

Katie Lessard

PULMONARY HYPERTENSION

"I was given much hope and I still have hope, even in rejection, that I will live many more years and will continue to thrive." I was a Navy helicopter pilot for nine years. In 2005, I ran in a San Diego marathon but started to notice that my running wasn't very good. I took a trip to Ireland and noticed how exhausting it was to climb stairs. I went skiing, and it was torture getting to the lift.

I mentioned my struggles to my flight surgeon and she began ordering tests. Everything came back normal. But she knew something was not right so she just kept ordering more tests. I eventually had an echocardiogram. The hushed whispers and the gathering of doctors and nurses around the echo screen told me they had found the problem. After a right heart catheterization, I was told that I had idiopathic pulmonary arterial hypertension.

The diagnosis was absolutely shocking. I didn't understand. I was healthy, I was a helicopter pilot, and I ran marathons. I was sent to University of California, San Diego and saw Dr. Nick Kim. I started oral therapies to battle the damage being done to my lungs. I told my then-boyfriend, Jeff, to run fast and far—this disease was going to get interesting! But he stayed by my side, and we married in September 2008.

A month later I was out for a walk and I started to feel weird. I stepped into the street and passed out. I woke up covered in blood and was surrounded by people. I had split my lip, ripped open my knee, and bruised up my face. I took a taxi to the hospital. After being stabilized, I was told that I was beyond their capacity and needed to be seen at UCSD exclusively. Dr. Kim wanted to start me on Flolan immediately. I agreed to the central IV. But I found the PEER mentor network and asked another PH patient about Remodulin. After talking with Dr. Kim quite a bit, I convinced him to let me try the IV Remodulin first.

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The cause of PAH is often difficult to determine. PAH can be from some known causes, such as inherited (called familial) PAH, or be caused by reasons that are never known (called idiopathic PAH). Other known causes of PAH (called associated PAH) are:

- Connective tissue diseases such as scleroderma or lupus
- Use of prescription amphetamines or diet pills
- Use of illicit drugs such as cocaine and methamphetamines
- Congenital heart defects
- · Liver disease/cirrhosis
- HIV

PAH is a serious disease that at this time has no cure but there are treatments available and new medications are in clinical trials. Early diagnosis and treatment are important to try to limit the progression.

Learn more: ATS Patient Information Series. "Pulmonary Arterial Hypertension" New York, NY: American Thoracic Society 2013. patients.thoracic.org

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Unfortunately, my husband had orders to Pensacola, Florida, and we had to move away. None of my doctors here were happy about it. There is a military program called Exceptional Family Member that is designed for people with exceptional medical cases, but it was too late. I was there for three years and got worse during that time.

When I was classified a Category 5 Exceptional Family Member we were able to get back to San Diego. I knew I wasn't doing so great, so I went to see Dr. Kim for right heart catheterization in April 2012, and he told me that I needed a lung transplant. I received a double lung transplant on June 23, 2012. I barely survived the surgery but was out of the hospital in 21 days. I went into chronic rejection due to acid reflux nine months post transplant. I had the Linx surgery and have been doing photopheresis. My lung capacity dropped by half from the rejection but I have gained a bit and am now at 40 percent lung capacity and am doing really well.

My experience with military health care has been a relatively good one. I absolutely would not be here today without the Pulmonary Hypertension Association and the doctors at UCSD. I was given much hope and I still have hope, even in rejection, that I will live many more years and will continue to thrive. I know there is still a long road ahead for better treatments, cures, and better prognoses, but I'm confident that there will be a better quality of life for all lung disease patients.

Katie Lessard was a patient speaker at the ATS 2014 International Conference in San Diego.

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