OTHER SUPPORT			
Government Contracts and Grants	$3,273,580	$3,273,580	$3,455,372
Biobank Program Revenue	351,340	351,340	370,871
Special Events	441,347	441,347	183,092
Contributions	89,275	89,275	22,256
Listserv Income	5,400	5,400	500
In-Kind Contributions	1,141	1,141	491
Interest Income	31	31	424
Other Revenue	46,978	46,978	5,069
Total Revenue and Other Support	4,209,092	4,209,092	4,038,075
Net Assets Released from Restrictions	58,133	-	-
Total Revenue and Other Support	$4,267,225	$4,209,092	$4,038,075
EXPENSES			
Program Services			
General Programs	$3,400,452	$3,400,452	$3,842,792
Policy	1,550	1,550	65,030
Supporting Services			
General and Administrative	20,186	20,186	28,058
Fundraising	24,582	24,582	33,459
Total Expenses	$3,446,770	$3,446,770	$3,969,339
Net Increase (Decrease) in Net Assets	820,455	762,322	68,736
Net Assets, Beginning of Year	117,158	524,641	$455,905
Net Assets, End of Year	$937,613	$1,286,963	$524,641

Operating Fund Sources



Fund Spending



Statement of Financial Position

as of September 30th of each year

ASSETS	2011	2010
Cash and Cash Equivalents	$65,007	$123,298
Accounts Receivable	399,578	397,334
Grants Receivable	425,663	380,746
Prepaid Expenses	29,536	31,811
Deposits	12,718	12,718
Furniture & Equipment	732,967	144,964
Total Assets	$1,665,469	$1,090871
CURRENT LIABILITIES		
Accounts Payable and Accrued Expense	$310,764	$489,483
Capital Lease Obligation, current portion	6,609	7,286
LONG-TERM LIABILITIES		
Deferred Rent	59,783	61,502
Security Deposits	1,350	1,350
Capital Lease Obligation, net of current portion	-	6,609
Total Current Liabilities	378,506	566,230
NET ASSETS		
Unrestricted	937,613	117,158
Temporarily Restricted	349,350	407,483
Total Net Assets	1,286,963	524,641
TOTAL LIABILITIES AND NET ASSETS	$1,665,469	$1,090,871

Genetic Alliance

WWW.GENETICALLIANCE.ORG

T: 202.966.5557
F: 202.966.8553
info@geneticalliance.org

4301 Connecticut Ave., NW
Suite 404
Washington, DC 20008-2369