

November is PH Awareness Month

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.

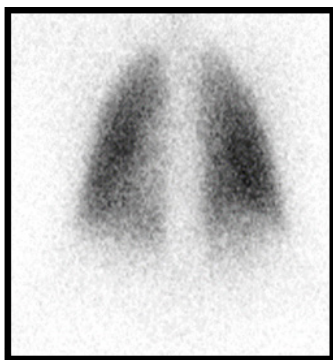


Figure 1 shows normal air flow in healthy lungs.

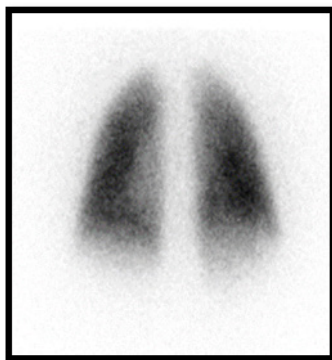


Figure 2 shows normal blood flow in healthy lungs.

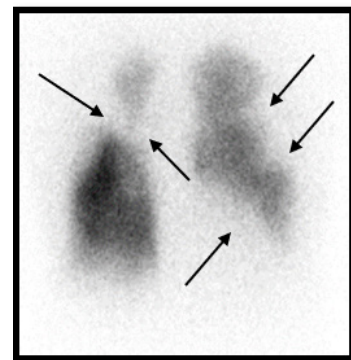
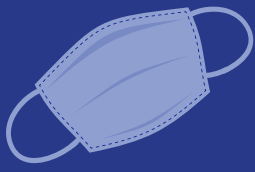


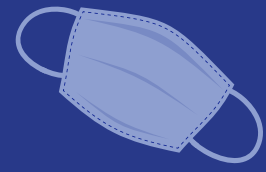
Figure 3 shows white areas (indicated by arrows above) where blood clots are preventing normal blood flow through the lungs.

Images courtesy of the Pulmonary Vascular Research Institute





Patient Story: Jamie Prettner



I was diagnosed with pulmonary emboli in May 2016 as a result of using birth control. I was hospitalized for four days, as the severity of the emboli was causing significant right heart strain.

When I was released, I was put on supplemental oxygen and blood thinners. A month later, I was able to get off supplemental oxygen. In December, I had a follow-up CT scan that showed the emboli had resolved. I was told I could discontinue blood thinners, but I was still experiencing significant shortness of breath and fatigue.

In February 2017, I was referred to a pulmonologist and underwent a V/Q scan. The scan showed chronic thromboembolic pulmonary hypertension (CTEPH).

My pulmonologist told me the best treatment for CTEPH was a surgery called a pulmonary thromboendarterectomy (PTE). During the eight-hour surgery, you are put on a heart-lung bypass machine, and your body is cooled down to about 68 degrees to protect the organs. Blood circulation is then stopped periodically

“These wonderful people gave me the hope and strength I needed to beat this disease.”

— up to 20 minutes a time — so the surgeon can get into the pulmonary arteries and remove the chronic clots. After all the clots are removed, your body is warmed to normal body temperature.

Due to the rareness of this disease, there were only two places in the U.S. that performed the surgery. After some research, I decided to have the surgery at the University of California-San Diego. After a successful surgery Aug. 1, 2017, I was released nine days later.



Jamie Prettner with her surgeon, Michael M. Madani, M.D., F.A.C.S.

I was grateful that PTE surgery actually cured my CTEPH. I will always have inflammation and pain from surgery and will be on blood thinners for the remainder of my life. But that is nothing compared to what PH patients go through on a daily basis.

I am extremely grateful to have my life back. Although CTEPH caused me a lot of pain, sadness and anger, it gave me the opportunity to meet amazing, supportive people through conferences and support groups.

These wonderful people gave me the hope and strength I needed to beat this disease. I will continue to volunteer my time and resources to help PH patients fight this difficult disease.