Learning More and More at Each Symposium
By Christina Hom

It has been several years since I attended a conference about my disease. I remember my first Wegener's (WG) Symposium was to give me hope. The next Symposium, I went to educate myself about Wegener's and found myself reaching out to others as well. This year I attended the Vasculitis Foundation's 1st European Patient's Symposium to broaden my horizons about vasculitis and learn about becoming proactive in caring for myself.

Meeting others with different vasculitides, along with the medical presentations and personal conversations gave me the "bigger picture" of my WG. For example, an "ah-ha" came to light while watching slides explaining vasculitis and different types using the illustration of a puzzle and its pieces.

At this symposium, although we knew the topic, we didn't always know the medical specialty of the physician who was presenting. This was an advantage, as we were not limited by our questions to a specific organ or its treatment. For example, a nephrologist mentioned that lung biopsies can be done two different ways and one of them has more false positive results. Much important research and technical information was shared.

It was interesting to hear the different philosophies, the dosage markers in treating vasculitis from a European standpoint, which are not the same as in the United States. Certain medications are used significantly more in Europe, such as Rituxan that is produced in the United States. Markers for using prednisone looked at minimal doses versus none.

One of the sessions I attended was on "Quality of Life and Lifestyle". This included comments from patients and reference slides from Dr. Gary Hoffman's study of "reduced daily activities by 80%". Some countries, such as Holland have patient education programs in this area.

The tables at the closing celebration dinner were set for special guests with fine china, and a gourmet meal. Can you imagine starting off with "Avocado, Wild Mushroom & Potato Gateau with Fresh Asparagus Vinaigrette"! Food helps people to relax and converse. It was a real eye opener for me to learn that my seated Churg Strauss neighbor and I both have legs that suffer from peripheral neuropathy and our legs have involuntary leg movements especially at rest.

I picked up a 20-page booklet by the Stuart Strange Vasculitis Trust on Living with Vasculitis. I quote" Being diagnosed as having vasculitis often involves change and uncertainty of some sort or another. .....Finding out information about your condition is an important way of helping ourselves. It is just as important as keeping active, taking prescribed medication and learning to listen to your own body. Please remember that living with vasculitis requires a team approach and you are a vital member of that team." I am so grateful to those who made this seminar possible.