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DEAR PF COMMUNITY,

In this spring edition of the Breathe Bulletin, we would like to celebrate the individuals who are making a difference in pulmonary fibrosis (PF). We will explore the many ways in which patients, caregivers, physicians, politicians, and others are improving the lives of those affected by PF. I hope that you will find the profiles in this issue as compelling and inspirational as I do.

Providing lifesaving assistance through organ donation is one of the biggest gifts anyone can bestow. Transplantation greatly benefits our community as well as other organ specific diseases. April is National Donate Life Month. I encourage everyone to visit www.donatelifeline.net to learn more about organ donation and to join Donate Life America's 20 Million in 2012 effort. As you will read in the Q&A article with Jesse White, Illinois’ Secretary of State, organ donation is truly a heroic act.

Other champions we would like to highlight are the researchers committed to finding effective treatments for PF. In this edition of the Bulletin you will be able to read about new developing therapies, the Foundation’s research program, and the commitment from the National Institutes of Health to support PF research. Additionally, one of the Foundation’s major initiatives this year will be to implement a ‘blueprint’ for a national PF patient registry. This program will eventually provide critical data that can help investigators develop successful treatments for PF. More information about the registry will be provided in the coming months.

The Foundation prides itself on fostering collaborative relationships throughout the PF community. Important programming, such as last year’s IPF Summit 2011, brought together a diverse group of people, including patients, researchers, physicians, nurses, members of the bio-pharma industry, and representatives from the financial community. It is our intention that this type of activity will lead to improved diagnosis, better patient care, and can stimulate new translational research. In this issue you can learn more about the conference, how to view the archived webinars, and the dates for Summit 2013.

National Volunteer Week is April 15 through April 21, and the Foundation would like to thank all of the volunteers who help us. I am continually impressed by the commitment and compassion of our team of volunteers; this includes our Board of Directors, event coordinators, and our advocates who support us with their time, resources, and passion. Furthermore, I am thrilled to announce our new volunteer fundraising initiative—Team PFF—that will unite and connect those impacted by this disease. Our 2011 Volunteers of the Year just hosted their second annual Broadway Belts for PFF! This event received ‘rave’ reviews and raised over $50,000. You can read more about the volunteers and the all-star Broadway cast in the Bulletin.

Lastly, I want to remark on how important individuals like you are to the Foundation. Individual giving accounts for approximately 90% of our fundraising dollars—without you we could not do the work that we do. On behalf of the Foundation, and all those who benefit from your generosity, thank you for your financial support.

In closing, I would like to say how honored I am to be part of such a remarkable organization and community. As many of you know, we have an amazing staff at the Foundation that is extremely hardworking and profoundly dedicated to helping everyone impacted by this disease. I want to genuinely thank them and all of you as well. Together we will make a difference in PF!

Sincerely,

DANIEL M. ROSE, MD
President and Chief Executive Officer
Secretary White, thank you for helping us raise awareness about organ donation. Would you tell us about your role as Illinois’ Secretary of State?

I’ve had the great pleasure of serving the people of the State of Illinois for the past 14 years. I run the largest Secretary of State office in the nation, with a $365 million budget, 4,000 employees, 138 offices, and 23 agencies. I’m in charge of the library system and the Organ and Tissue Donor Program, which is one of the largest in the nation. It’s an honor for me to talk to the Foundation about organ and tissue donation.

What spurred your interest in organ donation and organ donation advocacy?

Well, my brother fell ill and while he was on life support a member from the regional organ bank asked if, by chance, he happens to pass away, could they use his organs for transplantation purposes? I said no, don’t bother me, don’t bother us, leave us alone. I thought that it was an experimental program at the time. My brother passed away, and I didn’t think any more of the conversation until two years later, when my sister wasn’t feeling well and was in dire need of a kidney. There was not a match for a donor within the family, and so she put her name on the transplant list, and as a result of someone else’s generosity, she got a second chance in life. And that opened my eyes about the importance and value of the Organ and Tissue Donor Program.

When I became the Secretary of State in 1999, the Organ and Tissue Donor Program was under the jurisdiction of the Secretary of State’s office and my team and I decided that we were going to do all we could to promote this program—since I knew the importance of it, I knew the value of it, I knew what could be derived from it.

How has the program progressed since you came into office in 1999?

When I first came into office, the process for signing up to be an organ donor was to sign the back of your driver’s license and have two individuals sign as witnesses. However, we found out that 20% of the people who had signed up to be organ donors did not have their organs recovered, because of the stress of the moment and at the thought of losing their loved one, the family did not consent.

So in 2006, we went to a new order of business called First Person Consent. The law makes your decision to be an organ and tissue donor legally binding so your wishes will be honored. If you decide to become a part of this program, you are added to our database, so when that moment arrives there will be a smooth transition, and we will not have to communicate with your next of kin.

How has First Person Consent impacted the program?

Our numbers are going off the chart. There has been a great improvement in people signing up. In Illinois, we are at over 50% of the population, with well over five million people that have signed up. And as a result of this new approach, and the ease in signing up, we are one of the top states in the nation with regard to the Organ and Tissue Donor Program.

Of all the things you’ve done, would you tell us where this initiative sits in regards to some of your other accomplishments?

In my lifetime, I have been successful in saving the lives of young people, but when you think in terms of people who are ill, people who have only a few months or a few days to live, organ donation sits quite high on my list, because they don’t have the time to waste. It’s important for us to make sure that we give them a second chance in life, the gift of life by way of an organ, or help to improve their quality of life with organs or tissue.

Pulmonary fibrosis has no known cure and no FDA-approved treatment. However, lung transplantation can improve the quality and longevity of life for some patients. Therefore, organ donors are very important to our community. Can you talk to people who might be considering organ donation about why it is so important to be an organ donor?

Well, many times we think of a hero as being someone who’s helped to extricate someone from an automobile crash, rescued someone from a fire, or saved someone from drowning. Those people are heroes. But when I think about people who have had a positive impact upon the lives of others, the people I also consider to be heroes are those who have become organ donors.
“When you’ve gotten the gift, you know how you felt before, you know how you feel now, and now you’re telling others, and that’s a powerful story.”

I coach a team called the Jesse White Tumblers. One of my tumblers was shot and killed coming out of Ford City Mall, and as a result of that tragic situation, six individuals got a second chance in life. And then a personal friend of mine passed away; she died of an aneurysm. Eight organs were used for transplantation purposes, and one gentleman received the corneas of her eyes. So there’s a lot to be said about this wonderful program. I would just hope that everyone who reads about the benefit of organ donation in your publication responds by participating.

What’s the one thing you would say to me to convince me to become an organ donor?

I tell people you may not have a need today, you may not have a need tomorrow, but sometime during your lifetime, you or someone that you know, or someone who’s related to you, may have a need. We want to make sure there’s an adequate supply of organs available when that moment arrives. I would just hope that you would consider your fellow man and woman and participate in this meaningful program.

What is so gratifying about being an organ donor advocate?

When you see a person who’s in dire need of an organ, and all of a sudden their quality of life has improved because someone else cared enough to become an organ donor, it’s a win-win situation for all of us.

Organ donation is so easy, wouldn’t everyone do it?

One of the easiest things a person can do is to sign up to be an organ donor. I just cannot conceive of a person not wanting to participate in this program. Aside from some religious reasons, I cannot think of a reason as to why an individual would not want to give someone else a second chance in life. I say when you’re alive and well, give blood, when you’re no longer here, give organs, and when you’ve done those things, you will have made a positive impact on society.

“I say when you’re alive and well, give blood, when you’re no longer here, give organs, and when you’ve done those things, you will have made a positive impact on society.”

Where can people go for more information or resources on organ donation?

If people want more information about organ donation, Donate Life America is a wonderful organization. Just go to Donate Life America’s website at www.donatelife.net.

And what about information for people in Illinois?

In Illinois, if people want more information about how to become a part of our Organ and Tissue Donor Program they can go to one of my 138 driver’s license facilities, they can go to our website at www.lifegoeson.com, or they can call 1.800.210.2106.

Do you have any statistics on how many people are on waiting lists and how many people we lose?

Here in Illinois we have 5,000 people on waiting lists and we lose about 300 people each year. On a national level, it’s about 113,000 people on the list for organs, and about 18 people die each day because organs are not arriving in a timely manner.

We have time for one last question. Have you ever known anyone that has received an organ who didn’t become an advocate for organ donation?

I have never seen an individual who has received an organ who has not been grateful. No one has ever said don’t count me in, I’m not going to go out and promote organ donation. They always say count me in, I want to go out and I want to promote this program because I see the value in it. Matter of fact, people who have received organs are the ones who really serve as the drum majors and cheerleaders, they pass the word on about how they are here today because of the generosity of someone else. When you’ve gotten the gift, you know how you felt before, you know how you feel now, and now you’re telling others, and that’s a powerful story.

Jesse White is Illinois’ 37th Secretary of State. White was first elected to the office in 1998 and won landslide victories in 2002, in which he won all 102 counties, and again in 2006. On November 2, 2010, White was re-elected to a fourth term, winning another landslide victory in which he earned over 2.5 million votes statewide—more than any statewide constitutional candidate in over 30 years.

In 1999, White founded the internationally known Jesse White Tumbling Team to serve as a positive alternative for children residing in and around the Chicago area. Since its inception, more than 11,500 young men and women have performed with the team. White has spent 50 years working as a volunteer with the team to help kids stay away from gangs, drugs, alcohol, and smoking, and to help set at-risk youth on the path to success.

A SNAPSHOT OF ORGAN DONATION AND TRANSPLANTATION IN THE UNITED STATES

As of April 1, 2012

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Source: United Network for Organ Sharing
View the up-to-date statistics at www.unos.org
Organ transplantation was once considered an experimental procedure with a low success rate. Many transplanted organs survived just a few days or weeks. But researchers have transformed transplant surgery from risky to routine. It’s now the treatment of choice for patients with end-stage organ disease. Each day, about 80 Americans receive a lifesaving organ transplant.

“The outcomes of transplantation are really so good these days that it truly makes a difference for the people who receive organ transplants,” says Dr. Sandy Feng, a transplant surgeon at the University of California, San Francisco. “The organs are clearly lifesaving.”

The problem now is that there aren’t enough organs to meet the demand. In early 2011, more than 110,000 people were on the nationwide waiting list for an organ. An average of nearly 20 of them dies each day while waiting.

The kidney is the most commonly transplanted organ. More than 16,000 kidney transplantations were performed in the U.S. last year. The wait, though, can be long. In February 2011, nearly 90,000 people were on the national waiting list for a kidney. Next most commonly transplanted is the liver, with more than 6,000 surgeries in 2010. That’s followed by the heart, lungs, pancreas and intestines.

You can donate some organs—like a kidney or part of your liver—while you’re still alive. You have 2 kidneys but really need only one. And the liver can re-grow if part of it is removed. But donating these organs requires major surgery, which carries risks. That’s why living donors are often family or friends of the transplant recipient.

NIH-funded scientists are exploring a variety of ways to improve organ transplantation. The biggest problem is that when an organ from one person is transplanted to another, the recipient’s immune system attacks the implant as though it’s a disease-causing microbe.

“Most organs, though, are donated after the donor has died. The organs must be recovered quickly after death to be usable. Many come from patients who’ve been hospitalized following an accident or stroke. Once all lifesaving efforts have failed and the patient is declared dead, then organ donation becomes a possibility.

“When a person dies, it can feel like a burden to a family to make decisions about organ donation,” says Feng. “So it would be a real gift to a family to indicate your decision to be an organ donor while you’re still alive, so they don’t have to make the decision for you.”

In addition to organs, you can donate tissues. One of the most commonly transplanted tissues is the cornea, the transparent covering over the eye. A transplanted cornea can restore sight to someone blinded by an accident, infection or disease. Donated skin tissue can be used as grafts for burn victims or for reconstruction after surgery. Donated bones can replace cancerous bones and help prevent amputation of an arm or leg. Donated veins can be used in cardiac bypass surgery.

NIH-funded scientists are exploring a variety of ways to improve organ transplantation. The biggest problem is that when an organ from one person is transplanted to another, the recipient’s immune system attacks the implant as though it’s a disease-causing microbe.

“We’d hit a home run if we could find a way to re-educate a person’s immune system so that it continues to fight infection just as effectively as ever but it didn’t recognize a transplanted organ as foreign. That’s called transplantation tolerance,” says Dr. Nancy Bridges, chief of the transplantation immunology branch at NIH.

To prevent organ rejection, recipients must take drugs, called immunosuppressants, usually for the rest of their lives. “Immunosuppressant drugs have revolutionized our ability to do organ transplantation over the last 30 years,” says Dr. Jerry Nepom, who heads an NIH-funded program called the Immune Tolerance Network.

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“But those 3 decades have also taught us that these immunosuppressants are not very selective, which is a big problem.”
Immunosuppressants knock down the entire immune system, so that the body has trouble fighting off infections. The drugs also boost the risk for cancer, especially skin cancer. In addition, over time, these potent drugs can damage the kidneys and raise the risk for diabetes, high blood pressure and cardiovascular disease.

“These medications are sort of a necessary evil. You can’t live without them, because you might reject your organ. But it’s difficult to live with them because they cause side effects that need to be managed,” says Feng.

If a patient stops taking immunosuppressants, the transplanted organ nearly always fails. But in very rare cases, people can go off their medications. Last year, NIH-funded scientists spotted a pattern of gene activity in patients who had successfully stopped taking their immunosuppressants after a kidney transplant. Other researchers are testing whether certain liver transplant patients could be weaned off their medications.

“Ultimately, it would be valuable if we could do a blood test to predict who could stop taking their drugs or maybe be on a lower dose,” says Bridges. “We have evidence that it might be possible, but we’re not there yet.”

In other studies, Nepom says, “we’re exploring how to get the recipient’s immune system in a receptive mode, so that it doesn’t become excited and angry when a transplanted organ comes into the body.” In one small clinical study, researchers gave a kidney recipient some of the donor’s bone marrow before surgery. Bone marrow produces cells that fight infection. The procedure created a hybrid immune system in the recipients that better tolerated the transplants. A few patients were able to go off their immunosuppressants within a year after surgery.

While some scientists continue to improve current methods, others are exploring completely new ideas. One cutting-edge approach is to create artificial transplants that won’t trigger an immune system attack. Although years of research will be needed to apply these emerging techniques, researchers have made progress toward engineering livers, lungs and other organs.

You can help reduce the need for donated organs in the first place by living well. Lower your risk of developing a long-term disease that could lead to organ failure by being physically active and eating a healthy diet rich with high-fiber foods, fruits and vegetables. Talk to your doctor about your weight, blood pressure and cholesterol. And while you’re taking these healthy steps, be sure to sign up to be an organ donor so you can help others as well.


Editor: Harrison Wein, PhD
Assistant Editor: Vicki Contie

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**Become an Organ Donor**

Sign up as an organ and tissue donor in your state’s donor registry.

Go to: www.organdonor.gov/stateMap.asp.

- Show your choice on your driver’s license. Do this when you obtain or renew your license.
- Tell your family about your donation decision. Even if you’ve signed up, your family is consulted before organ donation.
- Tell your physician, faith leader and friends.
- Prepare and sign a living will and an advance care directive. These legal documents can clarify your choice as an organ donor.

Source: NIH News in Health, March 2011

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**links**

United Network for Organ Sharing
www.unos.org

OrganDonor.gov
www.organdonor.gov

Organ Transplantation
www.health.nih.gov/topic/OrganTransplantation

History of Transplantation
www.niaid.nih.gov/topics/transplant/pages/history.aspx

What is a Lung Replacement?
www.nihbi.nih.gov/health/health-topics/topics/lungtxp/
Wisdom Beyond Years: On the Transplant List at 20

“It’s a choice, but I am pro-organ donation. I’m for it 110%. I was before I needed an organ.”

At the age of 20, Hélène Campbell and her mother have made Toronto a temporary home. Instead of a young woman who is living a normal, active life, attending college and preparing for a career, she is separated from her father, siblings, and home in Ottawa, Ontario, waiting for a phone call. It’s the call that will say—thanks to a donor—that organs are available for her double-lung transplant.

Hélène’s story is similar to that of so many people afflicted with idiopathic pulmonary fibrosis (IPF), except for her age at diagnosis. In July of 2011, to help diagnose the cause of Hélène’s breathing difficulties, doctors looked closely at her lungs and general health. They found inflammation in her lungs and hoped that it had not progressed to scarring. Unfortunately that wasn’t the case, the cause of the scarring was a mystery and Hélène was diagnosed with IPF. The doctor said Hélène needed a double-lung transplant—and a compatible organ donor to make that happen.

It’s a tough wait, but this heroic young woman waits patiently, keeps her spirits up, and has made it her mission to tell everyone how organ donation saves lives. However, Hélène needed a mechanism to deliver her important message. With a friend doing the taping, Hélène sat in front of a video camera and told the story of her disease, how she’s waiting for a transplant, and how an organ donor could let her live a normal life.

People needed to see her video to make her story known. As a huge fan of Ellen DeGeneres and The Ellen DeGeneres Show, Hélène had an idea. Ellen could be the help she needed to tell her story and that of so many others waiting for a lifesaving transplant. She sent Ellen the tape, hoping for a response, never imagining what would happen next. The impact of Hélène’s story on Ellen was tremendous. Ellen told Hélène’s story on the show, played the tape, and even surprised her with a guest appearance via Skype. Hélène is now known to television audiences all over the U.S. and Canada as the young woman waiting for her lung transplant.

Hélène’s message is one that should be heard by everyone. “If we can change not just the mindset, but the feeling towards organ donation of just one generation, it will follow us for years to come. Because we shouldn’t see organ donation as a bad thing.” Facing the challenges of this terrible disease, Hélène has become wise beyond her years. “I know it’s facing [your own] mortality [to consider organ donation], and it’s a tough time, and it’s not easy. But we can talk about it once, not dwell on it, and close that door, because it is something that we can benefit from in the future.”

“I’m just going a day at a time, hoping that when it’s the time for me to get the call, I’ll get the call.”

As we go to press with this issue of the Breathe Bulletin, Hélène is still waiting for her transplant and trying to stay healthy. “When [the disease] first started I’d have more good days, but now it’s veering toward that they’re mostly mediocre days and bad days. I feel like I’ve aged much faster than I should.” What keeps her going is the support she gets from family, new friends like Ellen, and support from patient organizations like the Pulmonary Fibrosis Foundation. “I’m just going a day at a time, hoping that when it’s the time for me to get the call, I’ll get the call. And I’m supported and have the team working with me and for me, and my mom, and family, and just the support is amazing.”

Hélène’s bravery would be astounding for someone at any age, but for a young woman of 20, it is remarkable. “People are really stronger than they think they are. And they’re put up to this, to face stuff like this, and we can do it, it’s in us.”

Editor’s Note: As this issue goes to print, we are pleased to report that Hélène has undergone a double-lung transplant, thanks to the generosity of an organ donor. Everyone at the PFF wishes her a smooth recovery.

“People are really stronger than they think they are.”
Words to Live By: Living with New Lungs

“I’ve been very tenacious in taking care of myself.”

On March 19, 2012, Mike Henderson celebrated what he calls his sixth ‘transplant-iversary.’ With family and friends, he commemorated the sixth year since his lifesaving double-lung transplant for idiopathic pulmonary fibrosis. Now age 65 and living in Portland, Oregon, Mike basically leads a normal life—semi-retired and living each day to its fullest. As a husband, father, and grandfather, he relishes time with his family and enjoys hobbies such as fishing, clamming, and crabbing in the Northwest. In his spare moments, he’s active on several boards of directors, most recently joining the board of the Pulmonary Fibrosis Foundation.

Mike’s health and excellent quality of life are direct benefits of his lung transplant in 2006. The care from his medical team was outstanding. But that’s not the only reason for his quality of life today. Mike’s unrelenting perseverance in advocating for his own health was undoubtedly a major contributor. Mike asked the questions and did the research, finding the information he needed to make important decisions on his own behalf. Post-surgery, this same tenacity served him well in recovery.

Mike was already being treated for coronary artery disease when he started having shortness of breath. Was it his heart or lungs that were causing the problem? He had always been an active guy, exercising all the time, but then one day as Mike recalls, “I went out to do a run and could barely walk it.” Eventually, even normal physical activities, like climbing a few flights of stairs, became impossible. Doctors responded by treating his heart disease with another cardiac stent. After that intervention failed, he was diagnosed with chronic obstructive pulmonary disease and given an inhaler.

Neither treatment worked; nor did cardiac rehabilitation. It was finally Mike’s cardiac rehabilitation therapist who recommended that he see a pulmonologist.

The pulmonologist gave Mike an X-ray, CT scan, and a true pulmonary function test. The diagnosis was idiopathic pulmonary fibrosis. According to Mike, the doctor’s only comments on the disease were, “there’s no known treatment that I believe to be effective and no cure.” Mike was told to come back in six months and that was it. Reflecting on the diagnosis, Mike said, “the one thing he didn’t do which, that in retrospect really surprised me, was even mention lung transplant as an option. Never came up.”

Luckily Mike isn’t a guy who takes this kind of information lying down. “It just didn’t sound to me like there was absolutely no treatment available, or I didn’t believe him, so I started doing research.” He joined a Seattle support group for pulmonary fibrosis patients and learned that he wasn’t alone with the disease. More importantly, he learned that lung transplantation was an option. “I felt sorry for myself for about one day, and then I just went to work trying to figure out what I could do about it.” So Mike researched doctors at several universities, finally deciding on Dr. Ganesh Raghu and the program at the University of Washington.

continued on next page >
Dr. Raghu and Mike discussed a transplant on Mike’s first visit “because I knew it was something that I should pursue, whether I wanted one or not. I knew that I wanted to be listed so I had the choice—not to have someone make it for me.” After numerous visits to his office, in the summer of 2005, Dr. Raghu felt that Mike’s disease had progressed to a point where it was time for him to be placed on the transplant list. He moved to Seattle to be near the transplant center and after a few false starts Mike got his new lungs on March 19, 2006. Then, as Mike puts it, “the challenging times really start. It’s quite an adventure for everybody concerned.”

Mike will tell you his recovery wasn’t easy, but that the end result was worth it. He struggled with cardiac and blood pressure difficulties, and reactions to the pain medications. Then he had a setback requiring a follow-up pulmonary surgery called a decortication. True to form, Mike pushed himself to recover. He did his exercises faithfully, in spite of the weakness from the surgeries, and like all transplant recipients, he had to learn how to breathe normally again. Six months after his life-changing journey began, Mike returned home to Portland. At home, Mike continued to challenge himself and his new lungs. Considering a pulmonary function score of 60% to be mediocre, he increased his aerobic exercises to four or five days a week and achieved a score of 75% after just a few months.

Mike Henderson’s story is similar to many others. From the very beginning he was keenly aware that something was wrong with his breathing. He pushed for answers from his doctors. And when he didn’t get enough answers, he put himself in charge. He did his own research, including turning to support groups and learning from people who shared his disease. He studied the options that were open to him, carefully decided on where he wanted medical treatment and from whom, and pushed to get appointments and insurance approval. Knowing the risks, the potential benefits, and the statistics, he decided that a lung transplant was his best hope for a longer life. And he took care of himself until that day finally came. Persevering through recovery wasn’t easy; it seldom is. But today he says, “I feel great. I don’t have the breathing capacity that I’d love to have, but I have enough to do most of the things I like to do. You can get back and do what you did before. The difference is that you appreciate every day more than ever.”

Mike will be the first to tell you how lucky he was to get a lung transplant and he is grateful for its success. What advice does he offer others? He says to keep knowledgeable about what treatments are available, because there are things coming down the road that are going to help. Over time there will be new treatments, even if they are not a cure. Find a support group and a doctor who specializes in your disease. Participate in a clinical trial if you are able. Consider whether a transplant is right for you. And he says to have a sense of humor and sense of optimism and to do what you can to make your life as good as it can be every day.
On a daily basis, when you walk in the door, you're dealing with patients or you're working on research. What is the single thing that challenges you the most from a clinical perspective every day?
The thing that drives me to come in to work every day, whether it's in clinic or in the lab, is the question "Why?" Not understanding why the disease occurs is the most frustrating aspect, because every single visit someone asks, "Why did this happen to me?" In the lab we ask the same question: "Why does this happen?"

If you channel this frustration into energy to continue to ask more in-depth questions, at some point we're going to identify a new avenue of research and potentially a novel therapy. The lack of a clear understanding as to why pulmonary fibrosis (PF) occurs drives you as a clinician and researcher.

Whether it's pulmonary fibrosis related to asbestos exposure or exposure to medications, pulmonary fibrosis related to a connective tissue disease, or the idiopathic form termed idiopathic pulmonary fibrosis, the initiation of the process may be different but may all result in a progressive fibrotic lung disease. Perhaps suggesting a common pathway leading to fibrosis.

If we investigate all those different types of fibrotic lung diseases, at some point we'll find common shared mechanisms that may be unique in some ways to the initiation of the disease, but common to the development of that end stage or progressive fibrosis. We try to parse each and every form of fibrosis out. Clinically, it is important as the prognosis may vary from one form of fibrosis to the next. The reason why individuals with one disease do not progress, whereas individuals with another form of lung fibrosis do, is very important. If we can understand why this occurs, it may lead us down the pathway to better understanding the mechanisms of fibrosis in general and help us identify potential therapies.

"The thing that drives me to come in to work every day, whether it's in clinic or in the lab, is the question “Why?”

So many patients struggle for years to get an accurate diagnosis. Then they finally get the diagnosis of a dreadful disease. It must be hard to tell a patient that they have pulmonary fibrosis.

I can tell when someone understands the complexity and gravity when we discuss their diagnosis and prognosis. They become upset and oftentimes tearful. In some ways the level of understanding leads them to a feeling of empowerment. Knowledge can lead to a new level of comfort and understanding of one's possible future. Patients oftentimes tell me that some clarity, amidst the uncertainty that naturally accompanies the evaluation of patients with pulmonary fibrosis, is comforting.

There are tremendous things we can offer to patients in addition to knowledge. We can’t offer a cure yet, but we can offer making sure they understand their disease, making sure that they know simple things to lead the best and healthiest life—simple things like oxygen support, nutrition, or exercise to maximize their level of activity. While that might diminish over time, keeping them as healthy as possible is the mainstay of our care until we can identify a cure or therapy that at least begins to halt the progression of the disease.

continued on next page >
How does the Pulmonary Fibrosis Foundation play a role in the PF community?

The resources provided by the Pulmonary Fibrosis Foundation allow for better patient support and help to facilitate care. With a few clicks on the Internet, you can identify a regional center of excellence near you or find patient resources such as information on participating in clinical trials, the best way to deliver oxygen, or how to find a support group.

It’s the answer to these basic questions that oftentimes aren’t available to many patients. The Foundation is focused on advancing the field of pulmonary fibrosis and improving our understanding and the care of patients with these diseases.

Physicians and researchers joyfully collaborate and try to participate in anything that the Foundation does, because they see, at the end of the day, it will move our understanding of this disease forward and enhance the care of their patients.

What advice for maintaining lifestyle do you give patients living with this disease? Is there a patient story you would like to share as inspiration to other patients?

The perfect example is a young woman who is an expert skier. She developed a devastating lung disease and pulmonary fibrosis. Fortunately for her, her disease was more amenable to therapy than most and she was able to recover some lung function, but she still required oxygen, particularly when she traveled to eight and nine thousand feet at a ski resort. She said, “Well, I can never go skiing again.” I replied, “Why not?” She said, “Well, you know, I’ll need oxygen when I go skiing.” I responded, “Well, simply turn it up and make sure your saturation is greater than 90%.” One of the best gifts I received that year was a picture of her skiing down the mountain with a huge grin on her face!

Patients are limited by the fact that they have to use oxygen, but they’re not limited in terms of what they can do, as long as they maintain a normal oxygen level. In most patients, it is safe to be breathless as long as their saturation is greater than 90%.

The use of oxygen is socially awkward, whether you’re a male or a female that’s utilizing it. Patients feel stigmatized at first, but oxygen therapy should not be seen as a restraint, but as a medication that enhances your health. It allows individuals with significant lung disease—whether that is COPD or pulmonary fibrosis—to lead a more normal life.

I think the focus of care for our patients is to help them to continue to do the things that make them happy. We need to move forward, whether it’s in the clinic, or in the lab, to identify those therapies that not only stabilize the disease and prevent it from getting worse, but to identify ‘the cure.’ That’s the ultimate goal of any researcher. We want to be able to help patients.

“Physicians and researchers joyfully collaborate and try to participate in anything that the Foundation does, because they see, at the end of the day, it will move our understanding of this disease forward and enhance the care of their patients.”

“That’s the ultimate goal of any researcher. We want to be able to help patients.”
What do you tell your patients about lung transplantation?

Each conversation about lung transplantation is unique to the patient based on their overall health, disease progression, and age. For some people, lung transplantation can improve the longevity and quality of life. I would love to give you a standard answer about lung transplantation for PF patients, but there are many factors involved in determining who would make a good candidate for a transplant, both medically and personally. I would recommend that people who wish to learn more about lung transplantation discuss it with their pulmonologists. Currently, it is the only effective therapy for progressive pulmonary fibrosis. It is estimated that each year, approximately 40,000 patients develop idiopathic pulmonary fibrosis with just slightly more than 1,800 lungs being transplanted in the United States. Two important issues are raised by these data. First, I would recommend that people sign up for organ and tissue donation for the benefit of all those who are in need. Secondly, we are desperately in need of a treatment to more effectively care for patients with pulmonary fibrosis. Lung transplantation will certainly benefit a select group of patients but the majority of patients with pulmonary fibrosis will succumb to their illness until we identify effective therapies for the disease.

Dr. Cosgrove is a member of the Pulmonary Fibrosis Foundation’s Medical Advisory Board and served as a Faculty Member for IPF Summit 2011. He is currently an Associate Professor at National Jewish Health and University of Colorado Denver.

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The U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients

Table 12.4

Transplant Recipient Characteristics, 2000 to 2009

Recipients of Deceased Donor Lungs

<table>
<thead>
<tr>
<th>PRIMARY DIAGNOSIS</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
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<th>2007</th>
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<td>472</td>
<td>405</td>
<td>425</td>
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<td>460</td>
<td>430</td>
<td>425</td>
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<td>449</td>
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<tr>
<td>Cystic Fibrosis</td>
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<td>165</td>
<td>170</td>
<td>202</td>
<td>202</td>
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<td>219</td>
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<tr>
<td>Idiopathic Pulmonary Fibrosis</td>
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<th>2007%</th>
<th>2008%</th>
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</thead>
<tbody>
<tr>
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<td>45.60%</td>
<td>39.40%</td>
<td>39.70%</td>
<td>36.80%</td>
<td>32.70%</td>
<td>30.70%</td>
<td>29.00%</td>
<td>28.10%</td>
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<td>Cystic Fibrosis</td>
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<td>15.90%</td>
<td>17.50%</td>
<td>14.40%</td>
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<tr>
<td>Idiopathic Pulmonary Fibrosis</td>
<td>14.60%</td>
<td>16.20%</td>
<td>20.50%</td>
<td>22.20%</td>
<td>23.90%</td>
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<td>33.60%</td>
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<tr>
<td>Alpha-1-Antitrypsin Deficiency</td>
<td>7.70%</td>
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<tr>
<td>Idiopathic Pulmonary Arterial Hypertension</td>
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<td>3.60%</td>
<td>4.90%</td>
<td>4.10%</td>
<td>2.90%</td>
<td>2.80%</td>
<td>2.40%</td>
<td>2.00%</td>
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<td>2.20%</td>
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<td>Other</td>
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<td>13.10%</td>
<td>18.00%</td>
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<td>–</td>
<td>–</td>
<td>0.10%</td>
<td>–</td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL (%)** 100.00% 100.00% 100.00% 100.00% 100.00% 100.00% 100.00% 100.00% 100.00% 100.00%

Source: OPTN/SRTR Data as of October 1, 2010.

(–) = None in category.

These data include multi-organ transplants, other than heart-lung, in which a deceased donor lung was one of the organs transplanted.
The Pulmonary Fibrosis Foundation (PFF) places enormous importance on creating an environment that will assist in the development of effective treatments for pulmonary fibrosis (PF). We are pursuing this by directly funding research, promoting advocacy efforts, encouraging collaborative relations between industry and academic researchers, delivering key communications to patients, and developing solutions to bridge existing gaps in PF research.

Funding for Research
The Foundation directly funds important peer-reviewed research through the PFF Research Program; we also participate in partnership grants with other institutions and organizations.

Advocacy
Our staff routinely communicates with members of Congress and their legislative aides, promotes patient advocacy action days, and enlists the help of our constituents to support awareness.

- Support for Legislation
  - Pulmonary Fibrosis Research Enhancement Act (PFREA)
  - Faster Access to Specialized Treatments (FAST)
  - Transforming the Regulatory Environment to Accelerate Access to Treatments (TREAT)

- Participation in National Action Campaigns and Petitions
  - NORD Rare Disease Day
  - FDA Rare Disease Patient Advocacy Day
  - National Donate Life Month
  - National IPF Awareness Week
  - Petition to Increase NIH Funding
  - And Others

Building Key Relationships
The PFF actively fosters relationships to enhance drug research and development:

- Food and Drug Administration (FDA) — discussions regarding valid endpoints for clinical trials
- National Institutes of Health (NIH)/National Heart, Lung and Blood Institute (NHLBI) — working with the IPFnet and development of a patient registry
- National Organization for Rare Disorders (NORD) — collaboration on mutual advocacy programs
- Communications with other disease specific organizations to advance best practices and work together on common advocacy issues

Physician, Researcher, and Industry Education and Collaboration
The PFF helps create platforms for professionals to expand their knowledge of PF, partner in drug development, and widen their contacts:

  - Provided a venue where leading researchers could exchange ideas
  - Presented a forum for expediting PF drug development
  - Displayed new research at the poster presentations (Read about the 2011 winning poster presenters on page 24)

- Partnerships and sponsorships for other meetings, colloquia, seminars, and conferences (See pages 16 and 17)

Patient Communications
It is critical for patients to be able to advocate for and participate in their own health care. The PFF is an excellent resource for patients, family members, and caregivers to learn about:

- Clinical Trials
- Important Research
- Safety Issues
- Advocacy Efforts

Bridging the Gaps
Through communication with its Medical Advisory Board and members of industry, the Foundation attempts to identify key gaps that may impede the development of successful treatments. One major deficiency is the lack of a pulmonary fibrosis patient database. The PFF has embarked on the ambitious goal of establishing a national PF patient registry. Currently in the planning stages, we are collaborating with many institutions and key stakeholders to determine the objectives, scope, structure, and partners for a national (and eventually international) PF patient registry. The PFF will provide more information about this exciting endeavor as it becomes available.
How does the PFF decide which research is funded?

All grant requests undergo rigorous peer review from a panel of experts. This group decides which research projects will provide the best opportunities to move forward in finding a cure for pulmonary fibrosis. The peer review grant program is directed by Jesse Roman, MD; reviewers include members of the Research Advisory Committee. (See page 31 for the members of our Research Advisory Committee)

What else is the PFF doing to ensure that the best research is being funded?

Pulmonary fibrosis is thought to result from an abnormal inflammatory response to repetitive lung injury. In the U.S. there are no approved therapeutic agents available to prevent the progression or enable the reversal of lung fibrosis.

Results in experimental lung fibrosis, while providing insights into the pathophysiologic mechanisms, have not been translated into effective therapies for patients with the disease. More recent approaches utilizing genomic or proteomic platforms have similarly not resulted in the development of effective therapeutic agents. Based on this lack of progress in treating fibrotic diseases of the lung, it may be worthwhile to critically evaluate the state of research in lung fibrosis and provide a ‘blueprint’ for future research.

How is the PFF helping researchers establish a ‘blueprint’ for PF research?

In order to help provide investigators with direction for future research projects, the PFF has agreed to co-fund, along with the American Thoracic Society (ATS) and the European Respiratory Society (ERS), two leading professional societies dealing with fibrotic lung diseases, a research symposium to develop a ‘white paper’ on “Future Directions in Lung Fibrosis Research.” This project will re-evaluate the state of research in lung fibrosis and provide a ‘blueprint’ for future research based on newer techniques, promising early findings, and an updated understanding of disease pathogenesis.

What about research into other fibrotic diseases? Is there information that should/could be shared across organ systems?

On March 8–11, 2011, the PFF, in coordination with the ATS and the Coalition for Pulmonary Fibrosis, worked closely with the scientific community to bring together experts in lung, liver, kidney, and skin fibrotic disorders for a workshop in fibrosis across organ systems. The goal of the Fibrosis Across Organ Systems Symposium was to gain insight and direction in the basic scientific understanding of fibrosis that could ultimately lead to new and better treatments.
2011 GRANT COMMITMENTS

In 2011, the Pulmonary Fibrosis Foundation solely or jointly funded twelve grants. Award recipients were:

• Dr. Erica Herzog of Yale University – “Prospective Evaluation of IPF Biomarkers”
• Dr. Aldo T. Iacono of University of Maryland – “Open Label Use of Inhaled Cyclosporine in Lung Transplant Recipients” (Year 2)
• Dr. Daniel J. Kass and Dr. Naftali Kaminski of University of Pittsburgh – “Targeting the Relaxin Pathway in Pulmonary Fibrosis”
• Dr. Imre Noth of University of Chicago – “miRNA Expression in Patients with Rapidly Progressive IPF Versus Stable IPF” (Year 1)
• Dr. Patricia J. Sime of University of Rochester – “Translational Studies of New Therapeutic Targets & Biomarkers in PF”

**ATS/PFF/CPF Partnership Grants**

• Dr. Erica Herzog of Yale University – “Semaphorin 7a and Alternative Macrophage Activation in Idiopathic Pulmonary Fibrosis”
• Dr. Steven Huang of University of Michigan – “The Regulation and Pattern of the DNA Methylome in Pulmonary Fibrosis”
• Dr. Philip Simonian of University of Colorado Denver – “Protection from Inflammation-Induced Pulmonary Fibrosis by IL-22”
• Dr. Beiyun Zhou of University of Southern California – “Endoplasmic Reticulum Stress Induces Epithelial-Mesenchymal Transition in Alveolar Epithelial Cells: Role in Pulmonary Fibrosis”

**ATS/PFF International Partnership Grant**

• Anne Holland, PhD of La Trobe University, Australia – “Where Does Pulmonary Rehabilitation Fit in the Management of Pulmonary Fibrosis?”

**ATS/PFF/CPF Young Investigator Partnership Grants**

• Dr. Jia Guo of University of Rochester – “Fibrocyte Differentiation is Regulated by Yin Yang 1 in Pulmonary Fibrosis”
• Dr. Yan Sanders of University of Alabama at Birmingham – “Epigenetic Regulation of Caveolin-1 by TGF-beta Mediated Signal Pathway in Lung Fibroblasts”

2011 SPONSORSHIPS

• UC Davis Medical Center, University of California San Francisco, and Stanford University Medical Center – Understanding Pulmonary Fibrosis: A Seminar for Patients, Caregivers, and Families
• National Jewish Health – Familial Pulmonary Fibrosis Genetic Counseling Program
• Pittsburgh International Lung Conference
• Yale University – Fifth Annual Symposium on Nephrogenic Systemic Fibrosis and Allied Systemic Fibrosing Disorders
2012 GRANT COMMITMENTS

In 2012, the Pulmonary Fibrosis Foundation has committed to solely or jointly funding fifteen grants. Award recipients are:

- **PFF Research Fund Young Investigator Awards (2)**
  - Dr. Erica Herzog of Yale University – “Prospective Evaluation of IPF Biomarkers” (Year 2)
  - Dr. Aldo T. Iacono of University of Maryland – “Open Label Use of Inhaled Cyclosporine in Lung Transplant Recipients” (Year 2)
- **PFF Research Fund Established Investigator Awards (2)**
  - Dr. Daniel J. Kass and Dr. Naftali Kaminski of University of Pittsburgh – “Targeting the Relaxin Pathway in Pulmonary Fibrosis” (Year 2)
  - Dr. David J. Lederer of Columbia University – “Subclinical Interstitial Lung Disease in MESA: The MESA Lung Fibrosis Study”
  - Dr. Imre Noth of University of Chicago – “miRNA Expression in Patients with Rapidly Progressive IFP Versus Stable IFP” (Year 2)
  - Dr. Patricia J. Sime of University of Rochester – “Translational Studies of New Therapeutic Targets & Biomarkers in PF” (Year 2)
  - Dr. Andrew Tager of Massachusetts General Hospital – “Profibrotic Mechanisms of the LPA Pathway”

**ATS/PFF International Partnership Grants**

- 2012 Award to be announced September 2012
- Anne Holland, PhD of La Trobe University, Australia – “Where Does Pulmonary Rehabilitation Fit in the Management of Pulmonary Fibrosis?” (Year 2)

**ATS/PFF/CPF Young Investigator Partnership Grants**

- Dr. Jia Guo of University of Rochester – “Fibrocyte Differentiation is Regulated by Yin Yang 1 in Pulmonary Fibrosis” (Year 2)
- Dr. Yan Sanders of University of Alabama at Birmingham – “Epigenetic Regulation of Caveolin-1 by TGF-beta Mediated Signal Pathway in Lung Fibroblasts” (Year 2)

2012 PARTNERSHIPS

- 17th International Colloquium on Lung and Airway Fibrosis (ICLAF)

2012 SPONSORSHIPS

- American Thoracic Society – Fibrosis Across Organ Systems Symposium
- National Jewish Health – Familial Pulmonary Fibrosis Genetic Counseling Program
- Pittsburgh International Lung Conference
- University of Maryland – Hales Lung Conference
- University of California – Update in Interstitial Lung Disease: Diagnosis and Management CME Course

As of April 2012.

ABOUT THE PFF YOUNG INVESTIGATOR AND ESTABLISHED INVESTIGATOR AWARDS

In November of 2011, the Foundation established guidelines for Young Investigator and Established Investigator Awards to be awarded through the Pulmonary Fibrosis Foundation Research Fund. These funds can play a vital role in supporting the investigator at a crucial time in the research process. Referred to as ‘bridge grants,’ these resources will provide support to the investigator in accruing enough research documentation to secure larger federal grants.

The Pulmonary Fibrosis Foundation Research Fund offers four awards, each given over a two-year period:

- **Young Investigator Awards (2)**
  - Each award for $50,000, given over a two-year period, is designed to encourage young investigators (individuals within five years of completion of their formal training) to maintain and enhance their interest in PF research during the early stages of their academic career.

- **Established Investigator Awards (2)**
  - Each award for $50,000, given over a two-year period, is designed to help established investigators explore innovative areas of research that may not yet be eligible for an NIH (or similar) grant.

To learn more about the PFF’s Young Investigator and Established Investigator Awards, please visit www.pulmonaryfibrosis.org/research.
Promedior Receives U.S. Orphan Drug Designation for PRM-151 for the Treatment of Idiopathic Pulmonary Fibrosis (IPF)

Promedior, Inc., a clinical stage biotechnology company developing novel biologic therapeutics for the treatment of fibroproliferative diseases, announced that the United States Food and Drug Administration (FDA) Office of Orphan Products Development has granted an Orphan Drug designation to Promedior’s lead drug candidate, PRM-151, for the treatment of idiopathic pulmonary fibrosis (IPF).

PRM-151 is a recombinant form of human Pentraxin-2 (rhPTX-2), a naturally circulating human protein that treats fibrosis by regulating the monocyte-derived cells (macrophages and fibrocytes) that control the fibrotic process.

In a Phase 1 clinical study, PRM-151 was shown to be generally safe and well tolerated. PRM-151 currently is being tested in a Phase 1b clinical study in idiopathic pulmonary fibrosis (IPF) to evaluate the safety, tolerability and dose-responsive changes in validated cellular and soluble biomarkers of disease activity. For further information about this trial, please go to http://www.clinicaltrials.gov/ct2/show/NCT01254409?term=PRM-151&rank=2 or e-mail clinicaltrials@promedior.com

Content edited for space.

PFF COMMENT: An “orphan” designation confers certain commercial and marketing incentives.

Pacific Therapeutics Ltd. Provides Update on the Development of Lead Drug Candidate PTL-202

Pacific Therapeutics Ltd. is a development stage specialty pharmaceutical company focused on the identification and development of drug candidates to treat diseases of excessive scarring (fibrosis).

One candidate drug is PTL-202, a fixed dose combination of Pentoxifylline (PTX) and NAC. There is growing evidence that PTX has significant anti-inflammatory and anti-fibrogenic effects in lung tissue. PTX decreases neutrophil sequestration and inhibits production of free oxygen radicals. More recently, PTX has been shown to inhibit proliferation of interstitial lung fibroblasts and myofibroblasts, as well as collagen synthesis.

PTL-202 is currently being formulated as a once a day pill. Identification of potential recipients and appropriate dosage has been completed. The first clinical trial of PTL-202 is expected to commence in the second quarter of 2012.

Content edited for space.

PFF COMMENT: There is increasing interest in combination therapies.

Biogen Idec to Acquire Stromedix

Biogen Idec and Stromedix, Inc. announced that they have entered into a definitive agreement under which Biogen Idec will acquire Stromedix Inc., a privately held biotechnology company focused on innovative therapies for fibrosis and organ failure.

Stromedix’s lead candidate, STX-100, is a novel humanized monoclonal antibody that selectively disrupts the TGF-beta pathway, which plays a central role in fibrotic disease. STX-100 exhibited significant anti-fibrotic activity in preclinical animal models of fibrotic disease and demonstrated an attractive safety and tolerability profile in a Phase 1 trial. STX-100 is entering a Phase 2 trial in patients with idiopathic pulmonary fibrosis (IPF).

“Fibrotic organ failure, and in particular IPF, is a terrible disease with a high mortality rate, and there are no effective treatments at this time,” said Douglas E. Williams, EVP, R&D of Biogen Idec. “We believe STX-100 has the potential to be a best-in-class therapy and it is an excellent strategic fit with our focus on highly differentiated programs with the potential to make a real difference for patients. The Phase 2 program complements our scientific expertise and advances our research and development efforts in immunology.”

In August 2010, the FDA granted orphan drug designation to STX-100 for the treatment of IPF. Stromedix has completed a Phase 1 clinical trial of STX-100 and is currently initiating a Phase 2 trial in patients with IPF. Stromedix believes that STX-100 has potential therapeutic application across a broad number of fibrotic diseases.

Source: Biogen Idec Press Release, February 14, 2012
Content edited for space.
New Study Shows Investigational BIBF 1120 Demonstrated Positive Trend in Reducing Lung Function Loss in Idiopathic Pulmonary Fibrosis

Boehringer Ingelheim’s investigational tyrosine kinase inhibitor (TKI) BIBF 1120 demonstrated a positive trend in reducing lung function decline in patients with idiopathic pulmonary fibrosis (IPF), according to phase II clinical trials in a study recently published in the New England Journal of Medicine (NEJM). IPF is a progressive and severely debilitating lung disease with a highmortality rate, for which there are no approved treatments in the United States.

In the study, known as TOMORROW (To Improve Pulmonary Fibrosis with BIBF 1120), patients treated with 150 mg of BIBF 1120 twice daily demonstrated a 68 percent reduction in the rate of forced vital capacity (FVC) decline compared to placebo. FVC is the volume of air that is expelled into a spirometer following maximum inhalation. FVC, which is a test that measures lung function, is a part of the examinations conducted in IPF patients and is scientifically accepted for assessment of IPF treatment effects. Patients treated with 150 mg of BIBF 1120 twice daily also had a lower incidence of acute exacerbations, defined as sudden deterioration of clinical status, compared with placebo. Acute exacerbations are associated with rapid disease progression, severe abrupt decline in FVC and high mortality.

In addition, treatment with 150 mg of BIBF 1120 twice daily resulted in a small decrease in impairment of quality of life, as measured by the St. George’s Respiratory Questionnaire (SGRQ). SGRQ scores measure the impact of quality of life, with higher scores—as well as increasing scores—signaling greater impairment. In contrast, increased impairment was reported among patients receiving placebo.

“People who suffer from IPF are in great need of a safe and effective treatment to preserve lung function so they can maintain physical activity and reduce the impact on their independence for as long as possible,” said Luca Richeldi, MD, PhD, lead study author and director of the Research Centre for Rare Lung Diseases, University of Modena and Reggio Emilia, Modena, Italy. “The positive trends in slowing the decline in lung function over time, reducing the incidence of acute exacerbations and improving the quality of life with BIBF 1120 are a promising proof of concept.”

BIBF 1120 received orphan-drug designation from the U.S. Food and Drug Administration in June 2011. Two pivotal phase III clinical trials are currently underway enrolling a total of 970 patients in 20 countries. The first patients entered the trials in April and May 2011, respectively. For more information about the phase III clinical trials or to learn how to enroll, please visit clinicaltrials.gov (identifiers NCT01335464 and NCT01353477).

“The results of the phase II clinical trial for BIBF 1120 in IPF give us the confidence to continue assessing the compound’s potential in phase III clinical trials,” said Christopher Corsico, MD, MPH, senior vice president, Medicine and Regulatory, North America, Boehringer Ingelheim Pharmaceuticals, Inc. “Boehringer Ingelheim remains committed to identifying an effective treatment for IPF to help bridge the unmet therapeutic need for the thousands of people suffering from this fatal disease.”

Source: Boehringer Ingelheim Press Release, September 21, 2011

Statins May Increase Risk of Interstitial Lung Abnormalities in Smokers

Use of statins, medications used to lower elevated cholesterol levels, may increase the development of interstitial lung disease (ILD) in smokers according to a new study in the American Journal of Respiratory and Critical Care Medicine.

Some earlier studies have suggested that statins might be beneficial in the treatment of fibrotic lung disease. However, more recent investigations have indicated that statins may promote the secretion of proteins that enhance the formation of lung fibrosis.

“Based on earlier case reports of statin-associated ILD, and data suggesting that smoking is associated with the interstitial lung abnormalities (ILA) which underlie ILD, we hypothesized that statins would increase the risk for ILA in a population of smokers,” said George R. Washko MD, MMSc, and Gary M. Hunninghake MD, MPH, of the Division of Pulmonary and Critical Care at Brigham and Women’s Hospital in Boston. “Accordingly, we evaluated the association between statin use and ILA in a large cohort of current and former smokers.”

continued on next page >
Assessment included pulmonary function testing and CT scanning for radiologic features of ILA. After adjustment for a number of covariates, including a history of high cholesterol or coronary artery disease, statin users had a 60 percent increase in the odds of having ILA, compared to subjects not taking statins.

“While statin use was associated with ILA in our study, caution should be used when extrapolating these findings to the care of patients,” concluded Dr. Hunninghake. “The significant benefits of statin therapy in patients with cardiovascular disease probably outweigh the risk of developing ILA, and statin use may benefit some patients with respiratory disease. Clinicians should be aware, though, that radiological evidence of ILD can develop in some patients treated with statins.”

Content edited for space.

PFF COMMENT: As authors point out, there are significant benefits to statin therapy. Until further information is available, they should probably not be discontinued.

**Investment in Medical Research Saves Lives, Boosts Economy**

“Cutting the federal budget deficit should not mean cutting money for medical research that has countered tuberculosis, HIV, heart disease, cancer and other conditions that diminish lives,” says the dean of the University of Washington School of Medicine, Dr. Paul G. Ramsey.

With the nation’s economy in poor health, the congressional “super” committee appointed to propose areas for cuts to reduce the national deficit offered the promise of a cure. But when it ended deliberations without a proposal, it provided instead a bitter pill—$1.2 trillion in mandatory across-the-board cuts, half from defense and half from domestic programs, including medical research supported by the National Institutes of Health (NIH).

For millions of Americans and their families who suffer from serious illnesses and conditions, medical research provides hope for better health. Our nation’s investment in NIH-funded medical research over the past 60 years has catalyzed many of the advances that now help Americans live longer and healthier lives.

Because of medical research, the death rate for heart disease is more than 60 percent lower—and the death rate for stroke, 70 percent lower—than in the World War II era. Cancer death rates have dropped 11.4 percent among women and 19.2 percent among men over the past 15 years because of better detection and more-effective treatments. Research related to HIV has helped increase survival for millions of people, while the average life span of an individual has never been higher.

Medical research also improves our economic health. A new study by Tripp Umbach, a national economic consulting firm, found that federal- and state-funded research conducted in 2009 at the nation’s medical schools and teaching hospitals supported nearly 300,000, or 1 in 500, U.S. jobs and added nearly $45 billion to the U.S. economy.

The NIH is the largest single funder of basic medical research in the United States; the research it supports provides the foundation of knowledge that drives innovation and improves health. But reaping the full benefits of medical discoveries can take decades. That is why a long-term, sustained investment in medical research is essential.

We all want to reduce the federal budget deficit. But let’s not jeopardize the next generation of cures—and further stress the economic health of our communities today—by cutting funding for medical research.

Content edited for space.

PFF COMMENT: The Foundation is actively working with a number of other advocacy organizations to actively support medical research funding at the NIH, CDC, and the Department of Defense.
Peripheral Blood Proteins Predict Mortality in Idiopathic Pulmonary Fibrosis

A recent study from the University of Pittsburgh was performed to attempt to identify and validate plasma proteins that would be predictive of the clinical course of IPF.

Plasma samples were analyzed for concentrations of matrix metalloproteinase (MMP)-7, MMP-1, surfactant protein D adhesion molecule (ICAM)-1, IL-8, vascular cell adhesion molecule (VCAM)-1, and S100A12. Associations of biomarkers with mortality, transplant-free survival, and disease progression were analyzed using a variety of statistical methods.

High concentrations of MMP-7, ICAM-1, IL-8, VCAM-1, and S100A12 were predictive of poor overall survival, poor transplant-free survival, and poor progression-free survival. The results of this study suggest that plasma proteins should be evaluated as a tool for prognosis determination in prioritization of patients for lung transplantation and stratification in drug studies.

Source: American Journal of Respiratory and Critical Care Medicine, January 2012
Content edited for space.

PFF COMMENT: This approach, to attempt to stratify patients’ disease progression based on blood biomarkers, is important. It can help determine timing for transplant and may eventually help with implementation of appropriate therapy.

National Institutes of Health (NIH) Funding for Pulmonary Fibrosis, 2006–2011

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Source: NHLBI Congressional Hearing, February 29, 2012

What is the ARRA?
The American Recovery & Reinvestment Act of 2009 (ARRA) provided $8.2 billion to the NIH to help stimulate the United States Economy by funding research with the potential for progress in a two-year period. To learn more about the NIH and the ARRA, please visit www.grants.nih.gov/recovery.

SUMMIT TAKES THE PFF TO NEW HEIGHTS

IPF Summit 2011: From Bench to Bedside Receives High Accolades from PF Community

IPF Summit 2011: From Bench to Bedside was the Pulmonary Fibrosis Foundation’s inaugural national scientific conference on idiopathic pulmonary fibrosis (IPF). The goal of the Summit was to foster a collaborative environment to improve education and awareness of IPF, and to identify new approaches to treat and ultimately find a cure for this devastating disease. The Summit featured innovative continuing medical education programs for physicians, researchers, registered nurses, and allied health professionals to improve their clinical understanding of IPF, as well as a one-day program to address the growing educational needs of IPF patients, family members, and caregivers. The Summit was planned in accordance with the Essentials and Standards of the Accreditation Council for Continuing Medical Education, in partnership with The France Foundation and National Jewish Health, and was endorsed by the American Thoracic Society.

Educational objectives for the Summit were identified in a needs assessment. Following completion of the sessions participants were able to:

- Explain the pathophysiology of IPF based on the most current data
- Accurately diagnose IPF using a systematic approach
- Effectively implement key diagnostic procedures including HRCT scanning and surgical lung biopsy
- Discuss recent evidence for treatments in the management of IPF
- Recognize genetic components of IPF
- Describe the role of lung transplantation in IPF, and the factors that affect candidacy and timing
- Provide patient lifestyle management tools that improve functional status
- Develop a comprehensive approach to the management of IPF, that includes both pharmacologic and non-pharmacologic therapies

“The Summit was an important milestone for the PFF and launches the next stage of the Foundation’s role as a resource and catalyst for the PF community.”

– DANIEL M. ROSE, MD PRESIDENT AND CHIEF EXECUTIVE OFFICER AT THE PFF
“The IPF Summit is the first meeting of its kind to bring together both the scientific and clinical medical communities dedicated to treating, and one day curing, idiopathic pulmonary fibrosis. Dedicating significant portions of the program to the needs of patients and caregivers highlights the Foundation’s desire for the Summit to be a resource for the entire pulmonary fibrosis community.”

– KEVIN K. BROWN, MD  IPF SUMMIT 2011 PROGRAM CHAIR AND CHAIR OF THE PFF MEDICAL ADVISORY BOARD

**MISS ED THE OPPORTUNITY TO ATTEND? WANT TO REVIEW A PHYSICIAN SESSION?**

View all of the Summit sessions on-demand via webinar at www.pulmonaryfibrosis.org/summit

Webinars sponsored in part by grants from InterMune and the Pacific Northwest Friends of the Pulmonary Fibrosis Foundation.

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**The Summit’s Reach**

**IPF SUMMIT 2011 ATTENDANCE STATISTICS**

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<tr>
<td>Live Webcast Viewers</td>
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**SAVE THE DATE!**

**DECEMBER 5–7, 2013**

The PFF’s second biennial Summit, retitled *PFF Summit 2013: From Bench to Bedside*, will be held Thursday, December 5 through Saturday, December 7, 2013. The location will be announced soon.

To pre-register, or for additional information, please email summit@pulmonaryfibrosis.org or call 888.733.6741.

Visit www.pulmonaryfibrosis.org/summit for up-to-date information.
The Summit was truly exceptional in bringing together the medical, scientific, and patient communities to learn and collaborate in a mutually beneficial environment.”

– GREGORY P. COSGROVE, MD IPF SUMMIT 2011 FACULTY MEMBER AND PFF MEDICAL ADVISORY BOARD MEMBER

Congratulations to Our Poster Winners

IPF Summit 2011: From Bench to Bedside emphasized the importance of new research; twenty-six young academic investigators were chosen to give poster presentations on their basic, clinical, translational, or social science/quality of life research. The researchers presented original ideas that will help improve the understanding of pulmonary fibrosis. All submissions were peer-reviewed and graded; awards were given for the first, second, and third place posters. Award recipients were recognized at the Foundation’s New Decade, New Reach tenth anniversary dinner.

1st Place
Jonathan Kropski, MD
Vanderbilt University
“Herpes Virus Infection Exacerbates Endoplasmic-Reticulum Stress and Acts as a ‘Second-Hit’ in the Development of Lung Fibrosis”

2nd Place
Adam Booth, PhD
University of Michigan
“Fibroblast Responses to Decellularized Human Lung Slices Implicate the Extracellular Matrix in Directing Fibroblast Phenotypes”

3rd Place
Adita Mathur, MD
Yale University
“Role of Semaphorin 7a in Lymphocytes in TGF-β Driven Lung Fibrosis”

Honorable Mentions
Stephenie Takahashi, MD
University of Chicago
“The Inhibitory Molecule, BTLA, Regulates Pulmonary Fibrosis in a Mouse Model”

Anand Iyer, MD
Hampton University School of Medicine
“Angiogenic Mediators Regulate Single-Walled Carbon Nanotube-Induced Fibrogenesis in Human Lung Fibroblasts”
The Summit Faculty

KENNETH ADLER, PhD
North Carolina State University
Raleigh, North Carolina

JOHN DAVID ARMSTRONG II, MD, MA
National Jewish Health
Denver, Colorado

BRIAN BAIRD, MS, PhD
Former U.S. Representative to Congress
Vancouver, Washington

RITI S. BARAL
CANACCORD Genuity
New York, New York

TIMOTHY S. BLACKWELL, MD
Vanderbilt University Medical Center
Nashville, Tennessee

WILLIAMSON BRADFORD, MD, PhD
InterMune, Inc.
Brisbane, California

KEVIN K. BROWN, MD
National Jewish Health
Denver, Colorado

HAROLD R. COLLARD, MD
University of California, San Francisco
San Francisco, California

GREGORY P. COSGROVE, MD
National Jewish Health
Denver, Colorado

BRENDA CROWE, CRT
Exempla Lutheran Medical Center
Wheat Ridge, Colorado

ARYEH FISCHER, MD
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University of Colorado
Denver, Colorado

KEVIN R. FLAHERTY, MD, MS
University of Michigan Health System
Ann Arbor, Michigan

CHRISTINE KIM GARCIA, MD, PhD
University of Texas
Southwestern Medical Center
Dallas, Texas

CHARLES HOOPES, MD
University of Kentucky College of Medicine
Lexington, Kentucky

ALIYA N. HUSAIN, MD
University of Chicago
Chicago, Illinois

SUSAN S. JACOBS, RN, MS
Stanford University
Stanford, California

MIRANDA G. JAMES, Esq
Caring Voice Coalition
Mechanicsville, Virginia

NAFTALI KAMINSKI, MD
University of Pittsburgh School of Medicine
Pittsburgh, Pennsylvania

DOLLY KERVITSKY, CRT, CCRC
Pulmonary Fibrosis Foundation
Chicago, Illinois

TALMADGE E. KING, Jr., MD
University of California
San Francisco, California

JOSEPH LASKY, MD
Tulane University
New Orleans, Louisiana

KATHLEEN LINDELL, PhD, RN
University of Pittsburgh
Pittsburgh, Pennsylvania

BRONWYN LONG, DNP, MBA, RN
National Jewish Health
Denver, Colorado

ROBERT B. LOVE, MD
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Maywood, Illinois

MARIANNE MANN, MD
Consultant
Washington, DC

FERNANDO J. MARTINEZ, MD, MS
University of Michigan
Ann Arbor, Michigan

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Nashville, Tennessee

KENNETH R. MCCURRY, MD
Cleveland Clinic
Cleveland, Ohio

A. BRUCE MONTGOMERY, MD
Cardeas Pharma
Seattle, Washington

IMRE NOTH, MD
University of Chicago
Chicago, Illinois

GANESH RAGHU, MD
University of Washington Medical Center
Seattle, Washington

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Stanford University School of Medicine
Stanford, California

DAVID A. SCHWARTZ, MD
University of Colorado Medical Center
Denver, Colorado

MARK SHREVE
Pulmonary Fibrosis Foundation
Chicago, Illinois

JEFFREY J. SWIGRIS, DO, MS
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Denver, Colorado

ANDREW TAGER, MD
Harvard Medical School
Boston, Massachusetts

JANET TALBERT, MS, CGC
National Jewish Health
Denver, Colorado

SHELIA VIOLETTE, PhD
Stromedix
Cambridge, Massachusetts

GAIL G. WEINMANN, MD
National Heart, Lung, and Blood Institute
Bethesda, Maryland

TIMOTHY P. WHELAN, MD
Medical University of South Carolina
Charleston, South Carolina

ERIC S. WHITE, MD
University of Michigan Health System
Ann Arbor, Michigan

DAVID A. ZISMAN, MD, MS
Sansum Clinic
Santa Barbara, California
On Friday, December 2, 2011, the Pulmonary Fibrosis Foundation (PFF) recognized ten years of measured growth and support for the pulmonary fibrosis (PF) community and looked toward the ambitious initiatives planned for our second decade at our New Decade, New Reach tenth anniversary dinner. We welcomed over 325 guests for a special evening, bringing together patients, family members, physicians, health care providers, sponsors, and friends of the Foundation.

Co-chairs for the dinner were Illinois Senator Mark Kirk, former Congressman Brian Baird, Julie Halston, and Ralph Howard, all of whom have been personally affected by pulmonary fibrosis and are extremely dedicated to our efforts.

The dinner was held in Chicago at The Field Museum. The scene was set in Stanley Field Hall, where holiday lights accented the elegant columns, white marble staircases, and the sky-lit vaulted ceiling. Guests started the evening with a pre-dinner cocktail reception sponsored by Wodka Vodka and enjoyed the opportunity to view SUE, the famous Tyrannosaurus rex and the Chocolate: Around the World exhibition.

Mary Ann Ahern, NBC5 anchor, served as emcee and oversaw the evening’s program with Daniel M. Rose, MD, President and Chief Executive Officer of the Foundation. Speakers included Brian Baird, Julie Halston, Ralph Howard, and Jesse Roman, MD. A highlight of the evening was a video produced by ProVideo & Film, Inc. as an in-kind gift to the Foundation. It was an inspirational video featuring patients, caregivers, physicians, and Foundation representatives.

YOUR SUPPORT MAKES A DIFFERENCE

New Decade, New Reach Anniversary Dinner Recognized

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NEW DECADE
NEW REACH
Ten Years of Milestones

Additional highlights of the dinner included the announcement of the Leanne Storch Support Group Fund, recognizing the achievements of Leanne Storch, former Executive Director at the PFF and the presentation of our Volunteers of the Year Awards to D. Michael Dvorachak, Sue Frost, Julie Halston, and Ed Windels for their work in raising awareness and funds for PF in their annual event, Broadway Belts for PFF!

The evening ended with a special dessert created especially for the New Decade, New Reach dinner by Chef Joe Bonavita. Chef Bonavita lost his grandfather, Michael Bonavita, to pulmonary fibrosis and is committed to using his passion and talent to help raise awareness and funds. The Foundation was honored to have an up-and-coming chef create a unique experience for our guests.

Please plan to join us again this year for our annual dinner on Saturday, October 13. Visit www.pulmonaryfibrosis.org for updates as they become available.

Read more about Broadway Belts for PFF! on pages 30–31

View more photos from the New Decade, New Reach dinner at www.pulmonaryfibrosis.org/newdecade

To see the video produced for the New Decade, New Reach dinner, go to www.pulmonaryfibrosis.org/10years

Ways to Give

Many of the valued donors to the Pulmonary Fibrosis Foundation (PFF) support us by giving a gift in memory of a person who died of pulmonary fibrosis (PF) or in honor of someone living with PF. You may be one of these supporters. These gifts are vital to our success in serving the PF community by helping to find a cure, increasing awareness and advocacy, and supporting those affected by this disease. Donors like you have provided much of the support needed by the PFF during our first decade.

Did you know there are many other ways to help support our mission and make a difference? You’ve read about our patients, learned about how we support research, and been inspired by how our volunteers raise awareness and funds. There are many ways to support the Foundation. You don’t have to know someone with the disease to support our important initiatives.

• You can simply go to our website — go to www.pulmonaryfibrosis.org—and click on the ‘DONATE’ button. Follow the prompts to give securely and quickly online using your credit card

• Or, if you prefer, you can mail a check to:
  Pulmonary Fibrosis Foundation, 811 West Evergreen Avenue, Suite 204, Chicago, Illinois 60642-2642

• Another option? We would love to talk with you. Call us to give a donation directly to one of our staff — 888.733.6741.

It’s also possible to double or triple your gift with a matching gift from your employer. Visit www.pulmonaryfibrosis.org to learn more about employer matching gifts. And you may work for a company that supports their employees’ causes through their own philanthropy or marketing sponsorships. Inquire if your employer offers financial support for nonprofit organizations and let us know.

Please consider including the Pulmonary Fibrosis Foundation in your estate plan. Contact your financial advisor to get started. It takes significant financial support to fund research to find a cure. If you would like to give a generous gift of $10,000 or more, you will make a major impact in forwarding our mission.

And if you have not already done so, please give us your email address. In addition to emailing you updates about the Foundation and other PF-related news, it’s easy to contribute by clicking on the ‘DONATE’ button in the email.

The Pulmonary Fibrosis Foundation, and everyone struggling with this terrible disease, is deeply appreciative of your support for our mission.
INTRODUCING TEAM PFF AND SHOP PFF

Fundraising Just Got Easier — Announcing Team PFF!

New Foundation Initiative Serves to Unite, Connect, and Inspire

The Pulmonary Fibrosis Foundation (PFF) has benefited over the years from people committed to making a difference in the pulmonary fibrosis (PF) community. These dedicated people have helped raise funds to benefit the PFF through events as diverse as organizing a car show to participating in a marathon — while increasing awareness of the disease in the process. To better support these fundraisers, and create a stronger network of PFF advocates, the PFF is excited to announce Team PFF.

Created to unite, connect, and inspire the pulmonary fibrosis community to fundraise and make a difference today, Team PFF encourages every individual to help in any way that he or she can. Whether it is planning an auction or a golf outing, or competing in your favorite athletic event, the key is to take action and join in the fight against pulmonary fibrosis.

Inspired by the current enthusiasm of PFF supporters, Team PFF exists to amplify this enthusiasm. Volunteers across the country work tirelessly to fundraise for the PFF, as well as raise awareness of pulmonary fibrosis in their community. After working with many of these fundraising event planners and athletes, the Foundation has realized that there is potential to create a greater network of support, and stronger connections, among the dedicated members of the community. The PFF believes that connecting and working together is instrumental in truly making a difference. For instance, one initiative of Team PFF is to connect experienced fundraisers with prospective fundraisers who may need a mentor to turn their ideas into action.

“Becoming a Team PFF fundraiser is as simple as deciding that you want to take action against this disease,” says Patti Tuomey, Chief Operating Officer at the PFF. “People find many ways to incorporate the things they love to do in order to honor a loved one. We are grateful to those who choose to raise money and awareness to combat pulmonary fibrosis.”

Another key component of support developed by the PFF is the new Fundraising Leader’s handbook: “Team PFF Short Guide: Fundraising to Benefit the Pulmonary Fibrosis Foundation.” The guide outlines the process of organizing an event to benefit the Pulmonary Fibrosis Foundation and includes planning steps, helpful tips, and forms to help simplify everything from event budgeting to donation collection.
A few veteran Fundraising Leaders tested the “Team PFF Short Guide” to ensure its effectiveness. Cheryl Hampton was one of those leaders; she found the guide to be extremely helpful in planning her Second Annual Richard G. Hall Memorial Golf Tournament. “The guide creates a simple outline to help Team PFF Fundraising Leaders get started. The new forms helped me get organized and the guidelines answered all of my questions about fundraising. Because of the new resources, I am confident that this year’s tournament will be a big success,” said Cheryl.

Individuals and families from all over the country are honoring the memories of their loved ones while raising funds for the Foundation and awareness of pulmonary fibrosis. Are you one of these people? Let us know how you are part of the team!

For more information about fundraising events, and to learn more about Team PFF for athletes, visit www.pulmonaryfibrosis.org/teampff or email teampff@pulmonaryfibrosis.org. Why not take your first step during National Volunteer Week, April 15–21, 2012?

Need help getting started? Call into the new Fundraising Leader discussion forums, Team PFF Talks. These group calls provide leaders, and prospective leaders, with event tips, access to PFF staff members, and the opportunity to discuss the event process with other Team PFF Fundraising Leaders. The first series of Team PFF Talks will be held on May 5 at 11:00 am CDT, May 8 at 6:00 pm CDT, and May 9 at 6:00 pm CDT. To RSVP for a Team PFF Talk, please email Lyla Catellier at lcatellier@pulmonaryfibrosis.org.

We look forward to hearing about your ideas and learning more about your events!
SECOND ANNUAL BROADWAY BELTS FOR PFF!  
A SMASH HIT

With honors ranging from the Rock’n’Roll Hall of Fame to the Tony Awards, Broadway’s best performers gathered on Monday, February 27 to raise awareness of pulmonary fibrosis, and honor the memory of Associated Press theater critic and reporter, Michael Kuchwara. Hosted by award-winning actress and devoted Pulmonary Fibrosis Foundation (PFF) advocate Julie Halston, Broadway Belts for PFF! returned to Birdland in New York City for a second successful year and raised over $50,000 for the Foundation.

The evening got its start in 2011 when Ms. Halston (currently starring in Anything Goes) and her friends came together to honor the memory of their friend Michael Kuchwara who passed away from idiopathic pulmonary fibrosis (IPF) in May of 2010. Unlike most people, Ms. Halston was already acutely aware of this disease; her husband, Ralph Howard, had a lung transplant for IPF in 2010. Because Kuchwara was an Associated Press theater critic and reporter, the group decided to honor him with Broadway’s best singing his favorite tunes. Julie Halston, and her fellow organizers, D. Michael Dvorchak, Ed Windels, and Sue Frost—all friends of Mr. Kuchwara—were the 2011 recipients of our Volunteers of the Year Award.

This year’s event opened with Sirius Satellite Radio’s Seth Rudetsky’s amusing monologue about belting and his favorite belters, including last year’s surprise guest Liza Minnelli. Broadway stars showcased their belting abilities under the musical direction of Jesse Kissel and returning director Carl Andress. The all-star cast included: Tony nominees Adam Pascal (Memphis) and Andrew Rannells (The Book of Mormon), Robert Creighton (Anything Goes), Lindsay Mendez (Godspell), Betsy Wolfe (Encores! Merrily We Roll Along), Heidi Blickenstaff (Now. Here. This., [title of show]), and Julia Murney (Queen of the Mist/Wicked). In a touching moment of remembrance, theater critic Adam Feldman took the stage and gave a heartfelt tribute to his friend and colleague, Michael Kuchwara.

“Five years ago, I had never even heard of pulmonary fibrosis. First my husband was diagnosed and then I lost my close friend Michael to the disease. Now I want to make sure everyone knows about the Pulmonary Fibrosis Foundation, so that no one with the disease has to go through this alone. Together we can raise awareness and fund the research that will bring us closer to finding a cure.”  

– JULIE HALSTON

Save the Date | February 25, 2013

Anytime Goes’ Julie Halston, Robert Creighton, and Surprise Guest Joel Grey Join Legendary Belter Darlene Love for the Second Annual Broadway Belts for PFF!
“The success of Broadway Belts for PFF! is a testament to the hard work of Julie Halston and her amazing team. Their efforts amplify the Pulmonary Fibrosis Foundation’s mission, increasing awareness on Broadway and beyond. By raising over $90,000 in just two years through this event, Julie makes our goal of finding a cure that much more feasible.”

– PATTI TUOMEY  CHIEF OPERATING OFFICER, PULMONARY FIBROSIS FOUNDATION

The evening’s surprise guest was famed Joel Grey, currently starring as Moonface Martin in the Broadway revival of *Anything Goes*. He joined the stage with fellow *Anything Goes* cast member Robert Creighton to sing a duet of “Give My Regards to Broadway” and then an impromptu rendition of “Wilkommen” from his Tony Award and Oscar Award winning role as the Master of Ceremonies in *Cabaret*. The evening culminated with the spectacular Darlene Love delighting the audience with “Today I Met the Man I’m Going to Marry” and “I Know Where I Have Been.” The entire cast joined Ms. Love on stage for an all-star, grand finale of “Da Doo Ron Ron.” Next year’s event will be held on Monday, February 25, once again at Birdland.

View videos and photos from Broadway Belts for PFF! at www.pulmonaryfibrosis.org/broadway/2012/highlights

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