



finding a cure

Pulmonary Fibrosis Foundation

through Research, Education and Advocacy

Pulmonary Fibrosis Foundation Newsletter

Volume 6 Issue 2 - April 2005

OUR MISSION

The Pulmonary Fibrosis Foundation is dedicated to finding a cure for and raising awareness of Pulmonary Fibrosis, an often terminal disease. We are devoted to improving the quality of life for those afflicted with Pulmonary Fibrosis. The Foundation provides hope for patients through funding and supporting research, education and advocacy.



PRESIDENT'S MESSAGE

As the first quarter of 2005 draws to a close the Foundation continues to fulfil its mission in supporting research, providing educational materials to the medical and patient communities and advocating the cause of Pulmonary Fibrosis in both the media and on Capitol Hill. Although Pulmonary Fibrosis continues to remain a relatively obscure disease, its notoriety is on the increase. We find more mention of it in the various media and the awareness of the general public has become more widespread.

Our effectiveness on Capitol Hill has resulted in the establishment of a National Network of Clinical Research on Pulmonary Fibrosis which is funded entirely by the National Institutes of Health. Initially only six centers were to be funded but due to our increasing influence the number of centers has been expanded. This shows the importance of visiting our congressmen and women, as well as writing to them asking for additional funding for research. It is important to realize that expenditure on research is an investment which pays dividends in reducing the cost of health care which bites deeper every year into our national budget.

The foundation's investment in research, to date is well over one half a million dollars. These grants increase our understanding of Pulmonary Fibrosis as well as work towards finding a cure. We must expand these efforts so that we can reduce the numbers of people taken from us each year by this terrible disease. Unfortunately we cannot remain successful at this endeavor without the support of Pulmonary Fibrosis patients, their family and friends. In addition to personal financial contributions, we need your help in planning events that will not only raise funds but will also increase the public's awareness of Pulmonary Fibrosis. We have gotten off to a good start in our 50 in 50 campaign, but there are still many states in which participation is lacking.

Together we will win the fight against Pulmonary Fibrosis. "Many hands make light work", so lets all pitch in. The harder we work, the sooner it will happen. We will find a cure!

Michael Rosenzweig, Ph. D., President and CEO

April 2005

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**SOMEONE YOU SHOULD KNOW
LEMUEL H. TATE
PULMONARY FIBROSIS
PATIENT AND BOARD MEMBER**

Lem Tate, a native of Bartlett, Tennessee, graduated from Webb School, a boy's preparatory school, in 1944. He served in the United States Navy from 1944 to 1946 as a Hospital Corpsman. In 1948 he began a 35 year career with Illinois Bell Telephone Company, a division of AT&T as a Service Engineer.

Lem was recalled from the Active Reserve by the Navy in June of 1950 during the Korean War and served from 1950 until 1952.

He was active in several different Chambers of Commerce and was elected President of the Village of Wilmette, Illinois. In 1964 he was President of the Wilmette Rotary Club and served as Chairman of the Board of Trustees. He retired from the Telephone Company in 1982.

Later in 1982, he was hired as Director of Telecommunications by Northwestern University. He later advanced to Executive Director where under his direction the University installed a state of the art voice and data switching network for Northwestern University and the associated hospitals under Northwestern Memorial Hospital Group. Before his retirement in 1988, he was named President of Northwestern Telecommunications Service.

Following retirement, Lem served as a Telecommunications Consultant for various companies such as Harold Washington Library in Chicago, Illinois. He has lectured at various meetings nationwide and at Beijing University in Beijing, China.

In 1992, Lem and a small group of investors formed the North Shore Community Bank and Trust Company in Wilmette. He served as Chairman of the Board of the Wilmette Bank until the mandatory age for retirement of 75, at which time he was named Chairman Emeritus.

Lem Tate retired in December, 2004 and now resides in Hot Springs Village, Arkansas with his wife Caryl, to whom he has been married for 59 years and one of his three sons, Lem Tate, III.

The Pulmonary Fibrosis Foundation is honored to have such a dedicated and hardworking individual serve on the Board of Directors.

**WE ARE THRILLED TO WELCOME A NEW
MEMBER TO
OUR BOARD OF DIRECTORS:**



Susan Rattner, MD

Dr. Susan Rattner is a Board Certified Obstetrician-Gynecologist with the American Board of Obstetrics & Gynecology, and the founding member of Women Physicians of North Virginia. Dr. Rattner is also a Fellow of the American College of Obstetricians and Gynecologists. She received her medical degree in 1982 with distinction from George Washington University, and completed her internship and residency in Obstetrics and Gynecology at the George Washington University Hospital in 1986. During this time she received several awards for providing outstanding medical care.

In addition to general obstetrics and gynecology, Dr. Rattner's interests and specialties include high risk obstetrics, infertility, laser surgery, laparoscopic surgery, and menopause issues.

Dr. Rattner has been named as one of Washington, D.C. area's best Obstetrician/Gynecologist by both *Washingtonian* and *Washington Families* magazines for the past eight years.

Dr. Susan Rattner's father passed away in November, 2004 from Pulmonary Fibrosis. The Rattner family has started a George Rattner Memorial Fund in memory of their father. One hundred percent of the donations are allocated to research to find a cure for Pulmonary Fibrosis.

**Pulmonary Fibrosis Foundation
Board Members**

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Suszette McKay, RN
Susan Rattner, MD
Nancy Rodriguez
Frank Rose, MD
Lemuel Tate
Tom Terrill
Traci Toutant

Save The Date

Join Us In Celebrating

An Evening of Recognition
Five Years of Progress in the Fight Against Pulmonary Fibrosis

Saturday, September 17th, 2005

The Tasting Room
1415 West Randolph Street
Chicago, IL 60607
7:00-11:00 PM

\$125 per person including 1 free raffle ticket with advance purchase
\$125 a ticket at the door

Delight in the skyline of Chicago

Relax while the Damian Espinoza Trio plays jazz for your listening enjoyment. Treat your taste buds to delicious appetizers, cocktails and mouth watering desserts while conversing with new friends

Raffle

Purchase a raffle ticket for \$25 and win great prizes

Silent Auction

Look forward to spectacular auction items!!

Be A Sponsor

Publicize your business and enjoy premium benefits including mention in media announcements and special recognition at the event. Please contact the Foundation for sponsorship opportunities.

Tribute

Honor your loved one with a page in the program book.

Quarter Page	\$75.00
Half Page	\$150.00
Full Page	\$300.00

Welcome Out of Town Guests

Please contact the Pulmonary Fibrosis Foundation for suggestions on hotel accommodations, dining and other Chicago Attractions. All funds will be used to continue our mission of supporting research, education and advocacy.

ASK LEANNE

UPDATE ON THE LOVE AND REMEMBRANCE SERVICE

Dear Leanne,

Should I take prednisone?

From: Charlie in Illinois

When I was first diagnosed with IPF in January, 2003 and was told it is a terminal disease, I wanted "something" to make the problem go away. Even though you are dealing with a terminal disease, the doctors have a wait and see attitude, which was totally frustrating to me. So, I took prednisone. 60 mgs. at first, tapering down to 20 mgs for 1 1/2 years. Perhaps you can benefit from my experience.

In the beginning, prednisone was a feel good drug that masked the trouble I had going on. It also disrupted my sleep, caused mood swings, loss of concentration and weight gain. After all that, my pulmonary function tests remained stable and continues to remain stable 2 years later with a bit of a decrease in my DLCO.

Prednisone, a Corticosteroid, is similar to natural hormone produced by your adrenal glands. Our bodies produce approximately 5 mgs a day and when this amount is medically increased, prednisone suppresses inflammation. Prednisone is also used to help prevent rejection of organ transplants.

When weaning off prednisone, be patient. Your adrenal glands have to step up production of cortisol and depending on the length of time you're on the drug; this can be a slow process. Don't ever just stop taking prednisone.

One negative side effect of Prednisone is it acts to speed up the aging process. Hardening of the arteries will accelerate, cholesterol is higher, osteoporosis is faster and more severe, blood sugar is higher, cataracts form, skin thins, muscles atrophy and lose of strength. In general, think of any aging effect that you see on any organ and prednisone will accelerate this affect.

Please do research on prednisone or any drug your doctor prescribes. Prednisone is a great anti-inflammatory but it causes stress on your body and you have to decide whether the side effects are worth it.

Leanne Storch



Riverside Presbyterian Church in Riverside, Illinois was lit by candlelight on February 13, 2005 for a memorial service honoring those who have died from pulmonary fibrosis. This memorial service brought together friends and family members who have lost a loved one to this dreadful lung disease.

Families gathered around 350 candles while they shared stories and photos of their loved ones. Nancy Rodriguez of Forest Park, Illinois said "the service offered a chance to meet other families who have lost loved ones to the disease."

After her father died, Rodriguez became affiliated with the Pulmonary Fibrosis Foundation and now serves on the board. "I found out about the foundation on-line, unfortunately, it was too late. However it is nice to know other people have gone through the same situation. And we can pass along support to each other."

The memorial service was intended to honor and remember those who have lost their battle with pulmonary fibrosis. We intend to have this memorial service as an annual event.

READER'S CORNER SUGGESTIONS FOR COPING WITH GRIEF FOR CHILDREN

1. *Blow Me a Kiss, Miss Lilly* by Nancy White Carlson
When her best friend, old lady named Miss Lilly, passes away, Sara learns that the memory of a loved one never dies.
2. *Everett Anderson's Goodbye* by Lucille Clifton
Everett Anderson has a difficult time coming to terms with his grief after his father dies.
3. *The Fall of Freddie the Leaf: A Story of Life for All Ages* by Leo Buscaglia, Ph.D
Dedicated to all children who have suffered a permanent loss, and to the grown-ups who could not find a way to explain it.
4. *A Funeral for Whiskers* by Dr. Lawrence Balter
Sandy is very sad and upset when her cat Whiskers dies, but her parents help her understand and accept the loss.
5. *Grandma's Shoes* by Libby Hathorn
A young girl copes with her grandmother's death with the help of the old woman's shoes and some special memories.

OUR GOAL FOR 2005 - 50 events in 50 states



UPCOMING EVENTS

CHECK YOUR STATE AND JOIN US!!

TO PLAN YOUR OWN EVENT PLEASE CONTACT THE FOUNDATION AT 312.587.9272

Tempe, AZ- Leslie Bull is competing in an Iron Man Competition in memory of her father. The competition is in Tempe, Arizona on April 9, 2005. If you would like to make a donation toward this event please contact the Foundation.

Vacaville, CA- Char Archibald is hosting her 3rd Annual Golf Tournament & Raffle in memory of Bernice Dunlop. It will be held in Vacaville, California on July 12, 2005. For more information, please call Char at 707.864.9404.

St. Augustine, FL- Stacey and Steven Stanfield are selling lemonade in honor of their grandfather. For more information, please call Stacey and Steven at 904.827.9844.

Chicago, IL- The Pulmonary Fibrosis Foundation is Celebrating 5 Years of Progress. It will be held in Chicago at The Tasting Room: 1415 West Randolph, Saturday September 17, 2005 from 7:00-11:00 PM. For more information, please contact the Foundation at 312.587.9272.

Chicago, IL- LuAnn Luizza will be hosting her 3rd Annual Cocktail Benefit in memory of her father Nicholas Mormando. The cocktail benefit will be in Chicago early November of 2005. For more information, please contact LuAnn at 773.489.1648.

Chicago, IL-Jennifer Wingit is having a garage sale in memory of her dad Michael. All proceeds will go to the Foundation. For more information, please email Jennifer at: wingit13@hotmail.com.

Anderson, IN- Lana Hall is hosting a roller skating event celebrating her six months post transplant recovery. The roller skating event will be in Anderson, Indiana at Anderson-Roll Arena on March 21, 2005. If you would like to make a donation toward this event, please contact the Foundation.

Massachusetts- Christine Richard's is hosting a Fashion Show and Silent Auction in memory of her mother who passed away at the age of 56. For more information, please contact Christine at 781.662.0860.

Massachusetts- Heather Leverone is hosting a Golf Event in honor of her father. For more information, please email Heather at: hmlevrone@msn.com.

Macomb County, MI- Patti Moran is hosting a 1st annual JAM to fight Pulmonary Fibrosis event, it is a bowling fund-raiser in memory of her father in Macomb County, MI at Kingswoods Lanes on April 9, 2005. If you would like to make a donation towards this event please contact the Foundation.

Utica, NY- The New York State Pulmonary Fibrosis Foundation is hosting their 2nd Annual Golf/Reception Benefit in August 2005. For more information, please contact the NYS Pulmonary Fibrosis Foundation at 315.724.6512.

North Carolina- Wendy Tussey is hosting her 1st Annual Golf Tournament honoring her mother. For more information, please contact Wendy at: theglassshop@lexcominc.net.

North Carolina-Tamara Watts a Pulmonary Fibrosis patient will Bike Across America starting on April 18, 2005 beginning in Cape Hatteras, North Carolina. Tamara said that is planning to cover 40 miles per day "if my lungs hold out." For more information, please email Tamara at: Tcabikeusa2005@aol.com.

Ohio- Tom Quinlan is participating in a walk-a-thon in memory of his father-in-law. The marathon is called the flying pig marathon and it is being held in Cincinnati, Ohio on May 1st. For more information, please email Tom at: tomquinlan@insightbb.com.

Texas/New Hampshire- Kathy Bascom is collecting favorite recipes of her sister Linda Bascom Taylor who died of PF. The recipe book will be available July 1st for \$9.95. All proceeds will be donated to the Pulmonary Fibrosis Foundation. For more information, please contact Kathy at 512-248-2838.

Bellow Falls, VT- Donna Lund of the "Framery of Vermont" is donating a percentage of sales for a week in May in memory of her sister Linda Bascom Taylor. The Framery sells hand-crafted hardwood frames, custom frames and has a gallery. For more information, please email Donna at: framery@sover.net.

Wisconsin- Elli Olmstead a PF patient is making a quilt. If interested in making a bid please contact the foundation at 312.587.9272.

Any States that are in *Italics* have been completed. Your participation in these events will help us fulfill our mission.

For updates check our website at: pulmonaryfibrosis.org/events.htm/

WE HAVE MOVED



TO A LARGER OFFICE!!!

1332 North Halsted, Suite 201
Chicago, IL 60622

Phone: 312-587-9272
Fax: 312-587-9273

EMAIL: breathe@pulmonaryfibrosis.org

Grief Outreach Program

In January 2005, the Pulmonary Fibrosis Foundation began a Grief Outreach Program. This program offers support to the family and friends who have lost a loved one. We understand as a Foundation how difficult it is to cope with the death of a loved one to Pulmonary Fibrosis. This program aims to help grieving individuals in this process.

The Grief Outreach Program provides assistance for a year. Every few months the family or friend will receive helpful grieving tools. We hope that by providing this service we will be supporting the Pulmonary Fibrosis community. If you are interested in being a part of the Foundation's Grief Outreach Program, please contact Leanne Storch at (312) 587-9272 or by email at: breathe@pulmonaryfibrosis.org.

Alice J. Bergna Memorial Fund

Alice J. Bergna, a longtime Santa Clara schoolteacher and coach who advocated for equal opportunities for girls in sports, died of pulmonary fibrosis at the California Pacific Medical Center. She was 75.

She spent 17 years as a teacher in the Santa Clara Unified School District, and she coached several girls sport teams including track and swimming at Wilcox High School in Santa Clara.

Born in Berkeley, Mrs. Bergna was a tomboy who grew up playing sports with her father and two brothers.

Mrs. Bergna studied physical education at San Jose State University, where she also earned her teaching credentials. It was there that she met her husband, George, also a physical education major. They had five children.

After raising her children, Mrs. Bergna pursued a career in education, spending many years at Wilcox. In addition to teaching, she was the school's athletic director. She lobbied school officials in the 1970s to build a second gym so girl's teams had a place to play volleyball and basketball. When the gym was finally built people nicknamed the building Alice's Palace.

Although Mrs. Bergna retired in 1987, Wilcox High still has a scholarship for the outstanding female athlete/scholar of the year named in her honor.

Mrs. Bergna's generous family and friends created the Alice Bergna Memorial Fund with the Pulmonary Fibrosis Foundation. A hundred percent of donations will go toward research to find a cure for pulmonary fibrosis.

ONE BRICK

A nonprofit organization isn't anything without volunteers and we would like to thank ONE BRICK for making our 10,000 piece newsletter project look easy! 27 volunteers came out on a Sunday morning and in two hours our newsletter was labeled and ready to go. Thank you ONE BRICK.

This wonderful organization offers their services in three cities, Chicago, New York City and San Francisco. Check them out for your not-for-profit needs at www.onebrick.org.

Chazaq "Advocacy" Award

Leslie Bull Competes in Ironman Competition

Leslie Bull will be participating in the April 2005 Ironman in Tempe, Arizona. The competition will raise money for the Pulmonary Fibrosis Foundation as part of the Janus Charity Challenge. She will also have a team along her side, the Bull's Rasbutniks, volunteering at the event and cheering her on.

Leslie Bull's father George Bull passed away almost two years ago. George was diagnosed with Pulmonary Fibrosis, and from the beginning they talked about doing something to raise money to help find a cure for Pulmonary Fibrosis.

An Ironman competition involves a consecutive 2.4-mile swim, 112-mile bike-ride and a 26-mile run. Please support this incredible feat by making a contribution today. If Leslie succeeds in being amongst the top fundraisers, The Janus Group will make an additional contribution up to \$10,000 to the Pulmonary Fibrosis Foundation. Leslie's goal is \$25,000; please help her reach her goal!!! Donations may be sent to the Pulmonary Fibrosis Foundation at 1332 North Halsted Street, Suite 201, Chicago, Illinois, 60622. Please note that your contribution is to support Leslie's Ironman effort.



In honor of the late Paul Clayton, who served as an inspiration and advocate for those with pulmonary fibrosis, the Pulmonary Fibrosis Foundation will annually present the Chazaq Advocacy Award to an individual or group that has successfully advocated

Why Chazaq? Paul Clayton had a way with words. At the end of each letter he would sign off with Chazaq!! More than a few of us were curious about this word since we had never heard of it. Paul explained, "Chazaq means to be strong, to be courageous." Through his words and actions Paul lived his life with Chazaq!

About Paul: His presence in our online support groups was legendary. His story is even bigger than he was! In March 2004, Paul was given a week to live and was told by the "white coats" to go home and call hospice as there was nothing more they could do. Paul came home and then went on to live a lifetime in the 10 months he was granted by Him. Armed with PFF brochures Paul would tool around the Super Wal-Mart looking for others with oxygen tanks to talk about his disease. Using his way with words Paul became a guest columnist for his local paper, The Haskell Free Press. Paul used this new medium to reach even more people. In 2004, Bard Lindeman, a noted journalist, and Paul became fast friends as the two collaborated on articles about Paul and his amazing ability to be an advocate for pulmonary fibrosis research. Paul passed away on January 17, 2005 after enriching the lives of many he never met.

The Pulmonary Fibrosis Foundation will recognize an individual or group for their commitment to advance pulmonary fibrosis research, education, and advocacy:

- Actively encouraging family/friends to advocate for pulmonary fibrosis issues with local and state policy makers and/or the media
- Providing support and information for other patients and families to advocate for pulmonary fibrosis issues
- Advocating pulmonary fibrosis issues at the local, state, or national level
- Organizing other groups or individuals to advocate for Pulmonary Fibrosis

If you know anyone who you would like to nominate for this award, please submit your nomination to Jennifer Bulandr by emailing: Jennifer@pulmonaryfibrosis.org or by calling the foundation at 312-587-9272.

Disclaimer:

The information contained in this newsletter should not be construed as medical advice. Always consult with your health care provider for medical advice, or specific treatment options.

Foundation Staff

Michael Rosenzweig, Ph.D., President & CEO
Leanne Storch, Executive Assistant
Jennifer Bulandr, Director of Community Relations
Elyssa Jacobs, Communications Associate
Vakarie Roberts, Developmental Associate

Yes, Sign Me Up! I want to support the work of the Pulmonary Fibrosis Foundation and would like to make a contribution.

Here's my check for: \$5,000 \$1,000 \$500 \$100 \$50 Other _____

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____ Email _____

Please send your check to: Pulmonary Fibrosis Foundation, 1332 N. Halsted Street, Suite 201, Chicago, IL 60622

If you would like to charge your Contribution: Visa MasterCard Discover American Express

Account Number _____ Expiration Date _____

Credit Card Contributions may also be made by Phone: (312) 587-9272 or Fax (312) 587-9273

Please contact the foundation if you wish to be removed from our mailing list

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