

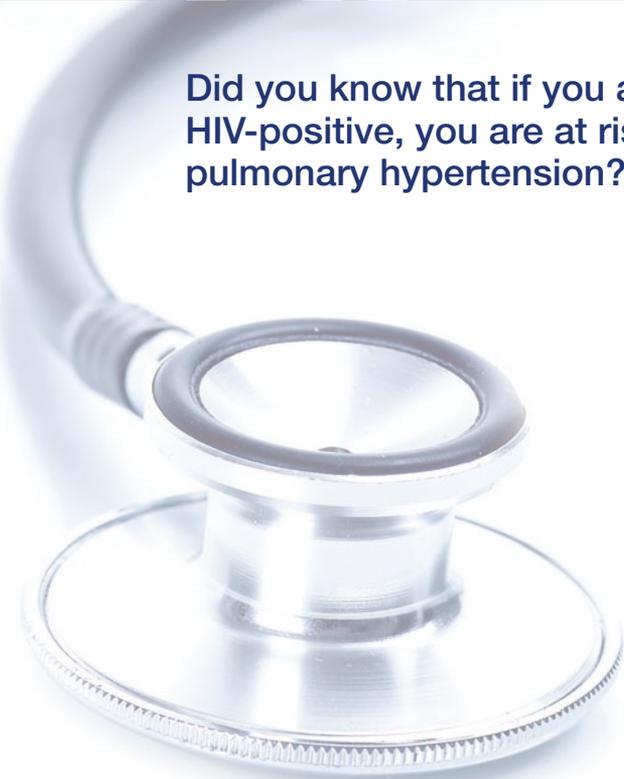
HIV

&

PH

Pulmonary
Hypertension

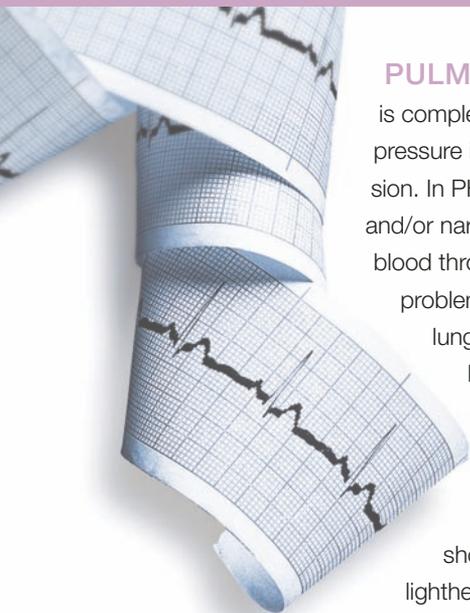
Did you know that if you are
HIV-positive, you are at risk for
pulmonary hypertension?



Pulmonary Hypertension Association
Empowered by hope

www.PHAssociation.org

About Pulmonary Hypertension



PULMONARY HYPERTENSION, OR PH,

is complex and often misunderstood. PH means high blood pressure in the lungs. PH is different from regular hypertension. In PH, the blood vessels in the lungs become damaged and/or narrowed and the heart has to work harder to pump blood through them. PH can be caused by many different problems such as heart failure, diseases that damage the lung or multiple hardened blood clots, to name a few.

It is important to understand that not all PH is the same.

PH affects people of all ages and ethnic backgrounds. The most common symptoms are shortness of breath with physical activity, fatigue, lightheadedness and sometimes fainting. Because these

symptoms can be caused by any number of other medical problems, diagnosis is often delayed. Identifying a case of PH can be difficult and may require a specialist. Once the type of PH is diagnosed, however, treatment can begin immediately.

One form of PH is called pulmonary arterial hypertension (PAH). PAH is a complex, progressive type of PH where the high blood pressure in the lungs occurs because tiny blood vessels that carry blood through the lungs (pulmonary arteries) are narrowed, thickened and stiff. As PAH advances, the heart may lose its ability to pump enough

blood through the lungs to meet the needs of the body.

There are several types of PAH. Idiopathic PAH (IPAH) means that the patient develops PAH without any other obvious medical problem leading to high blood pressures in the lung. Heritable PAH (HPAH) comes from abnormal genes that cause PAH. Heritable PAH may be passed on to some members of your family. PAH can be associated with other medical conditions such as connective tissue diseases (scleroderma and lupus for example), chronic liver disease, congenital heart disease, or HIV infection. Finally PAH can be associated with

past or present drug use, such as methamphetamines or certain diet pills. It is not known exactly how these medical problems or drugs cause PAH.

PAH is a serious condition, and without treatment, symptoms can only become worse, leading to heart failure and even death. Proper diagnosis and therapy from a doctor who understands PAH is essential. Every patient is different. The choice of treatment is based on how sick a patient is and the risks and benefits of any particular therapy. Regardless of risk, is it important that patients and their healthcare providers engage in frequent follow-ups with ongoing discussions about the management of their condition. Current guidelines suggest that changes in therapy should be considered for patients not reaching their treatment goals.

While no cure has yet been found for PAH, increased research has resulted in treatments that allow patients to live longer, fuller lives with far less interference from the disease. Even more promising research is being conducted every day that is not only advancing our understanding of the PAH disease but also potentially identifying new treatment options for patients in the future.



HIV-Associated PH

What do I need to know about pulmonary hypertension in connection with HIV-associated PH?

First of all, it is essential to know that pulmonary hypertension and HIV are two separate conditions, and that PH does not cause HIV. However, there have been HIV patients who have developed pulmonary hypertension. Scientists are continuing to study this to see if there is a connection, and what that connection might be.

The first case of pulmonary hypertension in an HIV-infected individual was reported in 1987, and since that time research has been ongoing. About 150 patients with HIV infection and pulmonary arterial hypertension have been reported since that time. It is possible that there are other unreported cases. Because the first several HIV-associated PAH cases that were reported had occurred in patients with hemophilia (a congenital tendency to

HIV-Associated PH (cont.)

have uncontrolled bleeding), researchers originally (and incorrectly) thought that the cause of HIV-associated PAH was the hemophilia itself or perhaps had to do with problems associated with the hemophilia. However, since that time, more HIV-associated PAH cases have been found in patients who do not have hemophilia at all. Therefore, scientists have decided that the development of pulmonary hypertension in HIV patients is in some way related to the HIV infection itself.

How common is HIV-associated PAH?

PAH is still an uncommon complication of HIV infection. As research into HIV continues and as new and better therapies are developed to combat the disease, HIV patients are living longer lives. As a result, the chance that an HIV-positive individual may develop PAH may increase as time goes on.

We can still safely say that PH occurs more frequently in the HIV-infected population than it does in those who do not have HIV. Thus, idiopathic pulmonary arterial hypertension (pulmonary hypertension that results from unknown causes, in this case an HIV-negative group of people), occurs less frequently than it does in those who are HIV infected. Those who are infected with HIV have roughly six to 12 times the occurrence of PAH than the uninfected general population.

Who is most susceptible to HIV-associated PH?

HIV-associated PAH occurs more frequently in males and in slightly older individuals than is usually seen in IPAH.

A high rate of stimulant use (methamphetamine or cocaine, depending on the region of the country) is common among individuals who are both HIV-infected and afflicted with PAH. (As a side note, intravenous drug use is also associated with development of pulmonary hypertension, even without HIV infection).

Does having HIV make PH worse?

There doesn't seem to be any data to indicate that HIV makes PH worse. The usual symptoms of HIV-associated PAH are similar to those in other individuals with PAH, shortness of breath being the most common.

Does PH make HIV worse?

It's hard to say. When tested, some HIV patients who also suffer from PH have lower pulmonary artery pressures than those who have PH alone. Despite this, their survival rate appears worse. Medical professionals are not sure whether this has to do with a combination of the two conditions, or whether other problems associated with HIV contribute to the lower survival rate.

Why do PH and HIV seem to occasionally occur together, then?

This is another question that medical

science is searching to answer. We do know that many HIV-infected individuals have other problems and other risk factors that can lead to PH. A direct cause-and-effect relationship between HIV infection and pulmonary hypertension has not yet been found, and proteins associated with HIV have not yet been found in the lining of the blood vessels of the lungs.

Medical researchers have not yet been able to say for sure what role HIV infection plays in the development of PAH. It is not yet known, for example, whether HIV itself can directly cause pulmonary hypertension, or whether HIV is simply a trigger for the development of PAH in susceptible individuals. HIV remains a complicated disease that can cause many problems that weaken blood vessels, and these, too, can play into the development of PAH.

Should an HIV patient be tested for pulmonary hypertension?

HIV patients know that medical supervision is critical to their best possible long-term health and that any change in their condition should be brought to the attention of their doctors. Changes that may have to do with PH might include difficulty when attempting physical activity; swelling of the feet, ankles, legs or abdomen; increased shortness of breath; worsening fatigue; chest discomfort or pain; and light-headedness or fainting. However, because these symptoms are

general and may have to do with several types of problems, the patient's doctor should always be contacted.

How is testing for PH carried out?

An echocardiogram is a useful screening tool. Unfortunately, it alone is not accurate enough to make the diagnosis of HIV-associated PAH. A test known as right-heart catheterization remains the most accurate way of diagnosing HIV-associated PAH.

Can pulmonary hypertension be treated the same way in HIV patients as in those without HIV?

Researchers are working to find the answer to this question, but to date, there have been few studies done with HIV patients who have PAH. The fact that the population of HIV-associated PAH patients is very small has been a problem for researchers. Another problem has been that the long-term survival of HIV-associated PAH patients is lower than those who have PH without the addition of HIV. In all cases, however, the sooner PH (or any other complicating problem) is diagnosed in an HIV patient, the better the outlook is for the patient.

PHA Resources



The Pulmonary Hypertension Association (PHA) was founded by and for PH patients. The organization has led the way in bringing pulmonary hypertension into the national and international consciousness. PHA is constantly increasing its services to the medical community through educational programming, membership sections for medical professionals, and much more:

Website:

PHA's website is a comprehensive source of information for patients, caregivers and medical professionals. Please visit us at www.PHAssociation.org.

Find a Doctor:

The "Find a Doctor" section of PHA's website allows patients and referring physicians to search for PH-treating physicians by state at: www.PHAssociation.org/Patients/FindADoctor. While PHA does not endorse any of these physicians, PHA strongly recommends that all PH patients see a PH specialist who will be able to provide them with the best PH care.

Pulmonary Hypertension: A Patient's Survival Guide:

This extraordinary 300+ page book was written by a patient and is medically reviewed and updated annually. It presents the illness in a very human and readable way, covering a wealth of topics like the mechanics of PH, the latest treatments, patient care and lifestyle issues. PHA members receive a discount on this resource. The *Survival Guide* is available for purchase as a paperback and an e-book at: www.PHAssociation.org/SurvivalGuide.

Online information about PH:

For information on PH diagnosis, symptoms, treatments and more, visit www.PHAssociation.org/Patients/AboutPH.

Support Groups:

From the first support group started in 1990 around a kitchen table in Florida, PHA grew to 45 groups in 2001 and to more than 245 in 2013. In many places, patients have the opportunity to meet, learn from and find common understanding with others in similar circumstances. Find a support group in your area at www.PHAssociation.org/LocalSupportGroups.

About the Pulmonary Hypertension Association



The mission of the Pulmonary Hypertension Association is to find ways to prevent and cure pulmonary hypertension, and to provide hope for the pulmonary hypertension community through support, education, research, advocacy and awareness. PHA's members form a community that is fighting back against this terrible illness.

PHA fulfills its mission through:

- Funding for research
- Quarterly medical journal *Advances in Pulmonary Hypertension*
- *PHA Online University* offering free CME credits and the latest information on pulmonary hypertension (www.PHAOnlineUniv.org)
- Professional membership sections:
 - ▶ PH Clinicians and Researchers (PHCR)—for physicians and doctorate-level researchers
 - ▶ PH Professional Network—for nurses and allied health professionals
- Educational conferences and materials for medical professionals and patients
- A wealth of information in the *Survival Guide*
- PH patient support groups
- Quarterly newsletter *Pathlight*
- Advocacy and awareness campaigns
- Toll-free Patient-to-Patient Support Line (1-800-748-7274)
- PHA website with PH discussion boards, email groups and online support chats (www.PHAssociation.org/ConnectOnline)

More Information on HIV

AIDS.gov: www.aids.gov

AIDS Healthcare Foundation:
www.hivcare.org

POZ Magazine: www.poz.com

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