



# November is PH Awareness Month and CTEPH Awareness Day

## Could you have CTEPH? Find out with a V/Q scan

If you have pulmonary hypertension (PH), make sure you get tested for chronic thromboembolic pulmonary hypertension (CTEPH). CTEPH is a form of PH caused by chronic blood clots in the lungs.

The first step to identify or rule out CTEPH is a ventilation/perfusion (V/Q) scan.

A V/Q scan is a radiologic test that screens for chronic or undissolved blood clots in the lungs. The clots can lead to chronic thromboembolic pulmonary hypertension (CTEPH).

A V/Q scan takes two images of your lungs and compares them to each other: One identifies ventilation (air flow); the other, perfusion (blood flow). Both scans use nuclear imaging to take pictures of your lungs.

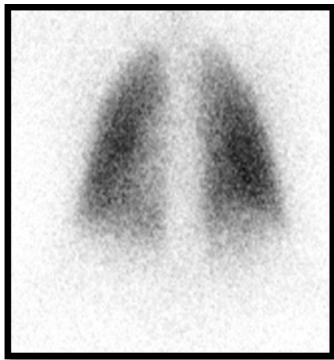
During the ventilation scan, you will breathe in a small amount of safe radioactive gas through a breathing mask or mouthpiece. Pictures from the

scan can show areas of the lungs that don't receive receiving enough or retain too much air.

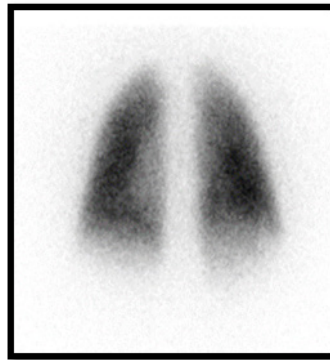
The perfusion scan shows where blood flows in the lungs. To check blood flow in the lungs, you will receive an injection of a safe radioactive dye, called a tracer, through an IV inserted in your arm. Pictures from the scan can show areas of the lungs that don't receive blood as expected.

If the lungs are working normally, blood flow on a perfusion scan exactly matches air flow on the ventilation scan. Areas that are ventilated but not getting blood flow (on the perfusion scan) are called mismatches and raise strong suspicion of blood clots.

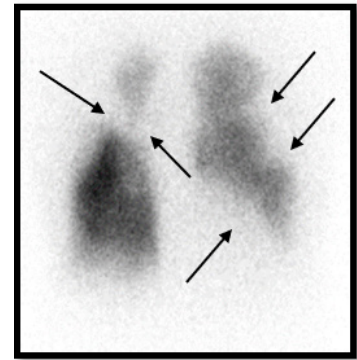
If your test is abnormal, you might need additional testing, such as a pulmonary angiogram. Your PH care team will be notified and will contact you with further instructions or treatment options.



**Figure 1** shows normal air flow in healthy lungs.



**Figure 2** shows normal blood flow in healthy lungs.



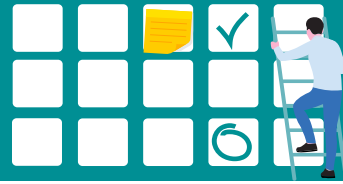
**Figure 3** shows white areas (indicated by arrows above) where blood clots are preventing normal blood flow through the lungs.

*Images courtesy of the Pulmonary Vascular Research Institute*



# Patient Story:

## Mark Porter



In July 2020, I started to feel short of breath. I was 46 years old and considered myself to be in-shape. My primary care doctor prescribed me an inhaler and some lung steroids to help with my breathing. This helped but by October, the treatments weren't providing any relief.

In early November 2020, I developed a limp and couldn't figure out why my right calf was swelling. By the week of Thanksgiving, I couldn't walk. I consulted the internet, which told me I had blood clots, and immediately made an appointment with my doctor.

My doctor examined my right calf and ordered an ultrasound. After the ultrasound, I had a CT scan, which revealed I had a large deep vein thrombosis (DVT) in my right calf from my knee to my ankle. More alarming, the CT scan showed a large saddle pulmonary embolism (PE) in my pulmonary artery. I was told to immediately go to a hospital, 30 miles away, that can handle any PE complications.

The hospital put me on blood thinners and medication to dissolve the clots. I was released the evening before Thanksgiving and was put on Eliquis to dissolve the clots. I was told I would be on the medication for six months and be back to normal within a few months.

In August 2021, I developed chest pain, shortness of breath and fatigue. I thought I had another PE. My doctor ordered another CT scan, ultrasonics on my right calf and a stress test. The scan didn't show anything new, and my heart looked fine. He said my chest pain might just be acid reflux.

By December 2021, my chest pain was unbearable. I saw another doctor as mine was on vacation. After reviewing my previous testing, they referred me to a cardiologist.

The cardiologist ordered blood work to find the reason for my initial blood clots. He also ordered several new tests like a V/Q scan and heart catheterizations. I was put back on Eliquis as a precaution. After additional testing and describing my symptoms, I was referred to a pulmonologist who works with doctors at the University of California San Diego (USCD) hospital.

In February 2022, I met with my pulmonologist and was diagnosed with chronic thromboembolic disease (CTED) and was in the process of developing chronic thromboembolic pulmonary hypertension (CTEPH). I was so excited and relieved to finally receive a diagnosis. My symptoms were real, and the doctors were there to help.

After three months of waiting, I received a call from Nick Kim, M.D. at USCD that they received my referral and wanted to schedule an evaluation. I had my evaluation on Aug. 23 and my pulmonary thromboendarterectomy (PTE) surgery on Aug. 30.

After the surgery, my surgeon, Michael Madani, M.D., FACS, said the surgery was successful and there was much more residual clotting in my lungs than the testing initially indicated. My entire right lung and most of my left lung was full of clots.

As of Sept. 30, I completed my second week at home post-surgery and notice a big difference in how I feel. I'm anticipating a full recovery in approximately three months and have ski trips planned for this winter. I'm confident I made the right decision to have the PTE surgery.

