

Breathe Bulletin



A Quarterly Newsletter of the
Pulmonary Fibrosis Foundation
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Letter from the President

It is with both deep sadness and gratefulness that we recently announced the retirement of Mike Rosenzweig. Mike has been the President of the Pulmonary Fibrosis Foundation essentially since its inception in September 2000.

My father, Albert Rose was an IPF patient, his sister Claire had died from IPF in 1994, and there was no national organization advocating for IPF patients. In addition to my father, the foundation was started with Dr. Marvin Schwarz, (a leading IPF physician at the National Jewish Hospital in Denver, Colorado), Joe Borus, (an attorney in Denver and son-in-law of Al), Mike, and myself. The primary goal of the foundation was to find a cure for the disease and advocate for the patients.

The foundation's first office was located in a back room at my father's place of business (a sewing machine warehouse) in Denver. Mike effectively did everything for the foundation. After my father died in February 2002, Mike moved the offices to Chicago. Initially he shared space with the American Lung Association, and the offices were moved to the present location on Halsted Street in 2005. Through his efforts the staff gradually has expanded to include an Executive Director, Leanne Storch, a Director of Development, Lindsay Thiemkey, a Web and Data Base Manager Myrrick Liontonia, a Development Associate, Monica Storch and an Administrative Assistant, Wendy Escobar.

Mike's accomplishments are many. He established an accomplished Board of Directors and recruited a Medical Board that contains a group of extremely talented and gifted physicians. The Foundation has committed to, or previously funded, research grants totaling over \$2,000,000 (see newsletter articles concerning the University of Chicago and University of Iowa). Furthermore, every day the Foundation speaks with IPF patients and families and has support groups in many cities as well as four online support groups (see corresponding article). I know my father would be extremely appreciative of all Mike's efforts and accomplishments. To honor all of Mike's achievements, Tom Hales (member of the Executive Committee and transplant survivor) has started the Mike Rosenzweig Pulmonary Fibrosis Research Fund. I along with all the other members of the Executive Committee have pledged to contribute to this fund.

Personally, I intend to expand upon the solid groundwork Mike has laid. Although there is still no cure for IPF, great strides have been made in the last 9 years. There is greater knowledge of the pathophysiology of the disease and better understanding of possible genetic and biologic markers for the disease (see articles on Hales Lung Conference, and GERD). New treatment therapies are in phase 3 clinical trials, and some investigators are recommending combination therapy or a "cocktail" as is currently employed in treatment for some malignancies and HIV (see article on University of Iowa). The success rate has improved for lung transplantation and some institutions have extended the age limit to 65 and older in otherwise healthy candidates.

As President, I will continue to seek input from my medical colleagues and aggressively pursue funding for research. I am having discussions with our board members and other prominent individuals to attempt to develop new strategies to achieve this goal. The only way we will ultimately cure the disease is through medical research. I look forward to the challenges ahead and am optimistic that we can fulfill my father's goal.

President and Chairman of the Board

- 1 Letter from the President
- 2 Dan Rose Bio
- 3i Tom Hales Lung Conference
ii New Trends in Lung Transplant Surgery
- 4 Homeopathy 101
- 5 A Night of Music and Heart
- 6i Support Groups
ii Caregiver/Patient Weekend
- 7i The Word on G.E.R.D.
ii Write Your Legislator
- 8 PFF Hero: Lori Lesutis
- 9 PFF Hero: Lori Lesutis (cont)
- 10 Event Tracker
- 11 U of C Thoracic Meeting
- 12 Iowa Research Grant

Disclaimer

The material contained in this newsletter is for educational purposes only and should not be considered as medical advice. Consult your health care provider for treatment options.

Dan Rose Biography



Daniel M Rose MD has been appointed the new President of the Pulmonary Fibrosis Foundation (PFF) effective April 1, 2009. Dr. Rose has been Chairman of the Board and has been involved with the foundation since its inception in September 2000. Dr. Rose's father an IPF (idiopathic pulmonary fibrosis) patient and Dr. Rosenzweig, also an IPF patient, started the foundation in 2000. The main mission of the foundation was and still is to find a cure for this debilitating and almost always fatal disease.

Dr. Rose was born in October, 1947 was raised in Denver, Colorado. He received a BA from Wesleyan University, Middletown, CT in 1969 and a MD from the University of Colorado in Denver in 1974. He did a general surgical residency at NYU/Bellevue hospitals from 1974-79 and was at the NIH (Heart Institute) in 1979-80. While at the NIH he did research in myocardial preservation and prosthetic tissue valve degeneration. He completed a cardiothoracic fellowship under Dr. F.C. Spencer at NYU in 1982. From 1982 – 88 Dr. Rose worked in Brooklyn, New York at Maimonides Medical Center and SUNY Downstate Medical Center. He was director of cardiovascular research at the 2 hospitals. Dr. Rose has authored or co-authored over 70 abstracts, journal articles, and book chapters.

In July 1988 he was appointed Chief of Cardiothoracic Surgery at St. Vincent's Medical Center in Bridgeport CT. After 19 years as Chief, Dr. Rose stepped down as Chief to pursue other interests and maintain a more normal lifestyle. He has subsequently helped develop cardiac "wellness and prevention" programs at St. Vincent's something in which he has always had an abiding interest.

Dr. Rose intends to build upon strong foundation that Dr. Rosenzweig has constructed hoping to be able to expand research funding and patient advocacy.



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Tom Hales Lung Conference Held at University of Maryland School of Medicine

The University of Maryland Medical School held the 2009 Hales Lung Conference: Clinical and Pathophysiological Aspects of Diffuse Parenchymal Lung Disease on April 27, 2009. Mr. Hales, a retired banker, IPF patient and member of the executive committee of the PFF, underwent bilateral lung transplant at the University of Maryland in February 2008. Out of gratitude for the care he received and his desire to further expand awareness and understanding of the disease, Mr. Hales and Hemagen Diagnostics (Columbia, MD) sponsored the conference.

Dr. Sergei Atmas and Dr. Jeffrey Hasday both from the University of Maryland organized the conference. A variety of researchers presented at the conference and included individuals

from the University of Maryland, University of Rochester, Johns Hopkins University, and the University of Michigan. The intent of the conference was to look at the physiology of idiopathic pulmonary fibrosis (ipf) and interventions that might alter or disrupt the pathologic process. These types of interventions can occur at different steps along the pathway to the formation of excessive fibrosis. This approach implies that after an event triggers a fibrotic response (environmental, infectious, or hereditary) specific interventions may disrupt, slow, or even reverse fibrosis formation.

One example is to prevent the stem cells from becoming fibroblasts (cells which produce the fibrosis) and transform them into benign fat cells.

Another approach is block excess or abnormal cytokine (compounds which attract the fibroblasts to the injured tissue) production.

In some patients there also seems to be an abnormality at the ends of the chromosomes. These ends are called telomeres and they seem to be shorter in IPF patients. There also may be genetic and cellular markers that would indicate a predisposition to IPF. In genetically susceptible individuals certain interventions may block the expression of these genes and prevent fibrosis from occurring.

In summary, the conference highlighted some of the newer basic scientific information regarding the pathologic process leading to IPF and possible future directions for therapeutic interventions.

New Trends in Lung Transplant Surgery

Two recent studies have highlighted recent advances and trends in lung transplantation. The first study was recently presented at the Society of Thoracic Surgeons in San Francisco and analyzed data from 1258 patients in the United Network for Organ Sharing (UNOS) database. Interestingly IPF is now the most common indication for lung transplantation surpassing COPD and cystic fibrosis. Close to 40% of transplants are for IPF. The study also suggested the bilateral or double lung transplant improved survival in high risk patients or about 25% of the individuals undergoing transplantation in the study.

In the lower risk patients which included about 75% of all patients in the study, a single transplant was as effective as a double. Risk was assessed using the criteria established in the Lung Allocation System (LAS). This was a retrospective study and one of the authors, Dr. Eric Weiss of Johns Hopkins University, commented that more prospective studies should be performed to address this issue.

Another study from UCLA published in the Journal of Thoracic and Cardiovascular Surgery demonstrated that individuals over age 65 can safely undergo lung transplantation.

Although older patients were more likely to receive “nonstandard” lungs (those which are considered less than perfect but still acceptable), survival at 3 years was almost identical between the younger and older patients. This is certainly encouraging for the older individuals who may require a transplant.

In general, the results for lung transplantation are improving. This is probably a result of increasing utilization of the procedure and better immunosuppressive therapies. In the future we will attempt to address some of the changes and improvement that are occurring with this therapy.

A Natural Alternative: Homeopathy 101

Homeopathy is one of the oldest forms of medicine, and can be related to Hippocrates, an ancient Greek physician, and his philosophies. It was developed by a German physician named Samuel Hahnemann in 1796, and was popular until the addition of pharmaceutical companies in the early 1900s. It embodies two philosophies: the human body as the ultimate healing tool and the “Laws of Similars”. The “Law of Similars” is a term coined by Hahnemann himself. By finding a remedy that most accurately induces the same symptoms in a healthy person, at higher doses, it will reinforce the healing component in our bodies, at lower doses, and neutralize, as well as expel the disease, leaving the body balanced (National Center for Homeopathy, 2007). It is making a comeback in the U.S., as well as in Europe and Canada, where you can actually find homeopathic remedies in pharmacies. Not only homeopaths employ these techniques: medical doctors, midwives, naturopaths, and even veterinarians are starting to adopt the practice, conjoining it with their own (Horstman, June 2006). The observations and evidence that Hahnemann accumulated over his years of studying have remained the same for over 200 years, making it the most stable out of all the branches of medical therapy (American Institute of Homeopath, 2007). Homeopathy takes a holistic, natural approach to medicine, meaning that the whole is greater than the individual parts. It’s based on the body being supreme among all the healing elements. All remedies are based on natural ingredients: minerals, herbs, or animal products.

Usually when a remedy is found, based on your symptoms, the results are immediate, all-inclusive, and permanent. Instead of suppressing the immune system, it works with your body, in turn curing your ailment, instead of disguising it. Homeopathy treats the body as a whole, treating the causes, or totality of symptoms, not the individual pathologic signs. Through different remedies the body is stimulated to heal itself, recognizing symptoms as the direct representation of the body’s attempt to heal itself, and compels the body to return to its natural equilibrium (National Center for Homeopathy, 2007).



There are two core beliefs that homeopathy embodies: “let like cure like” and minimal dosage. Hahnemann found a way, through extreme dilution, where a remedy that would usually cause the symptoms in a healthy person, will help the body heal itself in a person with the ailment. Here’s an example, if a person has a cough, a practitioner would find out the specific symptoms, and then prescribe a remedy that would cause the same symptoms in a healthy person. This along with the process of dilution creates the fundamental cornerstones for this type of practice. The dilution factor is the most controversial part of homeopathy.

Most doctors excuse it as a placebo effect, the phenomenon where a person believes that a remedy will work and it does. No one can explain how the dilution method works. There have been many studies, completely detached from homeopathy, that have proved that this approach has positive results on not just humans, but animals as well, where the placebo effect would be void. (American Institute of Homeopath, 2007)

There are two ways in which homeopathy differs from most conventional medicines. First, it can be difficult to prescribe the appropriate remedy, taking more time and patience than conventional medicine. There is no one remedy that can cure every person. One person experiences a cold completely different than another person. A homeopath takes this into consideration, and knows that one remedy may work for one person, and not others. Another obstacle is the boundless amount of remedies, which can be a bit overwhelming for our pharmacies. If your remedy is not one of the common thirty, it may be difficult to attain (National Center for Homeopathy, 2007). Unfortunately there are few studies, right now, on homeopathy’s effectiveness with pulmonary fibrosis patients. As increased knowledge is gained relating to homeopathy, it may become a viable option for patients suffering from this dreadful disease.

For more information please visit www.homeopathic.org and www.homeopathyUSA.org.

A Night of Music and Heart



This past February 15th the Kramer Family provided one of the local events the Pulmonary Fibrosis Foundation anticipates attending the most. The Fitzgerald's event was not only a fun time for all- with exceptional music acts, captivating artwork, and excellent food- it was also a gathering for some of the best smiles this side of the Des Plaines River. The art auction was a smash success, raising over \$880.00 in under 3 hours. That's almost \$5.00 per minute raised for pulmonary fibrosis research! The auction also provided fifteen artists from the Chicagoland area the wonderful opportunity to show off their craft. The art ranged from plaques to portraits to professional photographs to abstract paintings that filled the back walls of the legendary Fitzgerald's Night Club



The only thing hotter than the DiNico's pizza that was served, was the music acts that played for the seven hour event. Talk about variety, we had country, folk, pop, and hard rock acts that kept the audience's eyes glued while their mouths chewed. A special thank you goes to Tom Head, The What, Ron Lazaretti, Jeff Kramer, Big John, Jack Swain, Déjà Vu, Scott Momenthy, Naomi Ashley, Tori Soper and EarThorn for giving the night its soundtrack.



The Foundation's own Leanne Storch and Michael Rosezweig delivered heartwarming speeches to remind everyone to take care of themselves, their loved ones and to educate the attendees about Pulmonary Fibrosis and the Foundation. The tearjerker moment arrived when Jeff Kramer took the stage not to sing or play guitar, but to give his speech about the very special woman for whom the event was in memoriam for, Darlene Kramer Hohmann. Smile-ready Jeff is not the kind of guy who likes to show the world his frown ever,

but when it's time to talk about Mama Kramer he's not one to hold back his emotions. His speech-delivered with honesty, humility, love, and strength-outlines the love he has for his mother and his family. As the tears streamed down the sides of his Cheshire grin, his brothers stood straight like sentinels of respect and love while fixating their eyes and ears on the stage as if Jeff were reciting the pledge of allegiance, the Kramer allegiance.

"Loving,, energetic, non-stop caring, full of life, etc... most of all-the guiding light to so many lives! It may seem like a cliché to some, but I am the luckiest person in the world to have Darlene Kramer as my mother. And every one of my 4 brothers can attest to that!"

-Jeff Kramer



Myrrick Liontonia

Support Groups

Face-to-Face

Support groups are very beneficial to patients and their families while trying to come to terms with a diagnosis of idiopathic pulmonary fibrosis (ipf) or pulmonary fibrosis (pf). This disease not only affects the patient; pf affects the whole family.

Starting a support group can be as easy as meeting in a restaurant once a month to talk. Sometimes hospitals or medical centers will let your group use their meeting rooms for free. Pick a date and a time that is convenient for you. Some support groups invite speakers to come in and talk about topics of interest. i.e. pulmonary rehab, traveling with oxygen, yoga instruction, etc. It really depends on the group. Get people involved.

The Foundation will advertise your group on the website and send out email blasts to potential members. Here's the link to the current support group page: <http://www.pulmonaryfibrosis.org/groups.htm>. It is so important to talk to people who are going through similar situations because you then know you are not alone in this fight against this disease.

If you are interested in starting a support group and would like some help, please contact Leanne Storch – 312.587.9272 or email ls_pulmonaryfibrosis@yahoo.com.

On-Line Support Groups

We recently created a new online group for Lung Transplant patients. This group is for patients who are waiting for transplant, looking into transplant or have had a transplant. Here's the link: <http://health.groups.yahoo.com/group/Breathe-SupportLungTransplant/>. This group is Co-moderated by Ed Kuhn and Leanne Storch

We continue to offer three other on-line groups:

One for patients: <http://health.groups.yahoo.com/group/Breathe-Support/>. This group is moderated by Mary Beth Murtha

One for caregivers: <http://health.groups.yahoo.com/group/Breathe-SupportCaregivers/>. This group is moderated by Debra Beck

One for those who have lost a loved one to pulmonary fibrosis: <http://health.groups.yahoo.com/group/Breathe-SupportGrief/>. This group is moderated by Carol Hop

Special thanks to the moderators for their loving care of the boards they monitor.

Caregiver/Patient weekend in Orlando great success!!!

As a result of connections formed through the on-line support groups, a group of about 30 IPF patients and caregivers got together in Orlando in March for a weekend of togetherness and information. We heard speakers dealing with pulmonary rehab, oxygen use, hospice, the Social Security Disability process, lung transplants and financial matters. There was also an 11-year-old boy there who had lost his grandmother to IPF a few months earlier, and he gave much needed insights into just how much we should include the younger members of our families in dealing with this or any other potentially fatal disease. But probably of the most value was the chance to connect with one another. For some of us it was a time to reconnect with people we'd met at a previous conference. For others it was the first chance to meet face to face with those we'd been talking to online. In any event, the feedback after the weekend was very positive, and we hope that these meetings can be continued throughout the country so that as many people as want to will be able to participate. Plans are already in the works for another weekend in October. More information to follow.

A special thanks to Karen Dopher & Ramah Biederman for planning a weekend enjoyed by both caregivers and patients alike.



Have You Heard the Word on GERD?

If you have Idiopathic Pulmonary Fibrosis (IPF), chances are good that you have been told you need to make certain lifestyle changes. You may have been advised to choose a healthier diet, to exercise more, or to stop smoking. So you are now frequenting the produce aisle, dedicating an hour every day to staying in better shape, or even investing in everything from gum to patches in order to kick the nicotine habit... right? Well in spite of your efforts you still may be missing an important component of staying healthy with IPF!

What many IPF patients do not realize is that there could be a clandestine health threat lurking right under your nose... literally. Yes, your heartburn could be exacerbating your symptoms of IPF. Let me explain:

Firstly, when it comes to "heartburn," it is essential describe two separate but correlated conditions: "normal" reflux, a physiological occurrence where there is a sensation of food returning up the esophagus usually after a large or "spicy" meal resulting in "belching" or mild heartburn.

Gastro-esophageal reflux disease (GER or GERD), however, is less common and much more serious. GERD describes a regularly occurring backwashing (refluxing) of partially digested food, stomach acid, pepsin (an enzyme that aids in protein digestion), bile, and all of the other stomach contents into the esophagus. This is the result of an impaired "lower esophageal sphincter" (LES). This can result in chronic micro-aspiration and also damage to the lower esophagus.

Specifically, GER or GERD can play a considerable role in patients with IPF. In an article published in European Respiratory Journal and entitled "High prevalence of abnormal acid gastro-esophageal reflux in idiopathic pulmonary fibrosis" G. Raghu (a member of PFF medical advisory board) et al. assert:

Current concepts in the pathogenesis of IPF implicate epithelial-fibroblast interactions as a result of repeated insults to the lung parenchyma by a noxious stimulus over a long period of time, thus causing PF. The nature of the triggering and/or recurrent injury to the lung is unknown. Based on a very high prevalence of acid GER in IPF,

we hypothesize that chronic micro-aspiration of acid droplets associated with GER causes or contributes in part to the recurrent insults to the lung and development or progression of IPF (October 2006).

In other words, if you do not get your reflux under control, you could be causing your IPF to worsen. Another thing you should know is that reflux is more common than you may think. In the same article by G. Raghu et al., it is mentioned that "the prevalence of abnormal acid GER in the current IPF patients was 87%" (October 2006).

Even more shocking than its prevalence is there can often be a complete absence of symptoms. According to MayoClinic.com, "people with pulmonary fibrosis frequently have GERD, [but] they may not have typical GERD symptoms, such as heartburn and belching" (March 2009).

So now that we are assured you have heard the word on GERD there is no excuse to be absurd: Check with your health-care provider to make sure reflux does not exacerbate your IPF!

Lindsay Thiemkey

Write your Legislator

There are currently several milestone bills that have been introduced to Congress that would significantly better the living conditions of those who have been diagnosed with Pulmonary Fibrosis. Many of these bills have been referred to committees where they will be examined and modified before they are able to go to general debate. More often than not, bills and resolutions do not make it out of committee.

For this reason it is important for the pulmonary fibrosis community to pull together and contact our local legislators in support of the following bills:

H.R. 1079: Pulmonary Fibrosis Research Enhancement

To expand the research, prevention, and awareness activities of the Centers for Disease Control and Prevention and the National Institutes of Health with respect to pulmonary fibrosis, and for other purposes.

H.R. 1558: Preexisting Condition Patient Protection Act of 2009

To amend title I of the Employee Retirement Income Security Act of 1974, title XXVII of the Public Health Service Act, and the Internal Revenue Code of 1986 to prohibit preexisting condition exclusions in group health plans and health insurance coverage in the group and individual markets.

H.R. 1708: Ending the Medicare Disability Waiting Period Act of 2009

To amend title II of the Social Security Act to phase out the 24-month waiting period for disabled individuals to become eligible for Medicare benefits, to eliminate the waiting period for individuals with life-threatening conditions, and for other purposes.

H.R. 847: James Zadroga 9/11 Health and Compensation Act of 2009

To amend the Public Health Service Act to extend and improve protections and services to individuals directly impacted by the terrorist attack in New York City on September 11, 2001, and for other purposes.

Note: Many 9/11 first responders now suffer from pulmonary fibrosis.

For more information on how to contact your local legislator visit www.congress.org.

Pulmonary Fibrosis Hero

Meet Lori Lesutis:

A Living Hero

By Christa M. Gutzler

“I am good. I am loved and I feel safe. I have so much to jump up and down about!” These words, scribbled with the unadulterated honesty that demonstrates Lori Lesutis’ character, appear in her journal dated October 28, 2007. Some might assume these to be the thoughts of someone who just won the lottery or found out they landed their dream job. Instead, these irrefutably positive and grateful sentiments came from a woman nearly a week off of a respirator in the CICU facing the diagnosis she had waited over a year to be revealed: Idiopathic Pulmonary Fibrosis. Biological mother of two children, Christa and Ryan, and surrogate to thousands, Mrs. Lori Lesutis is a survivor; a survivor and a hero living with Idiopathic Pulmonary Fibrosis.

Despite having had to withstand a host of diagnoses, surgeries, doctor appointments, and tiresome medicinal schedules, Lesutis still wakes up every morning and stands in front of the classroom she has managed since 1994. As a biology, chemistry, and environmental science teacher at all girls’ private institution outside of Philadelphia, PA Lesutis has developed quite the reputation among her colleagues, students, family, and friends. Nowadays online social networks allow those who love and care to share commentary and encouragement through updates, pictures, and forums. One of the hundreds of messages reads, “I can’t express enough in words how you truly One of the hundreds of messages reads,



“I can’t express enough in words how you truly changed my life not only throughout Merion but forever [and] I am truly a better person because I knew you and I don’t know how many people that I can call such a good friend and mentor,” connoting the inspiration and motivation that Lesutis has shared throughout her life as a woman, mother, teacher, and friend. Over the last nineteen years, Lesutis has personified her very reasons for becoming a teacher. With a love for her students and the material covered, Lesutis has never wavered in her decision to become a teacher. Like her unwavering faith in the beauty of life and the power of optimism, her decision to become a part of evolving students’ lives and transform their scholastic experiences into both an educational and spiritual awakening has made all the difference. She further comments that “Teachers are there to build self esteem, share in the learning process step by step with our students, and incite our students to contribute their unique experience, insight, and collaborative donation.

I show them that I, too, make mistakes and can laugh at myself. It takes the pressure off them to feel the need to be perfect all the time, because in perfection is not where true learning takes place, for any of us.”

These imperfections not only exist in the actualization of learning but in the reality that most of life is out of our control. Lesutis has exemplified with grace and unparalleled prowess that how we choose to work with the gifts that we have been bestowed, despite setbacks and legitimate fear, truly determines the level of control that can actually be maintained in one’s life. By letting go and relinquishing control, we are often afforded the only chance to maintain any control. Lesutis learned in 2007 that the courage she had been mustering, assembling, and restructuring her whole life was about to be tapped into in a way no one could have prepared her for.

In 2006, with two adult children, Lesutis was basking in her blissful six years with second husband, Bob, as she approached her fiftieth birthday in January of the upcoming year. With years of science fairs and examinations administered behind her, and a future filled with love, laughter, and spirit ahead, Lesutis started to sense that something was wrong. Isolated episodic tales of shortness of breath while engaged in menial tasks like taking a shower or even coming down the stairs had become increasingly more frequent.

Pulmonary Fibrosis Hero (cont.)

A seizure at that time caused Lesutis to bite her tongue which led to a six month license suspension as a preventative measure against the consequences of future episodes. Lesutis describes this time leading up to her diagnosis as strange and unfamiliar. She “did not feel like [herself]” and was “alone in [her pain] of not knowing what was going on.” Bike rides and kayaking trips, normal adventures Lesutis both enjoyed and looked forward to, were becoming obsolete as she sought an answer to her physical transformation.

After almost a year of hospital and specialist visits, from ear, nose, and throat doctors suggesting a diagnosis of audiology issues to a cardiac catheterization that out ruled her heart as the source of the problem, and dealing with low energy and a persistent and debilitating cough, a clear diagnosis of breast cancer was made. “Finally, my pulmonary doctor said to get a mammogram and the biopsy proved it was breast cancer. I decided to get the mastectomy in September, 2007,” Lesutis explains. She was home within three days of the surgery but an urgent trip to the emergency room after an oppressive coughing fit finally clued Lesutis and her friends and family in as to the real cause of her mental and physical distress. It was Idiopathic Pulmonary Fibrosis, also known as IPF.

This interstitial lung disease causes irreversible lung scarring often leading patients to wear oxygen and habitually engage in oxygen level tests by way of strenuous walking and sleeping tests.

Lesutis is in the second year of her battle with IPF and continues to fight like a warrior. But this warrior is not only aggressive and ruthless; she is guided by faith and abounding love for herself, her family, and her relationship with a God who according to her, “has given me this gift to remind me why I am really here on this earth.”

Quotes like these appear in her journals, written in over the course of post-mastectomy and post-CICU treatments. Used to catalogue everything from personal thoughts, feelings, and insights, to the her prescription timetables, to the list of people to whom she wanted to send thank you cards, these journals serve as a testament to Lesutis’ undying spirit and dedication to living with IPF.

When she was placed in the CICU in September, 2007 on a respirator and feeding tube, her family and friends were by her side. Obstructed by the face wear, the tubes, and the strong medication, Lesutis still tried to communicate with her loved ones by picking up a pen and fervently attempting to jot down notes to them. They included, “Did people think I was going to die?” and “I was so scared” among other heartfelt honesty conveyed by way of her notes. She asked about particular people’s well-being and how they were holding up. She remembered details about their ongoing lives and was thirsty for the updates. Seemingly fearless and admittedly vulnerable, she was alive. When asked about her motivation then and how it’s evolved since, she explains that

“My motivation has always been my faith, my family, my life, and my prayers. I had a great deal of time to pray. Prayer is powerful. I thank all who prayed for me because I know all the prayers pulled me through.”

Always one to remind everyone to “giggle,” even her impending battle and everything she has withstood up until that point did not refrain her from maintaining a sense of humor. In the journal she kept during the last days of her hospital stay she wrote, “I am hearing there is a good possibility I just might go home in a few days. How nice it would be for Bob, for me, to be home for Halloween. Sounds a little funny, doesn’t it? ‘Home for Halloween!’” Well, she was one day late, but was home for good on November 1, 2008. Subsequently, she was forced to take the remainder of the academic school year off from teaching, but after a year of continuing treatments, doctor visits, and persistent battle, she was able to return for the 2008-09 academic year.

She is presently teaching on a full-time schedule amidst weekly doctor appointments and extreme exhaustion due to the effects of her terminal lung disease. Her persistence, determination, and unparalleled will to surmount her obstacles with gratitude and grace continue to inspire all that are lucky enough to know, love, and interact with Lori Lesutis. Everyday is a new day upon which to embrace the life she lives and as she explains, “My faith has only grown deeper. I believe in Jesus and feel His arms holding me and keeping me safe.”

2009 Event Tracker

The 50 Events in 50 States Fundraising Campaign creates awareness of pulmonary fibrosis and raises funds for research. These fundraising events are vital to our success. More information can be found at: www.pulmonaryfibrosis.org/events.htm. To host an event call (312) 587-9272

D.C.

- Pooja Baheti hosted a cocktail party in memory of her father, Pukh Raj Baheti. The event was held at the Eye Bar in our nation's capital this past twentieth of February.

Illinois

- Jeff Kramer and crew setup the 2nd annual benefit in memory of his mother, Darlene Kramer Hohmann, at the legendary Fitzgerald's Nightclub in Berwyn, IL on February 15th. The event was a blast, with an art auction, seven musical acts, and a feast provided by DiNico's.
- The Nuccio Family had their 2nd Annual Sal-Abration celebrating Sal's life through awareness of Pulmonary Fibrosis. The event was held April 19th, at The Abbington where there was a brunch buffet, a silent auction, and fun contests for all.
- The Pulmonary Fibrosis Foundation is partnering with the Respiratory Health Association of Metropolitan Chicago and other lung oriented organizations in organizing the Hike for Lung Health which will be in the Foundation's hometown of Chicago, IL this upcoming September 27th. The event will have the option of walking 1 mile, 3 miles, or virtual trail for patients.
- Coming back for another helping of fun and exploring Chicago this October 4th is Tim Dadabo's 2nd annual Treasures of the Southside (or T.O.S.S. for short). This event takes participants on a delightful bike ride through the near Southside of Chicago to expose the beautiful parks, statures, beaches, etc. that are not often shown on your standard Chicago tour. .

Massachusetts

- Nancy Derby will host the 2nd Annual Joanne Kelley Motorcycle Ride this August 22, 2009. For more info: 978-433-6204
- Heather Leverone hosts the 5th Annual Drive to a Cure event in Massachusetts this upcoming 14th of September at the beautiful Cranberry Valley Golf Course, Harwich, MA. The reception/auction/raffle will follow at the spectacular ocean front Wychmere Harbor Club, Harwich Port, MA. This event will be in memory and in honor of Bob Leverone.

Michigan

- Saddle up to paddle out this August 1st for 2009's 5th Annual "Paddle Out for Pulmonary Fibrosis" event. Once again Matt Dery and family host this fun canoeing trip down the Au Sable River in Glenzie, Michigan in honor of the Dery and Willacker Families.
- Tammy Walker is hosting the 2nd Annual Golf Outing in memory of Danny Walker Sr. on July 18th. The event begins at 8:30 a.m. at the Rattle Run Golf Course in St.Clair, Michigan and concludes with a steak dinner at The Boat Works. There will also be raffle, a 50/50, an auction, and other prizes.

Minnesota

- Judy Smith hosts her first golf outing in memory of her husband Jim Smith in the Oak Grove area this September 12th.

Missouri

- Jennifer Etling and crew hosted their 2nd Annual Washers for Wellness event in St.Louis, MO this past May 9th. The first toss started at 10a.m. and the day was festive with a raffle, good BBQ food, drink and T-shirts for all!

New York

- The Lore and Gehm Families are hosting their first Annual Joseph Lore Golf Outing this upcoming July 19th at LaFayette Hills Country Club in Syracuse, New York.

Ohio

- Vicki Mountain hosts the 7th Annual Barn Sale in memory of Lawrence Bray. The event is set to occur this October 10th-12th in Creola, Ohio.

Pennsylvania

- Caitlyn Berardi hosted the Rider Dances for All Ages at Rider University in Pennsylvania on March 7th and 8th.
- The Ryan, Manousos & Brown Families host the Run for Research 5K this upcoming August 6th in downtown West Chester, PA on a flat course. For more information go to www.runccrs.com.
- Rob Fiorillo will be hosting the 4th Annual Barbara A. Fiorillo Memorial Bike Run and Picnic on July 11th. The registration starts 9am at Primanti Bros.-Rt. 51 Pleasant Hill. For further information, contact Rob at 412-877-1617

- Join Jennifer Wescoe-Schaninger as she hosts the 5th Anniversary Wescoe Walk, it is to be held on Saturday, October 24, 2009. For further information, please go to www.wescoewalk.org

Texas

- "Every Breath is a Gift" is an event in memory of Gregory J. Blake who was diagnosed with IPF when he was only 30. He received a single lung transplant, but passed away at the tender age of 37. His sister set up this event to raise awareness and much needed research money. Donate at: www.active.com/donate/everybreathisagift

Wisconsin

- Linda Braeunert honored her brother Bill by helping raise awareness and donations for pulmonary fibrosis at the Manor Park Senior Center in Milwaukee.

A very special thank you and applause goes out to the event planners that are hosting their 2nd, 4th, 5th, and 7th annual events your support is phenomenal. Keep up the good work, we couldn't do it without you!!!

If you would like to host an event, please call the Pulmonary Fibrosis Foundation at: 312-587-9272 and ask for the Fundraising Handbook.

University of Chicago to Present Research Results at American Thoracic Society Meeting

Research from the University of Chicago partially supported by the PFF was recently presented at the American Thoracic Society. The meeting was held in San Diego from May 17 – May 20. The research team led by Drs. Imre Noth and Skip Garcia had a variety of presentations examining both clinical and experimental aspects of IPF. On the clinical side they looked at the relationship of IPF and GERD (gastro-esophageal reflux disease) and hiatal hernia (a clinical entity where the stomach partially slips into the chest). They also looked at possible genetic and peripheral blood markers for IPF.

The association of GERD and IPF has been well established, this study focused on the severity of IPF and GERD to see if there was a correlation. Patients with GERD who were receiving appropriate medical therapy had no worse lung function than patients without GERD. Further studies need to be done to determine if long-term treatment of GERD is beneficial in patients with IPF.

Hiatal hernia can be associated with GERD and micro-aspiration. No previous studies have examined the incidence of hiatal hernia in patients with IPF. The researchers examined CT scans of patients with IPF and found that 52% of IPF patients had probable or definite hiatal hernias on CT scans. This is much higher than the incidence in the general population, which is only around 5%. Further studies need to be performed to ascertain if the hiatal hernia acts as a trigger mechanism for injury to the lung alveolar epithelial cells.

Two other studies attempted to establish genetic and peripheral blood markers for IPF and the rate of disease progression. The variable rate of disease progression has often puzzled physicians taking care of IPF patients. The U of C group attempted to isolate genetic and peripheral blood markers that would be predictive of rate of disease progression. Although they only studied a small number of patients, the results are intriguing and need to be expanded to a larger population of IPF patients.

The is pleased to have been able to support these projects and looks forward to further studies which can better elucidate the genetics and pathophysiology of IPF. With a better understanding of these issues hopefully a cure can be found.

Yes! I want to support the work of the Pulmonary Fibrosis Foundation by making a contribution.

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PFF Announces Support For University of Iowa Research

The Pulmonary Fibrosis Foundation recently announced its support of a 2 year, \$400,000 grant to the Division of Pulmonary and Critical Medicine at the University of Iowa. The lead investigators of the study are Dr. Gary Hunninghake (Sterba Professor of Medicine) and Dr. Alicia Gerke (Associate Professor of Medicine). Dr. Hunninghake is one of the leading IPF researchers in the US.

The title of the study is Targeting Vascular Reactivity in Idiopathic Pulmonary Fibrosis. The study will look at the efficacy of employing a 3 drug "cocktail" to improve the symptoms (exercise capacity) and quality of life of individuals with IPF. The investigators will use a combination of a phosphodiesterase-5 inhibitor (sildenafil), an angiotensin receptor blocker (losartan) and an antioxidant (NAC).

As the study notes there are multiple theories as to the pathogenesis of IPF however no unifying process has been proven. The most commonly accepted hypothesis is of uncontrolled inflammation and abnormal proliferation of collagen and fibrous tissue (scar formation). Fibrosis can also occur as a result of vascular abnormalities or injury.

In humans there are complex regulatory mechanisms that control the blood pressure. There is an intricate relationship between compounds that constrict arteries (vasoconstrictors) and compounds that dilate arteries (vasodilators). These intricate regulatory mechanisms occur in both the systemic circulation (the blood pressure measurement taken in the doctors office) and the pulmonary circulation. Some recent epidemiological data have shown a "possible" relationship with systemic hypertension and IPF. Additionally, in patients with IPF there is evidence of vascular dysfunction with increased levels of oxidative stress and vasoconstrictors. Thus, abnormal or aberrant vascular function may perpetuate fibrosis and also produce pulmonary hypertension. Many patients with IPF have pulmonary hypertension and the degree of fibrosis may not correlate with the degree of hypertension.

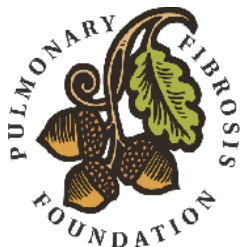
There are similar pathways of fibrosis and inflammation in hypertension and IPF. It has been suggested that therapeutic agents used with hypertension may have efficacy in IPF although there is sparse clinical data. Thus far no single agent has been successful in the treatment of IPF, therefore an approach using multiple agents (as in cancer or HIV),

which targets several pathways in the disease process, may prove to be more effective.

The drugs selected in the trial interact with the vasculature in different ways. Sildenafil, a phosphodiesterase inhibitor, acts as a pulmonary vasodilator by prolonging the effect of nitric oxide (a potent pulmonary vasodilator). Losartan, an angiotensin receptor blocker (ARB), has been shown to decrease circulating endothelin-1 (which will result in an increase in endogenous nitric oxide release thus decreasing pulmonary vascular resistance and pressure). Finally N-acetylcysteine (NAC) has antioxidant effects, which are important for maintenance of cell metabolism and survival and may help preserve lung function.

The study will be performed in a randomized, blinded fashion using various drug combinations along with a placebo. Study participants will undergo periodic pulmonary function assessment and exercise testing.

The foundation is excited about participating in this study utilizing a new "multi-drug" approach and hopes that type of methodology with prove efficacious.



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