

News-PHlash!!

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JULY/AUG, 2009

AM I DISABLED??

Only your doctor can tell you if you are sick enough to apply for disability, but most PH patients qualify for some benefits.

It can be tricky finding and applying for these benefits. There is a free service available to ALL PH PATIENTS called ACCESS (advocating for chronic conditions, entitlements and social services). ACCESS focuses on government entitlements. They can advise you on your options and help you every step of the way through the process of applying for Social Security Disability (SSD), Medicare, Medicaid, and Supplemental Security Income (SSI). They also help PH patients who are still working to hang on to their health insurance under COBRA and HIPPA. ACCESS has a free booklet that explains their program and gives an overview of federal medical and disability entitlements, plus tips on applying for disability. Call toll free: 888-700-7010.

Whether you apply for SSD or private insurance disability, there is paperwork to complete. Once you receive the necessary paperwork to apply for disability and complete the section to be filled out by the patient, there is a section that must be completed by your doctor. You can either mail or fax those to us, we will complete them as quickly as possible and forward them to the appropriate persons. Mail disability paperwork to: 1900 University Blvd 338 THT; Birmingham, AL 35294 or fax to (205) 975-9320.

Don't be discouraged if you are denied disability benefits initially. You may have to go to a hearing before an administrative law judge. However, if your doctor says you are disabled because of PH, you are very likely to win in the end. Our office is here to help you with the paperwork, and will write letters on your behalf to assist in obtaining benefits.

Most PH patients qualify for handicapped parking placards. The rules governing the availability and use of these placards varies from state to state. Apply within your local Department of Transportation (DOT). Here, in Jefferson County, applications can be picked up at any Jefferson County Revenue Department. The application requires a certification from your doctor, along with his/her signature. We are happy to provide you with that. You will need to either bring the application to clinic with you, or mail it to us and we will have it signed and mailed back to you.

—Kresti Bailey, RN



HEALTH CARE DIRECTIVES

You may have heard them referred to as a living will, or advance directive. Whatever you call them, they are a set of instructions to your doctor that explain in detail what you do or don't want to have done in the event that you are experience a medical emergency and are unable to communicate your wishes. In some states, Alabama

included, end of life decisions are left up to the next of kin. Therefore, along with writing a living will, you should discuss your wishes with your family and encourage them to do the same. While these conversations are never easy, it will ease the burden on loved ones faced with making decisions on your behalf.

You can find free information as well as a free downloadable form for use in the state of Alabama at: www.legislature.state.al.us/CodeofAlabama/1975/22-8A-4.htm

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DID YOU KNOW?

- ◆ Diets rich in antioxidants can improve lung function
- ◆ Foods rich in antioxidants include mangos, carrots, peppers, cantaloupe, sweet potatoes, apricots, whole grains, nuts, vegetable oils and wheat germ

HOW ARE YOU DOING?

Pulmonary Hypertension is a diagnosis that tends to stop you in your tracks when you hear it. Described as “rare and incurable” and requiring very expensive medications to control the symptoms, PH can be particularly overwhelming. Once you understand and accept the diagnosis, the next thought should be “what can I do to make life better?”

Simply taking your medications as prescribed is not enough. Ask yourself these questions: Are you taking your daily walk? Are you adhering to your salt and fluid restrictions? Are you having your monthly labs done (if on

tracleer or letaris)? Are you notifying our office 2 weeks prior to running out of medication to request refills? Are you calling our office or specialty pharmacy with your questions? Are you speaking to your specialty pharmacy each month when they call for counseling? Are you keeping your regularly scheduled Dr. appointments? Are you attending support group meetings?

If you answered no to more than 2 of these questions, then get in line for your spanking!!!

I won't really spank you, but seriously speaking.....these are

some of the things we must do to get better, both physically and emotionally. We must be proactive in the fight to save our own lives. Remember, we care about you and your health, but no one cares about your health more than you do! You must do your part, and together we will overcome this illness and hopefully, one dayfind a cure!

—Juanita Lenyard, LPN

Leader, B'ham PH support group



RIGHT HEART CATHETERIZATIONS

Patient's with PH undergo a procedure called “right heart catheterization” (RHC) several times in their lives. Initially, a RHC is performed to diagnose the illness and obtain accurate measurements of their pulmonary artery pressure (PAP). After diagnosis, a RHC is performed on a regular basis to determine how a patient is responding to treatment.

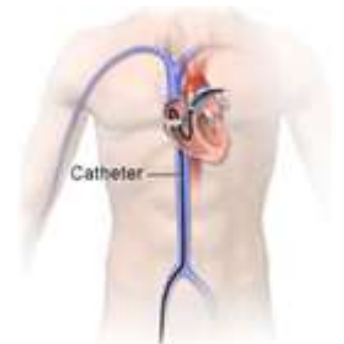
RHC is the most accurate way

to measure the blood pressure in your heart and the arteries of your lungs. During the procedure, the cardiologist inserts a very thin, flexible tube, called a catheter, into a vein in your body and guides it to your heart. Measuring instruments at the tip of the catheter allow the cardiologist to examine the inside of your heart and the large arteries of your lungs. During RHC, the cardiologist measures the pressures inside the pulmonary ar-

teries and chambers of your heart, how much oxygen is in your blood, and the amount of blood your heart is able to pump each minute.

As always, your doctor is your best source of information about this procedure and can answer any additional questions you may have.

—Kresti Bailey, RN



Right Heart Catheter

PHA RESOURCES

The mission of the Pulmonary Hypertension Association (PHA) is to seek a cure for pulmonary hypertension and provide hope for the pulmonary hypertension community through support, education, advocacy and awareness.

Join the PHA today:

www.PHAssociation.org/Join
or call: 301-565-3004 ext 756

Online community-Message boards, daily online support group chats, email listservs:

www.PHAssociation.org/connect

E-learning events: free monthly e-learning events via webinars, online Q&A and conference call discussions:

www.PHAssociation.org/classroom

PH fact sheets: written by medical professionals and reviewed by members of PHA's scientific leadership council:

www.PHAssociation.org/learn/factsheets



FROM THE OFFICE OF RESEARCH: **TRAVEL RECOMMENDATIONS FOR PH PATIENTS**

With summer in full swing, lots of people have big plans for vacation and travel. While this can be very exciting and even therapeutic, there are important issues to consider while planning.

Travel, whether by road, rail, sea, or air, requires advanced planning in patients with PAH. Patients with PAH should review travel plans with their doctors as early as possible so that they can assist in coordinating these efforts. Specific issues that should be discussed include the need for supplemental oxygen, the amount of medications/supplies that should be packed, and the altitude during travel (if flying) and at the travel destination.

OXYGEN AND TRAVEL

Air travel and travel to high altitudes can result in a decrease in the blood oxygen level. Hypoxia, or a low blood oxygen level, may rapidly worsen PH. Thus, all PAH patients planning air travel or traveling to high altitude should discuss the possible need for oxygen with their PH doctor, even if they do not require supplemental oxygen at home. For those who will require oxygen while traveling, it is necessary to contact the travel carrier (i.e. railroad company, airline, etc.), oxygen vendor, and travel agency well ahead (at least 2-3 weeks) of the travel date to make arrangements. If a non-stop flight is not available, and continuous use of oxygen is needed, portable oxygen may need to be obtained for use at connecting airports or during layovers. Finally, arrangements for oxygen at

the travel destination must also be carefully planned.

A pamphlet providing additional information about traveling with oxygen can be obtained from the American Association for Respiratory Care (<http://www.aarc.org>)

PREVENTING LEG CLOTS

While traveling, staying seated for prolonged periods may increase the risk of developing blood clots and leg swelling. It is recommended that all PAH patients stand up and walk a short distance at least every 2 hours. If traveling by car, frequent stops will be necessary. Exercises to contract the leg muscles even while seated may be helpful to reduce risk of clot formation. Wearing support stockings during long flights may also reduce risk, and prevent uncomfortable swelling.

SALT AND TRAVEL

Traveling often entails eating in restaurants or in other settings where unanticipated excess sodium (salt) may be consumed. For patients with pulmonary hypertension who may have a tendency to retain fluid, this can result in symptoms that can spoil a trip or require medical care. Visit with your health care provider about warning signs and guidelines for adjusting diuretic doses in event of fluid gain. Consider consulting a dietician for ways to avoid excess salt during travel.

When traveling, expect delays. Extra medicines and supplies should be taken along. Have a checklist of needed supplies; post it somewhere you will see it before you leave the house,

to be sure you don't forget a critical item. For longer trips, take an extra week's worth of medications beyond the intended duration of the trip. If traveling out of the country, it is advisable to check in advance to determine if there are any laws against bringing medical supplies into a specific country or if special documents are needed. The airline, cruise line, etc. should be contacted in advance to learn if any special requirements or procedures are necessary to administer these unique medications. Patients requiring supplemental oxygen should pack extra tubing. All medications (in their respective prescription bottles) and supplies should be kept with the patient, and not packed in the luggage that may be lost or misplaced. If possible, obtain the name of a physician familiar with PH at your travel destination that you can contact in the event of an emergency. Finally, a letter from your PH specialist describing specific medical requirements is often useful in order to simplify the process.

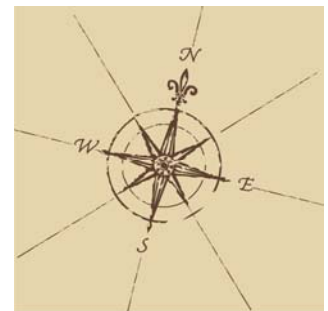
In summary, any type of travel by PAH patients can be stressful and requires careful planning. The availability of travel assistance and supplemental oxygen and the risks of the travel are all important factors to consider. A discussion with a PH specialist should always be undertaken before embarking on a long trip.

—Felicia Witherspoon, RN

—Rachel Culbreath, CCRC



Being informed and prepared is your passport to safety!



“Travel, whether by road, rail, sea, or air, requires advanced planning in patients with PAH.”

UAB HEALTH SYSTEM

Pulmonary Hypertension Program
 1900 University Boulevard
 338 THT
 Birmingham, Alabama 35294
 Phone: (205) 934-3438
 Fax: (205) 975-9320

B'ham PH support Group:
 Leader: Juanita Lenyard, LPN
 Email: jlennyard@uab.edu
 Phone: (205) 934-3438

www.health.uab.edu

BIRMINGHAM PH SUPPORT GROUP

2009 MEETING SCHEDULE:

AUGUST 25, 2009 12:00PM
 NOVEMBER 17, 2009 12:00PM

Unless otherwise specified, all meetings are held in
 "The Learning Center", located on the 1st floor in
 The Kirklin Clinic (TKC).

ANSWERS TO "THE RIDDLER"

- 1. Upside Down
- 2. Nothing between the ears
- 3. Spitting Headache
- 4. Despair
- 5. Water under the bridge

Disclaimer

We encourage readers to discuss their healthcare with their physicians. This newsletter is intended only to provide information on PH and not to provide medical advice on personal health matters, which should be obtained directly from a physician.

PHA and Birmingham PH support group will not be responsible for readers' actions taken as a result of their interpretation of information contained in this newsletter.

THE RIDDLER

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| H2O |

HAVE AN IDEA FOR AN ARTICLE?

We would like future "NewsPHlash" newsletters to include a column written by patients and their care givers.

Please forward all newsletter submissions via email to:

kresti@uab.edu

Article submissions should be no more than 200 words.

All submissions become property of
 The Birmingham Chapter -PH support group.