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At Last! Spring

Sharon Terry, MA, Genetic Alliance President & CEO:
As we greet spring, I find that warmer weather inspires me to linger over a brave daffodil and slow down a bit on the dog walk. I’ve also noticed that the longer days have the Genetic Alliance staff operating in a higher gear, bringing a tremendous amount of growth to our organization. With our Membership Department gaining strength and momentum, and with the addition of our newly formalized policy department, we continue to cultivate our mission.

With this issue of G.Advocacy I want to extend two very important invitations. First, I’m pleased to announce Genetic Alliance’s annual conference. As you know, our annual meeting is the signature event for membership. This year we promise to deliver our best work yet. I invite all members, partners, and supporters to attend: Leadership in Alliance, Leveraging Voices, Advancing a

Member Spotlight:
Crohn’s and Colitis Foundation of America (CCFA)

By: Rachel Jacobson, Genetic Counseling Student, Johns Hopkins University/NHGRI

About a month before beginning my Masters training in genetic counseling this fall, I got some upsetting news: the digestive troubles I had been experiencing for the previous five years could not be chalked up to stress after all - I had Crohn’s disease. Because I had spent some of my undergraduate days doing clinical research on the genetics of Crohn’s, I knew all too well what this diagnosis could mean.

The initial shock set in as I uprooted myself and settled in Baltimore to begin my studies. While I knew I was lucky to find a gastroenterologist who was patient and kind, I was beginning to realize just how big an adjustment this would be for me. When my medications failed to keep things under control, and when the stress in my life compounded the problem, I turned to haphazard Google searches, looking for any information that might ease my mind. I did not find much relief.

I had been doing a rotation at the Genetic Alliance for about 3 weeks, learning about how valuable advocacy groups can be for families facing genetic conditions, when I finally stumbled upon a brochure for the Crohn’s and Colitis Foundation of America (CCFA). The fatefulness of the situation dumbfounded me; here I was struggling to cope with my new diagnosis while at the same time sifting through hundreds of pamphlets designed for exactly this purpose. While I had done research on the genetics of inflammatory bowel disease (IBD) in school, and while I was well aware of the genetic component, I never thought about searching for a support group.

I joined CCFA at my first opportunity and I discovered that I was in good company; the CCFA has a proud membership of 50,000. Though the organization has a relatively long history - founded in 1967 - and enjoys a sizable budget - 100% of which comes from donations - their challenges and goals are strikingly similar to fledgling organizations that have only a handful of
Vision. This year's conference reflects Genetic Alliance's power as a representative organization by creating unique opportunities for networking with industry, policy leaders, government officials, and other member organizations. Leadership in Alliance brings to the forefront the core of our mission-serving our membership. We need you there to make it work.

My second invitation relates to our Policy Department, an important feature of our conference this year. In particular, we will highlight the critical role Genetic Alliance has played in the Coalition for Genetic Fairness, formed to ensure the passage of genetic information nondiscrimination legislation. I invite you to lend your voice to this very important effort by joining the Coalition. For more information, check out the Congressional Corner or the Coalition's website.

The most important ingredient to our success as a member-based organization is just that, the membership. We look forward to serving you, I mean, seeing you in July!

Warmly,
Sharon Terry

Genetic Alliance Continues to Grow!

We are very excited to introduce two new staff members at the Genetic Alliance. Chances are that you have heard from them on the MemberForum or Action Team lists already, but if not, keep your eyes open for excellent work from these two dynamic additions to our family.

Emily Alfano, Policy Coordinator

Emily brings to the Genetic Alliance a passion for policy work and a great scientific curiosity. She is a recent graduate of the University of Maryland, College Park, with a Bachelor of Arts in English Language and Literature. Although her focus was primarily English, Emily's coursework reflected her strong interest in public policy, science, and medicine. In addition to her work in the classroom, she gained affected families. CCFA's mission includes a dedication to improving the quality of life of those affected through education and support, but their main focus is funding research to find causes, treatments and a cure for IBD. In fact, they have raised over $100 million to this end.

Most recently, CCFA demonstrated its clout as the organizing force behind the effort to pass the Research Review Act. This important legislation specifically addresses the exorbitant expense of IBD treatments and the reimbursement problems IBD patients face as they take their claims to insurance companies.

Though I have only been a CCFA member for a month, I am already keenly aware of the benefits such an organization provides. Of course, having a large organization advocating for me on both the research and policy fronts is essential. But, on a more personal level, the organization - and its informative website - was able to open my eyes to a whole range of opportunities for me to become my own advocate. I do not have to rely on my doctor to tell me the best ways to cope, and I no longer have to spend hours of my time sifting through the latest IBD research on medical websites. Thanks to CCFA, I am confident that I have the tools to make decisions for myself and to be proactive about making the best out of my situation.

I am extremely grateful to have had the opportunity to be a part of the Genetic Alliance, an organization dedicated to increasing the capacity of organizations like CCFA. I now understand, in a very real way, the tremendous value of their work.

Congressional Corner

Prenatal Screen Legislation Introduced in the 109th Congress:

In March, the Prenatally Diagnosed Conditions Awareness Act was introduced in both the Senate [S. 609] and the House [H.R. 1353]. The aim of this legislation is to increase both the quality and quantity of information and support services offered to patients receiving a positive test result for Down syndrome and other prenatally diagnosed conditions. The bill strives to increase information about prenatally diagnosed conditions, allowing for more accurate monitoring of trends and the ability to provide patients with more effective healthcare. Currently, Genetic Alliance is providing a forum for discussion on this topic on our Public Health Action team. Stay tuned
invaluable political experience as an intern for United States Senator James M. Jeffords and non-profit advocacy experience as an intern in the Communications Department at the National Women’s Law Center. Originally from East Calais, Vermont, Emily is excited to begin work as a member of Genetic Alliance's policy team. She is dedicated to Genetic Alliance’s mission of advocacy, and is eager to learn from the organization’s diverse membership. Emily can be contacted at 202.966.5557 x201 or emailed at ealfano@geneticalliance.org.

James O'Leary, Program Coordinator
James offers the Genetic Alliance a considerable enthusiasm for both genetics and policy and by now, you have probably all heard from him at one time or another. James is a recent graduate of the University of Delaware with Bachelor's degree in Biology concentrating in Cellular & Molecular Biology and Genetics. While in Delaware, he gained significant research experience, specifically research relating to the study of Pseudoexfoliation Syndrome. Prior to joining us, James served as the volunteer coordinator for "PA Victory '04" a group supporting the John Kerry Presidential campaign in Berks County, Pennsylvania. James hails from Allentown, PA, and is very excited to be living in urban, Washington DC. James can be contacted at 202.966.5557 x206 or emailed at joleary@geneticalliance.org.

Help Build Family History’s Bright Future
At our upcoming annual meeting, "Leadership in Alliance," we plan to build on last year's successful sessions on genetics and underserved underrepresented communities (UUCs). To do so, we are offering a day-long concentration on these issues in addition to some exciting, new initiatives.

One of the issues we plan to focus on is our Family History Initiative. Family History is one of the most accessible and useful healthcare tools available, but in order for it to make a difference to both healthcare delivery and outcomes in UUCs it needs to be more easily customized. At the conference, Genetic Alliance will kick off a year-long initiative to develop a cultural competency "How-To" guide for the Surgeon General’s Family History Tool. The goal of this project is to create a document that will allow each community to customize the Family History Tool to meet their own unique needs.

Open Access
Genetic Alliance is pleased to report that, on February 3rd, the National Institutes of Health (NIH) announced a new policy regarding the accessibility of published articles resulting from NIH-funded research. NIH has created a policy that asks scientists to submit their published articles to PubMed Central (PMC) within twelve months of the date of publication. While article submission is not required and the onus is on the authors, we are hopeful that this policy will bring us closer to the day when we all have access to the knowledge that cutting-edge, taxpayer-funded research provides. Together with the Alliance for Taxpayer Access, we continue to work hard for open access. This may be a good step along the way - time will tell.

Genetic Information Nondiscrimination Act of 2005 [S. 306, H.R. 1227]:
On February 17th, the U.S. Senate passed the Genetic Information Nondiscrimination Act of 2005 [S. 306] by a vote of 98-0. On March 10th, an identical piece of legislation [H.R. 1227] was introduced in the U.S. House of Representatives. Currently it's in three committees and has 70 cosponsors. The Coalition for Genetic Fairness, a group of consumers, advocates and industry members led by Genetic Alliance, is thrilled with the support - both governmental and grassroots - that the Genetic Information Nondiscrimination Act has received to date. We are committed to seeing this bill signed into law this year, and we are actively working toward that goal. The time to act is now! Please join the Coalition and stay tuned for further updates and action alerts.

to our website for progress on this legislation.
In addition, the conference will also highlight successful strategies on UUC outreach around genetics, conduct an open project/community needs assessment, host a facilitated networking session, test-pilot our soon-to-come Technical Exchange Bank, and much more. Planning is still underway and we are sure the day will be fantastic. We hope you can join us!

**In the Incubator**

The Genetic Alliance Membership Department is pleased to continue our educational forum series. Forums are held the 2nd Wednesday of each month at 12:00PM EST at the Genetic Alliance offices.

**Upcoming Schedule:**

*May 11: Making Contact in the Electronic Universe: How to maximize your effectiveness in internet-based communication* - Michelle Brown, Genetic Alliance

*June 8: Genetics 101* - Joann Boughman, American Society of Human Genetics

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**Memberforum Cyberchats**

What is a Cyberchat you ask? It is an interactive dialogue on the MemberForum listserv that lets you ask questions of an expert on a certain subject.

**This spring we will be focusing on science.** Ever get tripped up over science terminology? Ever wonder which new technologies are the most promising for which diseases? Ever just want to know more about what is going on in the wide world of genetics? Well, here is your chance to find out. We encourage you to look at the subjects below and write down any relevant questions that come to mind between now and then. It is our pleasure to provide access to such dynamic individuals... make sure you take full advantage of the opportunity.

**Upcoming Cyberchats:**

- **April 25:** *Epidemiology* - Teri Manolio, (NIH/NHLBI)
- **May 2:** *Genetic Testing Overview* (kinds of tests, uses, ethical issues) - Andy Faucett & Joe Boone, CDC
- **May 9:** *Microarray technologies* - Thane Kriener & Katie Buck, Affymetrix
- **May 16:** *Pharmacogenomics and Personalized medicine* - Patrick Terry, Genomic Health

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**G.Advocacy** is the quarterly 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.

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**Credits**

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