It is vital for all pulmonary hypertension (PH) patients to make sure that they have received all the necessary tests required for a proper diagnosis. To accurately diagnose PH, doctors must use a right heart catheterization. Every patient should also be tested to rule out the possibility of chronic thromboembolic pulmonary hypertension (CTEPH). For many, the first step is getting a ventilation/perfusion (V/Q) scan.

For essential information on accurately diagnosing PH and the recommended required tests, we strongly encourage you to visit: bit.ly/PHtests

FOR AN ACCURATE DIAGNOSIS, ASK FOR: A RIGHT HEART CATH & A V/Q SCAN

A ventilation/perfusion (V/Q) scan is the recommended test to rule out the possibility of CTEPH – a type of PH caused by blood clots that create a blockage in the blood vessels of the lungs.

A V/Q scan examines both the airflow (ventilation) and the blood flow (perfusion) in the lungs. To check airflow, patients breathe in a small amount of benign radiolabelled gas through a breathing mask. To check blood flow, patients receive a small amount of radiolabelled solution through an IV inserted into the arm.

During the V/Q scan, patients must lie very still on a table beneath a special camera (or sometimes sitting in a chair in front of the camera). The test takes about an hour as several images of each lung are taken from different angles.

Doctors then examine the black and white areas of the images to identify regions of the lungs that might have old blood clots. Where there is airflow or blood flow, the lungs show up as black. This indicates that the gas and solution were able to get into the lungs without encountering a blockage. White areas indicate places where there are blockages to blood flow into the lungs.

Each image features a different angle of the left and right lungs together, one lung in foreground and the other in the background.

The images labeled VENT are from the ventilation scan and show normal airflow in both individuals. The bottom four images are from the perfusion scan. The bottom two images for person A also show normal blood flow. The bottom two images for person B show limited blood flow and indicate the presence of blood clots.

When testing for the possibility of CTEPH, doctors are looking at scans that show normal airflow but obstructed blood flow. Based on the scans, CTEPH can be reasonably ruled out for person A, but cannot be ruled out for person B.

The V/Q scan is the first step to diagnosing CTEPH and tells doctors whether they can rule out the possibility of CTEPH. To diagnose CTEPH, next steps include more testing, such as a pulmonary angiogram. Some patients may also be eligible for a surgery to remove the blood clots and cure their CTEPH.
My name is Angela Michelle and I’m from San Antonio. I was diagnosed with chronic thromboembolic pulmonary hypertension (CTEPH) in January 2018 and had pulmonary thromboendarterectomy (PTE) surgery August 7 at University of California, San Diego.

I have experienced shortness of breath since 2013 when I had first had an episode of pleurisy. For years I was misdiagnosed. They attributed my shortness of breath to allergies, asthma or my weight. Then in 2016 I had a stroke and they found multiple pulmonary embolisms. They discovered I have Antiphospholipid Syndrome (APS), which is an autoimmune clotting disorder. I was started on blood thinners and I was told that the clots would resolve on their own and that my shortness of breath would get better once they did.

Another year passed, but I was getting worse and just walking across the room left me short of breath with a racing heart. Finally an old high school friend who had become a heart surgeon saw my Facebook posts discussing my health challenges. He wrote me to tell me that based on my symptoms and history of the clotting disorder he thought that I might have CTEPH. It was the first I had ever heard of it. I brought it up to my doctors here in San Antonio. They were skeptical because they either didn’t know much about it or they said it was rare and they thought it was unlikely.

I continued to get worse and was on oxygen 24/7 at this point. With the guidance of my friend, my persistence and finally getting into the right doctors, I had the necessary tests done to reach the diagnosis. Six months after first hearing of CTEPH I was finally formally diagnosed. Luckily I was a surgical candidate and here I am almost three months post op and my life has been changed. I can breathe again!

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