

PATHLIGHT

A NEWSLETTER FOR PATIENTS WITH PULMONARY HYPERTENSION, THEIR FAMILIES AND PHYSICIANS.

VOLUME ONE NUMBER ONE MAY 1990

PATHLIGHT ARRIVES!

by Teresa Knazik

After months of research, corresponding, planning, and organizing we have finally made it to the printers! We have received much support and encouragement to form a patient support group so welcome to the first issue of Pathlight, a newsletter for patients with pulmonary hypertension (PH), their families and physicians. Because we live in various parts of the country this newsletter will serve as our forum.

Many of us have Primary Pulmonary Hypertension (PPH), but everyone with PH will benefit from the support offered through our group. With Pathlight we hope to encourage each other, offer emotional support, exchange hints and tips in coping with daily tasks, and keep informed about research and therapies.

You may look forward to seeing a few regular columns by contributors such as Dorothy Olson who uses her experience of living with PH for 11 years to help others. We have a column for patients to contribute their thoughts and ideas and one through which family members may share information about the special problems that they have in living with PH. We welcome contributions for upcoming issues of the Pathlight. Working toward these goals we hope to lessen the burden of fear, loneliness, and isolation that accompanies this rare and rarely understood disease.

THE FOUNDATION FOR PULMONARY HYPERTENSION, INC.

In late 1984 Mimi Hansel, a mother of three, organized The Foundation for Pulmonary Hypertension with her husband to promote research into Primary Pulmonary Hypertension. Mrs. Hansel had PPH and was felled by it in early 1985 before she had an opportunity to participate in the educational and research work of the Foundation. Under the direction of her husband, Stephen Hansel, the Foundation generated enough support to initiate a major research project at the Hospital of the University of Pennsylvania.

Under the direction of Dr. Alfred P. Fishman a standardized model of pulmonary hypertension was developed in sheep to study the nature and progression of the disease and to test the effects of therapeutic drugs. The Foundation also sponsors research addressing the need to improve single lung

transplants and to find an early detection system to replace heart catheterization. The availability to other researchers of the sheep model developed at HUP should prompt further exploration, fresh approaches and development of new medications. The research sponsored by the Foundation continues to be the only privately funded research concentrating on pulmonary hypertension.

For more information contact:

The Foundation for Pulmonary Hypertension, Inc.

10570 Scott Mill Road

Jacksonville, Florida 32217

(Information in this article was obtained from the annual newsletters of The Foundation for Pulmonary Hypertension, Inc.)

ALPHABET SOUP

Sound advise from Dorothy Olson

Having been diagnosed with PH 11 years ago, and still managing to do pretty well I hope to offer encouragement to others. I was hospitalized with Pulmonary emboli resulting eventually with the PH diagnosis followed by periods of life support and the surgical implantation of a Greenfield umbrella in my Vena Cava. I was confined to a wheel chair for a while, but now I am "on hold" and doing OK all considered. I take bronco-dilators and blood thinners to keep the umbrella clear, Isordil, Nitro-stat and oxygen as needed. I attribute the umbrella implantation for the apparent stabilization of my condition.

Many things have happened in my life to make me a firm believer that all things happen for a reason. I feel that the reason I am here is to be

accessible to others with problems like myself. Our doctors can treat the physical problems, but communication with other people who share our fears is needed to treat our psychological and emotional needs.

THE THREE A's:

ACCEPT: This is probably the hardest. None of us want to hear that we have this illness. We deny it or think it is a misdiagnosis. After a while you realize that it is not going to change. This is it. **ACCEPT** it. Then you can take control, and in control is where you need to be. You aren't going to change it so **ACCEPT** it, and start making **EACH DAY COUNT**.

ADJUST: This applies to you and your family. There are many adjustments to make, and your abilities are limited. What you did before is not as easily done now. Use this time to learn new things you can do. Broaden your mind. Certain activities that you never considered before nor had the time for may become very enjoyable.

ATTITUDE: THIS IS THE MOST IMPORTANT! It will prolong your life and make it better for you and your family. We all have bad days. Well people have bad days. But there is tomorrow, so make each day count. If you mope around feeling sorry for yourself, thinking your life is over, then it will be. Nobody gets out of this world alive. Take control of your life. Do what you can, and enjoy and be thankful for the things you can do. My favorite thought is when you wake up in the morning and you don't hear organ music, smell roses. **GET UP!** Get going and enjoy the day.

In the past several years I have contacted many people on a one-to-one basis. Some people I have exchanged tapes with, others letters and phone calls. I will be happy to do this for anyone who desires.

SUPPORT CENTER

If you want a helping hand in coping with PH but prefer to network confidentially, the following volunteers may be contacted for support:

Dorothy Olson (PH patient)
3215 Monza Dr.
Sebring, Fl. 33872

[REDACTED]
[REDACTED]
[REDACTED]

Teresa or Robert Knazik (PPH patient and spouse)
1060 Pembroke Av. N.E.
Palm Bay, Fl. 32907
(407) 729-0256

Would you like to be a support volunteer? Do you want to hear from others on a more personal level? Please send you name, address and if you like your phone number for publication in the next issue of Pathlight. Pathlight Newsletter c/o Teresa Knazik 1060 Pembroke Av. N.E. Palm Bay, Fl. 32907

THOUGHTS OF A PPH PATIENT

by Shirley Brown

What can I say about this mysterious disease? One must cope daily with this restrictive and progressive disease.

I do well when I am sitting still, but abrupt quick motion leaves me breathless and my heart racing. I find that my mind runs way out ahead of my body. I sit there feeling perfectly normal and I think of these marvelous things to do. When I actually try to do them I am quickly aware of my restrictions. It is frustrating to say the least.

It would be wonderful to talk with someone who actually has PPH. Having such a rare disease leaves one to discover everything for oneself never knowing what to

expect next.

I fight depression mostly because I was so active before the onset of PPH. Even now I push myself very hard because I refuse to give in to this. I am concerned mainly about the quality of life. My doctor tells me that he would rather see me active than inactive.

I have a wonderful family and wonderful friends who help me. They make my life easier, and I am aware that without their help I would spend much more time just sitting with my oxygen and being "grounded." My husband equipped our motor home in which we travel with oxygen. I have a scooter with a lift that fits into a van which we tow behind the motor home.

I am one of the fortunate people with this disease as I have everything possible to make my life easier. You see, I have everything but good health and yet I have so much more than some healthy people. Even with PPH I am blessed.

IN MEMORY

This first issue of Pathlight is dedicated to the memory of the following individuals who were an inspiration in the development and organization of this support group:

MARY JEAN KING

JUDY JENNINGS

MADORA JAMES

WANTED:

STORIES, POEMS, MEDICAL NEWS, RECIPES, TIPS ON COPING, VOLUNTEERS

Please include with your subscription request.

ANOTHER VIEW

by Robert J. Knazik

Since my wife Terr was diagnosed with PPH, our family lifestyle has changed dramatically. As a family, we had enjoyed such activities as hiking in the mountains, camping, fishing, and long walks on the beach. In addition, Terr and I were both full time college students while I worked full time in the Air Force and she raised our toddler son. We tried to maintain all of these things while Terr's health was declining, since none of the doctors could tell us anything definite about her condition. When we finally did get a diagnosis, we realized that we had to make major changes in our lifestyle to improve Terr's chances of recovery.

Gone were the hikes in the mountains and the long walks on the beach. Terr was unable to do those things anymore. She could not continue in college because the exertion of going to class was too much for her.

The hikes in the mountains and the long walks on the beach were gone for me, too. I dropped out of college and the Air Force moved us to Florida, because we had relatives there. I started spending a lot of time sitting around the house with Terr when I wasn't working. For some strange reason, I started to run every day for exercise. My standard routine would be to get up early in the morning, go running, take my son to his school, and then sit around the house. In the afternoon I would pick up my son from school and then go to work on the evening shift. I was totally absorbed in Terr's illness and the very bad prognosis we had

received for her. I didn't know what to do or how to act. I was just going through the motions at work, not performing at the level I could have, but doing enough to get by.

After about eight months of this, I kind of woke up. I recognized my own paralysis and that it was not helping Terr. She was improving some with the help of her new doctor, but her goals and drive had fallen almost to the level mine had. I felt a strong desire to go back to school, which I did. I pursued my degree full time again, and my performance at work improved so much I was placed in charge of my section. Terr's enthusiasm seemed to pick up with the rise in mine, and we found new purpose in our lives.

I have since completed my degree, and the level of activities in both Terr's and my life has increased past the point it was before she was ill. We have replaced the long hikes with short walks, and we have started camping again. Although the medication that Terr takes has surely helped her, I think that regaining my enthusiasm has helped, also. I truly look forward to what each day holds for us, and it often fulfills my expectations.

Trees and vegetation help put oxygen back into the atmosphere. Plant a tree or shrub or buy one for a gift. Remember, native plants have a better chance to survive, require less maintenance than exotics and provide food and shelter for our vanishing wildlife! A tip from Teresa

ACTIVITIES

LOOKING FOR ACTIVITIES THAT YOU CAN DO? Here are some suggestions:

Enrich your mind. Take a class!

Languages, Photography, Arts, Genealogy, Writing, Crafts, Tai Chi, Humanities,

Support your cultural community.

Go to the theatre, museums, symphonies, ballet, concerts!

Join a social group. If there are none, start one!

Bridge or other card game;
Scrabble

Volunteer to help organizations with duties you can do.

Tutoring, Typing, Research, Writing, Drawing, Phoning, Sewing, Score-keeping,

Remember to check with your doctor first!

Learn about environmental concerns. Sit in on meetings of the Audobon Society, Native Plant Society, Sierra Club, or other local conservation group.

While these may lack the fellowship that you seek the following activities that you can do on your own are creative, relaxing, and enjoyable.

Reading, Container Gardening, Meditation, Writing (letters, poetry, stories, etc.), Find discarded materials in your closets to use in craft-making.

Who knows? You may discover hidden talents, you will meet new people, and you will learn so much. Most of all you will overcome our worst enemy - inactivity.

DEAR DOCTOR

...a question and answer column to promote awareness. If you have a question we will try to have it answered by a professional for publication in the next issue of Pathlight...

Dear Doctor,

I had never thought of children with this disease...it is very sad. Are these children on supplementary oxygen as we are required to use? What is their life expectancy? Is their medication the same as ours? Also how many children have the disease?

Shirley Brown Hanford, Ca.

Primary or idiopathic pulmonary hypertension occurs both in children and adults and rarely has a familial tendency. In children there is a 1:1 female-male ratio, but in adults females are predominantly affected with a ratio of 6:4. Children are most frequently diagnosed in infancy and usually there is an inverse relationship between the age of onset of the symptoms and the duration of illness until death.

It is interesting that based on our experience here at the Clinic we seem to see two groups. One is a group that presents in infancy where males and females seem to be similarly affected and this process is usually more rapidly progressive. There is another group of teen-age females and young adult women that we see between the ages of 15 and 30 who first present at that age with their pulmonary hypertension. Many of them have already had successful pregnancies which raises the question of whether or not this is an acquired rather than congenital phenomenon. People in

this age group will ultimately require oxygen and many of them will be on the same medications that older individuals utilize.

It is difficult to estimate how many children and young adults have this condition because there is no national registry.

Douglas S. Moodie, M.D.
Chairman Dept. of Pediatric & Adolescent Medicine, Pediatric Cardiology, The Cleveland Clinic

We encourage readers to discuss their healthcare with their doctors. Pathlight will not be responsible for readers' actions taken as a result of their interpretation of information contained in this newsletter.

SUGGESTED READING

DIET AND NUTRITION:

How To Save Your Life, Earl Ubell, Harcourt Brace Jovanovich, 1973, 308pp.

The Low Salt Diet & Recipe Book, Beverly Barbour, Simon & Schuster, 1982, 144pp.

The Save Your Life Diet, David Reuben, M.D., Random House, 1975, 173pp.

The Healing Foods, Patricia Hausman & Judith Benn Hurley, Rodale Press, 1989, 461pp.

TEXT:

The Pulmonary Circulation: Normal & Abnormal Mechanisms, Management, & the National Registry, Alfred P. Fishman, M.D. editor, University of Pennsylvania Press, 1990

ENRICHMENT, SELF-HELP & IMPROVEMENT, INSPIRATIONAL:

Love, Medicine & Miracles, Bernie S. Siegel, M.D., Harper & Row, 1986 244pp.

Quantum Healing, Deepak Chopra, M.D., Bantam Books, 1989, 278pp.

I'll Take Tomorrow, Mary Gohlke with Max Jennings, M. Evans & Company, Inc., 1985, (Autobiography of the first successful heart-lung transplant recipient).

Please send information on books or tapes that you recommend.

MANY THANKS

...to Dr. Moodie for answering our questions; to Stephen Hansel for providing information about The Foundation for Pulmonary Hypertension, Inc.; and to all of our volunteers, contributors, and supporters.