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Welcome

From the President's Office:
The leaves have changed and the new season nudged us back indoors. While we’re sad to lose the daylight, we’re eager to hunker down and work in earnest through the winter. The overwhelming success of the conference offers ample inspiration for what lies ahead. The Genetic Alliance, with a newly tooled mission, enhanced technological platform and the largest, most skilled staff to date, is poised for the best year ever. With that, I’m delighted to introduce our newsletter, G. Advocacy.

Some of you may remember The Alert and many have asked that we bring the newsletter back to life. We’ve met the challenge and raised the bar. This HTML E-letter underscores our work and the forward thinking technological advancement we’ve worked

Member Success Spotlight:
BARTH Syndrome Foundation

By: Shelley Bowen, President

At the Genetic Alliance annual conference in Washington DC this summer, I was one of dozens crammed into the 2 part Board Basics meeting with Gene Early. Even though we wanted to take in as many workshops as possible, I rounded up the rest of my board for part two of the session. My reasoning was strategic: the Barth Syndrome Foundation (BSF) was at a critical crossroads and the board needed to provide the organization the leadership needed to make major progress. I knew in an instant that with Gene’s guidance, our board could do anything.

With some finesse, and even some subtle pleading, Gene agreed to join the Barth board meeting we held in conjunction with the Genetic Alliance conference. With a simple two-hour gift of his time, Gene opened up an entire world of possibility and made clear the work it would take to realize it. We pleaded again, and invited him to the board retreat we were planning a few months later; he had no idea just what he agreed to.

Gene asked us to read Jim Collins’ management book, Good to Great in advance of our meeting, just as he had with the Genetic Alliance Board of Directors. We were all speed-reading to get ready for our September 24 gathering in Cocoa Beach. With Gene Early en route, along came Hurricane Jeanne. We rushed to change locations to a site in Orlando. But Jeanne “got wind” of our plans and changed her directions as well. Charged with urgency, I called a board member and announced, “you have one hour to find somewhere in the US safe from natural disaster for us to hold this meeting.” We decided on NYC.

Our meeting was designed to give us the tools to become a group that escalates from “Good to Great.” The work wasn’t easy. In fact, at times it was painful to lay our hearts on the table and concerns about issues that could impede
so hard to achieve over the last six months. Let’s talk about content. Each season we’ll feature an article about a member organization, keep you abreast of Congressional issues that need your attention, update you on upcoming events and highlight important developments in the field. We can’t think of a better way to stay in touch. The Genetic Alliance membership represents a powerful community of individuals living with genetic conditions. This newsletter should raise our spirits, keep us engaged and give us tools for our hard work. Look forward to finding it in your “in” box at the start of each season. Of course, if you have comments or feedback, we’re always happy to hear them.

Warmly,

Sharon Terry, President/CEO Genetic Alliance

the growth of BSF. Our first meeting was in the living room of the home of two of our Board members, the next day we were in a church and the last day of our meeting we overlooked Ground Zero. The scene was set, our resolve was certain and in the end, we made tremendous headway in becoming the group we envisioned.

The board of BSF is now looking forward to translating our new vision to our volunteers. We’re already planning our fourth workshop with Good to Great as our underlying philosophy. We’re incredibly proud of our accomplishments and grateful to the Genetic Alliance for the collective wisdom and leadership it represents. At the recent GA conference, I was thanked by another member for making our documents so transparent. So many other groups have courageously opened up their own process as they evolved; it is our responsibility to do the same. Though we are all in this for different causes, one fact remains - each of us is working to improve and save the lives of those we serve. The Barth Syndrome Foundation wishes the best to everyone in their organizational growth and adventures. Please call on us if we can help.

Editor’s Note: The Genetic Alliance is creating a Board Incubator - a program designed to increase the capacity of nonprofits through the kind of dynamic, intense hard work that Shelley describes here. Working with Gene Early, the Genetic Alliance Board and Staff are actively seeking funding for this program. In its initial phase, we will enroll six of our member groups. Stay tuned for descriptions and application materials!

Staff News

The Genetic Alliance would like to offer a warm welcome to the newest members of our team, Ngozi T. Robinson and Gwendolyn Hanh Ho.

Ngozi will take Project Connect to the next level as our new Director. Prior to coming to the Alliance, Ngozi worked as a program manager, facilitator and conflict resolution specialist. She has worked extensively on issues relating to race relations and cultural diversity. For two years she was on the staff of the Network of Alliances Bridging Race and Ethnicity at the Joint Center for Political and Economic Studies. There she helped to build from the ground up a network for community-based racial healing and youth-based organizations across the country and internationally.

Most recently working as a consultant, Ngozi provided services in: conflict resolution & facilitation; non-profit program management; web production and graphic design. She focused on contracts to: develop and launch

Sharon Terry: First Ever Advocate to Hold Gene Patent

Sharon Terry is the first known lay advocate to hold a patent on a gene, more specifically the gene that caused her two kids to develop PXE (pseudoxanthoma elasticum). The staff and board of the Genetic Alliance would like to applaud this recent accomplishment. Clearly the hard work and dedication of patient advocacy groups can make a marked difference in the course of scientific research both nationally and internationally. More importantly, Sharon notes that for her family, a PXE diagnosis was overwhelming if not devastating. “I have a strong recollection of sitting with a close friend and sobbing. And now, our kids even think PXE has opened the world to them in a way they would not have had an opportunity to engage in without it!” Sharon’s dedication has cleared a path for patient advocacy groups to have an even more significant impact on research. This is a stepping stone for all of us.

Congratulations, Sharon!
new programming; use her expertise in social justice and web-based technology; do significant research and writing; use her advanced facilitation and conflict resolution skills.

Ngozi received her Bachelor of Arts degree from Trinity College in Washington, DC and has a Masters of Science degree from the Institute for Conflict Analysis and Resolution at George Mason University in Fairfax, VA.

We would also like to offer a warm welcome to Gwen Ho, Executive Assistant to Sharon Terry. Gwen brings a wide range of non-profit experience and scientific curiosity to Genetic Alliance. She is a recent graduate of Johns Hopkins University with Bachelor’s degrees in Biophysics and History. She has been involved in numerous service and advocacy groups throughout college, especially those that involve human rights and healthcare. She has also worked in academic research labs at the Johns Hopkins Medical School and Hospital. Recently, she completed an internship at the Jessie Smith Noyes Foundation in New York City. Originally from San Jose, CA, Gwen is excited about the prospect of working at an organization such as Genetic Alliance in the heart of Washington, DC. She is eager to not only contribute her skills and experience to supporting the work of Genetic Alliance’s advocacy groups, but also to capitalize on the rich resource of knowledge and perspectives here.

Congressional Corner

Update on Genetic Nondiscrimination Legislation

The 108th Congress closed and it did not pass legislation to protect us from genetic discrimination. Although the Senate passed a bill (S.1053) 95-0 in October 2003, and President Bush supported such legislation, the House has not moved any bill to the floor for consideration. We worked hard all year, including holding a press conference in April and sending a letter with over 1000 signers to the Hill. We look forward to forging a plan early in 2005 to make sure the 109th Congress passes genetic nondiscrimination legislation. Stay tuned for next steps!

Update on Open Access

This year, the House Appropriations Committee recommended that the NIH create a plan for access to journal articles. Dr. Elias Zerhouni held several sessions to listen to the needs of all sectors of the community. He posted a plan - to ask that all journal articles resulting from NIH funding be deposited in PubMed Central after six months - on the NIH website for public comment. He will make a decision soon as to the best course of action, based on the comments received. We look forward to access to the articles we need to do our work!

Contacting Congress

To call your Senator or Representative to urge their support of this or any legislation, you can simply call the Capitol Switchboard at 202.224.3121. Ask to be transferred to your Representative or Senator’s office. If you do not know who your representative is, you can go to www.congress.org, enter your zip code and the site will automatically generate a list of your federally elected officials along with their contact information.

Connecting Communities at the Annual Conference

The overwhelming success of this year’s “Joining Our Journeys” conference was due in part to the outstanding representation from diverse communities. GA project partners from African American communities in Flint and Lansing, Michigan; an American Indian community in Pueblo Laguna, NM; and a Latino community in Washington Heights, NY added their voices to the chorus of consumer perspectives. These experienced advocates educate their communities about genetics and health and increase awareness about genetic disorders. The adult and youth participants left the conference with a clear resolve; their communities have a critical contribution to make to the genetics dialogue.
During the conference, advocates from different countries, cultures and ethnicities were united not only by their common ancestry, as pointed out by Steve Olson, but also by their common commitment to see that the promise of genetic advances become a reality. The inclusiveness of this year’s conference was the latest example of GA’s commitment to reach out to underserved populations and increase the diversity of the genetic community. Next year will be even better. After all, genetics is about all of us.

In the Incubator

The Genetic Alliance Membership Department is pleased to continue our educational forum series. We will host the Incubator Forum at our offices and via teleconference. These lunchtime meetings are an opportunity for participants to get more detailed information on a variety of topics that relate to organizational development, research and science, and public affairs. Forums are held the 2nd Wednesday of each month at the Genetic Alliance offices.

Winter Schedule:

January 12th 12:00PM EST: Strategic Planning
February 9th 12:00PM EST: Grant writing with Susan Dickinson
March 9th 12:00 PM EST: Introduction to the Interactive Guide

G.Advocacy is the monthly newsletter distributed by the 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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