The Advocates Partnership Program: Connecting Consumer Advocates with the Regional Collaboratives, Clinical Geneticists, and ACMG Leaders

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In March 2010, for the fifth consecutive year, the American College of Medical Genetics (ACMG) teamed up with Genetic Alliance to sponsor the Advocates Partnership Program at ACMG’s Clinical Genetics Conference. The Advocates Partnership Program is specifically designed to provide leaders of genetic advocacy organizations with an opportunity to connect with genetics professionals and the ACMG leadership. It offers participants an unparalleled opportunity to network with other advocates and with genetics professionals from around the world. Funding for the program is provided by the National Coordinating Center (NCC) for the Regional Genetic and Newborn Screening Service Collaboratives—housed at ACMG and supported by the Genetic Services Branch in HRSA’s Maternal and Child Health Bureau—and by Genetic Alliance. The NCC provides registration and travel support and Genetic Alliance is responsible for all program logistics and offers a stipend for participants. Several Regional Collaboratives matched the stipends provided by Genetic Alliance for the advocates from their regions.

Eight representatives of advocacy organizations participated in the Advocates Partnership Program at the ACMG Clinical Genetics Conference, held this year in Albuquerque, New Mexico. The diversity of the participants—including their conditions of interest, the communities they represented, and their engagement in local, state, national, and international initiatives—contribute to the richness of the discussions and the shared learning throughout the program. Additionally, four family members (including a 17-year-old daughter with interest in the field of genetics, a parent, and two spouses) accompanied advocates to share in the significance of the experience and offer support.

The first day of the Advocates Partnership Program began with introductions, an overview of the ACMG conference highlights, and strategies for successfully getting the most out of the sessions. Genetic Alliance staff and ACMG faculty shared what they were most excited about for the conference and, guided by the interests of the advocates, discussed sessions and workshops in detail and provided insider tips for networking at the meeting. Later in the evening, over an informal dinner, participants shared brochures from their organizations, their personal stories, and what they hoped to come away with after the five-day conference.

One advocate wrote: “The question I had hoped to answer in respect to participating in the program was, ‘will the current study of genetics make a difference in my consumer advocacy work and the cause I serve?’ In particular for people with intellectual and/or other developmental disabilities and their families there is, perhaps, an even more emotionally charged underlying question: ‘do you fully understand why me or my child is challenged?’ I found the answer to the first question to be a resounding YES, and the answer to the second question to be essentially the reason we were all in the program.”

Throughout the conference, the Advocates Partnership Program offered exclusive daily briefings with ACMG faculty, the HRSA Genetics Collaboratives’ leadership, and a wide range of clinical genetics professionals. Discussion in these one-hour meetings was often prompted by questions from the advocates in response to presentations they attended or conversations they joined or overheard. Guest speakers answered questions, provided insights from their personal experiences, and facilitated discussion about how advocates’ work can impact genetics professionals—particularly in the Regional Collaboratives. The advocates found these lively and thought-provoking discussions energizing and empowering and reported that their perspectives and input were highly valued by the guest speakers. They described the speakers as “caring,” “warm,” and “really wanting to make a difference for
families.” One advocate wrote: “I was impressed with the speakers...in addition to being knowledgeable about his/her particular study or field, it seemed as if our dialogues were genuine and open. Additionally, I didn’t have the impression that the speakers were guarded in communicating.”

Themes that arose in the discussions included:

- The importance of case management for families;
- What it feels like to know more than some professionals do about the health condition your child has been diagnosed with; and
- The relationship between the disability community and the genetics and newborn screening communities.

One discussion session focused on the importance of cultural competency training for professionals, with a Navajo participant sharing his experiences with a provider around his daughter’s diagnosis. Participants noted on numerous occasions their surprise at the commonalities in gaps and needs that were identified across conditions.

Many advocates stated that one of the beneficial outcomes of participating in the Advocates Partnership Program was networking with meeting attendees. Advocates met professionals working on their condition of interest or representatives from industry developing a treatment for their condition of interest, and they shared information with them about their organization’s initiatives. Having a forum to share and explore together, however, proved to be most valuable. In response to a question about preparing for participating in the Advocates Partnership Program, distributed at the end of the conference, one participant wrote, “I don’t think I could have prepared for just how helpful the informal sessions would be.”

At the conclusion of the conference, the advocates came away with ideas for new collaborations and outlets for their energy. One advocate said, “I was quite charged about changes we need to make at my nonprofit to incorporate what I learned!” In response to learning about advancements in the genetics for her particular condition of interest, another advocate shared, “I will go home to encourage our sickle cell families to become better advocates. We will work with them to know more about their disease and get involved with all the new changes.” All advocates felt that attending the ACMG Clinical Genetics Conference and participating in the Advocates Partnership Program made them want to keep learning more.

The Advocates Partnership Program at the ACMG Clinical Genetics Conference is made possible by the commitment of the HRSA Genetics Collaboratives and the NCC to engage consumers as partners in the advancement of genetics and newborn screening. The collaborations and ideas generated by the program enhance family and provider knowledge and awareness of key issues and challenges. At the same time, Genetic Alliance continues to engage the disease-specific organizations and the general public in the development of education and communication strategies and tools on a national level, while the HRSA Genetics Collaboratives provide an ideal setting for bringing ideas, information, and services to local communities.

2010 ACMG Advocates Partnership Program

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