SOUTHERN COLORADO PULMONARY HYPERTENSION GROUP



The Southern Colorado PH Group cannot answer individual questions relating

to the diagnosis or treatment of any disease or disorder.

Volume 3 – Issue 8 August 2003

MEETING DATES

Sunday, 17 August 2003 1:00 P.M.

Sunday, 21 September 2003, 1:00 P.M.

LOCATION

First Lutheran Church 1515 N. Cascade Ave. Colorado Springs, CO

FACILITATOR'S COMMENTS



"Pull yourself together! Snap out of it! There's something else ahead!"

I read the above quote in a recent book review (see page 4). It was timely!

July 28, I was informed, after my left and right heart catheterizations, that my cardiac output has diminished dramatically in the past few months. Tracleer (bosentan) is not working as it has for three years. Upon the advice of my PH specialist, I have three options Flolan, Remodulin, or remain on the Tracleer. Eligibility for any other clinical research study is out of the question since I've been on Tracleer

Many of you have known me since June 2000, when I was first diagnosed, and know that I denied Flolan treatment in favor of Tracleer. I realized the possibility of having to be treated with Flolan existed as an option; Tracleer might lose its effectiveness or liver function tests could change. Success with any of the innovative PH drugs is paramount – they're the stepping stones to a cure.

The quote also says it like it is: "there's something else ahead." So I'm "pulling myself together," starting a new phase in our lives, and for me, living until this dreaded illness is cured. My plan is to live until my grandchildren graduate from college; as I have no grandchildren yet, I'll probably live until I'm 120 at the rate they're going!!).

According to our PH specialists, a cure is on the horizon...just around the corner. I'll be standing in line on that corner when that time comes.

In the meanwhile, the plan is to become a "stripped-down whole other clear-eyed person" with a revised and healthier vision. Share with me my sorrow at diminished health, as I have shared with you over these years.

I can't be brave all the time; I'm just plain and simple me—afraid, sad, determined, and ready to "snap out of it!"

You, my PHriends, have been and continue to be my inspiration!

With love, Cheryl

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A STROLL THROUGH YOUR MEDICINE CABINET

Kelly A. Hendrick, RPh, and general manager at Accredo Therapeutics, Inc. in Denver, will be our guest speaker in August. Kelly is from North Carolina and obtained her pharmacy degree at the University of Chapel Hill. She has been with Accredo (formerly Gentiva) for nearly six years. She began her career with a company named Housecall Medical Resources in Tampa, Florida, focusing on acute infusion therapy.

Questions you'd like to ask Kelly: email her at kelly.hendrick@accredotx.com or call her at 1.303.799.6550 in advance so that she may research any unusual inquiries.

Kelly is also an Accredo team member in the Scleroderma Foundation's miniature golf fundraiser in August! \Diamond

"What I know for sure is that no matter where you stand right now--on a hilltop, in a gutter, at a crossroads, in a rut--you need to give yourself the best you have to offer in this moment."

--Oprah Winfrey

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It's been a rough month of our PHriends Stacy, Helen, and Eniza's mother, Maria. So glad each is doing better as reported at publication time!

HOW (AND HOW NOT) TO ACT WITH A PERSON IN CHRONIC PAIN

People with chronic pain want to know that you believe them and that you care. Here are some guidelines for dealing with someone in pain:

>>DO NOT judge the person. Pain is not a sign of weakness or bad character.
>>DO acknowledge the person's suffering.
>>DO NOT pretend that you don't notice the struggle.
>>DO act with respect.
>>DO NOT dwell on the future. Pain forces people to live in the present, so make

the present pleasant. Be upbeat.

>>DO offer assistance. Ask if there is anything you can do: run an errand, take him/her to a doctor, adjust a pillow, make a call. >>DO NOT dwell on your own problems. Talk about light subjects: a book you've read, a move you want to see.

>>DO treat the person the way you would like him/her to treat you.

--Excerpted from Parade Magazine July 20, 2002

Arthur Rosenfeld's new book, "The Truth About Chronic Pain" (Basic Books), explores the challenges of facing, understanding, and overcoming persistent pain.

If you read this book, send us a book review!

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DO YOU FEEL WEAK?

If your condition has made you less active than before, your muscles may be getting smaller and weaker. To rebuild your muscles, you need vitamins and minerals from fruits, vegetables, and grains. You also need extra protein.

The following foods can guide you in meeting your protein needs. Each item listed contains approx. 15 grams of protein. In order to get the daily recommended amount of protein (60-75 gms), you would need to eat 4-5 of the following items:

3 medium eggs (limit to once a week)
2 oz natural cheese (Swiss, cheddar, etc.)
1/2 cup cottage cheese
2 cups milk or yogurt
4 tablespoons peanut butter or 1/2 cup peanuts
1 cup cooked beans
(lentils, chickpeas, etc.)
3/4 cup cooked soybeans
2 cakes bean curd (tofu)
1/2 sunflower seeds

Weakness may also result from diuretics or water pills that cause the body to lose potassium. Other diuretics, however, spare your body from losing potassium. Check with your doctor. He may suggest that you need to add more potassium-rich foods to your diet.

Foods that are high in potassium include:

Milk
Oranges
Orange juice
Dried fruit
Bananas
Fresh pineapple
Beef
Legumes
Potatoes

This information was gleaned from Lincare's "Guides to Good Eating for the COPD Patient"

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JUST A REMINDER ABOUT THE ACCESS PROGRAM!

What is the ACCESS Program? Founded by the late Rachel Warner, Advocating for Chronic Conditions, Entitlements. and Social Services (ACCESS) is a program dedicated to helping find solutions to the social and economic problems that confront families facing chronic conditions. Rachel devoted the last six years of her life to exploring the paths to benefits and services available for chronically ill patients, as well as advocating on behalf of this community. Accredo Health, Inc. and its affiliates, Hemophilia Health Services, Inc. and Accredo Therapeutics. Inc., build upon her legacy by continuing to provide the ACCESS Program.

ACCESS helps families navigate the often complex maze of state and federal entitlement programs, as well as eligibility for health insurance through state high-risk pools and other alternatives, and through group health insurance continuation under federal laws (COBRA and HIPAA). Their goal is to reduce the time and effort required to obtain the benefits to which you may be entitled so that you may concentrate your efforts on managing your care and providing for your loved ones.

Various programs exist to help you and your family whether you are still able to work or can no longer work due to your disability. The rules governing eligibility for these programs are often quite complex and subject to change. Toll free number is 1.888.700.7010.

"Life engenders life. Energy creates energy. It is by spending oneself that one becomes rich."

--Sarah Bernhardt

ORGAN DONATION REGISTRY GROWING

Fort Collins--The number of Colorado drivers becoming organ and tissue donors is rising, experts say.

Although drivers have been able to donate for almost two decades, it wasn't until the Legislature created a state registry in 1998 that the wishes became legally binding.

Each year, thousands of people across the nation donate and receive hearts, livers, kidneys, lungs and tissue such as corneas and skin.

More than 351,770 drivers have signed up this year, according to the Donor Awareness Council, a Denver-based nonprofit organization.

From April to June, about 56 percent of the state's drivers said they wanted to be included on the registry, up from about 51 percent in the first quarter. In 2002, 699,177 drivers, or 44 percent, indicated they wanted to be included in the registry.

Amy Kusek, council program manager, attributed the increase to recent educational efforts, positive media stories, outreach and other efforts.

"I think people are feeling more comfortable with it." --Excerpted from The Gazette (AP)

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ON WORRYING

"T'ain't worthwhile to wear a day all out before it comes." --Sarah Orne Jewett

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Website resource:

www.healthprivacy.org-The Health Privacy Project
is dedicated to raising
public awareness of the
importance of ensuring
health privacy in order to
improve health care access
and quality, both on an
individual and a
community level.

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BOOK REVIEW The Contours of Pain

A Whole New Life: An Illness and a Healing
By Reynolds Price
Scribner
224p \$13

Reviewed by David Tuller CONSUMER HEALTH INTERACTIVE

Excerpted from My Health@Anthem.com; for full review, go to http://colorado.anthemhealth.com/sf/topic/brpain

Realistic as a sawed-off shotgun

This advice on coping with chronic pain is part of Price's essential message -- of acceptance of what's happened, of moving forward rather than looking back. Those who have suffered such enormous physical trauma, he advises, have to mourn the loss of their old selves and set out to discover, as soon as possible, the people they can now become. This, he says, is not just the ultimate key to survival, but to a "whole new life."

"Stanch the grief, by whatever legal means," he writes. "Next find your way to be somebody else, the next viable you -- a stripped-down whole other clear-eyed person, realistic as a sawedoff handgun and thankful for air."

In lesser hands, this sort of advice -- "Pull yourself together! Snap out of it! There's something else ahead!" -- could sound trite or banal or just plain cruel. But it's a testament to Price's skill, and his success in painting the contours of his own painful story, so that by the end of A Whole New Life, you appreciate the profundity and wisdom of his words.

David Tuller, a former staff writer for the San Francisco Chronicle, has written for The New York Times, the Washington Post, and Salon.com. He is also the author of "Cracks in the Iron Closet: Travels in Gay and Lesbian Russia" (Faber & Faber 1996).

First published July 30, 200

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"Every day brings a chance to live free of regret and with as much joy, fun and laughter as you can stand."

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UPCOMING MEETINGS

September Potluck October

Emergency Preparations
November
Awareness Month
December
Holiday Party

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