ASTHMA SUPPORT GROUP

They hailed from locales as far flung as California, Cincinnati, Buffalo, Atlanta, New Hampshire, Pittsburgh, Miami, and Canada, reaching out via conference call and Skype to share their experiences as severe asthmatics. Monday May 9th marked the newly revitalized Asthma Institute Support Group. Dr. Sally Wenzel, Director of UPMC’s Asthma Institute, facilitated discussion among thirteen participants from around North America, and posed the following questions for this first meeting: What is the biggest challenge you face as a result of your asthma? And how do you cope?

Challenges of Care and Communication
Participants shared their frustration with severe flare-ups lasting weeks, hospital stays, increases in severity of asthma with age, and steroid dependence. They sounded a common note of frustration with, as one woman stated, “Not being able to do what I want to do...Everyday things.” Participants reported struggling with the inability to engage in (or for adult-onset asthmatics, a reduction in) activities they love: “I used to hike.” “I used to run outdoors.” “I can’t sing how I would like to.” “I used to camp.” “I can’t keep up.” “I have to be careful about everything...I constantly feel I’m in a bubble.” Participants also discussed feeling, as one woman described, “mentally debilitated,” depressed, or anxious as a result of their disease. For another participant, who in addition to her own severe asthma is the mother of three severely asthmatic children, steroid use represents a defeat.”

These participants also shared the frustration of being misunderstood and poorly supported by some doctors, as well as by others in their lives, as a result of their asthma. It was agreed that many physicians are unprepared to manage severe asthma, particularly during an emergency room visit, and that physicians typically either overreact or underreact to exacerbations in severe asthmatics.

Participants also described difficulty communicating with others in their life about asthma, and the mistaken expectation that if asthma patients simply use their inhalers they will be fine. Unfortunately, according to Dr. Wenzel, the severe asthma community “is poorly served” by the extensive inhaler advertising in the U.S. that creates the impression that all asthma is so easily managed. Dr. Wenzel went on to describe how asthma is a more complex and diverse disease than many—both physicians and lay people—understand it to be. Childhood-onset asthma differs from adult-onset asthma, with the role of allergy components, family history, immune and inflammatory processes differing in each. This poses a challenge to researchers as well as clinicians.

Coping and Next Steps
How do severe asthmatics cope? Stated one woman, “I don’t quit... I am as active as I can be.” One patient “tries to do better record keeping” of symptoms and peak flow readings to better understand when she is at risk for an exacerbation. “I joke about it,” stated another participant. Participants described their efforts to avoid or reduce stress. As one woman stated, “If I do too many things...I will go downhill.” Others manage distress related to their illness with the help of psychotherapy and medications to manage anxiety and depression. Exercise helps, stated another participant, who also makes an effort to “try to relax, to get into a better place mentally.”

“It’s nice to know we are not alone!”
~Asthma Institute Support Group participant
May 9, 2011
Dr. Deborah Gillman, Clinical Psychologist, is now working with the Asthma Institute treatment team and is available to meet with patients during office hours at the Comprehensive Lung Center, Falk Medical Building, 4th Floor. She can be reached at (412)864-2404, at gillmanda@upmc.edu, or by speaking with your provider.

For information on any of our studies, please call the asthma research line at: 866-804-5278

How to address the difficulties communicating with others about their illness? It was suggested that group members could develop a shorthand guide to their treatment that could be presented to doctors who do not know them well. Indeed, this group offers an ideal format for asthma patients to share strategies for communicating with providers.

The Asthma Institute Support Group is scheduled to meet the third Monday of each month, from 6 – 7pm Eastern Standard Time. The next group is scheduled for Monday, June 20th. It is hoped that the meetings will incorporate discussion on special topics related to treatment, research, and living with asthma. Meetings will also permit participants to share their experiences and learn from each other. Participant feedback is welcome in planning for future meetings.

Meetings will be held at the Asthma Institute conference room, at 3459 Fifth Ave., Montefiore Hospital Building, 9th Floor NW, Pittsburgh. If you wish to receive email reminders in advance of the meetings please send your contact information to Deborah Gillman, Ph.D. at 412-864-2404 or gillmanda@upmc.edu.

To participate via Skype or Conference Call, please contact the Asthma Institute at: asthmainstitute@upmc.edu or 412-647-9955. Our Skype name is: asthmainstitute.

Non-Smoking Adults Diagnosed with Asthma Needed for Vitamin D Study

The Asthma Institute is recruiting patients for the VIDA (Vitamin D add-on therapy enhances corticosteroid responsiveness in Asthma) Study. Adults 18 and older who have been diagnosed with asthma and are non-smokers may be eligible for the study.

The purpose of this study is to find out if taking Vitamin D in addition to an inhaled steroid—the most effective treatment for asthma available today—will help prevent worsening asthma symptoms and asthma exacerbations in people who have low Vitamin D levels. This could be related to the increasing evidence that Vitamin D is a critical natural factor which reduces inflammation. “Despite how common asthma is, it remains poorly understood and, in many cases, poorly treated,” said Sally Wenzel, M.D., Director of the Asthma Institute. “The possibility that improving treatment may be as easy as taking a vitamin which is activated in the skin by normal exposure to sunlight is exciting.”

The VIDA Study is supported by the AsthmaNet Grant awarded to the Asthma Institute in 2010. AsthmaNet is funded by the National Heart, Lung, and Blood Institute of the National Institutes of Health. The University of Pittsburgh is one of nine AsthmaNet research sites across the United States participating in this study. The Asthma Institute will enroll approximately 50 subjects. Participants will be compensated. For more information, please call the Asthma Institute at 1-866-804-5278 or email us at asthmainstitute@upmc.edu.