Asthma and Advocacy with Guest Heather Snyder

In February 2011, Heather Snyder was critically ill with Idiopathic Pulmonary Fibrosis, a scarring lung disease, when she received a life-saving lung transplant at UPMC. Her life post-transplant has been marked by her dedication to education and advocacy for others with a similar diagnosis. As our conversations have turned recently to the topic of advocacy on behalf of severe asthma, we invited Heather to share her story and wisdom with us—for inspiration!

Heather began by describing the illness from which she suffered prior to her lung transplant. Idiopathic Pulmonary Fibrosis (IPF) is a rare lung disease of unknown origin, characterized by scarring of the air sacs of the lung. The experience of the patient with IPF is one of suffocating. Heather’s father had died of this disease in 1981 and she herself had the symptoms, and yet she was misdiagnosed with asthma for 10 years, given repeated breathing tests when she complained of inability to breathe, and treated with Prednisone. As her condition worsened, Heather eventually demanded a chest X-ray. Immediately prior to her transplant she was rushed by helicopter to Pittsburgh from Hershey, PA, was in full respiratory failure, and kept alive by machine, until donor lungs were found. Post-transplant, Heather was out of the hospital in 30 days, despite needing follow-up colon surgery and contracting a bad intestinal infection.

Heather says, “There are so many reasons I should have died.” She uses her trademark humor to cope with challenges, one at a time. “Attitude is Everything” is her motto. She believes she was born to be the kind of outspoken advocate for IPF awareness that she has become. In the year of her transplant, Heather spoke at events for the American Lung Association, the American Thoracic Society, and at the PA-IPF summit in Pennsylvania to raise awareness about Pulmonary Fibrosis. She has advocated on Capitol Hill for IPF research; established and participated in a 5K walk in her father’s memory; co-founded with her doctor a local support group for IPF patients; wrote a chapter for a book of testimonials about lung transplant; and worked closely with her state congressman on local Clean Air Act legislation.

Heather believes in “challenging people” to do things differently and states: “My vigilance is contagious.” Sally Wenzel (SW) asked Heather what is the one thing she is most proud of? Heather knows that because of her, there are hundreds and hundreds of people who are now better educated about IPF than they were.
For patients, this means knowing the importance of being treated at the right medical (transplant) centers. Social media has also been an important awareness building vehicle, also by sharing the stories of patients who have died. Her goal has been to make IPF—a disease not well understood or known by many lay people—a household name.

Heather’s vehicle for advocacy has been her personal story of illness, transplant and recovery. How did she get started? Heather’s first foray into advocacy began when she was invited by one of her UPMC providers to present at an IPF awareness-building event for Pennsylvania state legislators. With the help of a friend with audio engineering expertise, she created a video about her journey; Heather herself hid under the table during the audience’s standing ovation but after this event, took a position of “saying yes to everything,” meaning every opportunity or request that she can fit into her schedule (she works full time).

Debby Gillman (DG) inquired about the importance of using her story (as opposed to facts or statistics about her disease). Heather believes the personal story gives her message more weight. People who have a personal point of reference want to meet her and this gives them something to hang onto when taking her message forward.

We noted with some irony that while Heather’s goal is to make IPF a household name, severe asthma sufferers struggle with the fact that ‘asthma’ is too much a household name, and therefore patients with atypical and severe forms of the disease do not get the recognition they need. One caller—echoing what SW herself has argued—stated the importance of finding a new name for this kind of asthma. Other patients seconded the experience of being poorly understood by providers because they don’t present as typical asthma patients.

Heather acknowledges that her own story has its ‘feel good’ elements to it. SW asked this seasoned advocate how one would go about telling a story that is not so dramatic, thinking of the many severe asthma sufferers who have not experienced dramatic upturns in their care and health status, and who, in the eyes of the public, are lumped with other (healthier) asthmatics. Too often, the tendency among severe asthma patients has been one of turning inward, rather than taking a more vocal and assertive position.
Heather spoke to the importance of “defining yourself,” your own attitude towards your disease and your life. And she recalled a fellow-IPF patient who derived great benefit from their local support group in developing a more positive attitude towards living with IPF and going out into the world wearing oxygen.

Heather was asked to list her biggest resources. These included local physicians, including one with whom she has developed a close relationship and founded a local support group, the American Lung Association, the Coalition for Pulmonary Fibrosis, and the American Thoracic Society.

With this guidance, we discussed how severe asthma patients may:

- Approach physicians to inquire about speaking at MD continuing education sessions or professional gatherings. Said Heather “If you open yourself up to being a resource for the doctors, they can become resources for you!”
- Seek out opportunities to speak to other provider groups, such as respiratory therapists;
- Approach local chapters of the American Lung Association;
- Work through Asthma and Allergy Foundation of America (and special kudos to Support Group participants who have sent letters to the Foundation to call for more attention to severe asthma!!)

New advocates would do well to use their personal presence, share their stories, and take advantage of these and other organizations that have fundraising and other communications mechanisms already in place.

Where to start? Heather advises

1) Write your story down! This can be an important exercise in getting a script into your head that you can use in the future, whenever you need it, wherever you go.
2) Identify a place in which to focus your energies: perhaps contact your local media—who are always looking for stories of personal interest;
3) Contact your state senator. Heather has found a great ally in her senator. This can be a very effective way to start getting the word out about health-related topics that merit more attention
What about mentoring for advocacy? Heather was asked whether she modeled herself after anyone she knew—other transplant patients, physicians—and the answer seemed to be that Heather has truly carved her own path. She described how she is very careful to surround herself with people who challenge her to be a better person.

*The UPMC Asthma Institute Support Group is intended to provide support and information to the group’s participants. The professional guidance available through this group is not intended as a substitute for direct medical or psychological services.*