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BREATHE BULLETIN VOLUME 13 | ISSUE 01 SPRING 2013

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Breathe Bulletin is published biannually by the Pulmonary Fibrosis Foundation. Opinions expressed by the authors are their own and do not necessarily reflect the policies of the Pulmonary Fibrosis Foundation.

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

The mission of the Pulmonary Fibrosis Foundation (PFF) is to help find a cure for idiopathic pulmonary fibrosis (IPF), advocate for the pulmonary fibrosis community, promote disease awareness, and provide a compassionate environment for patients and their families.

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DEAR FRIENDS,

In this edition of the Breathe Bulletin, we would like to update you on recent Foundation activities and tell you about some exciting initiatives that we feel will greatly benefit all of you. One of the Foundation’s main goals is to improve the resources available for the entire pulmonary fibrosis (PF) community—patients, caregivers, physicians, and researchers—who all have a common objective to help individuals with pulmonary fibrosis live a better life.

If you attended the first PFF Summit in 2011, you might have interacted with two people interviewed in this edition—Dr. Andrew Tager and Susan Liegeois—a physician and a patient who recount their experiences at the conference. It was our desire to encourage multi-level interactions among all the participants at the Summit. This issue of the Bulletin contains information about the upcoming PFF Summit 2013: From Bench to Bedside, and we hope that the thought provoking program and world-class faculty will encourage you to join us.

Patient registries and care center networks are critical adjuncts to the development of successful therapies. The information gathered from a registry can be used to analyze the natural history of a disease, identify genetic components, isolate biomarkers, and facilitate drug development by expediting enrollment in clinical trials. Additionally, a care center network helps to standardize care, determine the impact of specific interventions, and improve the quality of life of patients.

In this issue we discuss the important benefits that a care center network/patient registry has had on cystic fibrosis (CF) patients in an interview with Dr. Bruce C. Marshall, Vice President of Clinical Affairs at the CF Foundation. The successful development of this model has dramatically increased the life expectancy and quality of life for cystic fibrosis patients. As a result of the success of the CF Foundation and other organizations, we have started planning a Care Center Network and national Pulmonary Fibrosis Foundation Patent Registry.

In the past year some of our international activities—which are discussed in the Bulletin—have included holding a Global Pulmonary Fibrosis Awareness Day, starting a Support Group Leader Network in the European Union, translating patient materials into eight languages, and participating in the International Colloquium on Lung and Airway Fibrosis (ICLAF) in Modena, Italy. Additionally, we discuss how we plan to follow up on some of these exciting initiatives. We think you will find this information quite exciting. We are thankful to those who believe in the Foundation as much as we do, and we will always do our best to maximize the benefits that these opportunities bring to the PF community.

Lastly, thank you to all of our supporters, the Team PFF Event Leaders and participants, our loyal donors, and the PFF ambassadors who recommend us as a resource for the PF community. You make it all possible.

Sincerely,

[Signature]

DANIEL M. ROSE, MD
Chief Executive Officer and Chairman of the Board of Directors
What were the Cystic Fibrosis Foundation’s early challenges in developing a Care Center Network and Patient Registry?

To add some context of time, the Care Center Network was started in the early 1960s. The Registry was started at the University of Minnesota in the mid-1960s, and was moved to the Foundation in the mid-1980s.

Regarding the Care Center Network, the physicians, respiratory therapists, and nutritionists who had an interest in cystic fibrosis (CF) were brought together; there was some evidence that a multidisciplinary approach resulted in better outcomes for CF patients. So the CF Foundation, which was an organization started by patients and families, developed an accreditation mechanism that set minimum standards.

One of the consistent challenges was having medical professionals, at varying levels of expertise, determining where to set the bar for what was an acceptable, certifiable standard of care. The Foundation pulled the experts together, and they were able to arrive at a consensus and establish the standards.

In the beginning, just three or four Centers were certified, but shortly thereafter in the late 1960s and throughout the 1970s another 20 to 30 Centers were certified. The Network really moved across the country.

“We early on, the visionary leaders recognized that if we were going to make any progress with this disease, we needed to have data, and we needed to track the natural history of the disease.”

We now have a mature Care Center Network that exists in every major metropolitan area and also in most midsize cities. They may not all be a full-fledged Care Center; some Centers will have an affiliation with one of the core Centers that is able to provide tertiary level services.

One of the challenges we have had over the last 15 to 20 years has been adult care. With the success of the pediatric model, which is where this all began, more and more CF patients survive into adulthood. We really needed to develop a complementary adult program at our Care Centers, which were largely housed within pediatric departments and pediatric programs. So we went through a second wave of developing and approving adult programs. They had to meet certain criteria that were established on a consensus basis, and this all started in the late 1980s and accelerated in the 1990s and 2000s.

We still have a few Centers that have had difficulty in developing an adult program, but the great majority of our Centers have them. Some adult programs function completely separate from the pediatric programs, in terms of clinical care, while others are integrated and share multidisciplinary teams.

The Registry was one of the core elements that was developed. Early on, the visionary leaders recognized that if we were going to make any progress with this disease, we needed to have data, and we needed to track the natural history of the disease. And as new therapies became available, we needed to know what the impact was of those therapies.
These individuals recognized the importance of a Registry. We mandated that all of our accredited Care Centers participate in the Registry, that they obtain institutional review board approval to participate in the Registry, and that they receive consent from patients to have their data included in the Registry. Only about five percent of patients at the Centers decide not to participate.

How do you determine funding support for the Care Centers?
The funding that we provide to the Care Centers is tied to the data that they enter into the Registry. We define what we call a full data set, and if they provide a full data set in that year’s funding period, they receive a base funding amount for each data set entered. We also have bonuses so that if we get a second full data set and a third full data set, they get two additional bonuses on top of the base funding. We are therefore able to incentivize data entry.

How has the data itself changed over the years?
Like many registries, its growth is organic. It is kind of like the art of topiary, where you can shape bushes into what you want them to become, and that happens over many iterations. The Registry started with annual data collection, submitted on paper forms, and then entered centrally. We have now evolved to a “web-based” application.

The data that we collect has also evolved. We started with just the basics, the key outcomes that people knew were important for CF, and over time we have added additional data elements, added new medications as they have become available, and therefore the Registry has changed. Sometimes we delete questions and sometimes we add questions.

We are at a point now where it is a very robust Registry. We collect quite a bit of data. It is a fine balancing act to acquire the right amount of data without overburdening the Care Centers. We need to get the key data to do the reporting and the research that we want to do.

It sounds like a difficult balance—too much data, too little data—to ensure that you have the information to answer the questions that become important to the community.

It probably is best to start with the minimum number of data elements that can provide important information, and to then build from there. In other words, you need to have the minimal amount of data that can provide meaningful information for the individual Care Centers and also be able to create a national report. You can then build on that early success and add or subtract data elements as necessary.

What do you think are the most important outcomes that you have seen from the Registry data?
Just tracking the progress of the disease at the national level has been very important. For a life shortening disease like CF, documenting any improvement was heartening to the community. I think that has provided them some hope and optimism.

As we evolved and started to use the data and analyze the data at the Center level, we discovered variations in practice patterns and outcomes. This became a driving force for quality improvement. When we looked at the data and realized that some Centers had much better outcomes than others, we asked ourselves why? Is it just that their patients were sicker, poorer, or was there some other attribute? When we really started to dig into the data, it became clear that a significant proportion of that variation related to practice patterns and the way care was organized at the Care Centers. So that is another way the Registry has really contributed to the CF community.

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There has been quite a bit of research done with the Registry. As the Registry matured and we had data over a long period of time, researchers used it for epidemiologic research, to look at what were the risk factors for poor outcomes, and that fostered additional research.

The Registry data has also been used to assess feasibility of clinical trials. In the clinical research arena, one of the things that you have to look at when you are developing a clinical trial is to determine what are your endpoints and what are your patient selection criteria. Do you have enough patients that meet the inclusion/exclusion criteria in order to conduct the trial? The Registry has that sort of data that we can look at and say that if we need this many people with pulmonary function in a specific range, we will have more than enough to complete the trial. To go even further we can determine which Centers have sufficient patients with the required pulmonary function—so it would be easier to do the study if we recruited from those Centers.

The initial goal of the Registry was very simple—determine the natural history of the disease. However, it has evolved over time so that it is now multifaceted and brings value to all that we do. We view the Registry and the Care Center Network as one of the crown jewels of the Foundation. People often think that only professional associations or professional societies can lead initiatives like developing a care center network and a registry, but we have done it as a patient advocacy organization and we are very proud of that.

Registries are very expensive endeavors, has this ever been a challenge?

We put a significant investment in them year after year, so it has been a challenge. The leadership of the organization have always felt that they were “must have” assets to accomplish our mission, so there has never been any hesitation about putting the money into funding the Care Center Network and Registry.

There were times when resources were very tight and tough decisions had to be made. There were cuts in programs, including our Care Center program. Most recently with the severe recession that we had back in 2008 and ’09, we, like many nonprofits, saw a drop in our revenues, so we had to cut many of our programs. We had to cut our Care Center budget and most of our Care Centers were impacted.

But we kept the Registry going. It had become so important and there was really no way to cut its funding. We have seen hard times when we have had to cut back a little bit, but I don’t think there has ever been a time when the Foundation said that it was too expensive to maintain and sustain. That was never on the table. People didn’t even consider that.

It sounds like the patient community really embraces this endeavor and finds it important.

I think so. For the most part the patients participate—about 95 percent sign up to have their data entered. In an era when people are very private and reluctant to share their information, we get widespread adoption. The Care Centers see the value in the reports, in research, and in quality improvement. I think patients and families see the value as well.

What is the most important benefit of the Care Center Network and Registry to the patient community?

It gets complicated because they are interconnected, but they are also separate assets. The Care Center Network provides patients with CF and their families some degree of confidence that there are Centers that have the experience and the credentials necessary to deliver good care. In turn, the data that comes from the Registry provides feedback to the Care Centers and facilitates their efforts to improve.

They are really interrelated, and they bring value by virtue of providing that safety net of a care model where certain standards are maintained. Additionally, we have the Registry as an outcomes tracking tool that we use not just at a national level, but also at a Center level, and we feed that data back to the Care Centers.

So it really is a learning network that we have created in CF. It is a community of people that are trying to improve. They have set aside whatever differences they might have in order to collaborate and learn from one another and raise all the boats in the water. It is that sort of community.
Do you think the Care Center Network has helped bring the physician community together to work more in unison for the patients?

Absolutely. We sponsor an annual professional meeting—the North American CF Conference. It is actually an international conference, the largest CF conference in the world, and brings together not just the physicians and the scientists, but also the multidisciplinary team members.

It is a venue where basic research, clinical research, and quality improvement are presented. There are networking sessions for the various disciplines. There are a variety of forums that we use to bring people together so that they can share knowledge and build trust. Health care is a difficult business and to sustain something like what we have created requires human relationships.

That is what our community is all about—bringing people together so that they can know one another, respect one another, and share with one another. There is some friendly competition going on when you talk about our Center outcomes. People want to do well—physicians are a very competitive bunch. They are used to being straight A students, and they want their Center to be at the top.

However, if they have created a program that has helped improve their outcomes, I have no doubt that they would have shared that information with everybody in the community. So it is a friendly competition with shared goals and a shared mission. Everybody wants to improve the quality of care. Everybody wants to have new therapies that sustain life. It is a mission-driven organization; it is a mission-driven community.

The Care Center Network really fosters a collaborative environment for physicians. Does this impact the rest of the care team?

Absolutely. We make investments there as well. For quality improvement work, we bring care teams together such as our mentoring programs for respiratory therapists and dieticians.

We developed mentoring programs for the various disciplines so that we can connect people new to CF with experienced peers. It welcomes them to the community in a very personal way, and it also gets them up to speed pretty quickly so that they can deliver better care.

This is key for a chronic disease like CF because most of the care actually happens on a day-to-day basis in people’s homes. These multidisciplinary team members have specialized knowledge, and they spend much of their time with the patients and families, so they build strong relationships. Those relationships motivate the patients and families to follow through on their difficult regimen for care.

About Bruce C. Marshall, MD

Dr. Marshall is the Vice President of Clinical Affairs at the Cystic Fibrosis Foundation.

For more information about the Cystic Fibrosis Foundation’s Care Center Network and Patient Registry, please visit www.cff.org.
The Public Health Burden of Rare Diseases

As defined by the Office of Rare Diseases Research (ORDR) at the National Institutes of Health (NIH): “A rare (or orphan) disease is generally considered to have a prevalence of fewer than 200,000 affected individuals in the United States [US]. Certain diseases with 200,000 or more affected individuals may be included in this list if certain subpopulations of people who have the disease are equal to the prevalence standard for rare diseases.”1

The most common form of pulmonary fibrosis (PF), idiopathic pulmonary fibrosis (IPF), is by definition a rare lung disease, affecting between 132,000 and 200,000 people in the US.2 When pulmonary fibrosis from other causes is included, the affected population is estimated at approximately 500,000. Unfortunately, these are only “estimates” based on research data that has been extrapolated from relatively small datasets.

Idiopathic pulmonary fibrosis is but one of approximately 6,500 rare diseases that affect an estimated 6–8 percent of the population in the US.3 Because these diseases are rare, data is inherently limited; the dispersion of patients further limits data collection for the study of rare diseases by individual institutions.4 Patient registries can aggregate data across the US, or around the world, to make it useful and available to researchers.

What is a Patient Registry?

According to the National Committee on Vital and Health Statistics, medical and public health registries are defined as “an organized system for the collection, storage, retrieval, analysis, and dissemination of information on individual persons who have either a particular disease, a condition (e.g., a risk factor) that predisposes to the occurrence of a health-related event, or prior exposure to substances (or circumstances) known or suspected to cause adverse health effects.”5

A patient registry specific to PF is important for a number of reasons. For example, are there geographic and demographic differences in the incidence and prevalence of PF? Also, a registry would permit health care providers to assess the effectiveness of specific interventions such as pulmonary rehabilitation, nutritional counseling, or new pharmacologic interventions. There are many other potential benefits from the creation of a national (and international) registry.

Learn about the causes of pulmonary fibrosis at
www.pulmonaryfibrosis.org/causesofpf.
The Role of a Care Center Network

An important adjunct to the implementation of the Pulmonary Fibrosis Foundation Patient Registry is the creation of a Care Center Network (CCN). The aim of the Care Center model is to provide a standardized and comprehensive, multidisciplinary approach to the care of patients. Although the approach to diagnosis and treatment is quite similar in most institutions, it is essential to identify and establish a “best practices” model for providing high-quality, comprehensive patient care. For this reason, the PFF intends to begin the Registry effort with the implementation of the CCN. The Registry/CCN concept combines research and patient care into a single setting that will facilitate a multidisciplinary team approach to solve the complex problems related to fibrotic lung disorders. Additionally, the development and implementation of the Registry/CCN will facilitate productive collaboration among patients, clinicians, researchers, government agencies, and the pharmacologic industry.

The Cystic Fibrosis Foundation’s Success

The previous success of other disease-specific registries and care center networks demonstrate their importance in improving the lives of patients with chronic disease. One notable example is the Cystic Fibrosis (CF) Foundation’s Patient Registry and Care Center Network (CCN). Prior to the implementation of their Registry/CCN, patients with cystic fibrosis usually died in early childhood. In 1962, the predicted median survival age was 10–15 years; today the predicted mean age of survival is more than 40–45 years. This dramatic improvement in survival is attributed to standardization of care, early diagnosis, and the development of new, effective therapies. These achievements would not have occurred without the creation and participation of the Registry/CCN. More recently, research and data that was developed in conjunction with the CF Foundation’s Registry/CCN has led to FDA approval of a new therapy (Kalydeco®) to treat a specific genetic mutation (G551D). The therapy is expected to significantly extend the lives of patients with this mutation. The CF Foundation’s Registry/CCN demonstrates how this model can play a pivotal role in extending and improving the quality of lives of patients and ultimately lead to the development of extremely effective treatments.

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Viability and Impact

To fund and create the PFF Patient Registry and Care Center Network, the PFF is establishing partnerships with clinicians, researchers, government agencies, and bio-pharma organizations. This initiative is central to the Foundation’s mission: it will increase research efforts to develop effective treatments; will improve disease awareness through expanded and consistent patient education; will enhance advocacy through a national, collaborative network; and will improve the quality of care for patients and caregivers by developing standardized “best practices” diagnostic and treatment protocols. The PFF, the patient care centers, and the research community all view the creation of a Registry/CNN as a vital and critical component in the goal of improving the care of PF patients and developing better and more effective therapies.

Robert J. Beall, PhD, President and CEO of the Cystic Fibrosis Foundation, will be the keynote speaker at the PFF Summit 2013. To learn more about the Summit, turn to page 17 or visit www.pffsummit.org.

WHAT ARE THE REQUIREMENTS FOR A PF CARE CENTER?

The participating institution must meet certain standards that have been developed by the Foundation and Registry/CCN Oversight Committee.

These requirements include a “care team” comprised of a medical director, clinic coordinator/nurse specialist, social worker, respiratory therapist, and research coordinator.

The Care Center must have the appropriate outpatient and inpatient facilities, essential consultative personnel (i.e., rheumatologist, dermatologist, radiologist), the ability to perform necessary diagnostic procedures, and the ability to provide adequate follow-up care. Additionally, the Care Centers should participate in research and encourage enrollment in clinical trials.

Sources:
4. Ibid.
profiles

TWO EXPERIENCES AT SUMMIT 2011

Dr. Andrew Tager: An Academic Physician’s Perspective

What brought you to specialize in pulmonary disease and pulmonary fibrosis in particular?

I enjoyed working in the medical intensive care unit [ICU] when I was doing my internal medicine residency and thought the focus of my career was going to be critical care. I was initially attracted to pulmonary medicine because of my work there. In the ICU, I would see pulmonary patients and fell in love with the clinical side of pulmonary medicine.

When I started doing the research component of my fellowship, I got very interested in the mechanisms of pulmonary fibrosis. It was really my lab investigation that first brought my attention to, and made me very interested in, pulmonary fibrosis. To bring my clinical pursuits in line with my lab pursuits, I started seeing more and more pulmonary fibrosis patients. I became taken with the disease and the plight of our patients.

I saw the tremendous need for more research to develop effective therapies. My practice is now limited to pulmonary medicine, with a focus on pulmonary fibrosis and interstitial lung disease. I spend most of my time in a research lab trying to figure out what is driving fibrosis in this disease.

Our lab has grown from its humble beginnings, for which I owe a huge debt of gratitude to the Pulmonary Fibrosis Foundation. The Foundation was among the first to provide funding for the work that we do. Now we have a great group of incredibly talented faculty members, pulmonary fellows, and post-doctoral fellows. We are all working on trying to figure out the driving forces of this disease so we can identify better therapeutic targets for pharmaceutical companies to develop drugs to hit. Right now, I spend about 90 percent of my time doing research on pulmonary fibrosis; the other 10 percent is spent in the hospital taking care of pulmonary patients.

You attended the Summit in 2011 as a clinician, researcher, and speaker. What were your overall impressions of the meeting? What did you find most valuable about the Summit?

I was very excited to attend the first Summit, and it exceeded my high expectations. A tremendous strength of the Summit was that the Pulmonary Fibrosis Foundation brought together everyone with an interest in this disease: patients, physicians taking care of those patients, researchers working on many different aspects of the disease, the pharmaceutical companies, and the regulatory agencies.

It was amazing to bring together all the people who either experience this disease personally, or work at some phase of trying to help those people who personally experience the disease. The Summit spanned a broader spectrum than usually occurs at [pulmonary and critical care] meetings, or at any other meeting that I had attended before.

I really gained a tremendous amount of insight by talking to researchers outside my own particular area, pharmaceutical company people, and individuals who currently work or have worked at the FDA. The interchange between those different levels of people working on pulmonary fibrosis was extremely informative.

Is there any group that you felt was not represented or under-represented?

I don’t think so. The Summit was the broadest assembly of all the stakeholders in the disease that I had ever been together with in one room. I applaud your efforts to be comprehensive and really think you hit the mark.

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In some cases the diagnosis of idiopathic pulmonary fibrosis (IPF) can be quite clear, when the data is consistent. But as often as not, the data is somewhat inconsistent, with CT [computed tomography] scan appearances and even biopsy appearances that don’t necessarily match each other or all fit together perfectly into a classic diagnosis of IPF. In those cases, and I would say that is as many as 50 percent, the interplay or interchange of information between the clinicians, the radiologists, and the pathologists is enormously helpful. In these instances, IPF centers have all of the different experts gather together to discuss the case, to go back and forth between what the radiology looks like, what the pathology looks like, and determine what we really think is explaining the presentation. In almost all cases, we are able to arrive at a consensus between all three groups—clinicians, radiologists, and pathologists. The group consensus is often different from the original diagnosis.

In pulmonary fibrosis we need to bring different diagnostic modalities together and have these experts speak with one another. Data has shown that this is essential whether it occurs in an academic medical center or a community hospital. So I would say for patients that are not being seen at a major ILD [interstitial lung disease] center, it would be important to find out if such a diagnostic conference occurs at their hospital. For more difficult cases, it is probably better if a patient is evaluated at an academic center with a lot of experience in IPF.

I would tell patients, if they are given a diagnosis of IPF, to ask their physicians whether their case appears to be one where all the data is very consistent and meets the consensus criteria for the diagnosis of IPF. If their case is more difficult, where the radiology, the clinical story, and/or the pathology don’t quite fit together, it may benefit the patient to be referred to an academic center for a second opinion.

I think this has become even more important given the results of the PANTHER-IPF trial that showed that combination anti-inflammatory therapy of steroids, azathioprine, and N-acetylcysteine [NAC] was actually harmful for patients. In the past, in cases where it really wasn’t clear whether the patient had IPF or another interstitial lung disease, like NSIP [nonspecific interstitial pneumonia], clinicians would often think a good course of action was to give a trial of that therapy to see if the patient responded.

Now that we have data that the combination anti-inflammatory therapy can actually be harmful for IPF patients, I think trying to get a more definitive diagnosis in those unclear cases becomes that much more important. So in those complicated, confusing cases, patients may be best served by having an evaluation at an academic center with considerable IPF expertise.

The benefit of community physicians being able to attend educational activities like the Summit, to see the benefit of a multidisciplinary diagnostic approach that can be easily replicated at their own hospitals, is enormously important. Also knowing that some patients, particularly those whose cases are quite complicated, or that may have an unclear diagnosis, will benefit from a referral to a center with specialized expertise in the diagnosis and management of fibrotic lung disease. When the patient first presents, the community physician and the community pulmonologist have an enormous role in determining what course to pursue.

I think all of those issues get addressed at educational opportunities like the Summit. Being able to facilitate the discourse between the community physician and the academic physician is one of the great things that comes out of these activities, where you have people from all these arenas present in the same room.

Do you think that your patients are better informed about the disease today than they were a year or two ago?

I have always been impressed with how well informed our patients are. I think that as we understand these diseases better, and communicate things more clearly to our patients in terms of what exactly IPF and PF are, and where they fit in the broader rubric of interstitial lung diseases, patients have been very quick to understand. And that has been enormously helpful to them in terms of understanding their disease.

It is important that patients have knowledge about the type of pulmonary fibrosis that they have, and also an understanding that all patients with pulmonary fibrosis will not behave the same—that there is heterogeneity with these diseases. I think that in general, the patients’ level of understanding of these diseases has gotten a lot more sophisticated. This is an area that has really blossomed in the pulmonary medical community in just the 15 years that I have been a practicing pulmonologist. There is much better understanding of IPF, and how it relates to other interstitial lung diseases, than there was when I was first doing my fellowship, and that has been very exciting.

Another goal of the Summit was to foster relationships and collaboration. From your perspective, did this impact you in any way?

Yes. I have to say that personally, I found this to be a huge benefit for our own research efforts. First of all, I thought the topics for the talks were particularly well chosen, and I have to express my thanks to Greg Cosgrove, who chaired the session I spoke at, for giving me a really terrific topic to speak about—the area of interaction between two cell types that we think are particularly important for this disease, the fibroblast and the epithelial cell.

In putting together that talk, I learned an enormous amount that has really informed our research. As a result of that talk, I was asked to write a review manuscript summarizing this area for a special issue of *Biochimica et biophysica acta—Molecular Basis of Disease* entitled “Fibrosis: Translation of basic research to human disease.” And once again, that has also really helped our own research.

Find a list of centers specializing in pulmonary fibrosis at www.pulmonaryfibrosis.org/medicalcenters.
At the Summit there was a great assembly of research experts, some like those in our lab who are trying to figure out the mechanisms that are driving the progression of fibrosis, and others that are trying to determine biomarkers that might better predict what the patients’ course will be. Prior to the Summit in 2011, that was an area in which we hadn’t really been involved, but now we are looking into.

In our research, there are some molecules that we think are very important and that are being targeted by pharmaceutical companies for new therapies for pulmonary fibrosis. We made some very nice connections to pharmaceutical companies trying to develop drugs to hit these particular molecules, or therapeutic targets. The relationships that came from participating in the Summit have been enormously helpful to our own research.

I also benefited from the terrific talks on the perspective of the pharmaceutical companies and what it takes to bring a new therapy into the clinic. Additionally, I found the perspective of the FDA, in terms of what they are looking for in approving new therapies for IPF in particular, and lung disease more broadly, very informative.

Everyone at the Summit had a collective goal to ultimately get new therapies that will work into the clinic to help our patients. Having that whole spectrum represented at the Summit is one of the great strengths of the conference and really had tremendous benefits for our laboratory.

What would you say to other medical professionals who are thinking about attending the PFF Summit 2013: From Bench to Bedside? What should their expectations be?

First, I would encourage them all to go. I thought the Summit in 2011 was a terrifically informative meeting on so many levels — really unique in terms of the number and breadth of people it was able to bring together. So I would say that any medical professional that is involved with lung disease generally, and interstitial lung disease in particular, would benefit enormously from attending the Summit.

There is really not a better distillation of what is going on in the field of pulmonary fibrosis right now than at the Summit.

The Summit encapsulates everything you could hope would be at a meeting that can get people up to speed about pulmonary fibrosis. There are great things for researchers to benefit from, for clinicians to benefit from — including clinicians at academic centers and clinicians at community settings — as well as benefits for pharmaceutical companies. I think there are huge benefits from us all coming together to inform each other on our individual roles in this common purpose of trying to help patients with pulmonary fibrosis.

As far as expectations, I would think that anyone attending the PFF Summit 2013 can realistically expect to get a completely up-to-date assessment of what is happening in the field of pulmonary fibrosis — from the most basic research, to the current clinical trials, to the clinical management of patients. You really will have as much information as you possibly can so that you can provide the best care for the pulmonary fibrosis patients that you encounter.

I give tremendous credit to the Pulmonary Fibrosis Foundation for bringing together, in one meeting, so many different experts from different disciplines. I think it is enormously beneficial, and I couldn’t recommend it more highly.

About Andrew Tager, MD

Dr. Tager is a physician-scientist in the Pulmonary and Critical Care Unit, and the Center for Immunology and Inflammatory Diseases, at the Massachusetts General Hospital (MGH), an Associate Professor in Medicine at Harvard Medical School, and an Associate Faculty Member of the Ragon Institute of MGH, MIT, and Harvard. Dr. Tager received his MD from Harvard Medical School, and completed both his internal medicine residency and his pulmonary and critical care medicine fellowship at the MGH. Dr. Tager began his own laboratory after his post-doctoral research training in the laboratory of Dr. Andrew Luster, also at the MGH. Dr. Tager’s lab is focused on identifying chemicals produced by the body that promote the development of fibrosis. Most importantly, his work aims to find ways to inhibit such molecules to prevent the progression of fibrotic diseases, and/or promote healing of scarred organs. He identified lysophosphatidic acid (LPA) and its receptor LPA1 as critical mediators of fibrosis in the lung and other organs, driving fibroblast recruitment, vascular leak, epithelial cell death, and profibrotic gene expression. Building on this work, drugs that inhibit LPA1 have been developed and are now entering clinical trials for idiopathic pulmonary fibrosis (IPF) and scleroderma.

Dr. Tager’s laboratory also identified a fundamental role for sphingosine 1-phosphate (S1P) signaling through its receptor S1P1 in protecting the lung from both exudative and fibroproliferative responses to injury, and augmenting this signaling represents another novel potential therapeutic strategy for IPF.
Please tell us a little bit about yourself.
I’m 49 years old and live in Milwaukee. I was diagnosed with NSIP [non-specific interstitial pneumonia] nine years ago. I know it has been nine years because I started feeling sick on my 40th birthday. I am going to be married for 25 years and I have one child. I used to work, but I am currently on disability. And I like to travel.

Could you tell us a little bit more about how you were diagnosed? Why did you see a doctor?
I was working as a medical assistant in a medical office when I was hospitalized for a month with pneumonia. When I went back to work, the doctors I worked for kept saying that I wasn’t any better. They were the ones that really pushed me on the issue of finding a different pulmonologist and that persuaded me to go see another doctor. I had video-assisted thoracic surgery [VATS], a lung biopsy, and got the diagnosis.

My husband noticed that I had shortness of breath, but I never noticed it. I was slightly overweight and needed to exercise more, so I just assumed those were the reasons for my shortness of breath and didn’t think much about it.

The doctors in the medical office are my guardian angels—that is what I call them. They are the ones that made me go for further testing. Otherwise, I would never have known.

You have NSIP. Do you also have an autoimmune disease?
They told me that I have rheumatoid arthritis and fibromyalgia, but symptoms of those diseases never bothered me before my diagnosis of NSIP. They did flare up after my diagnosis, though.

Do you feel as though your disease is stable?
I have had only a slight decline. I am now on oxygen, but I only need it at night and with activity. I don’t need it 24/7, so I am very lucky. I have really been trying to keep healthy—I eat healthy and do pulmonary rehabilitation. That has helped me a lot. I just try to exercise and stay active doing things I enjoy, like traveling.

I try not to let the disease control me. I am one of the lucky ones. I know that some people progress more rapidly than I have. I don’t know why, but I have been stable. I have only been on oxygen for one year, first just at night, and now with activities as well.

Besides having to use supplemental oxygen, has the disease impacted your life in other ways?
Definitely. I used to enjoy hiking and canoeing and all kinds of activities, and now I can’t do many of the activities that I once enjoyed. I get fatigued. I have good days and bad days. I am learning to adjust.

Everyday tasks like cleaning the house and even showering are harder. Showers are the hardest thing for me to do. I had to learn how to let go of things, so now my husband helps me with the laundry or washing the kitchen floors. That was a big change in my life.

How did you find out about Summit 2011 and why did you attend?
I found out about the Summit through Jennifer Bulandr, Director of Community Events and Social Media at the Foundation. I was in her online support group and found out about the Summit through the group. I also saw it promoted on Facebook, and then shared it on my page.

I attended the Summit because I wanted to learn more. We have a support group in Milwaukee. I went on their behalf. My support group has mostly elderly people in it and the live webcasts were not an option for them. So I went for the group and my son came with me. I went to get all of the information that I could and learn about the research. The topics were very interesting for us.
What were your impressions? What sessions do you think were the most valuable for you?

The most valuable topics to me were research, pulmonary rehabilitation, and the information about lung transplants. Those are the three main subjects that really interested me. Dr. Cosgrove’s session, “What is Pulmonary Fibrosis and What are the Causes?” was really good as well. The information is easier to understand when you hear it in person.

Was there anything that you learned at the Summit that really surprised you?

It was good to learn that there is more research going on than I knew about. I am one of those people that like to learn about the research on the internet, but most of the research that was presented at the Summit was new to me.

When I saw the other patients, I was surprised at the range of people affected by the disease. I thought that I was one of the youngest patients and now know that I am not. It gave me the impression that this disease is growing a lot.

Did you watch any of the webinars after the Summit? Did you recommend them to anyone?

Yes, I watched a couple of the webinars after the Summit to refresh my memory so that I could share the information with my support group. I also gave my group the information about the webinars so that they could watch the topics that interest them the most on their own time and at home. I think that was the best thing the Foundation did. It helped a lot of people who couldn’t be there in person, who can’t travel. That was the situation with my support group — none of them could travel. I was the only one that could be at the Summit in person.

What did you think of the roundtables? Did you find the discussions and opportunity to meet with the experts valuable?

Absolutely. I was lucky; I got to sit at Dr. Cosgrove’s table. We asked him a lot of questions. I was able to ask him about whether I should have oxygen when I travel. It was really nice; it was very one-on-one.

My son is interested in microbiology and sat at a roundtable with a researcher. She answered all of his questions. It was neat that the PFF offered the opportunity because sometimes people are nervous when they ask questions. The small groups created an environment where it was easy to ask questions, and it was easy for those answering them. I just asked little questions and listened to everyone and absorbed information, but I would have felt comfortable asking more important questions.

If someone was unsure about attending the Summit this December, what would you tell them the benefits in attending are?

I liked the materials that you handed out to us. I still have all the information. I thought it was very organized and very welcoming. The staff and the environment made me feel so comfortable. Plus you had the booths set up with all of the different exhibitors including oxygen suppliers. That helped me make the decision of who to pick for my oxygen provider. All the information helped me immensely and it was great to share the information with my support group.

I also made new pulmonary fibrosis friends. That helped a lot. I met people around my age and that was nice. Plus, I got to meet my online friends in person which was special — like a little reunion. When I entered the room I thought, wow, I am not alone. To meet people with different histories and different stories of where they are and what they are doing was a great benefit. One inspiring person that I was fortunate to meet traveled all the time. So I thought, if he can do it, I can do it. I thought it was special that I got to meet a lot of neat people.

Do you have any hopes for the future that you would like to share with the PF community?

My hopes are to find a cure and to get the word out about our disease. I know we are trying our darnedest to do that. I hope that someday our disease will have the same awareness as a disease like breast cancer, so that all doctors will know about pulmonary fibrosis and people can get an accurate diagnosis faster. We need better diagnoses and we need a cure.
“The Summit helps us fulfill our role as a resource and catalyst for the PF community.”

– DANIEL M. ROSE, MD
CEO AND CHAIRMAN OF THE BOARD OF DIRECTORS AT THE PFF

www.pffsummit.org
“The physician panel made listeners feel engaged and comfortable…it felt intimate and rewarding to be there.”

– SUMMIT 2011 ATTENDEE

View a current list at www.pffsummit.org/faculty.html.

*MEMBER OF PROGRAM COMMITTEE
“Inspirational for patients and professionals. The spirit of collaboration was evident. This event put the PFF on the map.”

– SUMMIT 2011 ATTENDEE
WELCOME RECEPTION AND POSTER PRESENTATIONS

All conference participants are invited to attend the Welcome Reception and Poster Presentations located in the Hyatt’s Pavilion on Thursday, December 5. Cocktails and hors d’oeuvres will be served. There will be approximately 40 academic and industry investigator poster presentations.

“Inspirational for patients and professionals. The spirit of collaboration was evident throughout. This event put the PFF on the map.”

– SUMMIT 2011 ATTENDEE

EXHIBIT HALL

The Exhibit Hall, located in the Pavilion, will be open:

**Thursday, December 5**
5:00 p.m.–8:00 p.m.

**Friday, December 6**
7:00 a.m.–5:45 p.m.

**Saturday, December 7**
7:00 a.m.–3:00 p.m.

LOUNGE AREAS

Due the popularity of our lounge seating at Summit 2011, we will once again offer lounge areas with live feeds of the professional sessions for flexibility and comfort.

KEYNOTE SPEAKERS

OPENING ADDRESS
ROBERT J. BEALL, PHD
PRESIDENT AND CEO,
CYSTIC FIBROSIS FOUNDATION

PATIENT ADVOCACY
JOHN F. CROWLEY
CHAIRMAN AND CEO,
AMICUS THERAPEUTICS

NETWORKING DINNER

All conference participants are invited to attend the complimentary poolside Networking Dinner at the Hyatt Regency on Friday, December 6. The buffet-style dinner is designed to create an evening of engagement and networking opportunities. Individual tickets may be purchased for those not registered for the conference.
CALL FOR ABSTRACTS

The Pulmonary Fibrosis Foundation (PFF) invites academic and industry researchers to submit abstracts of their scientific research for poster presentation at the PFF Summit 2013: From Bench to Bedside.

Subject matter deemed appropriate for poster presentation at the PFF Summit 2013 include original ideas that will help improve the understanding of pulmonary fibrosis in the following areas:

• Basic Research
• Translational Research
• Clinical Research
• Social Science/Quality of Life Research

The PFF’s Research Advisory Committee will review all academic abstracts. Notification of the Committee’s decision will be completed by October 31, 2013, and all presenters of accepted abstracts will receive complimentary Summit registration.

Industry posters are not subject to peer review. Space can be reserved by submitting an abstract and acceptance is based on a first-come, first-serve basis. Space allotted will be confirmed by October 31, 2013.

The call for abstracts will close on August 25.

PRESENTATION AND RECOGNITION

Poster presentations will take place on Thursday, December 5 from 5:00 p.m. to 8:00 p.m. in conjunction with the Welcome Reception. Presenting authors are expected to be present at their posters between 5:00 p.m. and 7:00 p.m.

Poster and travel awards will be granted to the top five presenting authors (or their designees). Note: Industry posters are exempt from scoring and will not be considered for awards.

• First place: $1,500 and travel award
• Second place: $1,000 and travel award
• Third place: $500 and travel award
• Honorable mentions (2): travel award

Learn more about the call for abstracts and poster presentations at www.pffsummit.org/posters.html.

“Best comprehensive coverage of the science and clinical management of PF [of any conference] I have ever attended.”

– SUMMIT 2011 ATTENDEE
PROGRAM AT A GLANCE

Thursday, December 5
Arrivals / Registration
3:00 p.m.–8:00 p.m.
Welcome Reception and Poster Presentations
5:00 p.m.–8:00 p.m.

Friday, December 6
Professional Sessions
7:00 a.m.–5:45 p.m.
Patient and Caregiver Sessions
8:00 a.m.–2:30 p.m.
Networking Dinner
6:30 p.m.–10:00 p.m. at
the Hyatt Regency La Jolla

Saturday, December 7
Professional Sessions
6:45 a.m.–4:45 p.m.
Patient and Caregiver Sessions
8:00 a.m.–2:15 p.m.

CONFERENCE VENUE

Hyatt Regency La Jolla at Aventine
3777 La Jolla Village Drive
San Diego, CA 92122, USA
858.552.1234
www.lajolla.hyatt.com

HOTEL ACCOMMODATIONS

Guest Room Block Rates
$179.00 for singles and doubles

Reservations
To make a reservation, call
888.421.1442 and reference
the PFF Summit 2013 or make
your reservation online at
www.pffsummit.org/venue.html.

The deadline for hotel reservations
is November 7, 2013.

“It was remarkable…the content and
organization/process were as if it were not
the 1st but the 101st Summit.”

– SUMMIT 2011 ATTENDEE

CME/CE INFORMATION

Accreditation and Designation Statements: This activity has been planned and implemented in accordance with the Essential Areas and Policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint sponsorship of National Jewish Health and the Pulmonary Fibrosis Foundation. National Jewish Health is accredited by the ACCME to provide continuing medical education for physicians.

National Jewish Health designates this live activity for a maximum of 15.5 AMA PRA Category 1 Credits™. Physicians should only claim credit commensurate with the extent of their participation in the activity.

National Jewish Health is an approved provider of continuing nursing education by the California Board of Registered Nursing. Provider Number CEP 12724. Nursing Contact Hours are pending.

Application has been made to the American Association for Respiratory Care (AARC) for continuing education contact hours for respiratory therapists.
**Update on Stem Cell Research:**

**Induced Pluripotent Stem Cell Technology to Advance IPF Research**

**Dr. Brigitte Gomperts at the University of California, Los Angeles** has been awarded a grant from the California Institute for Regenerative Medicine (CIRM) to collect blood samples from 250 patients with idiopathic pulmonary fibrosis (IPF) and 100 matched control samples. These samples will be reprogrammed into induced pluripotent stem cells and banked by Cellular Dynamics and the Coriell Institute for Medical Research. Since the discovery of the technology to make induced pluripotent stem cells from adult cells by Shinya Yamanaka in 2006, for which he jointly received the Nobel prize for Physiology or Medicine this year, induced pluripotent stem cells have been used to model complex diseases such as Parkinson’s disease and amyotrophic lateral sclerosis (ALS or Lou Gherig’s disease). As IPF is also a complex disease involving genetic changes and environmental factors, this technology holds great promise for creating models of IPF to further our understanding of the disease.

The technology of induced pluripotent stem cells involves taking adult cells from a person and inserting factors into the cells that “turn the clock back” on the cells, essentially making them like embryonic stem cells with the ability to then be coaxed back into making any cell type in the body. This technology has the potential for the development of cell-based therapies and modeling of diseases in a dish, in order to study the biology of the disease and perform high throughput drug screening to facilitate drug discovery.

**IPF** is one of seven diseases, including Alzheimer’s, autism, and heart disease, from which CIRM will fund the sample collection, generation, and banking of induced pluripotent stem cells. The IPF induced pluripotent stem cells that will be generated and funded by CIRM will be made available to the research community from the Coriell bank for just the cost of shipping. It is hoped that these cells will provide a tremendous resource to greatly accelerate research and advance our understanding of IPF.

The initial research was funded by Dave Steffy, a member of the PFF’s Board of Directors.

**About Brigitte Gomperts, MD**

Dr. Gomperts is a member of UCLA’s Jonsson Comprehensive Cancer Center and assistant professor of pediatric hematology/oncology. She joined the UCLA faculty in 2003 after completing a pediatric residency and pediatric hematology/oncology fellowship at Washington University in St. Louis, Missouri. She earned her medical degree from the University of Witwatersrand in Johannesburg, South Africa.

Dr. Gomperts is affiliated with the Eli and Edythe Broad Center of Regenerative Medicine and Stem Cell Research and the Molecular Biology Institute where she is an associate professor. Her research focuses on the role of adult stem cells in repair and regeneration of lung tissue. The goal of her research is to develop novel targeted therapies and prevention strategies for lung diseases.

Dr. Gomperts will participate in PFF Summit 2013.
Advance Pulmonary Fibrosis Research and Drug Development

Collaboration with the Food and Drug Administration
The US Food and Drug Administration (FDA) plays an essential role in drug development for fibrotic lung diseases by evaluating potential treatments and ensuring that they are safe and effective.

We are encouraging Congress to:
• Provide the FDA with the resources necessary to expedite the evaluation of vital new pulmonary fibrosis (PF) therapies.
• Ensure that the FDA receives appropriate guidance from patients, providers, and researchers when reviewing applications for new rare disease treatments.

Support for the National Institutes of Health
The National Institutes of Health (NIH), the nation’s medical research agency, performs and promotes innovative research that helps translate basic scientific discoveries into the cures of tomorrow.

We are encouraging Congress to:
• Protect programs that help researchers translate promising scientific discoveries into potential treatments.
• Provide the NIH with the funding needed to support essential research.

Promote Access to Care

Preserve Federal Health Care Provisions
People with PF need access to quality health care and treatments necessary to live longer and improve their quality of life.

We are encouraging Congress to:
• Support access to quality health care that adheres to the best practice guidelines developed by PF medical experts.
• Help PF patients access the medical care they need by reducing the unmanageable cost-share burden of this disease.

Protect Medicare and Medicaid
Medicare and Medicaid need protection in order to ensure that PF patients have access to the specialized quality care and treatments they need.

We are encouraging Congress to:
• Ensure that the federal government continues to provide the guidance and benchmarks needed to assist states in crafting policies that best serve the health needs of their residents with rare, chronic diseases.
Make Your Voice Heard by Congress

Finding adequate treatments for pulmonary fibrosis has been slow and the lives of people with PF are cut far too short. With the completion of several clinical trials and new trials underway, PF patients and their families have hope. The need for additional scientific research and clinical trials is critically important. We desperately need the public’s continued support to help extend and improve the lives of those afflicted with PF.

How can you help?

- Communicate with members of Congress—every time you communicate with members of Congress it counts
- Attend local “Town Hall Meetings” held by members of Congress in your home district
- Schedule a meeting with your member of Congress
- Spread the word through social media (e.g., Facebook, Twitter, LinkedIn)
- Enlist your friends and family to contact their members of Congress

Take action now! Visit www.pulmonaryfibrosis.org/takeaction to make your voice heard about legislation important to the PF community by contacting your Congressional leaders using our quick and easy online advocacy tool.

Share this information and recruit others to join the fight against PF. By working together we can ensure that PF has a place on the Congressional agenda.

IDIOPATHIC PULMONARY FIBROSIS TO BE INCLUDED AS PART OF THE FDA’S PATIENT-FOCUSED DRUG DEVELOPMENT INITIATIVE

On April 11, 2013, the US Food and Drug Administration (FDA) announced its selection of sixteen diseases, including idiopathic pulmonary fibrosis (IPF), to be addressed during the first three years of its five-year Patient-Focused Drug Development Initiative. Inclusion in this initiative is significant since this is the first time the FDA will incorporate input from IPF patients in its drug marketing approval process.

The initiative fulfills the FDA’s federally mandated performance commitments, which are part of the fifth authorization of the Prescription Drug User Fee Act (PDUFA V). The initiative’s purpose is to provide a more systematic approach for the FDA to obtain patients’ input on specific disease areas, including their perspectives on their condition, its impact on daily life, and available therapies. Access to this information not only enables the FDA to acquire a more thorough understanding of a disease, but also gives patients a direct stake in FDA decisions.

Input from the reviewing divisions at the FDA and the public was considered in finalizing the list of diseases to be included in the program. Daniel M. Rose, MD, CEO and Chairman of the Board of Directors at the Pulmonary Fibrosis Foundation (PFF), and Dolly Kervitsky, Vice President of Patient Relations and Medical Affairs also of the PFF, provided public comment in support of including IPF at the FDA’s public Patient-Focused Drug Development meeting in October 2012. The PFF also encouraged IPF patients, caregivers, and medical professionals to send letters of support to the FDA. Congressman Erik Paulsen (R-MN) and Senator Christopher Coons (D-DE), who have led PF legislative efforts in the US House and Senate, also contributed a joint letter.

“We are extremely grateful to the FDA for including idiopathic pulmonary fibrosis in the Patient-Focused Drug Development Initiative. We are hopeful and optimistic that this will facilitate the development of more effective therapies for this devastating illness,” said Dr. Rose.

Learn more at www.pulmonaryfibrosis.org/FDApatientfocus.


Learn about the FDA’s Patient Representative Program at www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/PatientInvolvement/ucm123861.htm.

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Initiatives to Improve Patient Advocacy, Education, and Awareness

The PFF’s Inaugural Global Pulmonary Fibrosis Awareness Day

Expanding global disease awareness is extremely important to the pulmonary fibrosis (PF) community. Increasing awareness could improve funding for research, lead to earlier diagnosis, improve standards of care, and expand support from governmental agencies (e.g., FDA, NIH, and European Medicine Agency).

The Pulmonary Fibrosis Foundation (PFF) conducted the first Global Pulmonary Fibrosis Awareness Day on September 22, 2012, with educational patient programs held in Modena, Italy, and Denver, Colorado. For those who could not attend in person, the events could be seen via a live webcast.

Some of the topics presented at both events included: “What is Pulmonary Fibrosis?”, “Tools for Living Better with Pulmonary Fibrosis”, “The Role of Support Groups”; and “The Benefit of Support Groups from a Patient’s Perspective.” After the presentations there was an interactive Q&A session with attendees and online viewers that was quite stimulating.

The webcast from Modena was simultaneously translated into French, German, Italian, and Spanish. Additionally, translated copies of the Foundation’s the Pulmonary Fibrosis Patient Information Guide were available and could also be downloaded from the PFF website.

View the webinars at www.pulmonaryfibrosis.org/webinars.

The PFF’s Pulmonary Fibrosis Patient Information Guide is available in English, Dutch, French, German, Italian, Spanish, and Portuguese at www.pulmonaryfibrosis.org/patienthandbook.
In 2007, the United States Congress supported the designation of a “National Idiopathic Pulmonary Fibrosis Awareness Week” that would take place annually in September. In 2012, as part of a month of awareness activities, the Foundation designated September 22 as the inaugural Global Pulmonary Fibrosis Awareness Day. Also during September, after a robust “grassroots” campaign, the Foundation was awarded a $10,000 grant from Chase Community Giving, and in Chicago over 100 people participated in the Hike for Lung Health to raise over $17,000. These funds will help support research. During the month we also partnered with National Jewish Health to support the continuing medical education program, “Improving the Care of Patients with Idiopathic Pulmonary Fibrosis.” Finally, we were privileged to take part in activities surrounding World IPF Week held September 23–30, which was presented by the Italian association AMA Fuori dal Buio in collaboration with the Center for Rare Lung Diseases at the University of Modena and Reggio Emilia.

Our Team PFF volunteers did their part to raise awareness in September by organizing 11 events in eight states and creating a “buzz” on social media with over 600 new “Likes” to the PFF Facebook page. They also helped us generate our highest “Daily Total Views” on Facebook for the year, through “Shares” and “Likes,” that resulted in 23,064 people viewing our page on a single day. We also promoted other awareness events that took place during the month on our website, in e-communications, and on social media.

World IPF Week volunteers in Modena, Italy.
Establishing a Patient Support Group Network in the European Union

The Pulmonary Fibrosis Foundation (PFF) is dedicated to providing resources to all patients and caregivers in need of information or support for their battle against pulmonary fibrosis. In September 2012, we made a commitment to expand our Support Group Network to include the international PF community. The Foundation partnered with Luca Richeldi, MD, Director and Founder of the Center for Rare Lung Diseases at the University of Modena and Reggio Emilia, to organize a Support Group Leader Workshop on September 29, 2012. The Workshop took place prior to the start of the International Colloquium on Lung and Airway Fibrosis (ICLAF) conference that was held in Modena, Italy. The goal of the Workshop was to assist in the development of a Support Group Network in the European Union (EU).

“It is our shared belief that support groups make a significant contribution to improving total patient care and quality of life,” remarked Daniel M. Rose, MD, Chief Executive Officer and Chairman of the Board of Directors at the PFF.

Representatives from over 90 EU interstitial lung disease centers and 12 patient advocacy groups were invited to attend the Workshop. Dr. Richeldi began the program with a welcome introduction. Dr. Rose then discussed the mission of the Pulmonary Fibrosis Foundation and the role of patient advocacy organizations. Dolly Kervitsky, RCP, CCRC, Vice President of Patient Relations and Medical Affairs at the PFF, discussed steps for creating effective support groups and introduced the PFF’s new Support Group Leader Guide. The Guide had been translated into six languages for the Workshop. Kathleen O. Lindell, PhD, RN, member of the PFF’s Medical Advisory Board, presented a case study of the University of Pittsburgh’s Simmons Center IPF Support Group. The last speaker, Stephen A. Wald, PhD, member of the Board of Directors of the PFF, gave a moving talk on the benefits of support groups from a patient’s perspective.

The workshop concluded with a lively interchange between the speakers and the audience. One of the important topics discussed was how to better engage the European patients and family members, and how to effectively develop support groups in the EU.

The Support Group Leader Workshop and Global Pulmonary Fibrosis Awareness Day were funded by Boehringer Ingelheim (platinum sponsor), The Culliton-Metzger Family (silver sponsor), and InterMune (bronze sponsor).

“It is our shared belief that support groups make a significant contribution to improving total patient care and quality of life.”

The PFF’s Support Group Leader Guide and accompanying Support Group Handouts and Forms Packet are available in English, Dutch, French, German, Italian, Spanish, and Portuguese at www.pulmonaryfibrosis.org/supportgroups/create or email info@pulmonaryfibrosis.org for a print version.
“…participating in the conference has further strengthened our strategic relationships with the global leaders in PF and will assist in our efforts to improve the lives of all those affected by pulmonary fibrosis.”

Participation in the International Colloquium on Lung and Airway Fibrosis

The Pulmonary Fibrosis Foundation (PFF) was honored to be a partner for the 17th International Colloquium on Lung and Airway Fibrosis (ICLAF) that was organized by the Center for Rare Lung Diseases at the University of Modena and Reggio Emilia. The conference took place from September 29–October 3, 2012, in Modena, Italy and drew over 250 of the world’s leading researchers in lung fibrosis.

Daniel M. Rose, MD, Chief Executive Officer and Chairman of the Board of Directors of the PFF, gave a presentation at the conference on “The New Paradigm of Patient Advocacy Organizations.” It was the first time that a representative from a patient advocacy organization had been asked to speak at ICLAF. “We were honored to participate in ICLAF and represent pulmonary fibrosis patients at the conference,” commented Dr. Rose. He observed, “participating in the conference has further strengthened our strategic relationships with the global leaders in PF and will assist in our efforts to improve the lives of all those affected by pulmonary fibrosis.”

In 2014, the PFF will participate in the 18th ICLAF meeting in Mount Tremblant, Quebec, Canada. The conference will take place September 20–24, 2014, in association with the Canadian Pulmonary Fibrosis Foundation, the Pulmonary Fibrosis Foundation, McMaster University, St. Joseph’s Healthcare Hamilton, Firestone Institute for Respiratory Health, and Meakins-Christie Laboratories. Learn more about ICLAF at www.iclaf.com.
The Pulmonary Fibrosis Foundation’s (PFF) annual dinner last October, *Breathe Benefit 2012: Community Inspiring a Cure*, took place at locations around the world. The Chicago Dinner that was organized by the PFF was held at The Drake Hotel and dedicated volunteers from Alabama to Sweden hosted their own Global Dinners. The events raised over $175,000 and will help fund important research and provide support for our many patient initiatives. Importantly, the events also helped increase much needed awareness about pulmonary fibrosis (PF). The Foundation is deeply appreciative of the many people who helped bring the PF community together to make the *Breathe Benefit 2012* a success.
The Drake Hotel’s Grand Ballroom was the setting for the inspirational Chicago Dinner. Over 240 individuals attended the event. Dinner guests included patients, caregivers, family members, researchers, medical professionals, and other valued supporters of the PFF. For the second year, the Foundation was honored to have Mary Ann Ahern from NBC5 News emcee the evening. She and her husband, Tom Ahern, also served as honorary chairs for the event. Co-chairs for the dinner were Kathy Petrak and Chuck Lawless. Special guests were award-winning Broadway actress, comedienne, and devoted PFF advocate Julie Halston and her husband, news anchor for the Howard 100 News, Ralph Howard. The audience was truly moved when Mr. Howard related his own personal story as a PF patient and lung transplant recipient.

One of the evening’s highlights was a tribute to Foundation co-founder I.M. Rosenzweig, PhD. Mike, as he was known to most, lost his courageous battle to idiopathic pulmonary fibrosis (IPF) on June 23, 2012. Dr. Daniel M. Rose, the PFF’s Chief Executive Officer (and nephew of Dr. Rosenzweig) and Dr. Karen Schwartz, Mike’s daughter, shared touching memories and recalled his tireless work for the PF community. In recognition of Dr. Rosenzweig’s dedication to funding research, the Young Investigator Awards were re-named in his honor.

The PFF Research Fund’s 2012 Young Investigator and Established Investigator grant recipients were recognized at the Dinner. The awards were presented by Kevin K. Brown, MD. Dr. Brown is the Chairman of the PFF’s Medical Advisory Board and a member of the Board of Directors. Dinner attendees were inspired by Dr. Brown’s remarks about the importance of supporting investigators such as the evening’s grant recipients in the development of successful therapies for PF. Additionally, the Foundation announced the six recipients of the 2012 Leanne Storch Support Group Fund awards.
The Foundation also presented two awards to recognize individuals and corporations that have made significant contributions to the PF community. Longstanding Foundation advocate, Charles P. McQuaid, was given the “Legacy Award” for his continued guidance and support of the Foundation’s mission. Booz Allen Hamilton was honored with the “Impact Award” for generously lending staff time and expertise to help develop the Foundation’s Care Center Network and Pulmonary Fibrosis Patient Registry. Carl Salzano, Senior Vice President at Booz Allen Hamilton and member of the PFF’s Board of Directors, accepted the award on behalf of his company. Dr. Rose, noting the award recipients, stated that, “The Foundation is thankful we had the opportunity to honor Mr. McQuaid and Booz Allen Hamilton. Their support and commitment to our mission has been instrumental in making the Foundation the leading pulmonary fibrosis patient advocacy organization. Their assistance will greatly help us achieve many of our goals.”

I.M. ROSENZWEIG YOUNG INVESTIGATOR AWARD RECIPIENTS
- Dr. Haitao (Mark) Ji of University of Utah – “Design and Synthesis of Selective Beta-catenin/T-Cell Factor Inhibitors for the Treatment of Idiopathic Pulmonary Fibrosis” Funded by a grant from InterMune, Inc.
- Dr. Rebecca Keith of University of Colorado, Denver – “Therapeutic Targeting of PTPN-13 in Idiopathic Pulmonary Fibrosis”

ALBERT ROSE ESTABLISHED INVESTIGATOR AWARD RECIPIENTS
- Dr. James S. Hagood of University of California, San Diego – “Extracellular Vesicles Alter Cell Phenotype in Pulmonary Fibrosis”
- Dr. Glenn Rosen of Stanford University – “Analysis of Novel Functions of Human Telomerase RNA in IPF”

LEANNE STORCH SUPPORT GROUP AWARD RECIPIENTS
- Dr. Kathleen O. Lindell of University of Pittsburgh Medical Center Dorothy P. & Richard P. Simmons Center for Interstitial Lung Disease Support Group
- Myrna Taylor and Grace Jacobson, RN, of Eastern Idaho Regional Medical Center Eastern Idaho Pulmonary Fibrosis Support Group
- Dr. Hyan Kim and Melinda Bors of University of Minnesota Minnesota Pulmonary Fibrosis Patient Support Group
- Dr. Maryluz Fuentes of Baptist Medical Center South IPF Support Group of Montgomery
- Donna Serlin, RRT, of Edwards Hospital Edwards Hospital Pulmonary Fibrosis Support Group
- Dr. Anoop Nambar of University of Texas Health Science Center at San Antonio San Antonio Pulmonary Fibrosis Support Group
The Global Dinners

We were excited to offer the opportunity to participate in our Breathe Benefit 2012 annual dinner to everyone by inviting supporters to host a Global Dinner in their hometown. The Global Dinner concept enabled us to help foster a greater sense of community with our patients, families, and friends while recognizing the efforts of those who work tirelessly to support the Foundation’s mission of finding a cure for pulmonary fibrosis.

Each of our Global Dinner hosts were supported with an e-toolkit for the event and an online platform for guests to register and make donations.

The 2012 Global Dinners, held mostly on October 13 to be concurrent with the Chicago dinner, allowed an additional 200 people from around the world to be part of our special event. Dinner hosts included long time supporters and people new to the Foundation. We are thankful for their support.

GLOBAL DINNER HOSTS

Liliana Aguirre and Sharon Lovinelli • ILLINOIS
Madi Barrett • UNITED KINGDOM
Maria Chacon • NEW JERSEY
Cindy Chandler • NEW YORK
David Davenport • MISSOURI
Amanda Davis • NORTH CAROLINA
Judith Friedman • CONNECTICUT
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Use the donation envelope in this issue to mail a check to the PFF or use your own and address it to: Pulmonary Fibrosis Foundation 230 East Ohio Street, Suite 304 Chicago, Illinois 60611-3201

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Donating in honor of those fighting pulmonary fibrosis, or in memory of those who have passed, is a thoughtful and significant way to show support. Create a Tribute Page to honor a loved one today. Learn more at www.pulmonaryfibrosis.org/createtribute.

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Consider including the Pulmonary Fibrosis Foundation in your estate plan. Contact the PFF's Vice President of Development, Rodney J. Watt, at +1 312.239.6628 or your financial advisor to get started.

Your contribution today will have a positive and lasting impact on the PF community.

The Pulmonary Fibrosis Foundation is deeply appreciative of your support.

JOIN THE PFF!

We want to share with you ways to get involved. Join the PFF at www.bit.ly/joinpff or call 888.733.6741.
Golden Globe and Tony Award winners showcased their considerable talents on February 25, 2013, to raise funds and awareness for pulmonary fibrosis (PF) and honor the memory of Associated Press theater critic and reporter Michael Kuchwara. *Broadway Belts for PFF!* was once again hosted by the incomparable Julie Halston at the famous Birdland Jazz Club in New York City. The special evening united Broadway performers, patrons, and members of the PF community for a night of outstanding entertainment. The event raised over $70,000 for the Pulmonary Fibrosis Foundation’s (PFF) Michael Kuchwara Fund for Idiopathic Pulmonary Fibrosis Research, Education, and Advocacy.

Under the musical direction of Jesse Kissel and returning director Carl Andress, Broadway stars displayed their “belting” abilities. The all-star cast included: Tony winners Linda Lavin (*Broadway Bound*) and Debbie Gravitte (*Jerome Robbins’ Broadway*), Emily Bergyl (*Cat on a Hot Tin Roof*), Klea Blackhurst (York Theatre’s *Happy Hunting*), Max von Essen (*Evita*), Robert Creighton (*The Mystery of Edwin Drood*), Emma Hunton (*Spring Awakening*), and Edward Watts (Encores! *It’s a Bird… It’s a Plane… It’s Superman*).

**BROADWAY BELTS FOR PFF!**
A SMASH HIT FOR THE THIRD YEAR

Julie Halston Once Again Leads an All-Star Cast of...
Thank you to this year’s generous sponsors.

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Dave Steffy

Broadway’s Best

The evening’s highlights included Lavin and Gravitte’s original performances of their showstopping Broadway numbers: “You’ve Got Possibilities” from *It’s a Bird…It’s a Plane…It’s Superman* and “Mr. Monotony” from *Jerome Robbins’ Broadway*. Another highlight was the premiere of a new song from the Broadway-bound musical *Chasing The Song* called “Come Back When You’re a Man,” sung by Gravitte and Hunton.

Broadway’s Julie Halston has become a leading spokesperson for the PFF. Her husband, broadcaster Ralph Howard, has previously received a lung transplant due to pulmonary fibrosis and their friend Michael Kuchwara lost his life to this devastating disease. “I am thankful to my dear friends who give their time and talent year after year to help raise awareness and fund the research that will bring us closer to finding a cure,” says Halston.

“Broadway Belts for PFF! has raised almost $160,000 to fund research and generated significant awareness for the disease,” says Patti Tuomey, President and Chief Operating Officer at the PFF. “We are so thankful to Julie Halston, D. Michael Dvorchak, Ed Windels, Sue Frost, and Charlie Siedenburg for their efforts in producing such an amazing evening and for contributing so much to the PF community.”

Watch a video of Julie Halston and Ralph Howard discussing pulmonary fibrosis at www.pulmonaryfibrosis.org/broadwaybelts/history.


PHOTOS BY CHRIS O’FYOUNG
PF COMMUNITY EVENTS

MAY 17–22 • PFF @ ATS International Conference
American Thoracic Society
PHILADELPHIA, PENNSYLVANIA

JUNE • National Scleroderma Awareness Month
UNITED STATES

JUNE 5–8 • Thomas L. Petty Lung Conference
University of Colorado
AURORA, COLORADO

JULY 10–12 • PFF @ Curing Pulmonary Fibrosis: The Holy Grail BALR Summer Meeting 2013
British Association for Lung Research
NOTTINGHAM, ENGLAND

JULY 13 • BALR/PFF IPF Patient Support Day
British Association for Lung Research and the Pulmonary Fibrosis Foundation
NOTTINGHAM, ENGLAND

JULY 14–20 • Childhood ILD Week
American Thoracic Society
UNITED STATES

JULY 26–28 • PFF @ Scleroderma National Patient Education Event
Scleroderma Foundation
ATLANTA, GEORGIA

JULY 29–AUGUST 1 • PFF @ Stem Cells and Cell Therapies in Lung Biology and Lung Diseases
BURLINGTON, VERMONT

AUGUST 4–10 • Rare Lung Diseases Week
American Thoracic Society
UNITED STATES

AUGUST 25–31 • Scleroderma Week
American Thoracic Society
UNITED STATES

SEPTEMBER 7 • Global Pulmonary Fibrosis Awareness Day
Pulmonary Fibrosis Foundation
WORLDWIDE

SEPTEMBER 7 • Global Pulmonary Fibrosis Awareness Day Patient Event
Pulmonary Fibrosis Foundation
BARCELONA, SPAIN

SEPTEMBER 7–11 • PFF @ ERS Annual Congress
European Respiratory Society
BARCELONA, SPAIN

SEPTEMBER 7 • Support Group Leader Workshop
Respiratory Health Association of Metropolitan Chicago
CHICAGO, ILLINOIS

SEPTEMBER 22 • PFF @ Hike for Lung Health
Respiratory Health Association of Metropolitan Chicago
CHICAGO, ILLINOIS

TEAM PFF EVENTS

ONGOING • Book Proceeds to the PFF ANYWHERE!

ONGOING • Coins for the Pulmonary Fibrosis Foundation ANYWHERE!

ONGOING • Oceans for Julie ANYWHERE!

ONGOING • Paula’s Cards for PFF BLUFFTON, SOUTH CAROLINA

MAY 5 • Lilac Bloomsday Run SPOKANE, WASHINGTON

MAY 11 • Steve Lublin Memorial Golf Scramble ORLANDO, FLORIDA

MAY 15 • Team Jeffery Trivia Night STREAMWOOD, ILLINOIS

MAY 18 • Ogden Marathon OGDEN, UTAH

MAY 26 • TEAM PFF @ MB Financial Bank Bike the Drive 2013 CHICAGO, ILLINOIS

MAY 26 • Buffalo Marathon BUFFALO, NEW YORK

JUNE 1 • Pilot for a Cure Yard Sale WATER MILL, NEW YORK

JUNE 1 • San Diego Century Bicycle Tour SAN DIEGO, CALIFORNIA

JUNE 1 • The Tom Rutledge Memorial 5K BOSSIER CITY, LOUISIANA

JUNE 2 • 4th Annual Routine Run for Pulmonary Fibrosis LOWELL, MASSACHUSETTS

JUNE 2 • Caroline M. Fell 5K Memorial Walk/Run WAKEFIELD, MASSACHUSETTS

JUNE 8 • 1st Annual John Juul Memorial Benefit for the Pulmonary Fibrosis Foundation HIGHWOOD, ILLINOIS

JUNE 9 • 6th Annual Greg Chandler and Guy F. Solimano Memorial Golf Tournament WEBSTER, NEW YORK

JUNE 14 • 3rd Annual Pete DeVito Memorial Golf Outing MT. SINAI, NEW YORK

JUNE 22 • 8th Annual Barbara A. Fiorillo Memorial Bike Run/Picnic WEST MIFFLIN, PENNSYLVANIA

JUNE 30 • Huff-N-Puff Prom-A-Thon 2013 VIRTUAL

JULY 13 • Night at the Old Ball Park FISHKILL, NEW YORK

JULY 14 • New York City Triathlon Support Team Lichty Support Team Mullaney Support Team Nuyttens NEW YORK CITY, NEW YORK

JULY 20 • Door County Sprint Triathlon EGG HARBOR, WISCONSIN

JULY 27 • I Use My Lungs Memorial Run CINCINNATI, OHIO

AUGUST 1 • 6th Annual Benefit Ride in Memory of Joanne Kelley PEPPEREL, MASSACHUSETTS

SEPTEMBER 7 • 4th Annual Willacker Family Pulmonary Fibrosis Golf Outing WHITMORE LAKE, MICHIGAN

SEPTEMBER 13 • Redrock Relay SAINT GEORGE, UTAH

SEPTEMBER 21 • South Haven Triathlon SOUTH HAVEN, MICHIGAN

36 WWW.PULMONARYFIBROSIS.ORG
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WE THANK DANIEL BEREN, ESQ, FOR HIS SERVICE TO THE BOARD AND
HONOR HIM AS A BOARD MEMBER EMERITUS.

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View a current list of events at www.pulmonaryfibrosis.org/eventscalender2013.
register now!

DECEMBER 5–7, 2013 • LA JOLLA, CALIFORNIA

SAVE THESE DATES

Global Pulmonary Fibrosis Awareness Day → September 7
Breathe Benefit 2013 → October 26

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- Participation in PFF advocacy efforts

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