The University of Pittsburgh Asthma Institute@UPMC/University of Pittsburgh School of Medicine is used to getting patients from across the United States and Canada. These patients come for answers on lung disease and also to participate in research studies. But traveling halfway around the world, from a country “down under”, just to participate in a study of severe asthma?

**Rochelle Munro** recently elected to do just that! Rochelle is an early childhood teacher from Rotorua, New Zealand who developed asthma at the early age of 3. However, she was not diagnosed with severe asthma until the age of 18. Rochelle quickly found out that her severe asthma was not at all like “usual” asthma. It interfered with her life on a daily basis, could be life threatening at times and clearly did not respond well to usual asthma medications. Frustrated with countless failed attempts to find out why her asthma isn’t improving and growing tired of her questions being unanswered from doctors in New Zealand who, like many doctors, know a lot about asthma but not necessarily severe asthma, Rochelle took control of her situation.

She turned her computer on, typed the words “recent research for severe asthma” in the search engine and the link that caught her eye was Dr. Sally Wenzel’s research with the NHLBI and NIH funded Severe Asthma Research Program (SARP) study at the University of Pittsburgh Asthma Institute. After reading through our website, Rochelle decided to contact us. Rochelle reviewed study information and exchanged emails with Dr. Wenzel and her staff. After thoroughly reviewing all information, Rochelle had to decide whether to make the journey or not. For most clinical trials, compensation is only provided for the study visits and parking. Since Rochelle lives in New Zealand, she would have to take care of airfare, hotel accommodations and meals, all out of her own pocket. This was a big and very scary decision to make. However, after a year of saving, she finally decided to move forward with her trip. After all, efforts to find answers about her asthma that she had been seeking and the hope to get her life back were clearly the most important steps she felt she could take.

Rochelle started her monumental journey with a four and half hour flight to Sydney, Australia, followed by a thirteen hour trip to Los Angeles, California, and another four hours to Pittsburgh, Pennsylvania. Despite this exhausting journey, from the day she arrived at the Asthma Institute she felt welcomed by the entire staff and felt a weight lifted from her shoulders. “Dr. Wenzel was very approachable. She knew what I was going through and it was just nice to not have to explain every detail of my symptoms to her; she just got it”. Everything that was discussed prior to Rochelle’s visit involving her participation in the study was accurate. She “felt really good here. I felt as if I was being heard and taken care of in the best way possible. There were no surprises on the procedures that were discussed with me and I recommend other asthmatics that are looking for answers to take a chance and visit the University of Pittsburgh Asthma Institute. Dr. Wenzel just keeps it real with you”. Finding out why usual asthma medications didn’t work on her, why her asthma reacts the way it does, how severe asthma varies from person to person and how much remodeling/scarring was present in her lungs were just a few of the answers Rochelle found during her visit. Rochelle also knows that by pooling her results with many hundreds of other asthmatics that it is much more likely that new and exciting clues will be discovered and better treatments for severe asthmatics designed.

Since most of the procedures were performed during the day, Rochelle was able to explore the city of Pittsburgh by visiting the Incline on Mt. Washington, walking around Southside Works and taking a shuttle tour downtown close to the stadiums. While on this tour, she learned a little more of Pittsburgh when the shuttle driver pointed to the parking lot filled with Steeler fans and said “look at all the people tailgating” and Rochelle looked for cars that were driving too close to each other! When asked what she would like to say about her long distance travel to the Asthma Institute, Rochelle simply said, “Thank you for everything; it was all worthwhile.”

*Division of Pulmonary, Allergy and Critical Care Medicine*
The Asthma Institute Support Group took on the topic of communicating with doctors during emergency room (ER) visits. It can be challenging to get the best possible asthma care when meeting a doctor for the first time. We discussed the need for everyone to carry an ER Intro Letter to share with new providers. Dr. Sally Wenzel, Director of UPMC’s Asthma Institute, advised that these letters should be comprehensive but brief, with the most important information stated clearly. Some things to keep in mind when composing your ER Intro Letter:

- Include a summary statement about the severity and length of illness, any history of hospital admissions, and recent test results.
- List the medications that you have responded best to in the past.
- Describe how you have treated medication side effects in the past.
- Detail your current home treatment regimen.
- Include the name and contact information for the main physician in charge of your care and how to reach the doctor.

Some other tips participants shared include:

- Keeping this information on one’s computer/phone with regular updates
- Making sure your care partner has a copy of this information as well, in hard copy or online
- Determining whether your own physician is available to call ahead to the ER to advise them on the best course of treatment for you.

We hope participants in this group will continue to use it as a resource for sharing their experiences and suggestions on living with asthma.

To join the group or receive more information please send an email to: gillmanda@upmc.edu or call Dr. Gillman at 412-864-2404.