

Attending a Patient/Provider Conference Powerful Patient, 2009 Week 28

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What's it like going to a patient convention? Is it good or bad to meet others with your disease? Joyce speaks with Brian and MaryLou who attended the Annual Meeting of the VHL Family Alliance in Anaheim, California, in June 2009.

Patient/Providers Conferences

The VHL Family Alliance has held patient/provider conferences annually since 1994. The first time they met, people were shy, as most of them had never met another person with von Hippel-Lindau disease outside their own families. By the second day, however, people came wearing their VHL T-shirt, and were sharing stories about their surgeries and finding other people with similar issues.



Left to right: Camron King, Chairman of the Board of VHLFA; Calvin Cieslak, Woodland Hills, CA; Dr. Michael Yeh and Dr. Allan Pantuck of UCLA; Michelle Cieslak, Director of VHLFA; Joyce Graff, Executive Director of VHLFA

The doctors who have attended have always thanked us for inviting them. They are usually astounded to find the level of interest in the room, and the level of understanding of the scientific information presented. Patients are hungry for the information, and doctors are more than willing to share if asked the right way. Researchers are inspired to meet the people who are eagerly awaiting the success of their research. One researcher once said to Joyce, "I feel like going right home and spending Sunday in the lab! This is not just about writing papers, there are real people who really need what I'm working on."

Finding Fellow Travelers, Making Friends

Not only is there important information to be gained from the doctors, there is nourishment to be gained from the other patients. Just knowing you are not alone is the first and most important thing you take away. By the end of the meeting, you gain lots of hugs. You hear stories that sound a good bit like your own, but with a few new twists that may give you insight into your own situation. You learn new questions to ask your doctor, and new strategies to try out.

If you would like to see the presentations from the Anaheim meeting, please go to the Video Learning Center at the VHL Family Alliance website, where there are videos of the various presentations, including two particularly important ones on nutrition to support the immune system. See http://vhl.org/videos/2009_anaheim