Dear All,

Welcome to the “Year of the Advocate”! As we envision this, our 20th year, we envision an intentional surge of leadership in our community. Our culture will abound with excellence in leadership. We have all founded organizations and managed organizations, research projects, member services and education programs that have changed our communities. What if we stood shoulder to shoulder together and taught each other who we are? What if the leader within each of us was available to all of us? Pause a moment and ask yourself: what can I do unencumbered, with all the resources I need? Now characterize that vision, and we will plan the next steps together. Board and staff at Genetic Alliance are spending the fall in intense strategic thinking mode – thinking about you, our community and our world – and are ready to go to the next level together. We will change the future for leadership, for advocacy, and for all those affected by genetic conditions!

Warmly,

Sharon Terry,
As Dr. [Francis] Collins sang his song, I looked around the room, seeing you and the others who have overcome such great hurdles sing, smile and laugh...I was overcome with heart-felt emotion...I know I will make "lemonade" from yet another lemon that life has thrown my way; this time it is nice to know that there are support, resources and it does not have to be such a lone journey as it has been in the past.

—Gala attendee

Michele Lloyd-Puryear and Hanaa Rifaey at the Gala on September 27th.

The Genetic Alliance Gala was a community celebration of leadership. Advocates, health professionals, policymakers, industry professionals, and community leaders came together to recognize Genetic Alliance's first 20 years of accomplishments and look forward to future successes. Guests viewed the spectacular leadership exhibit featuring leaders from over 70 organizations, shared a meal, danced, and had fun!

Genetic Alliance Out & About

- **Genetic Testing Policy Webinar**: The FDA Guidelines on Genetic Tests - Preparing our Community to Respond: this virtual meeting will be held November 6, 12-2 pm EST.
- **James O'Leary** and **Hanaa Rifaey** were the
Genetic Alliance presence at ISONG, the International Society of Nurses in Genetics, in New Orleans, October 7-10.

- **Genetic Alliance and Advocates Partnership Program** participants attended the American Society of Human Genetics Conference in New Orleans, October 10-13.

- **Lisa Wise** was chosen to represent Genetic Alliance at ICORD-- the International Committee on Rare Disorders, October 25-26 in Madrid, Spain.

- **James O'Leary** made a presentation at the Heartland Collaborative Genetics Consortium Conference in Omaha, Nebraska, September 28-29.

- **James O'Leary** also presented at the National Nursing Stakeholders Meeting on October 23.

- **Hanaa Rifaey** will be in Marrakech, Morocco November 13-15 for the conference: Strengthening Newborn Screening in North Africa and the Middle East.

---

**Capitol Corner**

**Genetics Day on the Hill**

Genetics Day on the Hill was a smashing success with over 100 participants from Genetic Alliance’s diverse community of advocates, industry, research, and academia descending on Capitol Hill on September 27. The event began with a brunch briefing on key policy issues by Sharon Terry, President of Genetic Alliance; Dora Hughes, Legislative Assistant to Senator Barack Obama (D-IL), and Brian Petersen, Deputy Legislative Director to Congresswoman Judy Biggert (R-IL). Next, all participants worked with leaders who guided them through the schedule of six meetings with key Hill staffers. Finally, the event wrapped up with a debriefing and special group photo opportunity in front of the Capitol Building. Together, we promoted our message on genetic testing and genetic nondiscrimination policy to over 80 key officials and secured five new cosponsors of the Genetic Information
Mark your calendar’s for next year’s Genetics Day on the Hill – July 26, 2007!

Genetic Nondiscrimination Policy

The Genetic Information Nondiscrimination Act (H.R. 1227) continues to build momentum as the 109th Congress wraps up. With only a few weeks left in a lame duck session, the need for action on H.R. 1227 is greater than ever. In an effort to build support for the bill, Genetic Alliance has led the Coalition for Genetic Fairness in mobilizing grassroots stakeholders to take action on this important issue.

To date, 242 members of the House of Representatives have cosponsored H.R.1227. All members of the genetics community can help to grow this number and push for passage of the Act. To learn more visit Genetic Alliance’s Action page.

Genetic Testing Policy

Genetic testing is emerging as a national policy issue. Over the past few months, the genetics community’s activity with key government agencies -- the Centers for Medicare and Medicaid Services (CMS) and the Food and Drug Administration (FDA) – has increased dramatically.

In June, a letter in support of a genetics specialty under the Clinical Laboratory Improvement Amendments (CLIA) from Genetic Alliance to then CMS Administrator, Mark McClellan, elicited a negative response from CMS officials. Oddly, an identical request was sent to McClellan by the Genetics and Public Policy Center to which CMS gave a more positive response. Genetic Alliance has paired with the Genetics and Public Policy Center in asking CMS for an explanation of inconsistent response to written public appeals for such a policy. In addition, the two organizations have joined Public Citizen in a joint citizen’s petition to
Over 100 Genetics Day participants brought their message to Congress on September 27.

As many members of Genetic Alliance’s community have expressed interest in taking a formal stand in support of such action, Genetic Alliance is offering a sign-on letter to which member organizations can add their name by November 1. View the sign-on letter and further details on getting involved here.

Genetic testing has also been a hot topic at the FDA, where officials have proposed guidances on regulations for specific genetic tests. The guidances were released on September 7 and are open for public comment until December 6. One guidance concerns a category of diagnostic tests referred to as in vitro diagnostic multivariate index assays (IVDMIA). This subgroup includes genetic tests derived from in vitro assays and an algorithm for the purpose of obtaining clinical information that may lead to diagnoses or treatment. The other guidance concerns FDA’s position on commercially distributed analyte specific reagents (ASRs) and the role and responsibilities of ASR manufacturers. ASRs are the building blocks of laboratory-developed tests.

In an effort to educate its members about these policy issues, Genetic Alliance has invited FDA officials and genetics community leaders to present their points of view during a webinar on November 6 from 12-2pm EST. All members of the Genetic Alliance community are invited to call in for this special opportunity. To participate, RSVP with your name, organization, and full contact information by email to Email address protected by JavaScript. Please enable JavaScript to contact me. or call 202.966.5557 ext. 205.
Genetic Alliance is fortunate to have two talented interns this fall, whose hard work and energy have enhanced the services we offer. We're pleased to introduce Andria Cornell and Rebecca Sample.

Andria Cornell is pursuing a B.S. in biological sciences and a dual minor in business administration and art history at George Washington University. She came to Genetic Alliance to gain insight into the fields of genetic counseling and health care policy, and to learn how to view the health sphere from the patient's perspective. Andria is currently deciding between entering a genetic counseling program and medical school after graduation. She is originally from St. Paul, Minnesota.

Rebecca Sample is from Annandale, Virginia and graduated from the University of Virginia in Charlottesville this past spring with a bachelor's in biology and a focus in bioethics. She is currently planning to pursue a master's degree in genetic counseling, and has come to Genetic Alliance to gain a more in-depth appreciation for the community of patients and professionals she hopes one day to serve.

Strategies for Success

Upcoming Teleconference Schedule:

What Separates Quality Information from Junk: A Metric for Assessing Information on Genetic Diseases – Wednesday, November 15 at noon, EST.

Developing Quality Information on Genetic Diseases: A Toolkit for Making Sure the Bases are Covered – Wednesday, November 29 at noon, EST.

Creating your Organization's Brochure: Literacy, Levels and Look - Wednesday December 6 at noon, EST.

To register for any of these sessions please send the session title, your name, organization and full contact information to Email address protected by JavaScript. Please enable JavaScript to contact me. or call 202.966.5557 ext. 205.
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.

Credits
Editor: Karen White
Contributors: Lisa Wise, Orkideh Malkoc and Sharon Terry
Webpage: Kim Puchir

Copyright © 2004-2006 Genetic Alliance, Inc. All rights reserved. ISSN 1933-4176