The Advocates Training Partnership Program

Program Focus

In 2005, The American Society of Human Genetics (ASHG) and the Genetic Alliance established a program called the “Advocates Training Partnership Program” that encourages leaders of advocacy organizations to attend the ASHG Annual Meetings. The Genetic Alliance has a membership of >600 organizations, representing millions of consumers, patients, and their families. Advocates at the 2005 meeting were from organizations including The Birt Hogg Dube Family Alliance, Canadian Retinoblastoma Society, Cardio-Facio-Cutaneous Syndrome, Cornelia de Lange Syndrome Foundation, Costello Syndrome Family Network, the Foundation for Nager and Miller Syndromes, PXE International, Sudden Arrhythmia Death Syndromes Foundation, and the Spinal Muscular Atrophy Foundation. The goals of the advocates program are to

Provide access for leaders of advocacy organizations to the science and scientists of special interest to their group;
Encourage interaction between the lay organization leaders and the scientific community;
Offer opportunities for leading scientists to converse with these lay leaders in informal settings at the Annual Meeting; and
Identify common goals and challenges that can be better addressed through partnerships, including funding enhancement and policy efforts, improved access to patient populations, and opportunities to serve as scientific or medical advisors for local or national groups.

The success of this program will depend on the long-term relationships started during these face-to-face interactions and the strength of collaborations that result. This Society News strives to inform ASHG members of the program and to encourage interaction with the advocates attending this year’s meeting in New Orleans. Our initial effort was considered a resounding success, with very positive feedback from all who participated (scientists and advocates alike), and resulted in the initiation of at least one new collaboration between a scientist and an organization. In fact, the Advocates Program has been adopted by the American College of Medical Genetics for their annual meetings in the spring of each year.

Program Process

Each year, the ASHG Advocates Program application process begins in July, and 10–20 advocates are accepted into the program. Advocates pay their own travel and per diem expenses, whereas ASHG provides full registration for the meeting. Each advocate is expected to attend an orientation conference call and the daily briefings at the convention site. A brief tutorial is provided on how to navigate the Web-based meeting program and planner.

At the end of each day’s sessions, advocates gather with several scientists (e.g., members of the Board of Directors or Program Committee) in a designated room at the convention center. The scientists may start the discussion with brief comments about new findings or innovations presented that day that they considered of special import or interest. Very quickly, the conversation becomes engaging, and points of mutual interest to both the scientific and consumer groups are discussed and/or debated. Not only are exciting research results explained, but issues such as enrollment in research and clinical trials, identification of patients with rare disorders, patient perspectives on counseling and research, and funding challenges are also actively addressed. All participants then write a summary of their meeting experience for their own organizations, using whatever venues are available to them (Listserv, newsletter, etc.).

Genetic Support Groups

The Genetic Alliance provides a vibrant home for consumer genetic support groups, where their ability to influence the direction and pace of research, public policy, and health-care services is highly valued. Participation is encouraged. The goal of these groups is to build the capacity of their memberships, thereby providing information to the public and raising awareness of the needs of their special populations. Under the umbrella of the Genetic Alliance, these groups become empowered to face new challenges, shoulder new responsibilities, and overcome seemingly impossible obstacles.

Building Bridges

The scientific community cannot succeed in a vacuum. Recruitment of subjects for research in population- and disease-specific projects, patients for clinical care, and families for investigation can be greatly enhanced via knowledge of and working relationships with specific advocate organizations. To garner enhanced resources for the funding of research, as well as to influence policies that recognize and encourage responsible research activities, the message of the scientists is much more effectively stated—and certainly more noticed—if the message is delivered through consumer and patient groups. Our combined efforts will be much stronger than separate voices in many important spheres of influence. In addition, the educational goals of ASHG will in part be addressed by enhancing the partnerships with these groups, since they represent parties invested in having the very best and newest basic and clinical information possible.

ASHG is pleased to have initiated this Advocate Training Partnership Program, and we encourage all scientists attending the meeting to welcome the Advocates to our meeting in New Orleans.

JOANN A. BOUGHMAN
Executive Vice President
American Society of Human Genetics

Am. J. Hum. Genet. 2006;79:188–188. 0002-9297/2006/7901-0026$15.00