

## WY PULMONARY HYPERTENSION SUPPORT GROUP

307-856-6976 (Nancy) or 307-856-7783 (Cricket)

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# Breezeway

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### Did you know?

Every minute, the heart pumps our entire supply of blood -- about five quarts -- through the body.

In one day, the heart pumps nearly 2,000 gallons of blood. In a 70-year lifetime, it pumps about 51 million gallons.

In the average lifetime, the heart beats 2.5 billion times.

## ORGANIZATION PROVIDES ASSISTANCE

Anyone with a chronic condition knows how frustrating it can be to deal with insurance and disability issues when you don't feel well.

For more than a decade Accredo Therapeutics' ACCESS (Advocating for Chronic Conditions, Entitlements, and Social Services) program has been helping individuals with rare chronic conditions navigate the complex maze of state and federal entitlement programs like Social Security. They also help patients understand their rights to continuation of group health coverage based on federal laws and their eligibility for health insurance through state high-risk pools. ACCESS represents people in the PH community with Social Security Disability (SSD) and Supplemental Security Income (SSI) claims. Their services are free of charge.

Pulmonary hypertension patients should call ACCESS when they quit or lose their job and when they begin a new job. ACCESS can help individuals make informed decisions about healthcare coverage.

Other situations that should prompt a call to ACCESS are: getting married, adopting a child, having a child go to college,

getting a divorce, or moving to a new location. All of these life-altering situations can affect health coverage.

The protections provided by federal law can only help you if you know what those protections are and how they work. ACCESS provides information and counseling to help you understand these issues.

ACCESS can outline federal disability programs, as well as how COBRA, HIPAA, Medicare, and Medicaid intertwine with the disability process. They can help you decide if filing for SSD or SSI is right for you.

It is critical that you recognize those times and situations you're your access to health and disability benefits may be affected. Before making any major changes in employment or insurance contact ACCESS toll free 1-888-700-7010. Their professional staff will help you make the choice that is best for you.

## HELPING PATIENTS GET BACK TO LIFE



Caring Voice Coalition (CVC) is another organization that helps individuals with pulmonary hypertension. CVC puts the needs of the patients first and is committed to help with financial, emotional, social, and physical well being. It was established to help provide a positive impact on these otherwise negative situations. Their services are free.

Caring Voice Coalition requires patients seeking financial assistance to meet established guidelines; however, they will gladly help anyone, regardless of need, in all the other categories. Their staff can help patients and caregivers locate local agencies and assistance programs.

Pharmaceutical funding, corporate

and private donations provide the funds for this non-profit group. With this funding, CVC is able to provide its own grants and financial assistance to those who qualify. CVC offers assistance in finding methods of payment to cover prescription drugs as well as meeting the day-to-day needs of the patient. They also answer questions about specific health insurance plans and their benefits. CVC will help patients locate social service programs that help provide shelter, clothing, food and transportation in the patient's local community.

CVC's web site [www.caringvoice.org](http://www.caringvoice.org) has more information. Call CVC toll free 888.267.1440.

## PREVENT ADDITIONAL STRESS ON YOUR LUNGS

Exposure to indoor air pollutants — such as smoke, dust, pet dander, radon, mold and other pollutants— can pose serious health risks and contribute to respiratory disease.

If you must keep pets, bathe and groom them often.

Prohibit smoking in the home. Homes with one or more smokers often have particle levels several times higher than outdoor levels. Avoid exposure to secondhand smoke in the places you frequent outside of your home.

Try to avoid using aerosol products. Substitute pump-type or solid products whenever they are available. Some aerosol products release particles in the air that can be inhaled into the lungs and absorbed into the bloodstream. Stay away from chemicals such as ammonia,

bleach, and chlorine. Consider natural cleaners like lemon juice, boric acid, baking soda and vinegar, which are good alternatives to chemical cleaning agents.

Extremes in air temperature or humidity make the body work harder to maintain its normal temperature. If you go out in the cold, wear a warm but lightweight coat, and cover your face with a scarf or mask.

The kitchen and bathroom can introduce large amounts of water vapor and other contaminants into the home. Install and maintain hood exhaust fans of sufficient capacity over your kitchen range and in the bathrooms.

Ask your physician for suggestions on how to minimize exposure to potential irritants.

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*An EPA study indicates indoor air pollution may be two to five times higher – and occasionally more than 100 times higher – than outdoor levels. As a result, the EPA has identified indoor pollution as one of the top 5 urgent environmental risks to public health.*

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## SEXUALITY: CHRONIC ILLNESS & YOUR SEX LIFE

Sometimes when illness intervenes we may place our sexual needs on hold or may lose confidence in our sexuality. We may not feel sexual or think that others will not perceive us as sexual beings. Feeling sexy has a lot to do with our feelings that can often be linked to the way we nurture and care for ourselves.

Sex and sexuality are personal and private and have different meanings for different people. Our sexual relationships also differ; for some they are long-term partnerships, for others they may be brief or casual relationships. The reality is that people enjoy many types of sexual activities and find many ways of showing love and affection.

Research has shown that very few health workers consult people about issues surrounding sex and sexuality. Some health workers may be reluctant to raise these topics for discussion because they may feel it to be intrusive or insensitive. Others may feel they do not have the expertise to assist with such sensitive issues. If you feel this may be the case with your health worker, then consider asking to be referred someone who specializes in sexual health.

**How can a chronic illness affect my sex life?** People who have a chronic illness can feel tired and depressed a lot of the time. They may have pain, stiffness or trouble sleeping. They may need medicines or other treatments that can affect their sex life. They may have a surgery that changes how their body looks. As a result, they may feel less interested in sex, or they may not enjoy sex like they used to.

### **Suggestions for keeping your sex life healthy if you have a chronic illness.**

- Plan sexual activity for the time of day when you have the most energy and your health problem bothers you the least.
- Be sure that you are rested and relaxed.
- Wait at least 2 hours after you eat to have sex.
- If you need pain medicine to feel better, take the medicine 30 minutes before sexual activity.

- Limit the amount of alcohol you drink, and avoid using tobacco in any form. Alcohol and tobacco can affect sexual function.

The following might help you maintain your sex life:

- Hold hands, hug and touch your partner, even when you do not plan to have sex.
- Use your senses to make sexual activity more enjoyable. For example, have satin sheets on the bed, light scented candles or play music.
- Tell your partner what you like and do not like. Listen to your partner's likes and dislikes.
- Try different sexual positions to find positions that are comfortable for you and your partner or use pillows for comfort.
- Try personal lubricants (one brand name: K-Y Jelly) to help reduce discomfort with sexual intercourse.

**Talking to your partner.** Even with the best of intentions and preparation, there may be times during your illness when you decide that you do not want to be sexually active. Talk to your partner about how you feel and why you feel that way. Talk about how you can help your partner deal with his or her feelings and interest in sexual activity.

**Talking to your doctor.** It is important for those living with illness to feel that their concerns and experiences are affirmed. Discussing sex and sexuality can be difficult, so ask your doctor to create time and space to discuss it. When illness forces changes to the way we live and experience our lives, it often means that we also experience changes to our sexuality. Physical symptoms may also impact upon the ways we have sex. But this does not mean that our sexuality is not important to us. Research has shown that people who live with chronic illness place considerable emphasis on staying connected to a sense of their sexuality. It is important that health workers do not assume that our

sexuality no longer matters to us or that we do not relate to it because of illness or disability. Speak to your doctor about your sexual needs.



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Excerpts taken with permission from *Sexuality*, a booklet prepared by the Royal District Nursing Service of SA (RDNS) [http://rdns.org.au/research/unit/research\\_projects.shtml](http://rdns.org.au/research/unit/research_projects.shtml)

Browse the website listed above to find more information on the topic of coping with a chronic illness.

Additional information from American Academy of Family Physicians

<http://familydoctor.org/online/famdocen/home/article/768.html>

## TSA GUIDELINES FOR DISABLED TRAVELERS

Pulmonary hypertension patients are often afraid of air travel because of security requirements, yet travel is possible with minimal inconvenience. The Transportation Security Administration (TSA) gives some guidelines to disabled travelers.

Provide advance notice to your airline or travel agent if you require assistance at the airport. TSA can only assist you with the screening process. Your airline will assist you through the airport facility and the screening line.

If you require a companion or assistant to accompany you through the security checkpoint to reach your gate speak with your airline representative about obtaining a gate pass for your companion before entering the security checkpoint.

The limit of one carry-on and one personal item (purse briefcase or computer case) does **not** apply to medical supplies, equipment, mobility aids, and/or assistive devices carried by and/or used by a person with a disability.

Pack your medications in a separate pouch/bag to facilitate the inspection process. Ensure that containers holding medications are not too densely filled, and that all medication is clearly identified. It is recommended that passengers refrain from packing any medications in their checked baggage that they do not want exposed to X-rays. Instead, send larger quantities of medications to your destination by mail or any other way preferred.

If you have medical documentation regarding your medical condition or disability, you can present this information to the Security Officer to help inform him of your situation. This documentation is not required and will not exempt you from the security screening process.

Make sure all your carry-on items; equipment, mobility aids, and devices have an identification tag attached.

If you have a medical device (on the interior or exterior of your body) check with your doctor prior to traveling to determine if it is safe for you to go through the metal detector or be handwanded. If your Doctor indicates that you should not go through the metal detector or be handwanded, or if you are concerned, ask the Security Officer for a pat-down inspection instead.

Your personal supplemental Oxygen will need to undergo screening. Check with your Doctor prior to coming to the checkpoint to ensure disconnection can be done safely.

If your Doctor has indicated that you cannot be disconnected or if you are concerned, ask the Security Officer for an alternate inspection process while you remain connected to your oxygen source.

If you need an Oxygen Supplier to meet you at the gate, check with your airline well in advance of your departure about their procedures for allowing suppliers to meet you at the arrival's gate since these procedures vary from airline to airline.

CPAPs are allowed through security checkpoints once they have undergone screening. Passengers will be required to take their CPAP machine out of its carrying case and place the device in a bin for x-ray screening. Facemasks and tubing can remain in the carrying case.

More information on traveling with a disability, oxygen, and medical conditions (as well as updates) can be found on the Transportation Security Administration (TSA) website: <http://www.tsa.gov/travelers/airtravel/specialneeds/index.shtm>

Air travel can be managed with some organization and planning. Obtain all the necessary forms from the airlines and your doctor well before your departure date. Keep copies of all paperwork.




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**WYOMING  
PULMONARY  
HYPERTENSION  
SUPPORT GROUP**

1206 Timber Lane  
Riverton, WY 82501

PHONE:

307-856-6976  
OR  
307-856-7783

E-MAIL:

[pinnut3200@yahoo.com](mailto:pinnut3200@yahoo.com)

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.

**WY PULMONARY HYPERTENSION  
SUPPORT GROUP  
2009 MEETING SCHEDULE**

Meetings will be held at the  
Riverton Public Library (1330 W. Park Ave., Riverton, WY)  
from 1 PM – 3 PM (specific room locations may vary)

- February 21<sup>st</sup>** ..... “The Basics of PH” – Megan Liddicoat, RN  
Actelion Pharmaceuticals
- April 4<sup>th</sup>** ..... Remodulin Therapy – Elisha McKim  
United Therapeutics
- June 13<sup>th</sup>** ..... PH and its therapies – Elisabeth Ravazzolo, RN  
Accredo Pharmaceuticals
- August 8<sup>th</sup>** ..... Clinical PH Research – David Badesch, M.D.  
University of Colorado Hospital
- October 10<sup>th</sup>** ..... Not yet determined
- December 12<sup>th</sup>** ..... Not yet determined

**Write the dates on your calendar  
or clip out this section for future reference**



**WY PULMONARY HYPERTENSION  
SUPPORT GROUP**  
1206 Timber Lane  
Riverton, WY 82501

**Wyoming Support Group online**

<http://www.orgsites.com/wy/pulmonary-hypertension-support/index.html>  
<http://tinyurl.com/ywb6e3>

TO: