G.Advocacy Newsletter
Summer 2005

In This Issue
- Welcome from the President
- Spotlight: National Coalition for PKU and Allied Disorders
- Conference Program Highlights
- Congressional Corner

President’s Welcome
Dear Friends,
I hope your air conditioning is working, because summer is definitely here! For those of us willing to brave the heat and humidity, summer means picnics, baseball games, and, if we’re lucky, a trip to one of the most historically significant cities in the United States: Washington, DC.

Also this summer, in Bethesda, Maryland, just a few short miles from the Lincoln memorial and the Smithsonian, Genetic Alliance will host its annual conference: “Leadership in Alliance, Leveraging Voices, Advancing Vision.” This dynamic, content-packed conference is the defining event for both our membership and our partners. Without you, it just isn’t the same. So, if you’re thinking about coming but need a nudge to get you there, take a look at our conference program and check out some of the highlights in this issue of G.Advocacy.

Before your summer is all booked, make sure you mark July 28th – July 31st on your calendars. We’ll meet you at the door!

Warmly,
Sharon Terry

Member Spotlight: National Coalition for PKU and Allied Disorders

By: Matt Thomas, Genetic Counseling Student, Johns Hopkins University/NHGRI

One of the first genetic conditions I learned about in my graduate training was phenylketonuria, or PKU. Today, PKU can be identified through newborn screening programs, and controlled by a low-protein diet implemented shortly after diagnosis. As such, PKU is considered a tremendous success story for newborn screening programs and those who treat genetic conditions. Even so, the psychosocial impact PKU has on the lives of affected individuals suggests that additional support for children with PKU and their families is necessary.

While researching PKU as part of my graduate studies, I began an internship with Genetic Alliance. There, I spent much of my time working with Disease InfoSearch. It was through this tool that I discovered the National Coalition for PKU and Allied Disorders. Dedicated to “improving the identification, treatment, and management of PKU and [other conditions requiring a low-protein diet] through advocacy, education, and promotion/support of research,” the National Coalition for PKU, like Genetic Alliance, seeks to accomplish their mission through collaboration with other organizations that serve individuals with genetic conditions.

Among the activities conducted by the National Coalition for PKU is an initiative that aims to increase public awareness around the issue of newborn screening by providing information related to relevant legislation and media coverage. Another initiative unites affected families with others who have had similar, though not necessarily identical, experiences. National conferences and an email listserv, through which families can contact each other to share their stories and offer advice, provides additional support for individuals and families coping with a variety of diagnoses. Additionally, the National Coalition’s website contains resources for both families and health care professionals. Online, parents of a child with PKU can find answers to important practical questions, such
2004 Art of Listening Award winner: Steve Groft, with Wendy Chaite and Sharon Terry. More photos here.

My internship with Genetic Alliance opened my eyes to the full scope of resources available to those with PKU and other genetic conditions. I am confident that this experience has expanded my ability to pair affected families with the advocacy organizations, like the National Coalition for PKU, that are designed to meet their specific needs.

Conference Program Highlights - Leadership in Alliance: Leveraging Voices, Advancing a Vision

This year’s conference has more to offer than ever before, so much so that I don’t quite know where to begin! If I start with the tried and true, the Genetic Alliance Awards Dinner is up first. Every year we host this signature gala event to honor four individuals in the following categories: Art of Industry, Art of Reporting, Art of Advocacy, and Art of Listening. This is a wonderful celebration of individual and collective achievements. Read the full award descriptions and past winners here.

Now that you have nominated a friend and picked out an outfit, you can begin to prepare for this year’s exceptional networking and skill building opportunities. We have added an extra day to the conference, one that includes—but is not limited to—the Genetic Alliance Leadership Institute. Attendees will choose from a number of daylong workshops, all relating to governance or organizational development. Then, Saturday and Sunday feature an equally outstanding lineup of workshops centered around government and public policy. Highly regarded professionals with careers in public policy, genetics, and health care will lead these sessions.

While the fantastic conference workshops do not end here, this column must. But don’t worry, you can learn more from our online program.

See you in July!

Lisa Wise

Congressional Corner

Genetic Information Nondiscrimination

The Coalition for Genetic Fairness continues its efforts to ensure passage of the Genetic Information Nondiscrimination Act of 2005 [S. 306, H.R. 1227]. Since its passage in the Senate, this legislation has acquired 101 cosponsors in the House of Representatives (70 Democrats, 30 Republicans, and 1 Independent). Sitting in the Committees on Ways and Means, Energy and Commerce, and Education and Workforce, the most vocal opposition to date has been the US Chamber of Commerce and the National Association of Manufacturers (NAM). To ensure that the concerns of these employment organizations do not overpower the voices of the millions of Americans who fear genetic discrimination, the Coalition needs your help!

In order to help fund our efforts, Affymetrix has generously issued a challenge: they will match up to $10,000 in contributions made by nonprofits and individuals! We have already received contributions totaling $2,800. Your contributions today provide the funding necessary to ensure passage of substantial Genetic Information Nondiscrimination legislation this year.
Stem Cell Research

On May 24, 2005, the US House of Representatives passed two pieces of legislation addressing the issue of stem cell research. The more controversial bill, The Stem Cell Research Enhancement Act of 2005 [H.R. 810], reverses an executive order issued by President George W. Bush early in his first term by requiring that the federal government allocate funds for embryonic stem cell research (as opposed to limiting embryonic stem cell research to the stem cell lines already in existence). H.R. 810 passed by a vote of 238-194 and was sent to the Senate for consideration.

Also taken up by the House was The Stem Cell Therapeutic and Research Act of 2005 [H.R. 2520], a measure that would establish a nationwide cord blood stem cell transplantation system. Less controversial because it advocates the use of adult stem cells and stem cells from umbilical cords rather than those from embryos, H.R. 2520 passed the House by a vote of 431-1.

In the absence of federal funding, state legislatures across the country are taking up the issue of embryonic stem cell research. California, Connecticut, Massachusetts, and New Jersey, for example, are already working toward allocating public funds for embryonic stem cell research.

The National Institutes of Health: PubChem

In 2004, as part of the NIH’s Roadmap Initiative to speed the translation of new medical treatments and improved health care to all Americans, NIH launched an online database called PubChem. Focusing on small molecules that can be used as both research tools and as drugs, PubChem seeks to incorporate chemistry into biomedical research on a large scale by providing access to basic information about these molecules.

Recently, however, the American Chemical Society (ACS) has expressed concern that PubChem will threaten the financial stability of their Chemical Abstracts Service (CAS). (While access to the PubChem database is free, CAS charges a fee.) NIH maintains that PubChem and the CAS databases are complimentary rather than duplicative, but ACS has demanded that PubChem be substantially altered or shut down entirely so as not to compete. Currently, no resolution with ACS has been reached, and some members of Congress have considered offering language for the NIH appropriations bill that would restrict the growth of PubChem. Such language would devastate PubChem and the Molecular Libraries Initiative.