PATIENT PERSPECTIVE

My Experience as a Patient Advocate Fellow

COLLEEN ZAK

I had the privilege and honor of participating in the Patient Advocate Fellowship Program for DIA 2012, DIA's 48th Annual Meeting. Through this program, DIA awarded a full meeting scholarship and one year membership to select patient group leaders.

What made this DIA conference experience so special? I was amazed, as a first time attendee, at the sheer number of participants: A massive 7,000 potential new contacts and networking opportunities for the rare condition I represent – Autosomal Recessive Polycystic Kidney Disease (ARPKD) and Congenital Hepatic Fibrosis (CHF). It was a treasure trove of potential collaborations.

But it was more than that. It was a life-changing experience! I was given access to a wealth of enlightening educational sessions that offered distinctive new perspectives from industry and drug companies, and from policy makers and regulators. I was exposed to fascinating information about research positioning, study designs and precision medicine. I found myself involved in one roundtable discussion with industry, and in another with DIA leaders, academia and the FDA. All were very accessible and willing to chat. They felt more like old friends.

I better understand bringing drugs to market, fast-tracking medications, funding and incentives for all parties, consortiums, protocols, and improving patient outcomes. It was impossible to participate in every session I wanted to attend, but the full meeting registration I received through this Fellowship also provides post-meeting access to all available PowerPoint presentations and corresponding audio for those sessions I could not attend, a goldmine for sure.

The disease I represent is symptom managed, which means that as symptoms occur, they are treated; there are no therapeutic treatments or standards of care. Yet rare and orphan diseases are "hot topics" right now. The industry community has interest in rare diseases like never before – for example, the FDA approved 26 rare disease drugs in 2011. Research, development and discovery are happening at a faster and faster rate. It is the "Era of Rare." But genuine progress always includes the patient's voice, expressed through patient advocacy organizations like the ARPKD/CHF Alliance, from the beginning to the end. For patient-centered care and research, knowledgeable patient input is critical.

Proprietary physician-owned registries and repositories can be difficult, time-consuming, and problematic to access and use. Patient data, however, is frequently owned and managed by patient groups or advocacy organizations, data that is fully protected, can be neutrally shared, and brings patients to an equal seat at the decision-making table. Patient-held data repositories and registries are vital resources for research and clinical studies.

Patient Advocate Fellows were treated with respect and our conditions received lots of media and news attention; some Patient Fellows even had the opportunity to be interviewed on television. We participated in private meetings and luncheons with VIP mentors and pioneers to discuss current trends, issues and strategies. As the leader of a nonprofit patient group, the information I received on patient-reported outcomes, how to strengthen our voice in true partnership fashion, and similar topics, was invaluable. I also gained like-minded friends.

We were always encouraged to talk about the patient perspective throughout the meeting, and I was amazed at the interest my story created for ARPKD/CHF while I visited company booths in the Exhibit Hall. This resulted in a several potential donations and funding leads, plus an invitation to speak in Europe as a patient representative. This meeting was so full of great ideas that I returned home with well over 100 new patient impact goals and considerations, such as our direct involvement in generating and validating biomarkers and clinical endpoints, to "repurposing" drugs for treatments. As a major FDA representative explained, repurposing drugs for treatment in response to patient advocates "happens all the time."

A colossal "Thank You" to DIA for making these opportunities, tools, and experiences possible. The feelings and emotions linger long after; my relationship with DIA will not end after DIA 2012. I've already signed up for several Special Interest Area Communities and as I continue to follow up on leads from DIA 2012, I realize that this conference will have long-term impact for those I represent. As a 2012 DIA Patient Advocate Fellow, I am forever grateful for your focus on the patient. The patient. THE PATIENT. ●

Colleen Zak, RN, BSN, serves as CEO of the ARPKD/CHF Alliance. Please visit the Alliance online at *www.arpkdchf.org*.

New DIA Office in Washington

Last year, DIA opened a satellite office in Washington, DC, to facilitate access to government agencies, regulatory agencies, and other organizations and potential partners with shared interests such as the Institute of Medicine and the National Institutes of Health. This satellite office has just been relocated to new and improved office space.

Effective August 1, DIA's new Washington location is
1000 Connecticut Avenue, NW
Suite 900
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