Welcome from the President

Though it may sound trite, I am compelled to say: what extraordinary times we live in! In this chaotic world, the fields of genetics and advocacy – fortunately – are not exempt from upheaval. We are on the brink of tremendous change, and the Genetic Alliance network will be the heart of this systems revitalization.

At Genetic Alliance, we are engaged in profound transformation at all levels. The board of directors labored hard and long, with phenomenal commitment to this process, over the past three years. We are now ready to kick off 2008, the Year of Transformational Leadership, for ourselves and all of you.

In this context, we are all leaders. We will discover how we hold open space to nurture transformation personally, organizationally, and in the wider community. We understand that advocacy will be revolutionized and have begun to pave the road toward Advocacy 3.0!

We look forward to working with you this coming year, and wish you the very best in the coming holidays!

Sincerely,

Sharon F. Terry
President & CEO

Spotlight: Genetic Testing Summit

In the 21st century, genetic testing requires that we speak and seek the truth – about the systems that surround it, impede it, and support it. Eyes on the Prize: Truth Telling about Genetic Testing, held September 20-21 at the Renaissance M St in
Washington, DC, successfully fostered honest, stimulating discussions about genetic testing. As indicated by its title, the two-day summit focused on the genetic testing landscape as it relates to the ultimate outcome – health. Participants hailed from every sector of the genetics community – government, biotechnology companies, academia, advocacy organizations, laboratories, law/consulting firms, and professional organizations – and addressed issues pertaining to the whole genetic testing pipeline, from research and development to the practice of medicine.

National leaders like Francis Collins, Director of the National Human Genome Research Institute, and Janet Woodcock, Deputy Commissioner of the Food and Drug Administration, participated in the event. Others, like Senator Edward M. Kennedy (D-MA) and Health and Human Services Secretary Mike Leavitt recognized the importance of the gathering in furthering genetic information nondiscrimination legislation and personalized medicine.

Interactive discussion and a debate dinner the first evening resulted in a lively, open dialogue that characterized the proceedings. Several consensus points were reached along with action steps to effect the desired change: an overhaul of the oversight of genetic testing is urgently needed, federal genetic nondiscrimination protections are a vital foundation for continued growth in the field, and more summits to address specific parts of the pipeline, such as reimbursement and the third party review system, are also in demand. Genetic Alliance is producing journal articles and a monograph and hosting a webinar to publicize the Summit outcomes, and a full report will be available soon.

### Year of the Advocate in Review

As the Year of the Advocate comes to a close, we reflect on the recent successes that were a product of our advocacy and look forward to a year of Transformational Leadership ahead. The Gala on July 25 brought together 200 Genetic Alliance friends and supporters to honor Kathy Hudson and Frank Swain, leaders in the fight against genetic discrimination. The following day, over 100 stakeholders from across the country convened on the Capitol for the second annual Genetics Day on the Hill, visiting every Senator’s office to educate policymakers about genetic testing and the imminent danger of genetic discrimination. The Week of the Advocate concluded with the Genetic Alliance 2007 Annual Conference. Advocates, industry members, and leaders of government and non-governmental organizations exchanged ideas, expanded networks, and developed initiatives in a collaborative atmosphere inspired by four directed tracks: education and information, policy, research, and services.
Former Speaker of the House Newt Gingrich gave the conference keynote address. He spoke of the need for us to be both patient and visionary – on the brink of numerous new worlds. The pace of science has quickened to such a degree that as we envision the future today, we are akin to Isaac Newton trying to invent the iPhone. Genetic Alliance is up for the challenge!

**Mark your calendars for our signature events in 2008!**

**Transformational Leadership:**
Genetics Day on the Hill - July 10, 2008  
Annual Conference - July 11 - 13, 2008

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**Capitol Corner**

**Genetic Nondiscrimination Legislation**

On April 25, the Genetic Alliance community celebrated the passage of the Genetic Information Nondiscrimination Act (GINA) in the House of Representatives and awaited the Senate’s action on the same measure. In July, we were alerted to the Senate’s intent to expeditiously move the bill. However, that effort was thwarted by a hold placed on the bill, and we soon learned that Senator Tom Coburn (R-OK) was the source of that hold.

Within a week of learning of the hold, Genetic Alliance held the annual **Genetics Day on the Hill** during which over 100 participants visited each one of 100 Senate offices in a single day. The effort culminated with a number of contacts being made in Senate offices, but was unsuccessful in moving Senator Coburn.

Over the past few months, the Genetic Alliance community has stepped up efforts like never before. Members of our community from Oklahoma have visited with Senator Coburn. Members from across the country have faxed letters to their senators asking for favorable action to be taken on GINA. We have worked with reporters to feature GINA in national publications. Together, we are building momentum for GINA.

We need to keep the drive going. It is vital that every member of the Genetic Alliance community contact their senators on this issue. It takes just a few minutes to tailor a **sample letter** that Genetic Alliance has provided online and send it to your senators.
Genetic Testing Oversight

Genetic testing oversight has seen action in the past few months. In July, the Food and Drug Administration (FDA) released a follow up draft guidance on in vitro diagnostic multivariate index assays (IVDMIAs). Genetic Alliance drafted comments and over 40 nonprofits, corporations, and individuals endorsed those remarks to the FDA. The FDA followed up their draft guidance on analyte specific reagents (ASRs), released in 2006, with a final guidance in September.

The Centers for Medicare and Medicaid Services (CMS) has also taken recent action on genetic testing oversight. After months of formal requests to CMS by advisory groups, industry, and policymakers to create a genetics specialty under the Clinical Laboratory Improvement Amendments (CLIA), the agency balked at attempts to alter its policy. On August 30, CMS rejected a joint citizen’s petition from Genetic Alliance, the Genetics and Public Policy Center, and Public Citizen’s Health Research Group to create the genetics specialty. Genetic Alliance responded by submitting formal comments to the Centers for Disease Control’s Clinical Laboratory Improvement Advisory Committee on September 6. Genetic Alliance will continue to advocate for this vital policy.

Open Access Policy

Public access to federally funded research findings has taken another step forward. Both the Senate and House of Representatives included language in the FY2008 Labor-HHS-Education Appropriations bill to implement a mandatory deposit policy for all research articles stemming from NIH-funded research. Genetic Alliance sent numerous letters to members of both the Senate and House Appropriations Committees in order to communicate the importance of this policy. In addition, we drafted a sign on letter to all senators, which was endorsed by over 100 organizations and individuals. The support we brought to the effort helped to ensure its success.

National Consumer Center for Genetics Resources and Services

In collaboration with disease-specific advocacy organizations and family groups, the National Consumer Center for Genetics Resources & Services (NCCGRS) develops and makes accessible informational materials and educational programs for consumers. Further, the Center will bring consumers and their concerns to the attention of policymakers and government agencies. The NCCGRS seeks to promote the collaboration required to revolutionize networks and systems to serve the public’s needs. It includes the Access to Credible Genetics Resources Network, the Community

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Centered Family Health History Program, and the Consumer Focused Newborn Screening Projects.

WikiGenetics

Contribute to WikiGenetics! WikiGenetics is an open source, user generated encyclopedia created to explain genetics to consumers. 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.org

WikiAdvocacy

A compilation of the wisdom of the advocacy community, WikiAdvocacy offers a forum for advocates to share knowledge and experience in a fast-paced, interactive environment. It also holds the Interactive Guide to Advocacy, a manual that covers every aspect of founding, growing, and maintaining an advocacy organization. Members of the advocacy community continually add and refine the tips and tools offered through this resource. Be one of them! Check out what’s new at wikiadvocacy.org

Staff News

Do you want to become a part of all the action?

You can! We are expanding our staff. Genetic Alliance is currently seeking qualified professionals to fill two new positions:

**Director of Public Policy**
The Director of Public Policy leads, coordinates, and oversees Genetic Alliance public policy activities.

**Webmaster**
The Web Developer will be a creative, experienced self-starter with the technical skill base to develop, design, and maintain website(s) from the ground up.

Transitions

James O'Leary, formerly Program Manager, is now Chief Operating Officer of Genetic Alliance. As COO, James will facilitate strategic planning for the organization and implement Genetic Alliance’s vision to improve health through genetics. He will support
collaboration both within the staff and among Genetic Alliance and its partners.

**Amelia Chappelle** was promoted from Assistant Director to Associate Director of Genetics Resources and Services. In her new position, she coordinates the Access to Credible Genetics Resources Network, a project to provide accurate information about rare genetic disorders to families and healthcare providers.

*Genetic Alliance would like to thank our three fall interns for their dedication and valuable contributions to our programs:*

Mona Chughtai, Public Policy Intern, is from West Des Moines, Iowa and is a senior majoring in mathematics at Grinnell College, Iowa. Her internship focused on conducting policy research and publishing weekly policy bulletins, which are distributed to the Genetic Alliance network. She also provided support for Genetic Alliance's newborn screening initiatives.

Amy Garrison, Genetic Counseling Intern, recently graduated from George Washington University with a B.S. in biological science. She worked on a variety of projects at Genetic Alliance, including Disease InfoSearch, Access to Credible Genetics Resources Network, and Understanding Genetics.

Sim Wimbush, Programs Intern, is from Petersburg, Virginia and is a senior Anthropology major and Pre-Health Concentrator at Grinnell College, Iowa. At Genetic Alliance, she conducted research on educational materials in genetics and genomics for the use of public health professionals, maintained and distributed this resource list to a nationwide listserv, and provided post-production assistance for the Strategies for Success webinar series.

**Out & About**

**Heartland Regional Genetics and Newborn Screening Collaborative**

September 5 - 7, James O’Leary attended the Heartland Regional Genetics and Newborn Screening Collaborative annual meeting for the second year. In Oklahoma City, OK he presented on the spectrum of Genetic Alliance resources, programs, and policies for over 100 geneticists, clinicians, advocates, and other members of the genetics community.

**Clinical Laboratory Improvement Advisory Committee Meeting**

Orkideh Malkoc attended the Clinical Laboratory Improvement Advisory Committee meeting at the Centers for Disease Control, Atlanta, GA on September 6. She gave formal comments in
response to the Centers for Medicare and Medicaid Services’ rejection of the citizen’s petition filed by Genetic Alliance, the Genetics and Public Policy Center, and Public Citizen’s Health Research Group to create a genetics specialty under the Clinical Laboratory Improvement Amendments (CLIA).

National Society of Genetic Counselors (NSGC) Annual Conference
October 11 - 16, Amelia Chappelle and Heather Ferguson attended the NSGC conference in Kansas City, KS with participants in the 
Advocates Partnership Program. It was the second year that Genetic Alliance and NSGC partnered to encourage interaction between organizations and the scientific community and identify common goals and challenges that can be addressed through collaborations. Genetic Alliance was also invited to participate in a workshop on emerging technologies, where Amelia gave a WikiGenetics tutorial for 100 genetic counselors.

American Society of Human Genetics (ASHG) Annual Conference
Several members of the Genetic Alliance staff and Advocates Partnership Program participants attended the ASHG conference in San Diego, CA, October 23 - 27. This was the third year that Genetic Alliance and ASHG collaborated for the 
Advocates Partnership Program. All staff in attendance presented posters at the meeting of over 4000 people. Sharon Terry presented Genetic Alliance’s Disease InfoSearch; James O’Leary presented Community Centered Family Health History; Amelia Chappelle presented WikiGenetics; Natasha Bonhomme presented the Understanding Genetics Guide for Patients and Health Professionals; and Vaughn Edelson presented the Genetic Alliance Resource Repository. In addition, Sharon spoke about the Access to Credible Genetics Resources Network during the Platform Session Fragile X: From Bench to Population. Genetic Alliance board member Kemp Battle also participated in a platform session: DNA as Unique Identifier: Privacy, Trust, and the Future of Genomic Biorepositories, in which he spoke on Identifiability in Genome Research: A Participant’s Perspective.

Association of Public Health Laboratories Newborn Screening and Genetics in Public Health Committee
November 2 - 3, Natasha Bonhomme presented on Genetic Alliance services and the 
Consumer Focused Newborn Screening programs. As a new liaison to this committee, Natasha’s involvement will lead to greater incorporation of the consumer voice in discussing the progression of genetics and newborn screening in the larger public health arena.
Southeastern Regional Genetics Group Consumer Alliance Meeting

Vaughn Edelson went to Atlanta, GA, November 16 to participate in the Region 3 Genetics Collaborative Consumer Alliance focus group and meeting. Vaughn spoke to the group of 11 parents of children with genetic disorders about the variety of ways they can become involved with Genetic Alliance through our many programs and resources.

Strategies for Success

Register now for this Strategies for Success teleconference:

Genetic Testing Summit Report
Monday, December 17th at 12 noon EST (webinar)

Join us for our December 17th webinar to hear a follow-up report on Genetic Alliance’s Genetic Testing Summit. In late September, many stakeholders in the genetics community met for two days to consider the entire pipeline of test development, commercialization, oversight, and services. A number of important conclusions and action steps were recommended. We describe these recommendations and discuss next steps.

With presenter: Sharon Terry, Genetic Alliance
Sign up for a session.

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Sign up to receive podcasts.