Advocacy Follow-up

January’s advocacy follow-up call, in fact, touched upon a number of topics. We used a portion of the call to reflect upon our December conversation with Heather Snyder, on her suggestions and how they may be taken up by members our group.

Participants exclaimed over the way Heather has been fighting for so long in so many ways—for her diagnosis, and then for increased recognition of her illness (Idiopathic Pulmonary Fibrosis)—also with ongoing health concerns post-transplant. This led us to discuss a very real consideration in taking on advocacy tasks: setting realistic goals given your health status and energies.

One caller recalled organizing an ‘asthma team’ for an American Lung Association walk-a-thon some years ago. She recalled the tremendous amount of work that went into it, the success of that day, but then feeling the momentum of the event fade away. For her part, she was not physically able to complete the walk.

Advocacy: Different Approaches

Debby Gillman, Psychologist with the UPMC Asthma Institute, reflected that while this was one model of advocacy—one involving a large effort for short term impact, and also requiring a great physical effort—there are other models to consider, ones with lower risk of burn-out. Efforts including outreach calls, letters, and individual meetings, can also have an impact and may be less physically exhausting.

In recent months, two of our group members wrote letters to the president of the Asthma and Allergy Foundation, to call attention to the needs of severe asthmatics, but had not heard back. We then discussed the importance setting concrete, measurable goals for outreach efforts. For example, is the short-term goal to speak or meet directly with someone in an organization? If so, decide your timetable and plan for following-up on letters or emails. Is a longer term goal to develop educational programs for health care providers? Then perhaps the first step is to develop a list of potential partners to target.

One participant recalled that a former physician had offered to be a resource for her, although he would not be providing ongoing care. She decided today to plan to speak with him to ask for help in building awareness of severe asthma, perhaps among local providers or medical trainees. Dr. Sally Wenzel, Director of UPMC’s
Asthma Institute, suggested asking providers about their professional affiliations. Regional academic medical centers, in particular, offer educational programs to providers at all levels, and often need topics for these programs. Building on Heather’s recommendation to make use of pre-existing resources where possible, Dr. Wenzel noted that it is hard to take up these efforts as one patient, in isolation, but that larger treatment programs have the resources to identify other patients with similar needs.

Dr. Wenzel recommended that one participant bring a research article on Asthmatic Granulomatosis to her physician, to educate the physician that the diagnosis of “asthma” includes a range of inflammatory diseases and that not every patient will respond to the same treatments.

**Telling Your Story**

We discussed whether anyone had begun, as Heather had suggested, writing down their own story as a first step towards developing a plan for advocacy. This is clearly an emotional challenge for many in our group. One participant reported a comment by her adult daughter about how hard life in their family has been, given her mom’s illness. This patient’s story would thus have to include all the other ‘moms’ who have helped her care for her daughters over the years. Other participants are considering telling their story through song or video.

Returning to the concern of how much time and energy are required for advocacy efforts, our discussion turned to participants’ ability to work or not, and the very difficult decision, in some cases, to apply for disability. This may be a topic to take up in depth in another Support Group call, as participants discussed the range of feelings connected to this decision.

**Support Group: Possible Next Steps?**

Participants shared the impression that asthma, as portrayed in the media, minimizes the serious of the illness in the public eye. One participant questioned Dr. Wenzel on the extent to which some respiratory health organizations recognize severe asthma and take it seriously. While there is recognition, she acknowledged that there is not, in fact, an organization that dedicates its attention to severe asthma, a condition that affects approximately two million people. The question arose whether our own group—or a subgroup of our participants—would wish to form a team for joint advocacy efforts. One obvious strength would be our geographic diversity. We agreed to keep this question on
the table for discussion in coming months, wishing also to maintain Support Group calls as a place to discuss a many aspects of living with severe asthma.