Welcome from the President

In this edition of G.Advocacy, we report a very exciting and busy start to 2007. Genetic testing regulation, family history projects, genetic nondiscrimination legislation, and credible information tools have kept us very busy, but we also set aside time to reflect. This winter, the board of Genetic Alliance began to consider what it means to lead this amazing organization. Through many "open space" meetings, it has become clear to us that we must always be present to this question: "What is at stake?" and to the core issues that arise from it. If we remain "present," we are able to work as one, apart from egos, agendas, and other trappings that often either lead us astray or sap our energy.

It is also clear to those of us who have worked in this community for years, that the old models will not advance our goals as effectively as possible, and that we must together birth a new paradigm of leadership and community, rooted in the essence of our work. It is the age of open access, combined resources, the Long Tail and the Flat World. Our vision of our work must transcend traditional boundaries and recognize the "we" that will achieve the goals we have set. We will articulate this further in the coming months, but we invite you to set aside some time and ask yourself, your organization, your community: "What is at stake, What matters, What is precious?" Together we will coalesce our resources and energies to accelerate our work, the work of the "we." We are glad to hold the space to ask these questions, and we look forward to the journey together.

One tangible sign of the "we" is the Membership Drive. As we reach out, be sure to respond, so that we (all of us) can increase our presence in the world. We look forward to seeing you at the Gala, Genetics Day on the Hill, and the Annual Conference this summer!

Best Wishes,
Sharon Terry

**Spotlight: GINA Progresses in Congress**

Since its reintroduction in January 2007, the Genetic Information Nondiscrimination Act (GINA) has blasted full steam ahead! The legislation protects individuals from the misuse of genetic information in health insurance and employment decisions. GINA was introduced as a pair of companion bills by bipartisan teams in both the House and Senate, and has the President’s support. In the House, Representatives Slaughter (D-NY-28), Biggert (R-IL-13), Eshoo (D-CA-14), and Walden (R-OR-2) introduced H.R.493 on January 16. The next day, President Bush expressed his support for GINA during a visit to the National Institutes of Health. In the Senate, Senators Snowe (R-ME), Kennedy (D-MA), Enzi (R-WY), and Dodd (D-CT) introduced S.358 on January 22.

GINA quickly progressed in both chambers. On January 30, the House Education and Labor Subcommittee on Health, Employment, Labor, and Pensions heard the bill. The next day, the Senate Health, Education, Labor, and Pensions Committee approved S.358 by a vote of 19-2. On February 14, H.R.493 was unanimously approved by the House Committee on Education and Labor, the first of three committees of jurisdiction in the House. GINA continues its progress through the House and is expected to be heard in the Committees on Energy and Commerce, and Ways and Means in March.

As the Chair of the Coalition for Genetic Fairness, Genetic Alliance leads the fight for this important legislation. Within the first two weeks of GINA’s introduction, we mobilized over 200 consumer, industry, and professional organizations to send letters of support to GINA’s sponsors. These letters were critical to getting GINA started with a bang. We have kept up the momentum and contacted every member of Congress to ask them to cosponsor GINA. Volunteers have taken to the Hill and personally met with over 30 key offices to ask for their support. Members have been organized to contact their elected officials and ask for cosponsorship. Our multi-pronged strategy has resulted in over 210 House cosponsors and 25 Senate cosponsors for GINA. GINA is moving fast in both the House and the Senate for the first time in 12 years. We feel certain that the bill will pass this year!

You can help to boost support for GINA! Contact your members of Congress and ask them to cosponsor this important bill. Just follow these **five simple steps**.
Interested in learning more about GINA? Visit our page online for the latest information.

2007 Genetic Alliance Conference:
The Year of the Advocate

On July 27 – July 29, Genetic Alliance will hold its 2007 Annual Conference at the Bethesda North Marriott in Bethesda, Maryland. Like last year's conference, which was attended by nearly 300 advocates, health professionals, policymakers, industry professionals, and community leaders, the 2007 conference will provide an outstanding opportunity to participate in cutting-edge workshops and insightful discussions. To learn about our symposia and conference tracks, click here.

Genetics Day on the Hill

Genetics Day on the Hill is an amazing opportunity to impact policy issues that affect all of us. On Thursday, July 26, 2007, we will take our cause to key policymakers and educate them about genetic diseases, genetic testing policy, and other issues of concern. Washington policymakers have the ability to make decisions that impact laws throughout the nation, but we will exercise our role in influencing those outcomes! For more information, please see our website.

Gala 2007

Genetic Alliance celebrates The Year of the Advocate in 2007! Kicking off five days of events, we will celebrate the year with a gala on Wednesday, July 25 at the Galleria at Lafayette Centre in downtown Washington, DC. The Gala provides an opportunity to applaud the leadership and strength of our members and recognizes the critical impact Genetic Alliance makes in genetics and consumer advocacy. Join us for a fun evening, including a banquet dinner and cocktail reception. Genetic Alliance extends a special invitation to our members, industry partners, friends from Capitol Hill, and others who have helped shape our legacy as a leader in genetics and consumer advocacy. For more information, please contact Hanaa Rifaey at hrifaey@geneticalliance.org.
Genetic Testing Policy

Genetic Alliance testified at a meeting held by the Food and Drug Administration (FDA) about its draft guidance on in vitro diagnostic multivariate index assays (IVDMIA) on February 8. In more than 30 presentations, stakeholders expressed concerns about the guidance.

The IVDMIA guidance was released on September 5, 2006 along with another draft guidance on analyte specific reagents (ASRs). We drafted comments on both guidances and submitted them on the March 5 deadline.

Genetic Alliance leads the consumer community in developing dialogue and policy on this issue. On November 6, 2006, we hosted a webinar featuring speakers from consumer groups, industry, research organizations, and government. Earlier, in October 2006, we launched the Consumer Taskforce on Genetic Testing, a group of consumer leaders. The Taskforce will lead further cross-sector dialogue about genetic testing regulation and generate recommendations from a consumer perspective.

Want to learn more about genetic testing policy? Please visit us [online].

Membership Drive 2007

Now is a more exciting time than ever to participate in Genetic Alliance activities. Throughout 2007, we will be reaching out to you, our members. Find out about our new trainings and tools and how to update your Disease InfoSearch entry online to receive a discount on your conference registration. If you haven’t heard from us already, expect to do so in the next few months. In the meantime, involve more of your staff and volunteers in our Strategies for Success series, Advocates Partnership Program, Conference, Gala, Genetics on the Hill Day, and other great events. Our amazing opportunities are open to everyone in your organization!

Out & About

GA at NCHPEG

In February, Sharon Terry gave a plenary address on the Access to Credible Genetics Resource Network (ATCGRN) at the National Coalition for Health Professional Education in Genetics (NCHPEG) Conference. Sharon described the tools that the ATCGRN project is creating to set standards for accurate, credible information on single-gene disorders. She also introduced the concept of social network analysis and distributed a...
survey so that we could begin to map a network of the genetics community.

Genetic Alliance also participated in the NCHPEG poster sessions. Karen White, Director of Education and Information, presented a poster on *Understanding Genetics: A Guide for Patients and Health Professionals*. James O'Leary, Program Manager, presented a poster on the *Community Centered Family Health History* project. Both posters engendered a good deal of interest among conference participants.

**Living Profiles Project**

James O'Leary traveled to the Art Center College of Design in Pasadena, CA to share his expertise in family health history, community-based research, and genetic and rare conditions. The project, entitled Living Profiles, is funded by the Robert Wood Johnson Foundation and aims to create a transmedia system (such as iPod and iTunes) that would allow teenagers to collect their family health history as part of a personal health record. Genetic Alliance is a subcontractor on this project.

**Meet New Staff and Interns**

**Catherine An** joined Genetic Alliance in January as executive assistant to Sharon Terry. Catherine hails from Northern California, where she attended the University of California at Davis and studied English, sociology, and cultural studies. After graduation, she worked in journalism, public radio, and most recently was a program specialist for a civic education nonprofit in Sacramento, California.

A newcomer to the East Coast, Catherine looks forward to life in Washington, DC and her role as part of the Genetic Alliance team. She is eager to learn about public policy, federal government, and distinctive seasons.

**Amanda Shreders**, who joined Genetic Alliance in January, is our new Spring intern. Amanda’s internship focuses on the social network analysis we are conducting for the Access to Credible Genetics Resource Network. Originally from Connecticut, Amanda is now a senior at Marymount University in Arlington, Virginia with a major in biology. Next year, Amanda plans to start medical school; she has already been accepted at the American University of the Caribbean! Her plans include a masters in public health.

**Upcoming Teleconference Schedule:**
Money Matters II: Grant Writing Tutorial
Wednesday, March 21 at 12 noon EST (call-in)

With special guest presenter:
Laura DeShano, CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder)

To register for this exciting session, click here.

Celebrating our Leaders:
Candice and Crystal Sipe

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.

“Reach for the stars and miracles will find you; reach for each other and you will find the STARS!”

-Donna Apell

Candice and Crystal Sipe, HPS Network

Candice and Crystal Sipe are true STARS of the Hermansky-Pudlak Syndrome Network. They light up our souls with their music and shine brightly as our advocates. We are honored to have them as our ambassadors as they continue to educate the world about Hermansky-Pudlak Syndrome through their songs of hope and inspiration.

G.Advocacy is a monthly electronic newsletter distributed by Genetic Alliance. If you know someone who might also like to receive the newsletter, please feel free to forward him/her this message.

If you received this from a friend and would like to subscribe, sign up here.

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