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Fall 2010

Action Alert

The Quarterly Publication of the Coalition for Pulmonary Fibrosis

CPF Advocates Hold 50 Meetings With Congress During National Pulmonary Fibrosis Awareness Week

The Coalition for Pulmonary Fibrosis (CPF) held its eighth annual National Pulmonary Fibrosis (PF) Awareness Week, with special focus on meetings with Senators in order to discuss the newly introduced Senate version of the Pulmonary Fibrosis Research Enhancement Act (PFREA – S. 3703). Visits were also held with members of the House of Representatives and the bi-partisan House bill now has 145 co-sponsors. The bill may lead to treatments and a cure for the deadly lung disease that claims 40,000 lives a year, the same number lost to breast cancer.

The PF Awareness Week volunteer advocates, including patients and caregivers, met with nearly 50 legislators. The majority of the Capitol Hill meetings were strategically selected so that key leaders on committees related to health funding were targeted. The primary message was that the funding bill, which would establish a national registry, is essential to helping to save tens of thousands of lives each year. Volunteers found the response in legislative offices to be very positive and the campaign will work to add sponsors in both Chambers once elected officials return to Capitol Hill in November.

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The CPF and its members would like to express sincerest thanks to our key legislative leaders in the 111th Congress, Reps. Brian Baird and Mike Castle, and Senators Patty Murray and Mike Crapo, for their commitment to helping us find answers to Pulmonary Fibrosis.

Dear CPF Friends:

This organization owes much of its success and its victories to all of you reading this newsletter. Everything we do relies on the volunteerism, generosity, commitment and caring of everyone with whom we have talked or worked with in 2010.

To all of those who have supported us with their contributions or volunteer efforts, I offer our deepest thanks. Your support makes it possible for us to help make a difference in the life of a patient or caregiver on any day – it helps us fund cutting-edge research so that we can get closer to the answers needed to stop PF – and it makes a difference in our ability to spread the word as widely as possible, which is one of our biggest responsibilities if we hope to bring change.

To all our patients and family members, and the many friends of patients who step up when someone is faced with this challenge, we know how hard this road is and we are here to help. All of us at the CPF learn so much about courage and personal strength from everyone who is dealing with the disease. We have deep admiration for those who challenge PF by becoming activists for change and we sympathize deeply with all who struggle against it. That includes those who work to build support for the congressional bill, those who meet with other patients to offer empathy and strength, those who spread the word through their communities, and importantly, those who join drug trials to help the next generation of patients.

One of our jobs is to report progress to all of you. We are truly pleased to be able to say there is progress – there is increased research – there are new disease pathways being discovered all the time – there is a growing understanding of what is behind PF. All of this means hope and represents a huge change from 10 years ago.

The CPF staff salutes all of you. Every one of you is important and this work can only go forward with your continued involvement.

Thank You!

FROM
THE STAFF OF THE CPF



Education. Support. Hope.

“It is important that we drive the message of the urgency of this cause home,” said CPF CEO Mishka Michon. “There is no substitute for the testimony of patients and family members – you can discern the visible concern on the part of legislative team members when they hear the PF story. The volunteers who join us on the Hill, and clearly more than anything the patients in the group, are vital to communicating the powerful message of need for research.”



Kathleen Cooney, Mishka Michon, Rep. Henry Waxman (D-CA), Kristina Unutoa & Dolly Kervitsky.

The CPF anticipates re-introducing the bill very early in the upcoming session, in both the House and Senate. Capturing an extended list of co-sponsors now will help speed the process of gathering them early next year. Preparations are underway for that re-introduction and the CPF will be calling on its members to take up the task of contacting their legislators to once again garner support from both sides of the political aisle.

For further information on the CPF’s advocacy efforts, please visit www.coalitionforpf.org call us at (888) 222-8541, or email us at info@coalitionforpf.org.

About the CPF’s Efforts in Washington

Since 2002, the CPF has been leading a national advocacy effort directed toward Congress, the National Institutes of Health and the Centers for Disease Control to increase research funding for PF and accelerate efforts to find a cure for this devastating lung disorder. In 2007 the CPF, working closely with Rep. Norwood of Georgia, secured the passage of H.R. 182 – the first-ever recognition of the need for increased research funding and improved public awareness of PF in the United States.

That ground-breaking legislation led to a partnership with Rep. Brian Baird (D-WA), who, in 2009, introduced the first-ever legislation requesting an allocation of funds for the disease. That legislation currently has 145 co-sponsors. In response to the importance of this legislative effort, Sen. Patty Murray (D-WA) sponsored a similar bill in the U.S. Senate (S.3703). If no vote is held in 2010, the CPF will work to have the legislation re-introduced in 2011. At that time our members will be asked to assist in the effort to garner support from legislators across the country. The CPF has also actively advocated for passage of legislation important to the PF community in the areas of Medicare and Social Security coverage.

The message about funding for PF research is so important, that I was happy to join the CPF’s September advocacy trip despite my being wheelchair bound and on oxygen at all times. It was incredibly hard for me, but it is also hard for tens of thousands of others. I decided it was urgent that I speak out while I am still able.

I encourage anyone and everyone to make a call or write a letter on behalf of the Pulmonary Fibrosis Research Enhancement Act. I do know because of the presence of patients and caregivers, not just that of lobbyists, we had a huge impact on the Hill. If I am able, I’ll be back next year because we can’t stop fighting until our goals are achieved.

— Dorothy Jean Matson,
PF patient

CPF and Representative Brian Baird in Discussion About His Efforts on Behalf of the Cause

Rep. Baird introduced the PFREA in 2009 and has worked to help secure 145 co-sponsors in the House. He is the recipient of the CPF's 2010 Charles G. Norwood Memorial Advocate of the Year Award for his ground-breaking efforts to generate Congressional support for research on the disease.

What motivated you to begin the process of requesting support for PF research?

My personal experience with my dad was a powerful emotional stimulus to initially launch this effort. (Rep. Baird's dad died in his arms of PF after a two-year battle with the disease). But objectively, even if this had never happened to me, logic says that an illness of this lethality and this prevalence deserves serious attention, particularly given the increasing numbers. As I see it, if someone came to the members of congress and told them that there was a disease taking as many lives as breast cancer, and no one knows the causes and there is no treatment – logic would tell you that we need to do something. The current situation is particularly troubling because we are spending far less, proportionately to other diseases with far lower mortality rates, and so we continue to have very little understanding of PF and no treatments. You don't need to lose your father to this to understand the implications of the raw numbers.

How did the diagnosis of your dad impact you? How much were you able to learn about the disease at the time?

We didn't believe what we heard at first – and we didn't understand it. When a man can spend his whole day fishing at high altitudes and can trailer his boat and more, and then is told that he has a lung disease that is fatal – well, the diagnosis just didn't correspond with the health of my father. A few months later he was suddenly on oxygen and that's when it became real, but even then it's hard to comprehend. If you get a diagnosis of cancer, mortality immediately raises its head, but believing something completely unknown to you can kill you when you feel pretty healthy is very difficult. It doesn't make sense intellectually – especially to a healthy individual. But it becomes very real when the fight for breath begins. We just didn't understand how fast it would move.

What was your response when you learned there was no treatment available?

It was still disbelief. I went online to research options. I am a healthcare professional and I'm a fighter, as was my father. It was very frustrating to spend all that time on the internet and not find anything. We not only could not find the magic bullet out there, we couldn't find anything at all (in 2001). When the clock is ticking on someone you love tremendously and there are no resources, you feel utter helplessness. It's like watching someone drown because you don't have a life preserver. You run all over the boat looking for it, and while you do that, as in this case, the person literally drowns.

Did you feel the doctors understood exactly what they were dealing with and helped you understand it as well?

It was a challenge because my family was across the country from my dad, so we didn't have as much contact with the docs as I'd wished we had. We made some calls to clinics, but in general we got the "we're doing what we can". He resisted going on oxygen, but I wanted him to do it. He was stoic and an outdoorsman, and like many, he didn't like the image of being on oxygen or the possibility of dependency. He was an educator and a brilliant guy, so we persuaded him to do it when we raised the specter of brain damage and a reduced quality of life.

When you decided to work on the PFREA, what were you initially hoping to see happen?

One of the great frustrations, among the many rewards from serving in Congress, is that things that seem so obvious to me and make so much sense can be the most frustrating and difficult to pursue. We have tens of thousands of people running in walks and races across the country for other diseases, but we have nothing yet for PF. If 2 illnesses are comparable in lethality and prevalence (such as PF and breast cancer), how does one argue against comparable funding for research? I'm very frustrated. I started out this year saying one of my top priorities

continued on next page

was this. I am saddened that we didn't make more progress in this first go-around. We definitely got caught in the broader healthcare debate and though it's an alternative often used, I didn't feel that philosophically the answer was to tag ourselves onto some other bill.

What do you see us doing to succeed with this next congress?

To make this work, people need to continue to build individual relationships with multiple members of congress and keep telling the personal story to make it real. Be sure to tell the numbers to bring home the quantitative message and get constituents working on their own legislators. It makes all the difference to get in front of a legislator with stories from their own constituents.

How did the partnership with the CPF work for you?

I thought it was generally good – it has been constructive. The process of translating the interests of an interest group into reality isn't always an elegant one. It can be a challenge, but an understandable challenge. It's not unique to this situation. It may be possible to get something like this through without a group that's organized but when something is unknown, like PF, you need those affected to be individually asked to speak up, which is what the CPF does. The best way to make it work is for people to directly ask legislators for support by telling them what their personal stake is – they are dying from this and they need to say it. If the official needs their vote, they need to leverage that trade.

What would you like to see happen now?

I'd like to see two things. First, I'd like to see national awareness among the general public increase – that's the best way to bring about funding changes. This is not just about government funding, the private funding will also increase. Broad-based public appreciation and understanding will bring about a desire to eradicate this illness which could ultimately bring a congressional and administrative commitment and include the NIH down the line. You have to keep pushing for proportional funding and the application of a rational decision-making process. Look at a host of metrics – for PF there should be a higher ranking, even if just quantitatively. How do we make decisions about how we spend our healthcare dollars - if you do it right, you will see this is an outlier in terms of funding. The government really needs to step up for this.

What do you hope your legacy will be around the disease?

We started the ball rolling. I would have liked to have seen this completed. I know, because of the nature of these illnesses, it would be unrealistic and wildly hopeful to have the research to find the silver bullet this quickly. Perhaps we have at least put the ball on a course that will shorten the time it takes to see change. If we can't cure this, we can at least try to hold it in abeyance. It's clear that the number of people affected - not only patients but all those who love them - will only be increasing as the patient population grows. I would like to see us start to save those lives - soon.



Rep. Brian Baird and constituents

CPF Honors Individuals for Their Dedication

The Coalition for Pulmonary Fibrosis (CPF) has announced its annual awards honoring three critical areas of leadership that impact the work of the Pulmonary Fibrosis (PF) community. The recipients, Bob and Sandy O'Rourke, Congressman Brian Baird and Dr. Naftali Kaminski, are champions for the always-fatal disease by trying to create change, offering support and giving hope.

"The Coalition is proud to honor individuals who have made a visible and important difference for this constituency. They are not alone in working for change, but unfortunately, we cannot honor all those to whom we owe gratitude for their work on behalf of our patients, and they are many," says Mishka Michon, the CEO of the Coalition for Pulmonary Fibrosis.

Bob and Sandy O'Rourke of Pasadena, CA., will receive the Francis Cabral Humanitarian Award. This award is granted to those patients or caregivers who significantly improve awareness of Idiopathic Pulmonary Fibrosis (PF) in their community and nationwide, who selflessly further the mission of the CPF, and who shine as a beacon of hope and inspiration to all those suffering from this disease.

The O'Rourkes are honored for their outstanding efforts at bringing recognition of Pulmonary Fibrosis to households around the country. Bob has toiled at fulfilling his promise: "Before I take my last breath, I want to make PF a household word.

Recognition and awareness are key drivers in finding treatments and a cure. It has worked well in breast cancer and AIDS and it can work here. We just have to keep fighting." With a number of television, print and radio interviews, the O'Rourkes have increased awareness exponentially around the country.

Congressman Brian Baird (D-WA) has been awarded the Charles G. Norwood Memorial Advocate of the Year Award for the second time – recognizing his outstanding commitment to improving awareness of PF in his community and furthering the mission of the CPF. Baird introduced the first-ever bill establishing a Congressional research allocation for Pulmonary Fibrosis, the Pulmonary Fibrosis Research Enhancement Act (PFREA – H.R. 1079), making history in a way that may ultimately alter the future for all PF patients.

Having lost his father to the disease, he has a personal link to PF and says that, like most others, he was shocked and confused to learn that his father was dying of a fatal disease that was unknown to him, as it is to most Americans. When he realized that PF fatalities matched those of breast cancer, he was even more driven to work for increased research into the disease. His House bill led to a Senate bill, S. 3703, that also requests the establishment of a registry so that answers can be found for this 100 percent fatal disease. Although he is retiring at the end of the 111th Congress,

Baird's effort has brought 145 co-sponsors to the House bill, helped encourage the Senate bill (S. 3703), and what he introduced has set in motion what will be a continuing effort in the legislature to increase funding for PF.

Dr. Naftali Kaminski, director of the Lung, Blood and Vascular Center for Genomic Medicine at the University of Pittsburgh, will receive the Marvin I. Schwarz Research Award which recognizes a researcher's commitment to improving the quality of life of those living with PF through compassionate patient care, education, and support, while leading research efforts to find a cure.

Kaminski is an internationally recognized expert in Pulmonary Fibrosis. As a researcher he pioneered the application of genomic technologies in the study of interstitial lung disease. This technique uses information about the human genome to better understand disease. Kaminski was able to take a much broader look at PF in order to generate and test novel hypotheses. As a physician, he has worked with hundreds of patients suffering from PF and helped establish a means by which his patients improve their quality of life. His compassion and commitment have had a valuable impact on the patient and research community.

Special Patient Education Event at Beth Israel Deaconess Hospital in Boston

The physicians and staff of the Interstitial Lung Disease Center at Beth Israel Deaconess (BIDMC) and Brigham and Women's Hospitals (BWH) in Boston, held another very successful patient event this September. The speakers selected topics that give patients and caregivers a basic understanding of the disease and types of care, and the structure of the meeting allowed for small group breakout discussions on a variety of questions ancillary to the short and long-term challenges presented by PF.

Presenters included Dr. Peter Lacamera, who hosted the event, and Dr. Joseph Zibrack, who spoke on Clinical Trials for PF - both are from BIDMC. Dr. Ivan Rosas of BWH addressed the Current Understanding of PF Biology, and his colleague Dr. Matt Hunninghake shared information on Genetics of Interstitial Lung Diseases. Also hailing from BWH was Dr. Hilary Goldberg, who

educated the audience on the Lung Transplantation process. Pulmonary Rehabilitation, an important aspect of patient care, was described by Ms. Claudia Levenson, a Pulmonary Therapist from BIDMC; her colleague, Ms. Julie Knopp, a Nurse Practitioner, talked about the Meaning of Palliative Care

Patients were clearly grateful to be able to spend additional time at the end of the speaking sessions sharing their concerns, questions and suggestions with the doctors and the other patients and caregivers.

"We are most grateful to be included in this event, and thank BIDMC for the opportunity given so many PF patients and families to gather in one place and learn from one another. I look forward to a time when there are many more such events around the country." Mishka Michon, CEO of the CPF.

Please go to the CPF website, www.coalitionforpf.org, to see the presentations shared at the Beth Israel Deaconess Medical Center.



"It is gratifying for us to have the chance to address key topics of interest to most patients and to then spend time in smaller groups discussing one-on-one the issues and questions that are of foremost importance to them. Our patients' courage, and the commitment of their caregivers, is a huge motivation for us in our work, so we find these events as fulfilling for us as professional practitioners as we hope they are for our constituents.

— Dr. Peter Lacamera, event host

Garden Party 2010

The annual Butterfly Garden Party was held on October 9, and more than 100 guests joined the Roney/Cadarette family on the deck and lawn of their home overlooking the Pacific Ocean. Many of those attending were loyal CPF supporters, but there were new faces and new friends, and 2 patients who both traveled some distance to share the afternoon with CPF contributors.

The event raised over \$70,000 - noteworthy was a generous \$10,000 gift from the Bank of America – CPF CEO Mishka Michon indicated the funds will support the CPF's areas of activity which include patient outreach, funding of research, advocacy for Congressional funding, expanded public awareness, sharing of critical disease and research information via the internet and the Action Alert newsletter, and establishment and support of patient groups around the country.

Although the event's focus is a serious one, there was an atmosphere of warm camaraderie among those who gathered to share their commitment to changing the future for PF patients. The hosts, John Cadarette and Deirdre Roney provided guests with origami lessons, a blank art canvas on which everyone was welcome to paint their artistic bent, a Henna tattoo offering by Rita -Rukmini, and an excellent selection of food and drink from Cheers Catering.

Late in the afternoon, guests heard from John Cadarette, Mishka Michon and Deirdre Roney and applauded warmly as the the Frank Cabral Humanitarian Award for 2010 was given to Bob and Sandy O'Rourke for their outstanding, selfless efforts to improve awareness of PF in their community and nationwide. Michon stated that "the O'Rourkes are shining as beacons of hope and inspiration to all those suffering from this disease. Their willingness to say the hard truths about their experience so that the public can understand the cold reality of PF is of inestimable value."

Michon also talked about the increase in research efforts around the disease and the degree to which hundreds of legislators have become conversant with PF – a promising state of affairs for the ongoing effort to garner congressional funding. The hosts and CPF staff deemed the event a wonderful success.

Garden Party Sponsor List:

Emerald Monarch

Deirdre Roney and John Cadarette

Diamond Monarch

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Yvonne Lacko and
Denise Lacko Condra
The Venable Foundation

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Deirdre Roney (host), Kathleen McClure-Wight, Bob O'Rourke Sandy O'Rourke, Mishka Michon



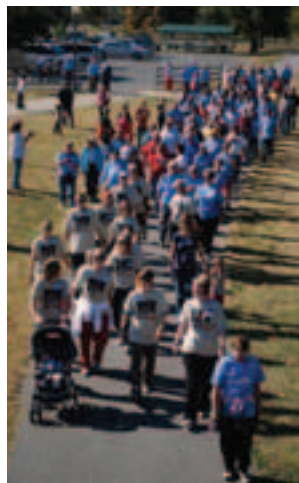
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Garden Party Guests and Supporters

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3rd Annual PF Walk for your Next Breath Continues Strong

Flooding of Vanderbilt University Medical Center's office basement almost suspended this year's plan for a walk in October, but the Middle Tennessee Coalition for Pulmonary Fibrosis Support Group, rallied by Rose Barton, put together the third annual Walk for your Next Breath. Despite the flood, this year's walk was as successful as previous walks as patients and families joined with many volunteers to celebrate the Next Breath.

"Over 50 volunteers (including students from Franklin High School's Health Occupations Students of America [HOSA]) came together. It was amazing to see this PF community throw an incredible fundraiser to support not only each other but CPF's services and research programs."

*— Rose Barton, 2010 PF Awareness Week DC Advocate
(Rose lost her husband to PF)*

Participants traveled from beyond the boundaries of Tennessee, from as far as Alabama, Mississippi, Illinois and Missouri. They were joined by nearly 200 people, including members of their Vanderbilt Medical Center healthcare team on a day filled with sunshine for the one mile community walk. Dr. James Lloyd, founder of the Idiopathic Pulmonary Fibrosis Center at Vanderbilt, encouraged the group by relaying information about continued development of potential treatments through research efforts ongoing at Vanderbilt and around the world.

Guests were treated to a delicious meal catered by Becky Player and Joyce Hawker. Player's husband died from PF and, to this day, she continues to be involved in the support group. The group was entertained by musician Colleen Lloy and there were several booths set up to offer helpful information including Tennessee Donor Services, the Coalition for Pulmonary Fibrosis, and United Medical. Participants also purchased Opportunity Tickets in hopes of winning one of over 40 raffle prizes. This year's Raffle Table was manned by Carol Sue Palmer of Missouri and many of the items on the tables were donated by her family or members of her community in memory of her husband, Michael.

During the Walk, time was dedicated to honoring and cheers went up for all the pulmonary fibrosis patients who were able to complete the one-mile walk, and remembering those who had passed away during the years prior. Between registration, a bake sale, opportunity tickets and contributions, and after 2 short months shy of planning, the Middle Tennessee group was able to raise nearly \$8,000. At the close of a very busy day, the volunteers celebrated the uniting of a community of people dedicated to the same goal – to cure PF!



Host Rose Barton and Volunteer Lynn Markley with raffled quilt

First Annual Cocktail Fundraiser Raises Awareness and Patient's Spirits

Like many affected by PF, patient Misti Nickens, wanted to do something in the fight against the disease. So she picked up the phone, made a call to the CPF, requested a Fundraising Kit in July and soon after started planning her first fundraiser. Misti held a cocktail and auction party on Friday, October 22, 2010 at BNY Mellon Center, Philadelphia, PA.

Misti and her cousin and event co-chair Melissa Roberts, solicited wonderful items for the opportunity tickets and auction – such as autographed Phillies' baseball and Eagles' jersey, weekend getaways, jewelry, gift cards, artwork and more. They offered a lively event for patients and their friends and family, with wonderful cocktails and hors d'oeuvres and entertainment by Four Keys Band, a jazz band.

During the evening's program, Misti shared her own personal PF journey, while Dr. Robert Kotloff, of the University of Pennsylvania Medical Center Lung Transplant Program, and CPF Board Member Dr. Gregory Tino, also from the Medical Center, spoke about the disease and their work in PF medicine. The two generously took time to answer questions from event attendees, who left the event armed with an enhanced understanding of the disease.

The first annual event gathered nearly 75 attendees, raised over \$14,000 and increased PF awareness in the community. Misti's family noted that she was empowered and energized by the experience, and are urging her to commit to another event next year.

"It was a labor of love but I was able to stay well and even felt better than I had been – knowing that I was making a difference." Misti Nickens



*Dr. Gregory Tino, Misti and Dr. Robert Kotloff,
University of Pennsylvania Medical Center*



Fundraiser guests enjoying the evening



Save Lives, Change the Future for Tens of Thousands and Lower Your Taxes – Simply by Signing Your Name!

If you contribute to the work of the CPF before December 31, 2010, you can help us save lives and take a deduction from your income taxes. Gifts are deductible up to 50% of your adjusted gross income.

You can ensure our ability to provide all our services and programs at no cost to the PF community. Nearly all of the funds for our work are from private donors.

THANK YOU.



Getting the Air You Need

Oxygen provision is a crucial component of treatment for PF patients – it is life-saving. There are many providers and many options when it comes to equipment choices and patients often must be their own advocates when it comes to finding the best equipment for their needs. University of California San Francisco Interstitial Lung Disease Program nurse Sally McLaughlin suggested that getting the best service involves learning the government guidelines for coverage and gathering as much information as possible from a nurse or pulmonary rehabilitation specialist. There are resources available to assist patients in understanding the options. Please find below excerpts from the pamphlet “Living Well with Supplemental Oxygen” on the UCSF Interstitial Lung Disease Program website. The entire booklet can be found at www.ucsfhealth.org/ild.

Some pointers from UCSF Interstitial Lung Disease nurse Sally McLaughlin on key oxygen provision issues:

“In my experience, doctors tend to leave the choice of equipment up to the nurses. This is fine because it takes a lot of time in terms of thought and advocacy to get equipment that meets the patients’ lifestyle needs – equipment that the patient CAN and WILL use. Pulmonary rehabilitation programs are very good resources for recommending equipment for patients to meet their lifestyle needs and oxygen needs... so are some oxygen suppliers – especially their respiratory therapists. Patients need to learn about the different kinds of oxygen equipment available today that will meet their needs and keep them active, and make sure they get it. In truth, suppliers are reimbursed the same amount whatever equipment they offer.

People with ILD are dealing with some challenges regarding their oxygen equipment because their oxygen needs may be low at first, but tend to increase over time:

1. Liquid systems tend to deliver higher flows for longer periods of time, but there is a trend amongst oxygen supply companies to no longer offer liquid systems because they are labor-intensive and therefore more costly.
2. Because of Medicare guidelines, it’s harder to switch oxygen suppliers after the first year. So, when patients with ILD start to need higher flows (greater than 5 liters per minute) and their current company doesn’t provide high flow equipment or liquid oxygen, which would serve them better, they are unable to switch to a new company that can meet their needs - they’re locked in, because Medicare will not pay another company until the patient’s 60 month rental cycle is over. Patients with ILD need to start out with a company that offers a variety of equipment.
3. Health care providers, including oxygen suppliers, don’t always understand that people with ILD may be sufficiently saturated while at rest, but as soon as they start walking, their requirement can shoot up. It is important that whoever is assessing the oxygen needs of the patient performs a walk test. Patients need to understand this and ask to be tested while ambulating.
4. The new portable oxygen concentrators are terrific for travel and other situations – they really keep people mobile – but there currently only two on the market that will go up to 3 liters continuously - the Invacare Solo with also goes to 5 liters per minute pulsed dose, and the SeQual Eclipse that which also goes to 6 liters per minute pulsed dose. All the other units on the market only deliver pulsed dose oxygen from 3 – 5 liters per minute. So it’s important for ILD patients to invest in a portable oxygen concentrator that will meet their higher flow needs. New equipment is coming out all the time, though, and I hope that we will see ones that delivers higher flows.”

Living Well with Supplemental Oxygen

Courtesy of UCSF Interstitial Lung Disease Program

The following information represents selected material from the UCSF Oxygen brochure.

For a complete copy please go to www.ucsfhealth.org/ild.

The Need for Supplemental Oxygen



Why Did My Doctor Prescribe Oxygen For Me?

Every body needs oxygen! In fact, every tissue and every cell in the body needs a constant supply of oxygen to work properly. The way oxygen gets into our cells and tissues involves the lungs – the lungs allow us to breathe in oxygen from the air, and pass the oxygen into the bloodstream through millions of tiny air sacs, called alveoli. Hemoglobin in the red blood cells then picks up the oxygen and carries it off to the tissues and cells of the body.

Interstitial lung disease can cause inflammation and/or scarring in the part of the lung tissue where oxygen passes into the bloodstream – the alveoli. This inflammation and scarring make it difficult for oxygen to move into the bloodstream. Therefore, the amount of oxygen in the blood drops, resulting in not enough oxygen to keep the tissues and cells functioning properly. Not enough oxygen in the bloodstream is called hypoxemia.

How Did My Doctor Determine That I Need Supplemental Oxygen?

The amount of oxygen in the bloodstream can be easily measured two ways:

Oximetry

This is the method most often used to measure the amount of oxygen in the blood. A small clip-on device shines a light through your finger or earlobe and measures the amount of light absorbed by the oxygen carrying hemoglobin in the red blood cells. By calculating the amount of light absorption, the device can measure the percent of hemoglobin that is carrying oxygen – the oxygen saturation of the blood (or O₂ sat). Normally, the oxygen saturation of the blood is around 95 – 100%.

Arterial Blood Gas Study

Blood is drawn out of an artery (usually in the wrist) using a needle and syringe. The blood is then sent through an analyzer to measure the amount of oxygen gas dissolved in the blood. This result is called the arterial oxygen pressure (paO₂), and is normally 80 – 100 mm Hg. When the O₂ sat falls below 89%, or the paO₂ falls below 60 mm Hg - whether at rest, with activity, or during sleep – the tissues are not getting enough oxygen, and supplemental oxygen is needed to correct the hypoxemia. Your healthcare provider can determine your supplemental oxygen needs by testing you while you are at rest and while walking, and can also order an overnight oximetry study to test your oxygen saturation at night.

When/How Much Do I Have To Wear My Oxygen?

The body needs enough oxygen to keep the blood adequately saturated so that cells and tissues get enough oxygen to function properly. Furthermore, cells and tissues can neither “save up” nor “catch up” on oxygen – they need a constant supply. When the oxygen saturation falls below 89%, or the arterial oxygen pressure falls below 60 mmHg – whether at rest, with activity, or during sleep – then supplemental oxygen is needed. Your health care provider will write a prescription for when and how much you should wear your oxygen, based on the results of your testing. The prescription should specify the appropriate oxygen flow rate or setting (as liters per minute [lpm or l/min] of oxygen) that will keep your saturations ≥ 90%, when you should wear your oxygen (i.e., with activity, overnight, or continuously), and should specify a type of equipment that will accommodate your lifestyle needs.

Why Would I Need to Wear Oxygen When I’m Sleeping?

Oxygen levels in the blood are lower for everyone during sleep, due to a mildly reduced level of breathing. Also, some alveoli drop out of use during sleep. If your waking oxygen saturation is greater than around 94% on room air, it is unlikely that your saturation during sleep will be below 88%. If there is a question about your oxygen levels while you are sleeping, however, an overnight pulse oximetry test can be ordered by your physician.

How Do I Know That I'm Using the Right Amount of Supplemental Oxygen?

The way to tell for sure if you are using the right amount of supplemental oxygen is to measure your oxygen saturation while using your oxygen. Your provider or a respiratory therapist from the oxygen supplier should test your oxygen saturation on oxygen while you are at rest, while walking, and, if indicated, while you are asleep. As long as your saturation is in the 90's you are getting the right amount of supplemental oxygen.

Should I Buy My Own Finger Oximeter to Test My Oxygen Saturations?

Some people feel more comfortable testing their oxygen saturation periodically throughout the day or with various activities, to make sure they are 90% saturated or more. Others learn how much oxygen they need at various activity levels to keep them saturated in the 90's through pulmonary rehabilitation programs. Still others are comfortable with periodic testing at their provider's office. Finger oximeters are available on the internet, through medical supply companies, and even in sporting goods stores. They can be expensive and have not been adequately tested for accuracy. You and your provider can determine together if a finger oximeter is necessary for you.

How Important Is Wearing My Oxygen As Prescribed?

When a person isn't getting enough oxygen, all organs of the body can be affected, especially the brain, heart, and kidneys. Wearing supplemental oxygen keeps these organs, and many others, healthy. There is evidence that, for people who are hypoxemic, supplemental oxygen improves quality of life and survival.

Will I Feel Better When I Use My Oxygen?

Supplemental oxygen can help relieve your symptoms. You may feel relief from shortness of breath, fatigue, dizziness and depression. You may be more alert, sleep better, and be in a better mood. You may be able to do more activities, including travelling and travelling to high altitudes.

But there are other reasons for symptoms such as shortness of breath besides lack of oxygen. In these cases, supplemental oxygen may not relieve shortness of breath. However, if tests show that you are not getting enough oxygen, it is still important that you wear your oxygen.

Does My Need for Supplemental Oxygen Mean That I Don't Have Long To Live?

People live for years using supplemental oxygen.

Will I Always Need to Use Supplemental Oxygen?

That depends on the reason oxygen was prescribed. If your lung or heart condition improves, and your blood oxygen levels return to normal ranges without supplemental oxygen, then you don't need it anymore.

Can I Become "Dependent On" or "Addicted To" Oxygen?

There is no such thing as becoming "dependent on" or "addicted to" supplemental oxygen – everybody needs a constant supply of oxygen to live. If there is not enough oxygen in your bloodstream to supply your tissues and cells with oxygen, then you need supplemental oxygen to keep your organs and tissues healthy.

Are There Any Side Effects From Using Oxygen?

It is important to wear your oxygen as your provider ordered it. If you start to experience headaches, confusion, or increased sleepiness after you start to wear oxygen, you might be getting too much. Oxygen settings of 4 liters per minute or above can cause dryness and bleeding of the lining of the nose. A humidifier attached to your oxygen equipment, or certain ointments can help prevent or remedy this.

Will I Be Able to Go Out and About With My Oxygen Equipment?

Our goal is to have you continue as many of your usual activities as you can. With that in mind, your healthcare provider, your oxygen supply company and you should work together to get oxygen equipment that will allow you to do these things. Choosing the right type of equipment for you and your lifestyle is very important - the right ambulatory oxygen equipment can play a major role in improving quality of life.



Your Oxygen Equipment

How Do I Choose the Right Oxygen Equipment for Me?

You, your healthcare provider and your oxygen supplier should all work together to choose the oxygen system that is right for you – one that takes into account your lifestyle and activities, as well as the amount of oxygen you need. The goal is to have oxygen equipment that you can and will wear, so that you can keep enjoying your activities. Some of the factors to consider when choosing the right system and equipment for you are:

- The amount of oxygen your doctor has prescribed for you (written as liter flow of oxygen per minute, such as 2 liters/min)
- How often and for how long you leave your house
- What activities you do while you are out
- Your size, strength, and endurance versus the weight of the equipment
- The size and layout of your home (2 stories, etc)
- Whether you breathe through your nose or through your mouth
- Your dexterity
- Your personal preferences

What Type of Equipment Is Available?

The two main types of oxygen systems currently available are:

- compressed gas systems
- liquid oxygen systems

Additionally, there are now portable oxygen concentrators (POCs) which can be used for travel. The compressed gas system consists of a concentrator to be used in the home and a small oxygen tank to be used outside the home, while the liquid oxygen system consists of a stationary concentrator or reservoir to use while you are in your home and an ambulatory tank to use when you go out. The portable oxygen concentrator can serve as both the ambulatory device and the stationary concentrator in certain circumstances.

Where Do I Get My Oxygen and Equipment?

Your provider will help you choose an oxygen company, or you may choose any company you want. Sometimes insurance policies dictate which oxygen company you must use.

Who Will Pay for My Oxygen and Equipment?

Most insurance policies cover supplemental oxygen when the medical necessity for oxygen is demonstrated. This necessity is based on the oxygen saturation or the arterial blood gas measurements. Generally, if your O₂ saturation falls below 89%, or your paO₂ falls below 60 mm Hg - whether at rest, with activity, or during sleep - then you qualify for supplemental oxygen.

How Do I Maintain My Equipment?

Your oxygen supply company will give you instructions for cleaning your equipment. Below are some basics:

- The nasal cannula should be changed every week
- The long tubing attached to your stationary equipment should be changed monthly. Neither the nasal cannula nor the long tubing from your stationary equipment should be washed
- If an oxygen face mask is used, it should be cleaned twice weekly with warm soapy water
- Oxygen concentrators usually require a weekly filter cleaning with warm soapy water
- If you are using a humidifier, empty it at least once a day, wash the bottle with soap and warm water, making sure all the soap is rinsed out, and then refill the bottle with distilled water. Do not use tap water, as the minerals in it can damage your equipment.



For government guidelines on oxygen provision, please go to:
www.portableoxygen.org/Oxygen_guidelines.html

Positive Results from Development Candidate

RTTNews - Biopharmaceutical company Geron Corp. (GERN) said Wednesday that its development candidate for fibrotic diseases, TAT153, showed positive results and slowed disease progression in an animal model of pulmonary fibrosis. The company said the data were presented at the American Thoracic Society 2010 International Conference in New Orleans.

TAT153, an orally available small molecule telomerase activator, was given twice daily for three weeks, in a standard mouse model of Pulmonary Fibrosis or PF. The chronic, progressive, and usually fatal lung disease is characterized by inflammation and scarring, or fibrosis, of the lung. Patients have an impaired ability to process oxygen and a reduced lung volume and experience coughing and shortness of breath.

In the animal model, the fibrotic process and accompanying deterioration of lung function were induced by bleomycin administration into the trachea. Progression of pulmonary fibrosis in the animals was assessed by lung function tests, quantification of inflammatory cells and collagen deposits in the lungs.

Results showed a 40% decrease in inflammatory cells in the TAT153-treated group, with a greater proportion of functional lung tissue being preserved in treated animals. The treated animals showed a 30% increase in lung compliance and a 30% decrease in airway resistance.

The positive effects were brought about by an approximately two-fold increase in telomerase activity in lung tissue samples, Geron said. Overall, the results demonstrated reduced inflammation, preserved functional lung tissue, slowed disease progression and attenuated loss of pulmonary function.

Source: *rttnews*, May 19, 2010

Familial Pulmonary Fibrosis Counseling Service

The CPF continues to support the first genetic counseling program for PF. The telephonic counseling program is operated by National Jewish, and funded, in part, by the CPF.

The program provides a qualified genetic counselor, who has expertise in familial pulmonary fibrosis, to discuss by phone various issues surrounding FPF. These can include preparation for and interpretation of genetic tests, and various life decisions, such as having children and planning for the future. Experts recommend talking to a counselor prior to having any genetic tests, so that people are prepared to learn the results.

For further information on the FPF genetic counseling program or to speak with a genetic counselor, call (800) 423-8891, ext. 1097

Important Reminder

Get your flu shot!
The pneumonia vaccine is also recommended for older patients.



NIAMS-Funded Scientists Find Potential Target for Fibrosis Treatment

Two separate research groups funded by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) have discovered that the molecule EGR-1 (early growth response 1), which regulates gene expression, plays a central role in the development of fibrosis, a condition in which organ-supporting tissue becomes thick, hard, and rigid, hindering normal tissue and organ function. Controlling EGR-1, say the scientists, could be a potential therapy for such disorders as scleroderma and pulmonary fibrosis. Their findings have been reported in the *American Journal of Pathology*.

Fibrosis is a disorder of the extracellular matrix, the mesh of proteins like collagen that makes up the body's connective tissue. It is a factor in scleroderma, among other diseases, and can affect many of the body's organs, including the lungs, liver, and skin. Its consequences can be devastating, even leading to death. Recent research has shown that cells in fibrotic tissue receive the wrong molecular signals, causing too many extracellular proteins to be made. One possible way to approach the fibrosis problem, scientists say, might be to try to interrupt such signals at critical points in the cellular pathways that they travel.

The two research groups, headed by Carol Feghali-Bostwick, Ph.D., at the University of Pittsburgh School of Medicine and John Varga, M.D., at Northwestern University's Feinberg School of Medicine, took separate approaches in discovering the importance of EGR-1. The University of Pittsburgh group induced fibrosis

in mouse and human fibroblasts (cells that make up the extracellular matrix) by utilizing a signaling protein called IGFBP-5 (insulin-like growth factor binding protein 5). The Northwestern team administered the antibiotic bleomycin to induce scleroderma in mice. Both research teams found that the experimentally produced fibrosis was associated with abnormally elevated EGR-1 activity. Furthermore, when they produced fibrosis in cells or in mice lacking EGR-1, the amounts of fibrosis were dramatically reduced. In further support of the findings, the Pittsburgh group found that EGR-1 levels were higher in lung tissues and fibroblasts of people with pulmonary fibrosis compared to controls. EGR-1, concluded the scientists, appears to be essential for the development of fibrosis, making it a potential target for therapy. The two studies also showed that independent signaling pathways, such as those for IGFBP-5 and bleomycin, both converge on EGR-1 to create fibrosis.

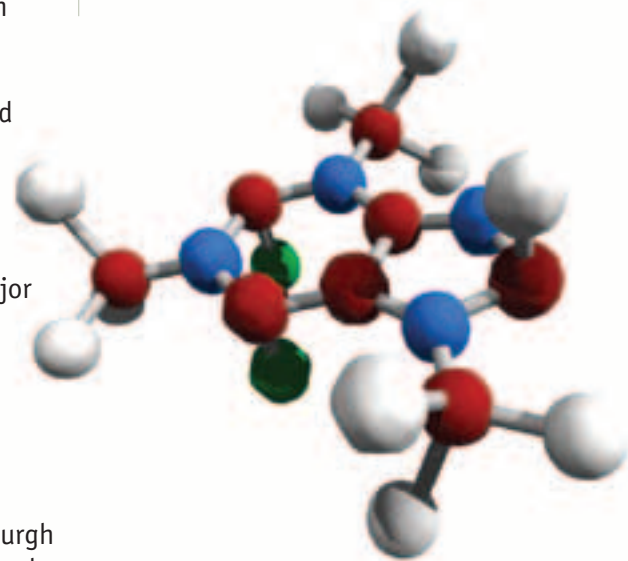
Fibrosis is a common disorder and a serious complication of many diseases. It is still considered hard to treat, with no currently approved therapies. Because the understanding of fibrosis is a major unmet medical need, any fresh insights into the disease process might open the door for novel therapies.

In addition to receiving NIAMS funding, the University of Pittsburgh work had support from the National Heart Lung and Blood Institute, the American Lung Association, the American Heart Association

Pennsylvania/Delaware affiliate, and the Uehara Memorial Foundation. Support for the Northwestern University work also came from the U.S. Department of Defense.

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the Department of Health and Human Services' National Institutes of Health (NIH), is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases.

Source: NIAMS, April 2010.
For more information about NIAMS, call the information clearinghouse at 301-495-4484 or 877-22-NIAMS (free call) or visit the NIAMS Web site at www.niams.nih.gov.



Men with PF May Suffer Less Shortness of Breath Than Women with the Disease

Gender influences health-related Quality of Life in PF

A recent study showed that women who suffer from PF may experience more significant shortness of breath than the men who suffer from the disease. Researchers from the University of Michigan Health System, the Mayo Clinic, the University of Colorado and National Jewish Health used demographic, pulmonary physiology and quality of life scoring data from the NIH-sponsored Lung Tissue Research Consortium (LTRC) to look at health-related quality of life (HRQL) in PF patients.

“The results are interesting and require further evaluation. They are interesting because a similar pattern has been observed in patients with COPD, thus raising suspicion that chronic respiratory diseases affect men and women differently. Why this might be is unknown. It is unclear whether the instruments used to measure dyspnea and HRQL “behave” differently in men versus women or whether there are true differences between the genders in these so-called patient reported outcomes (PRO). Whatever the case, we know that PRO are important to measure and that they yield meaningful information that pulmonary function tests, high-resolution CT scans, and walk tests do not deliver; so, it will be important to investigate gender in PF more closely in future studies,” said Jeff Swigris, DO, MS one of the study researchers and Assistant Professor of Medicine in the Autoimmune Lung Center and Interstitial Lung Disease Program at National Jewish Health.



In a study sample consisting of 147 men and 74 women, researchers compared diffusion capacity for carbon monoxide (DLCO) and found that it was the only baseline variable that differed between the men and women.

The researchers found significant gender differences between men and women with men reporting less severe dyspnea or shortness of breath. Dyspnea appears to have a greater impact on the physical health-related quality of life of men and the emotional health-related quality of life for women.

Source: Respiratory Medicine, Volume 104, Issue 5, Pages 724-730 (May 2010)



Education. Support. Hope.

All of the CPF's services are free to the PF community. We rely on private contributions to maintain our programs and hope you will consider a year-end gift so that we can continue to be there for everyone who needs help.

Stem Cells – A Still Experimental but Promising Frontier

Top Ten Things to Know About Stem Cell Treatments

Many clinics that are offering stem cell treatments make claims about what stem cells can and cannot do that are not supported by our understanding of science. The information on this page corrects some of the misinformation that is being widely circulated.

1. There are different types of stem cells—each with their own purpose.

There are many different types of stem cells that come from different places in the body or are formed at different times in our lives. These include embryonic stem cells that exist only at the earliest stages of development and various types of ‘tissue-specific’ or ‘adult’ stem cells that appear during fetal development and remain in our bodies throughout life.

Our bodies use different types of tissue-specific stem cells to fit a particular purpose. Tissue-specific stem cells are limited in their potential and largely make the cell types found in the tissue from which they are derived. For example, the blood-forming stem cells (or hematopoietic stem cells) in the bone marrow regenerate the blood, while neural stem cells in the brain make brain cells. A neural stem cell won't spontaneously make a blood cell and likewise a hematopoietic stem cell won't spontaneously make a brain cell. Thus, it is unlikely that a single cell type could be used to treat a multitude of unrelated diseases that involve different tissues or organs. Be wary of clinics that offer treatments with stem cells that originate from a part of the body that is different from the part being treated.

2. A single stem cell treatment will not work on a multitude of unrelated diseases or conditions.

As described above, each type of stem cell fulfills a specific function in the body and cannot be expected to make cell types from other tissues. Thus, it is unlikely that a single type of stem cell treatment can treat multiple unrelated conditions, such as diabetes and Parkinson's disease. The underlying causes are very different and different cell types would need to be replaced to treat each condition. It is critical that the cell type used as a treatment be appropriate to the specific disease or condition.

Embryonic stem cells may one day be used to generate treatments for a range of human diseases. However, embryonic stem cells themselves cannot directly be used for therapies as they would likely cause tumors and are unlikely to become the cells needed to regenerate a tissue on their own. They would first need to be coaxed to develop into specialized cell types before transplantation. A major warning sign that a clinic may not be credible is when treatments are offered for a wide variety of conditions but rely on a single cell type.

3. Currently, there are very few widely accepted stem cell therapies.

The range of diseases where stem cell treatments have been shown to be beneficial in responsibly conducted clinical trials is still extremely restricted. The best defined and most extensively used is blood stem cell transplantation to treat diseases and conditions of the blood and immune system, or to restore the blood system after treatments for specific cancers.

Some bone, skin and corneal diseases or injuries can be treated with grafting of tissue that depends upon stem cells from these organs. These therapies are also generally accepted as safe and effective by the medical community.

4. Just because people say stem cells helped them doesn't mean they did.

There are three main reasons why a person might feel better that are unrelated to the actual stem cell treatment: the ‘placebo effect’, accompanying treatments, and natural fluctuations of the disease or condition. The intense desire or belief that a treatment will work can cause a person to feel like it has and to even experience positive physical changes, such as improved movement or less pain. This phenomenon is called the placebo effect. Even having a positive conversation with a doctor can cause a person to feel improvement. Likewise, other techniques offered along with stem cell treatment—such as changes to diet, relaxation, physical therapy, medication, etc.—may make a person feel better in a way that is unrelated to the stem cells. Also, the severity of symptoms of many conditions can change over time, resulting in either temporary improvement or decline, which can complicate the interpretation of the effectiveness of treatments. These factors are so widespread that without testing in a controlled clinical study, where a group that receives a treatment is carefully compared against a group that does not receive this treatment, it is very difficult to determine the real effect of any therapy. Be wary of clinics that measure or advertise

their results primarily through patient testimonials.

5. A large part of why it takes time to develop new therapies is that science itself is a long and difficult process.

Science, in general, is a long and involved process. Understanding what goes wrong in disease or injury and how to fix it takes time. New ideas have to be tested first in a research laboratory, and many times the new ideas don't work. Even once the basic science has been established, translating it into an effective medical treatment is a long and difficult process. Something that looks promising in cultured cells may fail as a therapy in an animal model and something that works in an animal model may fail when it is tried on humans. Once therapies are tested in humans, ensuring patient safety becomes a critical issue and this means starting with very few people until the safety and side effects are better understood.

If a treatment has not been carefully designed, well studied and gone through the necessary preclinical and clinical testing, it is unlikely to have the desired effect. Even more concerning is that it may prove to make the condition worse or have dangerous side effects.

6. To be used in treatments, stem cells will have to be instructed to behave in specific ways.

Bone marrow transplantation is typically successful because we are asking the cells to do exactly what they were designed to do, make more blood. For other conditions, we may want the cells to behave in ways that are different from how they would ordinarily work in the body. One of the greatest barriers to the development of successful stem cell therapies is to get the cells to behave in the

desired way. Also, once transplanted inside the body the cells need to integrate and function in concert with the body's other cells. For example, to treat many neurological conditions the cells we implant will need to grow into specific types of neurons, and to work they will also have to know which other neurons to make connections with and how to make these connections. We are still learning about how to direct stem cells to become the right cell type, to grow only as much as we need them to, and the best ways to transplant them. Discovering how to do all this will take time. Be wary of claims that stem cells will somehow just know where to go and what to do to treat a specific condition.

7. Just because stem cells came from your body doesn't mean they are safe.

Every medical procedure has risks. While you are unlikely to have an immune response to your own cells, the procedures used to acquire, grow and deliver them are potentially risky. As soon as the cells leave your body they may be subjected to a number of manipulations that could change the characteristics of the cells. If they are grown in culture (a process called expansion), the cells may lose the normal mechanisms that control growth or may lose the ability to specialize into the cell types you need. The cells may become contaminated with bacteria, viruses or other pathogens that could cause disease. The procedure to either remove or inject the cells also carries risk, from introducing an infection to damaging the tissue into which they are injected.

8. There is something to lose by trying an unproven treatment.

Some of the conditions that clinics claim are treatable with stem cells

are considered incurable by other means. It is easy to understand why people might feel they have nothing to lose from trying something even if it is unproven. However, there are very real risks of developing complications, both immediate and long-term, while the chance of experiencing a benefit is likely very low. In one publicized case, a young boy developed brain tumors as a result of a stem cell treatment. Participating in an unproven treatment may make a person ineligible to participate in upcoming clinical trials (see also number 9). Where cost is high, there may be long-term financial implications for patients, their families and communities. If travel is involved there are additional considerations, not the least of which is being away from family and friends.

9. An experimental treatment offered for sale is not the same as a clinical trial.

The fact that a procedure is experimental does not automatically mean that it is part of a research study or clinical trial. A responsible clinical trial can be characterized by a number of key features. There is preclinical data supporting that the treatment being tested is likely to be safe and effective. Before starting, there is oversight by an independent group such as an Institutional Review Board or medical ethics committee that protect patients' rights, and in many countries the trial is assessed and approved by a national regulatory agency, such as the European Medicines Agency (EMA) or the U.S. Food and Drug Administration (FDA). The study itself is designed to answer specific questions about a new treatment or a new way of using current treatments, often with a control group to which the group of people receiving the new treatment

Continued on next page

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is compared. Typically, the cost of the new treatment and trial monitoring is defrayed by the company developing the treatment or by local or national government funding. Beware of expensive treatments that have not passed successfully through clinical trials.

Responsibly-conducted clinical trials are critical to the development of new treatments as they allow us to learn whether these treatments are safe and effective. The ISSCR supports participation in responsible clinical trials after careful consideration of the issues highlighted on this site and in discussion with a trusted physician.

10. Stem cell science is constantly moving forward.

Stem cell science is extraordinarily promising. There have been great advances in treating diseases and conditions of the blood system using blood-forming stem cells, and these show us just how powerful stem cell therapies can be. Scientists all over the world are researching ways to harness stem cells and use them

to learn more about, to diagnose, and to treat various diseases and conditions. Every day scientists are working on new ways to shape and control different types of stem cells in ways that are bringing us closer to developing new treatments. Many potential treatments are currently being tested in animal models and some have already been brought to clinical trials. In February 2010 the British company ReNeuron announced it had been approved to conduct a Phase I clinical trial of a neural stem cell treatment for stroke. The first embryonic stem cell-based treatment for acute spinal cord injury is currently under review by the U.S. Food and Drug Administration (FDA) and will hopefully move into clinical trials soon. Although it is sometimes hard to see, stem cell science is moving forward. We are tremendously optimistic that stem cell therapies will someday be available to treat a wide range of human diseases and conditions.

Source: International Society for Stem Cell Research

Special Note:

International Society for Stem Cell Research Concerned About Aggressive Marketing Of Treatments. “The International Society for Stem Cell Research says it’s concerned about aggressive marketing of treatments by clinics that may not have safeguards to ensure safety or likely benefit. In June, the society launched a website “ that “offers background information on stem cell research and suggests questions to ask at a particular clinic,” such as questions about the scientific evidence behind the treatment, clinic oversight, accreditation, and the risks as well as near- and long-term side effects of procedures offered. The site for the patient handbook on stem cell research from the Society is: www.isscr.org/clinical_trans/pdfs/ISSCRPatientHandbook.pdf

Source: AP, August 2, 2010

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Rheumatoid Arthritis-Interstitial Lung Disease-Associated Mortality

Olson AL, Swigris JJ, Sprunger DB, Fischer A, Fernandez-Perez ER, Solomon J, Murphy J, Cohen M, Raghu G, Brown KK

Division of Pulmonary and Critical Care Medicine, National Jewish Health, Interstitial Lung Disease Program & Autoimmune Lung Center, Denver, Colorado, United States.

RATIONALE: Mortality rates from rheumatoid arthritis-associated interstitial lung disease are largely unknown. **OBJECTIVES:** We sought to determine mortality rates from rheumatoid arthritis-associated interstitial lung disease in the United States from 1988 through 2004.

Methods/ MEASUREMENTS: Using data from the National Center for Health Statistics, we calculated age-adjusted mortality rates from the deaths of persons with rheumatoid arthritis-associated interstitial lung disease, determined the prevalence of interstitial lung disease in all decedents with rheumatoid arthritis, and compared the age and underlying cause of death in these two cohorts of decedents.

MAIN RESULTS: From 1988 to 2004, there were 39,138,394 deaths in US residents and 162,032 rheumatoid arthritis-associated deaths. Of these deaths, 10,725 (6.6%) met criteria for rheumatoid arthritis-associated interstitial lung results. Mortality rates from rheumatoid arthritis fell over the course of this study in both women and men. However, mortality rates from rheumatoid arthritis-associated interstitial lung disease increased 28.3% in women (to 3.1 per million persons in 2004) and declined 12.5% in men (to 1.5 per million persons in 2004). Because the rate of decline in rheumatoid arthritis outpaced rheumatoid arthritis-associated interstitial lung disease in men, the prevalence of rheumatoid arthritis-associated interstitial lung disease increased in both sexes over time.

CONCLUSIONS: Clinically significant RA-ILD occurs in a minimum of 10% of the RA population, and is associated with shortened survival and more severe underlying disease. While overall mortality rates in RA have fallen, those associated with RA-ILD have increased significantly in older age groups.

PMID: 20851924 [PubMed - as supplied by publisher]
Source: *Am J Respir Crit Care Med*, September 17, 2010

Whether you are a PF patient, a family member of a patient, or are close to someone with PF, the CPF is always just a phone call away. Our staff has counseled thousands of patients, and we are always here to provide you with the resources and support you need. Please call (888) 222-8541 to learn more.



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About the Coalition for Pulmonary Fibrosis

The Coalition for Pulmonary Fibrosis (CPF) is a 501(c)(3) nonprofit organization, founded in 2001 to accelerate research efforts leading to a cure for pulmonary fibrosis (PF), while educating, supporting, and advocating for the community of patients, families, and medical professionals fighting this disease. The CPF funds promising research into new approaches to treat and cure pulmonary fibrosis; provides patients and families with comprehensive education materials, resources, and hope; serves as a voice for national advocacy of PF issues; and works to improve awareness of PF in the medical community as well as the general public. The CPF's nonprofit partners include many of the most respected medical centers and healthcare organizations in the U.S. With more than 23,000 members nationwide, the CPF is the nation's largest nonprofit organization dedicated to advocating for those with pulmonary fibrosis. For more information please visit www.coalitionforpf.org or call (888) 222-8541.

Supporting the CPF

The Coalition for Pulmonary Fibrosis (CPF) relies on the contributions of individuals, corporations and associations who share our commitment to improving awareness and education of PF, and improving the quality of life for patients fighting PF nationwide.

Every service we offer is at no cost to the PF community. Through your generous support, the CPF will continue to provide information, resources and support to more than 128,000 PF patients, caregivers and families, and to the health care professionals who treat them.

Should you wish to make a tax-deductible contribution to the CPF, we encourage you to send your check or money order to:

Coalition for Pulmonary Fibrosis
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