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Did you know?

- An average of 78 organ transplants take place every day in the U.S.
- A single donor can save or enhance the lives of up to 50 people.
- A living donor can supply a kidney or a portion of their liver, lung, pancreas or intestine.

THE GIFT OF A LIFETIME

To increase a national focus on the critical need for organ, tissue, marrow, and blood donors, April was designated as National Donate Life Month in 2003.

“Organ donors save the lives of more than 28,000 Americans on average each year and close to half a million Americans benefit from the lifesaving and healing gift organs and tissue provide,” stated Sue Dunn the president and CEO of Donor Alliance, the organ procurement organization and American Association of Tissue Banks (AATB) accredited tissue bank serving Colorado and most of Wyoming.

In the United States, more than 84,000 men, women, and children are waiting for organ transplants. Patients on the waiting list are in end-stage organ failure and have been evaluated by a transplant physician at hospitals in the U.S. where organs transplants are performed.

Specifics of waiting list rules, which can be seen at the Organ Procurement and Transplant Network (OPTN) website, vary by organ. General principles, such as a patient’s medical urgency, blood tissue and size match with the donor, time on the waiting list and proximity to the donor, guide the distribution of organs. Factors such as patient’s income, celebrity status, and race or ethnic background play no role in determining allocation of organs.

Contrary to popular belief, waiting on the list for a transplant is not like taking a number at the deli counter and waiting for your turn in order. The list is just a giant pool of patients. There is no ranking or patient order until there is a donor, because each donor’s blood type, size and genetic characteristics are different. Therefore, when a donor is entered into the national computer system, the

patients match that donor, making the list different each time.

The other major guiding principle in organ allocation is local patients first. The country is divided into 11 geographic regions, and with the exception of perfectly matched kidneys and the most urgent liver patients, first priority goes to patients at the transplant hospitals located in the region. Next in priority are patients in areas in surrounding regions and finally elsewhere in the U.S.

In 2008, Wyoming’s donor designation rate ranked fourth nationally with 58 percent of people obtaining or renewing their driver’s license saying “yes” to donation. Officials are trying to increase that rate.

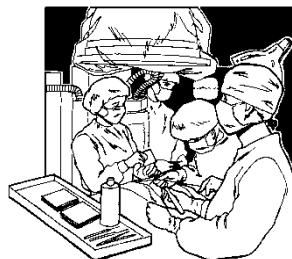
Wyoming residents can register their decision to be an organ, eye, and tissue donor in the following ways:

- online at www.DonateLifeWyoming.org
- at the Wyoming Department of Transportation the next time you obtain or renew your driver’s license
- by calling 1-888-256-4386

Source: www.DonorAlliance.org, www.organtransplants.org



PULMONARY HYPERTENSION & ORGAN TRANSPLANT



A transplant is an option when medical treatments for PH are no longer helping. According to the *Pulmonary Hypertension: A Patient's Survival Guide*, about 150 lung transplants are done each year on PH patients at one of the 70 or so transplant centers in the U.S. (The introduction of prostanoid therapies is probably mostly responsible for a drop in the percentage of PH patients among all lung or heart-lung transplant patients – from 13% in 1991 to 4% in 2001.)

When you get a transplant, you are trading one disease for another because you are required to take immuno-suppressive drugs for the rest of your life so your immune system does not reject the transplanted organ. On the other hand, transplant recipients often enjoy a vastly improved quality of life for 5 – 7 years, or even longer. PH has not been known to recur in a transplanted lung, but other

problems related to rejection of the organ and infection can limit the quality and duration of life.

So what types of transplants can help PH patients? Obviously they include those that involve the lung like heart and lung; bilateral-lung (two single lungs); single-lung; and living-donor lobes of the lung. However, even a liver transplant can help patients whose PH is related to the liver and hepatic system.

One of our support group members had a liver transplant in Colorado about two years ago. Look for her transplant story in a future issue of the newsletter.

To read more about transplants specific to PH patients, order a copy of the Patient's Survival Guide from PHA at www.phassociation.org

ORGAN DONATION - THE MYTHS & THE REALITY

Myth #1: If I agree to donate my organs, my doctor or ER won't work as hard to save my life. They'll remove my organs as soon as possible to save somebody else. **Reality:** When you go to the hospital, doctors focus on saving your life – not somebody else's. The doctor in charge of your care has nothing to do with transplantation.

Myth #2: Organ donation is against my religion. **Reality:** Organ donation is consistent with the beliefs of most religions. This includes Catholicism, Protestantism, Islam and most branches of Judaism. If you are unsure of or uncomfortable with your faith's position on donation, ask a member of your clergy.

Myth #3: I want my loved one to have an open-casket funeral. That can't happen if his/her organs or tissues have been donated. **Reality:** Organ and tissue donation doesn't interfere with having an open-casket funeral. The donor's body is clothed for burial, so there are no visible signs of organ or tissue

donation. For eye donation, an artificial eye is inserted, the lids are closed, and no one can tell the difference. For bone donation, a rod is inserted where bone is removed. With skin donation, a very thin layer of skin similar to a sunburn peel is taken from the donor's back.

Myth #4: I'm too old to donate. Nobody would want my organs. **Reality:** There is no defined cutoff age for donating organs. Organs have been successfully transplanted from donors in their 70s and 80s. The decision to use your organs is based on strict medical criteria, not age. Don't disqualify yourself prematurely. Let the doctors decide at your time of death whether your organs and tissues are suitable for transplantation.

Myth #5: I'm not in the greatest health, and my eyesight is poor. Nobody would want my organs or tissues. **Reality:** Very few medical conditions automatically disqualify you from donating organs. The decision to use an organ is based on strict medical criteria.

It may turn out that certain organs are not suitable for transplantation, but other organs and tissues may be fine. Don't disqualify yourself prematurely. Only medical professionals at the time of your death can determine whether your organs are suitable for transplantation.

Myth #6: My family will be charged if I donate my organs. **Reality:** The organ donor's family is never charged for donating. The family is charged for the cost of all final efforts to save your life, and those costs are sometimes misinterpreted as costs related to organ donation. Costs for organ removal go to the transplant recipient.

* * *

An excellent source of information on transplants, costs, and fund-raising can be found in the booklet "*What every patient needs to know*" available online <http://www.unos.org/SharedContentDocuments/WEPNTK2008.pdf>

HARMONICAS MAKE EXERCISES FUN

After demonstrating the basics of respiration and correct breathing, Karen Buck, RRT (Cheyenne Regional Medical Center) showed the group gathered for the April meeting how to have fun with a harmonica and improve and strengthen lungs at the same time. *At right*, Karen illustrates simple breathing exercises that could be done in bed, on the floor, or in a chair.



Once everyone understood the concept of abdominal breathing, the harmonicas provided by Accredo Health were distributed. In addition to the harmonicas, packets of exercises and songs for various skill levels were given to each person.

At first the songs were barely recognizable, but gradually everyone became more familiar with the instrument and the challenge of blowing and drawing to create the proper notes.

Center: Vickie M. from Evanston plays a duet of “Down in the Valley” with her mother.



Bottom right: Lenora Y. from Lander played a solo for the group.

Karen recommended doing the breathing exercises 10 times twice a day and to practice the harmonica daily. Barbara K., who accompanied Karen from Cheyenne and who is in Karen’s harmonica group, advised playing the harmonica during TV commercials.

Thanks to Accredo Health and Rachel Hamlin for providing the harmonicas and to Jen Rodriguez and United Therapeutics for providing lunch. We appreciate their support.

If you missed the meeting and want a copy of the songs and exercises, please contact Nancy (307-856-6976) or pinnut3200@yahoo.com



SPECIAL MEETING PLANNED FOR SOUTHWEST WYOMING PHERS



Currently, at least eight PH patients are known to live in Southwestern Wyoming. Because weather and road conditions, travel distance, and health issues make attending the meetings in Riverton too difficult for most of these members, a special support group meeting is scheduled for Saturday, May 8, 2010 in Green River, WY.

The meeting will be held at the Sweetwater Library, located at 300 N. 1st East, Green River, WY from 1 – 3 PM.

A representative from Intermountain Health Care Group or from Accredo Health in Salt Lake City will present

the educational portion of the meeting, but the gathering is also a time to meet and visit with others in this area of Wyoming who have pulmonary hypertension.

A light lunch will be provided by *the Pulmonary Hypertension Association Support Group Central Fund* supported by Platinum Sponsor *Actelion* and Bronze Sponsor *Teva*.

Please call (307-856-6976) or email Nancy pinnut3200@yahoo.com so she can order the appropriate amount of food for the meeting.

Contact Nancy (307-856-6976) if you have any questions.



TAGGING THE FLOLAN PUMP

Merle Reeseman - Support Group Leader for the Cleveland Area PH Support Group, Cleveland, OH shares this tip for Flolan users.

Walmart has a machine that makes metal “tags” for luggage. She printed on the tag:

IN CASE OF EMERGENCY – DO NOT DISCONNECT IV

She also listed her name, her PH center 800 number and direct

emergency personnel to ask for the PH Fellow on call.

Merle said the tag costs \$5 with a maximum of five lines. She clipped the tag now on her pouch.

Merle advises that any kind of luggage tag would do, the important thing is that it include: “DO NOT DISCONNECT IV” and the information of who to contact for further direction.

Answers to mind-benders on page 5: 1. Metermaid, 2. Steep curve, 3. Backdraft, 4. Up in smoke, 5. Sub-division, 6. Cancelled check, 7. Time after time, 8. Hurry up, 9. Out for a walk

**WYOMING
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WEBSITE:

Newsletter Archives &
Group News

<http://tinyurl.com/6x673h>

<http://tinyurl.com/ywb6e3>

PHA's National
Patient-to-Patient Helpline
800 - 748 - 7274

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.

Boost your brainpower by solving these puzzles. See if you can uncover the meaning in these words, letters, symbols and their positions. Each puzzle represents a common word, phrase, expression, person, place or event.

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Maid</div> | | <div style="border: 1px solid black; padding: 5px; text-align: center;">S
T
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P</div> | | 3. | <div style="border: 1px solid black; padding: 5px; text-align: center;">ftstD</div> |
| 4. | <div style="border: 1px solid black; padding: 5px; text-align: center;">SMUPOKE</div> | 5. | <div style="border: 1px solid black; padding: 5px; text-align: center;">S / U = B</div> | 6. | <div style="border: 1px solid black; padding: 5px; text-align: center;">C
A
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L
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| 7. | <div style="border: 1px solid black; padding: 5px; text-align: center;">TIMETIME</div> | 8. | <div style="border: 1px solid black; padding: 5px; text-align: center;"><i>Hurry</i></div> | 9. | <div style="border: 1px solid black; padding: 5px; text-align: center;">4 <div style="border: 1px solid black; padding: 2px; display: inline-block;">Walk</div></div> | |

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

- May 8th **Special Meeting – Green River, WY**
See specific information on page 4 of this newsletter
- June 12th Program to be announced
- August 14th Elisabeth Ravazzolo, Accredo Health Grp
Coordinating with ERs and EMTs
- October 9th Mike Fisher, M.D., WY Cardiopulmonary Services
PH & Sleep Disorders

NOTICE