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Did you know?

- Congestive heart failure affects about 5 million Americans every year.
- A healthy heart pumps 50% of the blood it receives in one beat; a failing heart, 40% or less in one beat.
- Information on diet, etc. for CHF can be found at <http://www.chfpatients.com/>

CONGESTIVE HEART FAILURE & PH

Heart failure, also called congestive heart failure (CHF), is a condition in which the heart can no longer pump enough blood to the rest of the body. It may affect the right side, the left side or both sides of the heart. Right-sided heart failure means the heart's right ventricle loses its pumping function. Left-sided heart failure means the heart's ability to pump blood forward from the left side of the heart is decreased.

As the heart's pumping action is lost, blood may back up in other areas of the body, producing congestion in the lungs, the liver, the gastrointestinal tract, and the arms and legs. As a result, there is a lack of oxygen and nutrition to organs, which damages them and reduces their ability to work properly.

It is the right side of a PH patient's heart that usually has problems. The bottom chamber, called the right ventricle, pumps deoxygenated blood through the pulmonary valve and into the pulmonary artery, which divides and carries blood to both lungs. If you have PH, the right ventricle has to work so hard to force blood through blocked lung vessels that it bulks up. The right ventricle is not designed to do such hard work; normally its pressure is only 20 to 25 percent of that in the left ventricle.

When pressures remain too high for too long, the right ventricle becomes so stretched out that it cannot contract effectively. This is called congestive right-heart failure or cor pulmonale. In pulmonary arterial hypertension (PAH), the right atrium also tends to enlarge because of the back pressure from the right ventricle.

This type of PH presents some good news: when the pressures in the lungs lessen (because of successful treatment with medications, treatment of the condition that

caused the PH, or the transplantation of a new lung or lungs), the heart tends to return to its normal size. So, after treatment, the patient may no longer have congestive heart failure. However, if the heart has been stressed so long that scar tissue has formed in its structure, it is still damaged. If, in spite of treatments, fluids continue to collect in the spongy tissues, the patient is said to have decompensated heart failure.

If you have heart failure, your doctor will monitor you closely. You will have follow-up appointments at least every 3 to 6 months and tests to check your heart function.

You will need to carefully monitor your weight daily to help manage your condition. Weight gain can be a sign that you are retaining fluid and that your heart failure is worsening. Weigh yourself at the same time each day, on the same scale while wearing little to no clothes.

In addition to monitoring weight, it is important to take your medications as directed and carry a list of medications with you wherever you go. Also, limit salt intake, don't smoke, and stay active. (Your doctor can provide a safe and effective exercise plan based on your degree of heart failure.) **DO NOT** exercise on days that your weight has gone up from fluid retention or you are not feeling well. Lose weight if you are overweight. Get enough rest, including after exercise, eating, or other activities. This allows your heart to rest as well. Keep your feet elevated to decrease swelling. Ask your doctor if these guidelines apply to you and your condition.

Sources:

Heart Failure, <http://www.nlm.nih.gov/medlineplus>
Pulmonary Hypertension: A Patient's Survival Guide, page 21.)

HELPING OTHERS GET THE CARE THEY NEED



Angel Flight West is a nonprofit, volunteer-driven organization that arranges free, non-emergency air travel for children and adults with serious medical conditions and other compelling needs. They fly patients to and from scheduled medical treatment. Other reasons for using this service include living in a rural area isolated from any international airports or being immunocompromised due to treatment. Angel Flights' resources limit them to fly no more than a 1,000 nautical miles. Patients are required to be ambulatory (able to walk and get in and out of the aircraft with little to no assistance) and be medically stable.

The network of 1,900 pilots throughout thirteen western states donate their aircraft, piloting skills, and all flying costs to help families in need; thus, enabling the patients to receive vital treatment that might otherwise be inaccessible because of financial, medical, or geographic limitations.

The pilots give freely of their time and money in order to restore health and hope to

those whose lives have been disrupted by illness, disaster, or other life-altering events. Their only reward is the joy of knowing how much of a difference they've made.

Because the flights are free of charge financial need is verified.

Flight requests require several documents (available online) from the referring party: a doctor's office, a nurse, or a social worker or case manager, who request the flight on the patient's behalf. Angel Flight West requires at least one week to coordinate the flight once paperwork is received. When a pilot has taken the mission, the pilot will contact the patient directly, and all other arrangements from that point on are made between the pilot and the patient. Unfortunately, Angel Flight West is not a guaranteed service.

Additional information is available at <http://www.angelflightwest.org/>

STOP STRESSING AND START LIVING

Try these tips for a more relaxed 2010

- Change how you see things. It isn't the stressful situation that causes the problem; it's your attitude toward the situation and how you react to it.
- Try to solve a problem that comes up. If between you and someone else, talk it out and negotiate a resolution. If it is a barrier to something you want to do, find a way around it!
- Organize your life. Eliminate unnecessary activities, do the most important and most difficult of your tasks first.
- Assess your skills – are you using all your strengths?
- Calm your sense of urgency. You are not

running a race but living a life. You have only now to improve the quality of the present moment.

- Escape for a while. We all need time out to renew ourselves and gain perspective.
- Don't try to be a super-person. You can't be perfect. Give the best of your effort and your ability, but don't feel guilty if you can't achieve the impossible.
- Consider changing your diet. Caffeine, sugar, and poor nutrition can elevate your level of tension.
- Keep moving! Exercise increases the level of endorphins in the body, calms the mind, and releases tension.

Source:
Pulmonary Paper, January/February 2010, pg 5.

Researchers revisit PAH survival rates

Survival improves but prognostication tool sorely outdated

Setting out to determine the survival of patients with pulmonary arterial hypertension (PAH), researchers at the University of Chicago Medical Center and their colleagues also discovered that an equation used for more than 20 years to predict survival is outdated. Accordingly, they developed and recently published a new survival prediction equation that will impact clinical practice and the drug development process.

In PAH, the pulmonary arteries, which carry blood from the heart to the lungs to pick up oxygen, become restricted, forcing the lower right chamber of the heart to pump harder. Often the condition goes undetected until it is advanced. Untreated, patients with PAH have a very poor prognosis.

That prognosis is determined using an equation developed by a landmark National Institutes of Health study published in 1987, well before there were any FDA approved therapies for PAH. The first such therapy was approved in 1995; today there are seven.

"Since 1987, great progress has been made in understanding and treating PAH, so a few years ago we decided that it was time to study contemporary survival," said Mardi Gomberg-Maitland, MD, MSc, Associate Professor of Medicine and Director of Pulmonary Hypertension at the University of Chicago Medical Center. "Our results show that survival is vastly improved today. That led us to rework the NIH equation, which has been a standard measuring stick for more than 22 years."

Gomberg and her colleagues at the Medical Center and Northwestern University's Feinberg School of Medicine studied the survival of 576 PAH patients in their registry. Of these patients, 282 had idiopathic, familial, and anorexigen-associated PAH, which matches the conditions of the 187 patients in the pioneering NIH study.

Using the NIH equation, these 282 patients would have been expected to have one-, three- and five-year survival rates of 65%, 43% and 32%, respectively. In fact, their survival rates were much higher: 92%, 75% and 66%, respectively.

"This new formula is important for patients who want to know what, on average, to expect from their disease and for doctors who want to give accurate advice," said Stephen L. Archer, MD, Harold Hines Jr. Professor and Chief of Cardiology at the University of Chicago Medical Center and co-author of the study. "We hope others will test our work. If it is validated by others it could be a very useful tool."

Patients survive longer

The researchers were not able to determine why PAH patients survive longer today than in the 1980s, even though they measured the survival impact of many factors, including pulmonary function, demographics, medications, exercise treadmill, laboratory markers, echocardiography, and hemodynamics as well as the cause of the disease, which includes heart and lung disease, genetics, blood clots, connective tissue disease and other conditions.

None of these factors or causes had a significant impact on survival in multivariate analysis (when tested together statistically)—except hemodynamics. This explains why the new equation only incorporates hemodynamic parameters.

"Based on this result, physicians should stop drifting away from cardiac catheterization, which is the gold standard test to determine exact hemodynamics," Gomberg said.

"Providers have been using more echocardiography and less cardiac catheterization but we need to reverse that trend because until you know the hemodynamics you can't accurately predict survival and or cure the disease.

"You can estimate hemodynamics with echocardiography but not accurately enough," she added.

Many clinical trials in PAH used the NIH equation to suggest improvement in survival by comparing observed survival rates on a study drug versus survival rates predicted by the NIH equation, the study says. Since the NIH equation understates contemporary survival, it has led to more favorable comparisons of clinical trials testing new drugs to treat PAH, according to Gomberg.

"Our research suggests a reason that the drugs currently approved to treat PAH do not always work as well as we hope—because they were not held to a higher contemporary standard during their development and post-approval," Gomberg said. "The new equation should ameliorate this bias.

"Although some of these drugs dramatically improve the condition of some patients, none of them improves hemodynamics to normal levels," she added. "Therefore, we, as a medical community, have to acknowledge the fact that we have not yet cured PAH."

Source:

http://www.eurekalert.org/pub_releases/2010-01/uocm-tr010510.php

PROTECT ASSETS & LOVED ONES THROUGH ESTATE PLANS



Bill Winter explains the difference between a living will and a healthcare power of attorney. Lora K. pauses from taking notes to ponder his points. Lora represented Mr. Winter's wife in several of illustrations on the advantages and limitations of wills, joint ownership and trusts.

Even though the topic of the February meeting was serious, the room filled with laughter as Estate Attorney, Bill Winter used group members and ordinary objects to explain different scenarios. A simple water bottle symbolized a Trust and the water represented the individual's assets. Through these illustrations the technical concepts became understandable to all.

Mr. Winter answered numerous questions from the members about long-term care insurance, life insurance, powers of attorney for finances and health, living wills, organ donations, asset protection, etc. He

explained how "trusts shine in a disability situation."

By the end of the presentation, everyone knew they had many choices to protect their assets and their family. They realized they had the power to make those choices and could personalize every decision.

Mr. Winter encouraged everyone to seek the assistance of a professional and to chose that person much like they do their physician: find one that specializes in trusts and estates and has adequate experience in that field.



Members eagerly asked Mr. Winter questions during the February meeting in Riverton. Lunch was provided by the PHA Central Fund.

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Disclaimer

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

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

If you get stumped by these word puzzles, the answers are below.

SPR
ING

yyyyyy
Decision

flrtd

pocket

nnnn policy

12345paint

person
ality

h h
a a
i
r r
s s

**Support Group Meetings for 2010
Held at the Riverton Public Library, 1 – 3 PM**

April 10th Karen Buck, RRT, Cheyenne Regional Medical Cntr
Breathing Lesson & Harmonica Techniques

June 12th Mike Fisher, M.D., WY Cardiopulmonary Services
PH & Sleep Disorders

August 14th Elisabeth Ravazzolo, Accredo Health Grp
Coordinating with ERs and EMTs

October 9th Bob Gunner, Gunner Medical Sales
Traveling w/ Portable Oxygen Concentrators

NOTICE

Puzzle Answers: Spring Break, Wise Decision, Backdraft, Corner Pocket, Foreign Policy, Paint by Numbers, Split Personality, Splitting Hairs.