



Sandra Rock

IPF AND SEPSIS

“My sepsis attacks go something like this: I wake up to a normal day and the attacks can come anywhere, anytime. All of a sudden I start to shake all over, my heart rate goes crazy, my blood pressure plunges, then the fever and dry heaves set in.”

In 2001, I was diagnosed with idiopathic pulmonary fibrosis. I could not walk across the room without being short of breath. Back then, information on IPF was hard to find except these dreadful facts: three to five years to live, no FDA-approved treatment, and no cure, except through lung transplantation.

With the help of the Coalition for Pulmonary Fibrosis, I started the Central Valley Pulmonary Fibrosis Support group with another IPF patient, Kathy. We had five members at our first meeting. Over 10 years, the group had grown to more than 60 members and I calculated that I lost 103 members and friends, including Kathy.

Health-wise I was doing well until 2009, when I had toxic myelitis, a reaction to a medication, which inflamed my spine and left me paralyzed. I was in the hospital for eight days, and they also found a brain tumor on my spine, but I was too weak to have surgery.

I was diagnosed with a Merkel cell carcinoma, a rare aggressive skin cancer. Seven days after surgery, I had my first case of sepsis, a potentially fatal whole-body inflammation caused by severe infection. My sepsis attacks go something like this: I wake up to a normal day and the attacks can come anywhere, anytime. All of a sudden I start to shake all over, my heart rate goes crazy, my blood pressure plunges, then the fever and dry heaves set in.

In January 2010, I was finally strong enough to have surgery to remove the brain tumor on my cervical spine. I made it through 2012 without a sepsis attack, and regained about 75 percent of my motor skills. But in 2013, I had a staph infection on my skin in different areas of my body, and then had my worst sepsis attack, a very high fever over 104, and several more attacks that became more severe.

Sandra Rock

SEPSIS

The word sepsis comes from the Greek meaning “decay” or “to putrefy.” In medical terms, sepsis is defined as either “the presence of pathogenic organisms or their toxins in the blood and tissues” or “the poisoned condition resulting from the presence of pathogens or their toxins as in septicemia.” Patients are given a diagnosis of sepsis when they develop clinical signs of infections or systemic inflammation; sepsis is not diagnosed based on the location of the infection or by the name of the causative microbe. Signs and symptoms include abnormalities of:

- Body temperature
- Heart rate
- Respiratory rate
- White blood cell count

Forty percent of patients diagnosed with severe sepsis do not survive. Until a cure for sepsis is found, early detection is the surest hope for survival.

Source: Sepsis Alliance. “Definition of Sepsis.” sepsisalliance.org

I will never forget that during all this chaos my husband, Jim, gently stroked my hair, and whispered to me that I was going to be OK as he placed cold compresses on my forehead and lips; or my daughter Julia at my beside, reading and saying, “It’s OK, mom. I’m here go back to sleep.” Gradually my strength returned.

It’s been 10 months since my last sepsis attack. The daily dose of Keflex is keeping it at bay for now. My husband is my guardian angel and caregiver—his goal is to provide me with “maximum happiness” every day. Without his love and care, I wouldn’t be here today. Jim and I went on a cruise that we have been trying to arrange for the past six years, and we will soon celebrate 44 years of marriage.

The fear of another attack is always there but we have to try and lead a normal life. It is hardest on my family because they watch what’s happening to me: all the IVs, the swelling from the fluids, sweating from the fever, exhaustion from the heaving, knowing that sepsis is very serious and often deadly so they wait and wait.

How I’ve managed to live through six attacks astounds everyone, especially my doctors. My friends call me the “Energizer Bunny” or “Wonder Woman” and are amazed that I lug my oxygen all around—traveling, shopping, to festivals, fairs, concerts everywhere, and dancing in the park on Sundays with Jim. All I know is somebody up there is watching over me and there must be something else I’m meant to do in this lifetime—I wish I knew what it was!

Sandra Rock was a patient speaker at the ATS 2014 International Conference in San Diego.