Welcome from the President

We blast into summer with many more staff, interns, and programs. We’ve been preparing many resources and events that have all exploded onto the scene in the last few months. Warning: we have not even begun to roll out what we have in store for you this year!

This year, we celebrate the Year of the Advocate as advocacy matures in very significant ways. Our Genetic Alliance “trifecta” of events gives you ample opportunity to celebrate, too. We will have a fun and easy-going Gala on July 25, followed by an intense day on the Hill on July 26th, culminating in our annual conference on July 27 to the 29th. Come and dig in – this is the most diverse cross-section of the stakeholder community together in one place – all focusing on moving leadership and advocacy to the next level. Our awardees and presenters are outstanding, informative and dynamic. Don’t miss these events!

We have fabulous new staff with exceptional skills gearing up to do great things for you in the genetics community. Our summer interns have already made their mark, as you will read about in this newsletter. In addition, “old” staff continues to be creative and swell the number of services we offer – take a look at all the remarkable resources below.

You may have noticed that this seasonal newsletter has been joined by a weekly (as needed) bulletin since we can’t wait to communicate all of the resources and services available to you! (If you are not receiving the weekly bulletin, please email network@geneticalliance.org.

Have a wonderful summer; envision great change so that together our network can revolutionize healthcare from within. We are with you, we work for you.

Sincerely,
Genetic Alliance celebrates the Year of the Advocate in 2007! We will celebrate advocates over the course of five days. The events begin with the Gala on Wednesday, July 25th, at the Galleria at Lafayette Centre in downtown Washington, DC. The Gala applauds the leadership and strength of our community. We are honored to showcase the premier unveiling of Rick Guidotti’s new Positive Exposure Exhibit. In addition, we will honor Frank Swain and Kathy Hudson for their volunteer work on genetic discrimination. Upholding Genetic Alliance tradition, this will be a fun Gala – no long speeches, no boring tributes! We extend a special invitation to all – join us for this celebration!

The celebration continues with ACTION! Genetics Day on the Hill brings hundreds of stakeholders to Capitol Hill on Thursday, July 26th. We will educate key policymakers about issues that impact individuals and families affected by genetic conditions. Genetic testing, personalized medicine, newborn screening, and health information technology are some of the issues of concern. We have invited Senator Barack Obama (D-IL) to speak at a breakfast briefing and Senator Edward Kennedy (D-MA) to speak at lunch. Participants will be guided by team leaders through the meetings with key Hill staffers. At day’s end, the whole group will debrief together before taking a group photo with the Capitol as the backdrop.

July 27 – July 29, Genetic Alliance will hold its 2007 Annual Conference at the Bethesda North Marriott in Bethesda, Maryland. This conference will provide an outstanding opportunity to participate in cutting-edge workshops and insightful discussions with approximately 300 advocates, health professionals, policymakers, industry professionals, and community leaders.

The conference kicks off with the Genetic Alliance Institute for Advocacy on Friday. This year, three concurrent daylong symposia — Transformational Leadership,
Organizations in Action, and Research in Action — will provide intensive training for individuals in numerous content areas.

Saturday and Sunday, July 28–30th, are organized around four concurrent workshop tracks: services, policy, research, and education. Conference topics will cover issues such as genetic testing, personalized medicine, newborn screening, underserved communities, clinical trials, evidence-based information, community engagement, and family history. View the program.

Register now for these three exciting events!

Capitol Corner

US House of Representatives Passes Genetic Information Nondiscrimination Act

Twelve years and thousands of hours of educating policymakers resulted in the Genetic Information Nondiscrimination Act (H.R.493) passing in the House of Representatives 420-3, on April 25, 2007! This is an enormous victory in the quest for federal protection against the misuse of genetic information in health insurance and employment decisions.

On the day the bill went to the floor, Representative Slaughter (D-NY) and Representative Biggert (R-IL), GINA’s lead sponsors, spoke eloquently about the need for protections against genetic discrimination and thanked the House chairs of the committees of jurisdiction for their work to move the bill. Members of the House from both sides of the aisle also stood in support of GINA and called for a favorable vote on the legislation. Members of the Coalition for Genetic Fairness participated in a campaign to ask for support for the bill. These efforts were rewarded with this monumental and historic victory for GINA in the House of Representatives.

GINA was introduced as S.358 in the Senate on January 22. It was approved by the Senate Health, Education, Labor, and Pensions Committee and is awaiting floor action – but don’t just wait – contact your Senators today and ask them to move the bill to the Senate floor and vote yes!!! This same bill has passed the Senate unanimously twice before! President Bush has repeatedly indicated his willingness to sign the bill.

Genetic Tests – Action on the Policy Front

Two bills affecting genetic testing regulation were introduced in March. Senator Kennedy (D-MA) and Senator Smith (R-OR) introduced the Laboratory Test Improvement Act (S.736) on March 1. The bill would
establish an FDA registry of such tests with a related classification structure and reporting requirements. Senator Obama (D-IL) and Senator Burr (R-NC) introduced the Genomics and Personalized Medicine Act (S.976) on March 23. The bill would establish the Interagency Working Group within the Department of Health and Human Services to facilitate cross-agency collaboration and issue recommendations on the collection, use, and analysis of genetic specimens. Both bills call for the Centers for Medicare and Medicaid Services (CMS) to establish a genetics specialty under the Clinical Laboratory Improvement Amendments (CLIA). Senator Obama (D-IL) sponsored a successful amendment to the Prescription Drug User Fee Act, or PDUFA, (S.1082) that charges the Institute of Medicine to study and prepare a report that includes recommendations to improve federal oversight and regulation of genetic tests.

Genetic Alliance is convening Eyes on the Prize: Truth Telling about Genetic Testing, September 20-21 in Washington, DC. Stakeholders will come together to discuss difficult questions that must be addressed in order to capitalize on the tremendous asset of genetic testing in its many applications. The resources, materials, and discussion will be distilled into recommendations for genetic testing — from development through to services.

Newborn Screening Grants

Genetic Alliance was awarded two cooperative agreements from the Genetic Services Branch of the Maternal and Child Health Bureau, Health Resources and Services Administration, DHHS. Both grants are three-year projects that will examine issues in newborn screening through consumer and medical home perspectives. The goal is to minimize harm and maximize the benefits of the newborn screening system for all participants. Find out more about these grants and other newborn screening initiatives.

Portal to Credible Information: Genetic Alliance & NCBI

Sorting out the morass of information on genetic conditions just got easier. In collaboration with the National Center for Biotechnology Information (NCBI), Genetic Alliance has created a new portal on the web that links Disease InfoSearch to National Library of Medicine (NLM)
research, directories, and educational materials. The resource offers clinical descriptions of diseases, directories of geneticists and genetic testing laboratories, clinical trials for those with genetic diseases, and much more. Users can even track emerging information over time through an email notification system. Read more.

**Dynamic Distribution: Genetic Alliance Resource Repository**

You've got great documents, materials, and resources, and need wide distribution. Genetic Alliance has a solution for you! In May, Genetic Alliance launched the new Resource Repository, a robust document repository service that aggregates the combined resources of advocates, healthcare professionals, government agencies, think tanks, and other contributors. These resources cover a wide range of topics, such as fundraising, FDA genetic testing guidances, advocacy at the state and federal level, media strategies, and clinical trials.

The new Resource Repository enables you to search by keyword or to browse categories such as policy, communications, and fundraising. Features include the ability to track new content tailored to your interests, a "What's New" box to see the latest content, and a "Frequently Downloaded Resources" button to view the most popular papers in the Repository. You'll get regular reports detailing the download count for documents you authored. Visit, browse, and deposit into the Resource Repository now.

**Out and About**

Institute for Pharmacogenomics and Individualized Therapy

On May 19, Sharon Terry, MA, president and CEO, was honored with the Institute for Pharmacogenomics and Individualized Therapy (IPIT) Award for Patient Service at the University of North Carolina at Chapel Hill. This award is given to an individual who has made significant contributions to empowering patients and who champion a focus on patients in the advancement of individualized therapy. “The completion of the Human Genome Project brought the promise of new tools for choosing the safest and most beneficial medicines for patients,” said Howard McLeod, director of the UNC institute. “But realizing these tools requires great dedication and leadership by experts from diverse areas of health sciences, leaders such as Sharon Terry.”

Biotechnology Industry Organization Annual Meeting
On May 7, Orkideh Malkoc, Associate Director of Public Policy, presented at the Biotechnology Industry Organization international convention in Boston, MA. Brian Petersen, Deputy Legislative Director for Congresswoman Judy Biggert (R-IL) and Robert Wells, Vice President for Affymetrix joined Orkideh to showcase the growth and development of the Coalition for Genetic Fairness and progress of the Genetic Information Nondiscrimination Act.

3rd International Conference on Birth Defects and Disabilities in the Developing World
In June, Hanaa Rifaey, Assistant Director of Membership, presented at the 3rd International Conference on Birth Defects and Disabilities in the Developing World, held in Rio de Janeiro, Brazil. Hanaa presented on “Advocacy and its Relationship to Genetics” and participated in the Brazilian Genetic Alliance meeting.

Family Voices National Conference
James O’Leary, Program Manager, and Natasha Bonhomme, Program Coordinator, led a roundtable discussion on how community organizations can help families collect their health histories and use that information to make positive health choices. They also unveiled the newest version of the Does It Run In the Family? toolkit. Read more about the toolkit and other family health history initiatives.

Meet New Staff and Interns

Heather Ferguson, MS, CGC, is our first Associate Director of Genetics Resources and Services. Heather Ferguson comes to Genetic Alliance with more than ten years of experience as a genetic counselor. Originally from Boston, Massachusetts, she relocated to Washington, DC in 2005. Before joining Genetic Alliance, she was Director of Genetic Counseling Services for GeneDx, a testing company that performs clinical testing for rare genetic conditions. Before that, she was the coordinator for a Harvard-affiliated research study for individuals with balanced chromosome rearrangements. Her clinical background is diverse and includes prenatal, cancer and adult genetics. She earned her genetic counseling degree from the Graduate School of Biomedical Sciences at the University of Texas Health Science Center in Houston. Heather has a special interest in genetics education. She is dedicated to training genetic counseling students, as well as other healthcare professionals, in a continued effort toward the improvement of patient care.

Amelia Chappelle, MS, MA is our first Assistant Director of Genetics Resources and Services. Amelia is interested in genetics and patient advocacy. Hailing from Mercer Island, Washington, she received her
undergraduate degree in neuroscience and behavior from Mount Holyoke College in Massachusetts. In 2003, Amelia worked for the National Institutes of Alcohol Abuse and Alcoholism in the Lab of Neurogenetics. In 2007, she graduated from Sarah Lawrence College with a dual Master’s degree in Human Genetics and Health Advocacy. During her graduate career, Amelia gained clinical and public health experiences in prenatal, pediatric, and cancer genetic counseling settings, as well as various advocacy groups and state genetics departments. As a new genetic counselor, Amelia is excited to be working to effect change in the genetics community and greater health community at large.

**Vaughn Edelson**, our new Program Assistant, grew up in Miami, FL. She earned a BA in biology from Brown University in 2007. Her studies emphasized leveraging community voices and expertise. In Providence, Vaughn worked with Rhode Island Legal Services to create educational outreach materials in environmental justice to inform at-risk community members of their rights. She is eager to immerse herself in the world of public policy. Vaughn enjoys modern dance, reading, and cycling - in 2005 she biked across the country from Providence, RI, to Seattle, WA. Anyone up for a long ride?

**Alyson Krokosky**, Program Assistant, returns for a second summer. She is the brains behind our genetic testing story project – categorizing and sorting more than 150 stories individuals and families have shared about genetic testing. Alyson begins the genetic counseling program at the University of Michigan in the fall and continues as a Genetic Alliance Fellow.

**Andria Cornell**, Public Policy Program Assistant, is surveying stakeholders in the genetics community about their policy concerns – she has communicated with more than 100 organizations and is beginning to put together priorities that are emerging from these surveys and interviews. Andria was an intern during the last school year, and just couldn’t stay away! She will return for her senior year at George Washington University. She has her sights set on medical school.

**Alex Rihm**, Program Assistant, also returns to us for a second summer. Alex is an incredibly proficient jack-of-all-trades and provides assistance for the Week of the Advocate, general office management, and executive assistance for Sharon. We have offered her great sums of money to stay all year round! Alas, she returns to Lewis and Clark in Portland, OR for her sophomore year, studying international affairs.
Yojiro Konno, Electronic Communications Intern, is from Yamagata, Japan and is a junior majoring in sociology with a concentration in neuroscience at Grinnell College, Iowa. He came to Genetic Alliance to learn how to improve the quality of life of affected individuals. Yoji's internship focuses on the development of wikis for the genetics and advocacy communities. He hopes to work for a management consulting company upon graduation in order to acquire leadership skills. Eventually, he hopes to go to medical school and become a dermatologist.

Sam Hwu, Public Policy Intern, will be a senior this fall at Duke University. He is majoring in public policy studies, with a focus on health policy, and plans to attend medical school. Sam chose to intern at Genetic Alliance to gain a stronger understanding of health policy to better serve patients as a doctor in the future. He is getting his feet wet on many issues, particularly PDUFA and health information technology. Sam is originally from Clemson, South Carolina.

Greg Gilmore, Public Policy Intern, recently graduated from the University of California, Irvine, with a B.S. in biological science. He is currently applying to medical schools to pursue his goal of becoming a physician and earning a masters degree in public health. Greg is interning this summer with Orkideh Malkoc, Associate Director of Public Policy.

Strategies for Success

Educating Members of Congress: The Basics
Tuesday, July 3 at 12 noon EST (Webinar)
Joann Boughman, Executive Vice President of the American Society of Human Genetics, leads an engaging session on effective communication with members of Congress. Though this opportunity has been tailored for Genetics Day on the Hill participants, all parties interested in educating members of Congress about policy concerns will find this session beneficial.

Genetic Testing Policy
Monday, July 16 at 12 noon EST (Webinar)
Kathy Hudson, Director of the Genetics and Public Policy Center, will share her wisdom about genetic testing policy with us. All those joining us for Genetics Day on the Hill, as well as any other interested parties, are encouraged to participate.

Getting the Most out of the Week of the Advocate
Wednesday, July 18 at 12 noon EST (Conference call)
Want to understand better all of the events occurring
during the Week of the Advocate? Have some questions before you decide to register? Already registered and want to be sure you make the most of your time? Hanaa Rifaey and Orkideh Malkoc will lead you through the five days of events and answer your questions.

To register for one or more of these informative sessions, click here.

Celebrating our Leaders: Cheri Gunvalson

Missed the Leadership Exhibit at Genetic Alliance's 20th Anniversary Gala in September? We will be honoring leaders from the exhibit throughout the year. Click to see full image.

Cheri Gunvalson,
Parent Project Muscular Dystrophy

"Cheri is a ‘heat seeking missile’: her eye on the target and Jacob in her heart."

- Pat Furlong

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