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Action Alert

The Quarterly Publication of the Coalition for Pulmonary Fibrosis

Daughter's Memory Drives Parents to Raise Funding and Awareness for Deadly Lung Disease

2nd Annual Lisa Sandler Spaeth Memorial Golf Tournament held at Woodmont Country Club in Rockville, Maryland

Two years ago, Dr. Jerome and Froma Sandler lost their daughter to the untreatable lung disease they now work to cure. Lisa Sandler Spaeth died from Pulmonary Fibrosis (PF) in 2007, the disease that continues to claim 40,000 lives each year, keeping pace with breast cancer fatalities. The Sandlers celebrated Lisa's life by hosting the second annual Lisa Sandler Spaeth Memorial Golf Tournament on September 14th at Woodmont Country Club in Rockville. Their son, Dr. Glenn Sandler, hosted the night's event and its live auction.

"The loss of our daughter is something we deal with every day and our hope is that by contributing to the search for a cure, we will help other families avoid this terrible tragedy," said Froma Sandler. "By asking the community to help

support the CPF and pulmonary fibrosis research, we honor Lisa's memory while searching for a cure."

The Sandlers are fully dedicated to changing things for patients and families by increasing awareness and funding for the disease. Because awareness of PF is unacceptably low, funding for research in the area is even lower.

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Underwriters Jerry and Froma Sandler, Glenn Sandler, Billie and Steven Sandler

CPF Advocates Hold 60 Meetings With Congress During the National Pulmonary Fibrosis Awareness Week

The CPF held its seventh annual National Pulmonary Fibrosis (PF) Awareness Week and added more than 15 additional Members of Congress as co-sponsors to the first-ever request for a Congressional allocation to fund research on this deadly disease. Currently, there are 60 co-sponsors of the Pulmonary Fibrosis Research Enhancement Act (H.R. 1079) in the U.S. House of Representatives. The bill may lead to work that brings treatments and a cure for the deadly lung disease that claims 40,000 lives a year, the same number lost to breast cancer.

Determined advocates for action on PF, including patients and family members, held 60 meetings on Capitol Hill. For the second year,

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Dear Friends:

“Thank you for all you do” is something we hear from those who have Pulmonary Fibrosis (PF) or who are working to help fight it. We love hearing it, but I am compelled to pass that gratitude back to the PF community.

Until you have been to Capitol Hill with us to see the courage and determination demonstrated by our amazing volunteers, you can't understand the enormity of their commitment. Until you have gone to a regional event and seen how hardworking small groups of caring people have spent weeks after working hours and on weekends marking out the details of a local event meant to raise funds to save future patients, you can't know how generous their hearts are. Until you attend a support group where patients, no matter how ill or weak, show up to help one another get through another month, you can't know how deep is their concern for one another.

Then there are the researchers. It's heartwarming to meet with some of the younger researchers who describe their excitement about working in one of the toughest areas of research because a discovery could change the future for PF patients in a remarkable way. Their dedication to this particular branch of research is desperately important and they stick with it despite the other, less challenging, research pathways for other diseases, where success might be far more easily obtained.

As we approach the season where we all stop to look back at the year past, I want to take a moment to do that here. In September, I saw two of our advocates, who are also patients, run around congressional office buildings keeping the same rigorous meeting schedule as the rest of us despite their fatigue and the effort that was required. Thank you for that sacrifice – it made all the difference. The same thanks needs to go to the other advocates who have watched their loved ones die from PF, or are witnessing it now, but who can overcome their grief enough to make the case to those in power.

We have had generous volunteers put together events to raise money because they know that without these funds, there would be no national effort, no advocacy, no patient support and no push on research. The time and energy and the emotion that goes into creating these events and seeing them through is considerable. We appreciate that they raise money but we also love that they develop new strength and, of course, that they raise awareness.

We were the fortunate recipients of a generous estate gift this year - \$100,000 from Joe Atchison, a patient with whom we had contact by phone only. Joe made a decision to continue to empower our work after he was gone and that impacts everyone touched by the disease. You can't hear us, Joe, but we are so grateful that you remembered all those waiting for a cure.

The CPF will continue to rely on its incredible supporters and volunteers help make it all happen.

If you are not yet working with us, please consider doing so. You will make a difference and earn the gratitude of untold thousands.

Best wishes,

Mishka Michon, CEO
Coalition for Pulmonary Fibrosis



Education. Support. Hope.

Continued from cover.

advocates focused on securing support for passage of H.R. 1079 and continued to raise awareness of PF issues to Members of Congress and in communities nationwide. The majority of the Capitol Hill meetings took place with Members who serve on the Energy & Commerce committee and subcommittee on health. The Energy & Commerce committee has jurisdiction for the PFREA.

“It was great to be on the Hill again this year for many reasons,” said Liz Darcy, a PF patient and mother of four adult children, two of whom joined her on the Hill. “I’m happy to still be alive and I’m thankful to be able to help further this cause and ask for support of H.R. 1079.” Darcy, who is awaiting a lung transplant, has been to Capitol Hill four years in a row. This year, her condition has further declined, forcing her to wear supplemental oxygen and slowed her progress through the halls of Congress. Fewer than 500 patients a year with PF receive the only known way to survive the disease – a lung transplant.

The CPF staff and advocates also met with their champions, Congressman Brian Baird (D-WA) and Congressman Mike Castle (R-DE) who introduced H.R. 1079. They stressed the bipartisan nature of the historic legislation that would authorize \$16 million in new federal funding to create the first national patient registry for PF, and provide much needed support for research into the deadly lung disease. Both Congressmen have lost members of their families to PF.



Congressman Brian Baird and Mishka Michon discuss the importance of PF advocacy as Dr. Jerry Sandler looks on.



National PF Awareness Week advocates and CPF staff with Reps. Castle and Baird

*CPF Advocates, Left to Right (back row): Paul Fogelberg, Dr. Jerry Sandler, Michelle McBride Campbell, Rep. Mike Castle, Olivia Kurtz (Rep. Castle’s health legislative assistant), Mishka Michon, Rep. Brian Baird, Jamal Abdi (Rep. Baird’s health legislative assistant)
Left to Right (front row): Teresa Barnes, Dolly Kervitsky, Amy Leggett, Joy McBride, Cynthia Fishman, Su Hwang, Annette Freytag, Rebecca Leggett*

“We are pleased to have such strong leadership on the bill and are working to increase momentum to soon gain passage of the Pulmonary Fibrosis Research Enhancement Act,” said Mishka Michon, CPF Chief Executive Officer.

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

More Help Needed to Pass the Pulmonary Fibrosis Research Enhancement Act

More than 15 Members of Congress signed on to the Pulmonary Fibrosis Research Enhancement Act (H.R. 1079) during and after PF Week bringing the total number of co-sponsors to 60. And the momentum is growing! **We need your help now to add even more members to the bill!** We need 100 Members on the bill to help it reach the floor of Congress. Please call or email your Member of Congress now! Your hard work has brought us great success - we urgently need our members to take action once again to get us closer to our goal! Please check to see if your Representative is a co-sponsor (see list below) and either thank them or directly request that they co-sponsor H.R. 1079. If you've called them before and they are still not on the bill, please call again.

Members of Congress Signed onto H.R. 1079 (as of publication date) and the dates they signed on!

Rep Bishop, Rob [UT-1] - 10/1/2009	Rep Loeb sack, David [IA-2] - 10/22/2009
Rep Blackburn, Marsha [TN-7] - 7/31/2009	Rep Lofgren, Zoe [CA-16] - 2/13/2009
Rep Boccieri, John A. [OH-16] - 5/6/2009	Rep Marshall, Jim [GA-8] - 4/27/2009
Rep Boozman, John [AR-3] - 9/10/2009	Rep McCotter, Thaddeus G. [MI-11] - 9/10/2009
Rep Boren, Dan [OK-2] - 3/11/2009	Rep McGovern, James P. [MA-3] - 4/27/2009
Rep Braley, Bruce L. [IA-1] - 10/22/2009	Rep Minnick, Walter [ID-1] - 5/6/2009
Rep Burgess, Michael C. [TX-26] - 6/12/2009	Rep Moran, James P. [VA-8] - 3/11/2009
Rep Cardoza, Dennis A. [CA-18] - 7/21/2009	Rep Murphy, Christopher S. [CT-5] - 9/17/2009
Rep Castle, Michael N. [DE] - 2/13/2009	Rep Napolitano, Grace F. [CA-38] - 5/6/2009
Rep Deal, Nathan [GA-9] - 2/13/2009	Rep Pascrell, Bill, Jr. [NJ-8] - 4/27/2009
Rep DeFazio, Peter A. [OR-4] - 7/21/2009	Rep Paulsen, Erik [MN-3] - 9/17/2009
Rep DeGette, Diana [CO-1] - 9/25/2009	Rep Pitts, Joseph R. [PA-16] - 9/22/2009
Rep Diaz-Balart, Lincoln [FL-21] - 9/17/2009	Rep Platts, Todd Russell [PA-19] - 6/12/2009
Rep Dicks, Norman D. [WA-6] - 2/13/2009	Rep Price, David E. [NC-4] - 5/20/2009
Rep Ellison, Keith [MN-5] - 10/6/2009	Rep Rogers, Mike D. [AL-3] - 9/17/2009
Rep Frank, Barney [MA-4] - 9/17/2009	Rep Roybal-Allard, Lucille [CA-34] - 9/17/2009
Rep Gallegly, Elton [CA-24] - 9/10/2009	Rep Sarbanes, John P. [MD-3] - 3/26/2009
Rep Gerlach, Jim [PA-6] - 2/13/2009	Rep Scalise, Steve [LA-1] - 10/6/2009
Rep Goodlatte, Bob [VA-6] - 3/11/2009	Rep Schakowsky, Janice D. [IL-9] - 9/22/2009
Rep Gordon, Bart [TN-6] - 3/26/2009	Rep Schiff, Adam B. [CA-29] - 10/6/2009
Rep Green, Gene [TX-29] - 9/17/2009	Rep Sestak, Joe [PA-7] - 6/12/2009
Rep Hall, John J. [NY-19] - 5/6/2009	Rep Sherman, Brad [CA-27] - 7/30/2009
Rep Harman, Jane [CA-36] - 2/13/2009	Rep Simpson, Michael K. [ID-2] - 9/10/2009
Rep Harper, Gregg [MS-3] - 5/6/2009	Rep Space, Zachary T. [OH-18] - 2/13/2009
Rep Jones, Walter B., Jr. [NC-3] - 9/10/2009	Rep Tierney, John F. [MA-6] - 2/13/2009
Rep Kaptur, Marcy [OH-9] - 2/13/2009	Rep Towns, Edolphus [NY-10] - 10/6/2009
Rep Kirk, Mark Steven [IL-10] - 2/13/2009	Rep Van Hollen, Chris [MD-8] - 9/10/2009
Rep Kosmas, Suzanne M. [FL-24] - 10/13/2009	Rep Welch, Peter [VT] - 5/20/2009
Rep Latham, Tom [IA-4] - 3/26/2009	Rep Wolf, Frank R. [VA-10] - 3/11/2009
Rep LaTourette, Steven C. [OH-14] - 2/13/2009	Rep Young, C.W. Bill [FL-10] - 2/13/2009

Please help us build on the momentum created by PF Week — Call or email your Member of Congress now! Your member may have joined since publication – for the most current list check this website: <http://thomas.loc.gov/> and type “H.R. 1079” in the search box. Then, click the radio button labeled “bill number” and hit “search.” You will come to a brief description of the bill and blue font that says “Co-Sponsors.”

CPF Submits Comments to CMS to Save Only Effective Therapy Available to PF Patients

Proposed Medicare Ruling Would End Pulmonary Rehab for Thousands of Patients

Today, pulmonary fibrosis (PF) patient Ellen Foley went to the pulmonary rehabilitation (rehab) program near her home in Middlesex, N.C. At the same time, the Coalition for Pulmonary Fibrosis (CPF) took a stand for her and thousands of patients like her. Soon, Foley may not be able to go to therapy if the Centers for Medicare and Medicaid Services (CMS) are successful in pushing forward a proposed ruling regarding pulmonary rehabilitation coverage that would limit coverage and eliminate patients with diseases like Foley's.

The CMS proposed ruling states "because there is not data to substantiate significantly improved outcomes for any other medical conditions, we are proposing to allow moderate to severe COPD as the only covered condition." There is, in fact, substantial evidence that there is significant benefit to PF patients and patients with other respiratory diseases.

The proposed ruling can be viewed at www.regulations.gov and is file code CMS-1413-P. The docket title is "Medicare Program; Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2010."

With patients like Foley in mind, the CPF submitted comments to combat the CMS proposal. "This is a case study in the challenges representative of patients fighting

rare diseases like PF. Namely, that healthcare coverage for those with rare diseases like PF is materially and negatively impacted largely due to the size of its patient population, a lack of awareness of the benefits of cardiac and pulmonary rehabilitation on these patients, and, frankly, the increased attention typically afforded diseases of higher prevalence, such as COPD, in Federal programs," said the CPF in its comments.

"I need my pulmonary rehab program," said patient Ellen Foley who has less than 50 percent lung capacity remaining. "It has helped me breathe better and helps me try to stay ahead of my disease. Even though I know my PF is getting worse, by going to pulmonary rehab, I can make the most of the lung function I have left."

Although Congress passed a national coverage policy for pulmonary rehab earlier this year that was designed to include patients with PF and other lethal or chronic lung diseases, CMS threatens to prevent them from receiving the benefit that Congress worked to provide. Patients and experts worry that private insurance payers will follow suit and no coverage for pulmonary rehab will be available for the majority of patients who suffer from deadly lung diseases like PF. The only disease CMS plans to cover, under the proposed ruling, would be Chronic Obstructive Pulmonary Disease (COPD); and even

COPD is being negatively affected by the ruling that plans to limit its coverage to basically only end stage patients.

"We are stunned that CMS would propose such a sweeping and negatively impacting ruling that harms so many patients. We hope that they will thoroughly review our comments and the more than 2,000 that have been submitted to them by concerned medical professionals and patient groups nationwide," said Mishka Michon, Chief Executive Officer of the CPF. "Then, it is hoped that CMS will reconsider its position and provide coverage for the many types of patients who need and deserve it."

The CPF also joined with those of other patient groups as part of the American Thoracic Society's (ATS) Public Advisory Roundtable (PAR) to make collective comment.

PF patients are referred by their physicians to pulmonary rehab for medically supervised exercise and therapy designed to preserve some of their lung capacity, help their bodies avoid infections and sustain or improve, for as long as possible, their quality of life.



Familial Pulmonary Fibrosis Counseling Service

The CPF and National Jewish Medical Center (Denver, CO) have launched the first genetic counseling program for patients and families affected by familial pulmonary fibrosis (FPF).

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

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

I am behind CPF in any way possible. My father-in-law was diagnosed with PF and it took his life a few weeks later. This absolutely shattered our family. And even more so when we found out he had the disease for years without anyone knowing. It was then I realized that anything I can do help create awareness, help further advancement in searching for a cure, and help educate people about this commonly misdiagnosed disease, I will do it, and that to me was working with the CPF because this is what they do.

— James Marsden, Actor

Considering Making a Charitable Gift of Stock? It's as Easy as Picking Up the Phone!

The CPF can accept charitable gifts of marketable securities through our financial advisors at Morgan Stanley. The gift of a financial instrument (stocks or bonds) allows you to make a gift for the full value of the instrument without incurring any transaction costs or recognizing any taxable gain- and apply that value in the preparation of their tax planning. Restricted stock gifts can also be accepted by the CPF taking custody of "Rule 144" restricted securities, and process the legend removal and sale of those securities with the same results as described above (or private equity until such time as there is a monetization event).

If you are considering a gift of securities as part of your year-end financial planning please contact, or have your financial advisor contact, the CPF's Mishka Michon at (888) 222-8541.



Patient Hosts Golf Event to Fund Cure for Disease that May Claim Her Life

Sandy Bennett Golf Event held at Wedgefield Golf Course in Orlando on Nov. 7

An Orlando Pulmonary Fibrosis (PF) patient held a golf event to raise awareness and funding to fight the disease that threatens to kill her. Sandy Bennett of Orlando hosted the event on November 7 at the Wedgefield Golf Course in Orlando to raise funds and awareness for PF, a deadly lung disease that is irreversible, relentless and suffocates its victims.

Bennett, 69, is working to raise funds to assist the Coalition for Pulmonary Fibrosis (CPF), in its ongoing work to help patients and families fighting the disease and in funding research to find a treatment and a cure (www.coalitionforpf.org).

"I'd been told that I do not qualify for a lung transplant and that there is no treatment and no cure for pulmonary fibrosis," said Sandy Bennett, PF patient and chairperson for the Sandy Bennett Golf Event. "The only hope for me and more than 128,000 other people is through the CPF with efforts to increase awareness and research."

Bennett, like most other Americans, had never heard of PF until she got the devastating diagnosis, although the disease carries with it a fate worse than most cancers. "I was astonished to learn how deadly the disease is and yet the awareness and attention for it was so low. My family had to get educated and now we are working to educate others and recruit them in this fight."

Sandy has learned, through her conversations with the CPF, that she was not alone in being shocked by her diagnosis – that the disease is largely unknown to the general public. She feels compelled to try and increase awareness of the disease so that there won't be thousands of others like her who are completely uninformed that PF might strike. Her regional event will help

inform another community about the truth of the disease. Because there are no survivors, this education process is in part up to patients and caregivers. And, by taking a stand, patients like Sandy reclaim some power over the disease.

"We are so grateful to Sandy for her heroic efforts. She is helping to bring much needed funding and awareness to a disease that has claimed too many lives and threatens thousands more. With her help, we can find desperately needed treatments," said Mishka Michon, Chief Executive Officer of the Coalition for Pulmonary Fibrosis. "Hopefully, they will come in time to help Sandy."

The golf event was Captain's Choice and Four Person Scramble, and includes lunch, awards for the top three and last place, and special raffle prizes. For any questions on this or other events, you may contact the CPF at (888) 222-8541 or www.coalitionforpf.org.

I support the efforts of the Coalition as they work for a better future for all PF patients. I am one of these patients. As a former Governor, I know that it takes a united effort to bring change. The Coalition is working for all of us to bring about that change, through education, a registry and research. I fully endorse this campaign for funding their vital work.

— *Olene Walker, former Governor of Utah*

Pulmonary Fibrosis Patient Leaves Legacy and Creates Endowment

Gene Dudley spent his life making the world a better place and his legacy gift to the CPF will ensure his efforts will continue. Gene was diagnosed with PF in January 2006 and he maintained a positive focus even though he knew his time would be short. He and his best friend and life partner, Dr. Richard Lieboff, decided to make a gift of a major endowment of \$100,000 to the CPF. Gene died in May at the age of 64. Dr. Lieboff sat down recently with the CPF's Mishka Michon to discuss Gene's illness and what they learned that may help other patients and caregivers.

How did you deal with the news that Gene had a fatal disease?

We first realized that the situation for Gene was closed-ended when we realized that the doctor was offering us very few options. The doctor made it clear that there wasn't anything that could be done to alter the course yet. Gene was philosophical about that – he decided to just keep on with whatever he could and not let the disease control what he would do with his time. A lung transplant was considered, but Gene had too many contraindications. As he got worse, his activities were more curtailed, but he never just sat still to await his fate – he kept on living.

What did you two do to help him make the most of his time?

One of the most important things I made certain to do was to hold a celebration of his life for him while he was still relatively healthy. It was my 60th birthday and, strangely, since I was born on 9/11, also a 5-year anniversary of that event... and a chance to bring all of our friends to the house to regale Gene while he was around instead of waiting until after he was gone. That was

one of the most important decisions we made. I would say that if I were to do it again, we could have looked at a wish list to see if there were any opportunities we should grab, like a trip somewhere. But we continued to go out to our house in the desert, lugging his oxygen, because he did not want to give up the pleasure of those excursions. Gene loved the desert and it provided a wonderful alternative to airplane trips that were not very feasible.

How would you describe Gene's mood through most of this?

He was not self-conscious about being sick, or the oxygen or any of it. He did not get depressed but instead faced it head-on. He did not expect any special consideration because he wasn't well. There's no question that the portable oxygen equipment helped him keep doing what he always did and until he needed a tank, he was not house-bound at all. But we dragged the tanks and concentrator out to the desert as well – he wasn't going to be deterred by that one factor.

How did Gene handle the last days?

It was also Gene's style to not think of the end of his life. He continued to make decisions regarding our finances and house, pay bills and whatever was needed, as though he had all the time in the world. Until his very last month, he was not in particularly bad shape, so he did not have to fight to get through the day. We did not know what to expect as time wore on, but it was not really tough going for most of the time. In addition, he had our cat Tibo (aka Beau) often by his side. You just knew Beau understood what was happening and stayed with Gene.

Do you think anything you two did helped him stay as centered as he did?

What I think was key was that we maintained an ongoing dialogue about what was happening. We didn't hide from it and he stayed in touch with the world, his friends, his regular life, so that he would not be isolated by the illness. Every holiday was celebrated as though things were just as they always were. We also kept researching PF information just to stay on top of things and see

if there were suggestions on how to deal with various issues that came up.

Did you take away any lessons about dealing with illness and the health care system?

Our physicians and ancillary medical personnel did not seem terribly well equipped to handle this disease, at least that's how it seemed... and we didn't get much support from them on how to deal with this. So I would counsel everyone to be their own advocate, do research, call the CPF, ask for second opinions, just take over the reins. And if there is a support group anywhere around, it's really important to go. The few times we went, we learned a lot and I was sorry we didn't have one nearby so that we could share our story and maybe help others with information we had gathered.

Were there complicating factors or challenges you had to work around?

Really, the only concrete challenge was working with the medical equipment supply company responsible for delivering oxygen and other durable medical equipment. I would expect many families have to figure what works best for them. You need to be assertive.

What were some decisions that helped make things easier?

We had already decided that Gene would never go to a facility and Kaiser's hospice service was everything we could ask for. A nurse visited once a week and

often twice a week towards the end. He had hospice for 9 months and we felt very comfortable that we could get what we needed through them. There was never any discussion about his ending up hospitalized or in any sort of nursing home. I realize that it was only because hospice was available that we were able to handle this so well. And Gene had always been philanthropic, so we set about establishing early on the shape of his legacy and how it would benefit others, which is a comforting factor.

If it's not too difficult a question, how was his last month or week?

He was really okay until the last month when he had very little appetite and then we did need more medicines to improve his breathing and to make him comfortable. But it was a relatively short period of time and the only challenge was for me to be sure and be with him as much as possible or arrange for others to be there. Since he now had limited mobility, that meant staying in the room with him and eating our meals at a bridge table, but that was not a sacrifice for me. As his breathing became more labored, we increased his medication, but even with that, he always knew I was there for him. For that I am eternally grateful.

Why did Gene choose to give such a wonderful legacy gift to the CPF?

We were both always philanthropic and one of his objectives was to do something for others suffering from PF. He couldn't think of anything better than to possibly help get the word out about the disease and he was impressed with the CPF's work and with the team. The lack of awareness of PF is something he wanted to change and if his fund will help get the word out, he will have accomplished his goal. His greatest wish would be for others to follow his example.

What did the CPF mean to you and Gene?

Every cause needs an advocacy organization. We were just so grateful that someone was out there fighting for the patients and making the right connections to get things moving. Both of us having been government employees, we knew too well how bureaucracies worked. With CPF, it was very reassuring to know that we could always make contact with someone there – it took away the sense of isolation that you might have if you were trying to make sense of PF without any help.



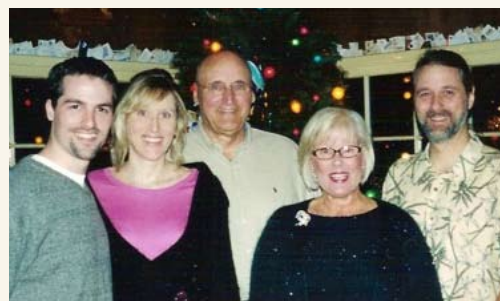
Dr. Richard Lieboff and Gene Dudley

First Annual ED'S WALK for Pulmonary Fibrosis is a Success

On a cool Sunday morning in Mission Viejo, Orange County, California, the sun broke through the clouds just as more than 110 people began their 5K walk to celebrate the life of Edward V. Kohout, Jr.

Ed's widow Bette and their children, Liz and Ed, hosted this first annual walk to generate awareness of PF. The group raised more than \$10,000 for the CPF at their inaugural ED'S WALK. A tribute was paid to Mr. Kohout, and in attendance were members of other families who have been dealing with PF. "We will grow together. We will work together to help those who have lost love ones, those who are dealing with the disease on a daily basis and those who still have yet to be diagnosed," said Bette Kohout. "We all know how urgently a cure is needed. This work will not be easy, but it will be a labor of love."

Mrs. Kohout is already making plans for a 2010 event. It will be held on the first Sunday in October 3, 2010. More information on the recent walk and next year's walk is available at <http://edswalk.org>



The Kohout Family

2009 Butterfly Golf Challenge

This fall the CPF and some of its volunteers are working as a team to help raise the funds needed to ensure the ongoing work of the organization. The special campaign, launched in mid-October, is the CPF's first-ever challenge campaign. Members are being asked to make a special fall gift to match the dollar amount raised by the Lisa Sandler Spaeth Golf event in Maryland in September. The hope is that the example set by the golf event, which raised \$200,000, will be seen as a funding "par" and concerned supporters across the country will help the CPF maintain that par via its Butterfly golf campaign. In the packet going out to all members is an outline of what the dollars can do for this important work.

We ask all our members to please step up for this campaign. With all the exciting promise of our legislative efforts, our burgeoning support group program, the huge growth in our membership and the need to bring awareness to the public about PF, all of our efforts must not only continue but increase. Success in fighting PF relies in large part on how much is invested in the struggle. Thank you for considering helping us win!

Please consider creating a fundraising page on www.firstgiving/coalitionforpf.org to help with the Challenge!

Continued from cover

The Lisa Sandler-Spaeth tournament is one way the Sandlers support the efforts of the CPF to find answers. To date, the Sandlers have raised nearly a half million dollars for the CPF.

The day after the golf tournament, Dr. and Mrs. Sandler were back on Capitol Hill for their second year, advocating for the passage of the Pulmonary Fibrosis Research Enhancement Act. They shared their personal story about the impact PF had on their daughter and all those in her life with Congressional leaders. The Sandlers have reached out whenever and wherever possible to advance the CPF's cause and their efforts have helped increase the number of congressional co-sponsors of H.R. 1079.

Dr. and Mrs. Sandler are such great role models for this cause. Their dedication to increasing the dollars available for this struggle is impressive. With their help, we will find desperately needed treatments.

— Mishka Michon, Chief Executive Officer of the CPF.



Kent Cacey – Golf Professional, Keynote Speaker and PF Patient

Special thanks goes to key sponsors of the golf event:

UNDERWRITERS

Ginny and Irwin Edlavitch
Froma and Jerry Sandler
Billie and Steven Sandler
Glenn Sandler

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Underwriters Erwin and Ginny Edlavitch



120 Golfers in the Mega Putt Contest

Prior to the Labor Day Muscular Dystrophy Association Telethon, the CPF sent out a press release to let others know about the connection Jerry Lewis shares with PF patients – he’s one of them. He has disclosed publicly that he has the disease and has lived longer, post diagnosis, than many other PF patients. Mr. Lewis could be a powerful voice in the effort to raise awareness of the devastating disease that affects so many Americans, including him.

The Show Goes on for Pulmonary Fibrosis Patient Jerry Lewis

His Longevity with the Deadly Disease Inspires Thousands of Dying Patients

When Jerry Lewis took the stage again on Labor Day 2009 for the Muscular Dystrophy Association Telethon, thousands of people who suffer from the same lung disease as he does were watching – and not just to hear the funny things he said. They were looking for inspiration from the funny man who suffers from a not-so-funny and little known fatal lung disease.

Lewis disclosed several years ago that he has Pulmonary Fibrosis (PF). PF patients have expressed their hope that he would take up the cause for that disease, one that is barely known by much of the public and is in desperate need of increased research funding to find ways to find treatments.

The CPF recognizes, of course, that Mr. Lewis has tirelessly devoted several decades to actively seeking a cure for Muscular Dystrophy, and we applaud him heartily for this. Together with our wishing him great success, and long life, we also hope that he’ll soon raise his formidable and respected voice to address PF, and its challenges and needs.

He’s been very fortunate” said patient Ellen Foley. “There is no FDA approved treatment for this disease and many of us are going downhill very quickly. He doesn’t seem to

be and I’m really happy for him. As for me, I’m on supplemental oxygen 24-hours-a-day.”

Lewis has spoken many times publicly about his disease but has not taken a public position on the need for research. The Coalition for Pulmonary Fibrosis (CPF) knows that celebrity attention to a disease can generate a huge increase in awareness and make a difference for hundreds of thousands of people who are and will soon be affected by PF.

“A celebrity voice could change the future for thousands of patients by bringing much-needed attention to the cause,” said Mishka Michon, the Chief Executive Officer for the CPF. “So many celebrities haven’t lived long enough with the disease to make their voices heard before they died, like Robert Goulet, Marlon Brando and Odette. We would see a huge shift in attention to PF with the help of someone with such visibility.”

One of the challenges faced by rare diseases is getting the attention of the public, including the media, on PF, even though the number of annual fatalities from PF is so dramatic. No major national media coverage to date has been known to focus on the disease that threatens the lives of all Americans and claims

40,000 lives a year – the same number as breast cancer.

As the Chairman of the Board for the CPF and to PF pulmonologist from the University of Denver, Colorado has stated about awareness, “We need to make sure that people understand that everyone is at risk for the disease. We don’t know what causes it, we don’t know how to stop it and we don’t know what to do to prevent it. Much more research is needed to find the answers we’ve been seeking for years and so urgently need.



Entertainer Jerry Lewis speaks during the 44th annual Labor Day Telethon to benefit the Muscular Dystrophy Association at the South Point Hotel & Casino September 6, 2009 in Las Vegas, Nevada. Photo taken from www.zimbio.com/pictures

Roe Williams Personal Campaign for Change

“To be suddenly robbed of your ability to BREATHE naturally is frightening! Something I took for granted for many years was my ability to walk quickly on the boardwalk, climb any mountain I chose, play any sport that I wanted, run just for the fun of it with my sons and now my grandsons and last but not least, dance the jitterbug with my hubby. This is what Pulmonary Fibrosis (PF) does. I am one of the lucky ones. Only in the

past year of a five year battle with this disease have I had to give up all of the above. Finding the cause of this disease through research and hopefully a cure through funding would be the ultimate gift that we could give to the 128,000 afflicted with PF and the 48,000 that join our club each year.”

On Friday, September 18, 2009, Roe, Brett, Mark, and Charlie Williams hosted a wonderful golf event in Mays Landing, NJ. Over 120 guests gathered to celebrate Roe, who is suffering from PF but who wanted to challenge the disease that is taking her life by sharing the day with her friends. Her guests enjoyed a pre-game lunch, 18 holes of golf, dinner and prizes. At this first-ever event hosted by the Williams family, they successfully raised over \$10,000 to benefit the CPF’s work to changing the future for patients.

New NIH Branch Will Study Rare Diseases

A unique new institute will look for ways to treat rare and neglected diseases and take the first and riskiest steps toward bringing new drugs to market, U.S. health officials said on Wednesday.

Congress has provided \$24 million a year for five years to start the Therapeutics for Rare and Neglected Diseases Program, or TRND at the National Institutes of Health, acting NIH director Dr. Raynard Kington told reporters in a telephone briefing. The program will use taxpayer money to get drugs through the most costly and dangerous phase of development, known as the “Valley of Death” because so many fail there. It will publish details of failures as well as successes to guide other researchers, the NIH said. “Twenty-five to 30 million Americans suffer from rare or neglected diseases,” Kington said.

A rare disease is one that affects fewer than 200,000 Americans, and NIH estimates there are about 6,800 of these conditions, ranging from

multiple symmetric lipomatosis or Madelung’s disease, characterized by large fat deposits around the neck and nervous system abnormalities, to pseudomyxoma peritonei, in which tumor cells swell up the abdomen. [Pulmonary Fibrosis is considered a rare disease]. Only about 200 of these conditions, many of which affect fewer than a dozen people, have treatments.

“We don’t know yet exactly which diseases this program will take on,” Dr. Alan Guttmacher, acting director of the National Human Genome Research Institute, told the briefing.

He said the new institute would be opportunistic, pouncing on promising research studies, some of which may be funded by advocacy groups for rare diseases.

Often drug companies are afraid to take on this work, Guttmacher added. “Getting a promising chemical through the pre-clinical stages of drug development is fraught with failure,” Guttmacher said.

“It is colloquially called the “Valley of Death.” This stage of drug development can take two to four years of work, costs tens of millions of dollars,” and still fail, he added.

90 PERCENT FAILURE

The NIH estimates that up to 90 percent of all potential drugs fail to make it from the lab into human volunteers for safety testing.

The group will publish details even of failures — something that rarely happens in the world of medical publishing now and a focus that can sometimes lead researchers to cover up or minimize dangers.

“We are going to tell everyone what we are doing,” said Dr. Christopher Austin of the NIH Chemical Genomics Center. “That alone will be revolutionary.” Early-stage research is often considered proprietary by companies.

Source: Reuters, 5/21/09, by Maggie Fox; content shortened for space

IPF Research Network Program Director Presents to CPF Advocates During National PF Awareness Week, Says “The Future is Here”

The National Heart, Lung, Blood Institute’s (NHLBI) IPF Research Network (IPFNet) Program Director joined CPF advocates during National PF Awareness Week in D.C. in Washington D.C. for a morning meeting. Herbert Reynolds, M.D., shared information about NIH programs, current and future studies, as well as the progress being made in PF through the IPFNet. “The future is here,” Dr. Reynolds said.

Dr. Reynolds explained the first IPFNet study, called *STEP*, on sildenafil (under the commercial name Viagra), completed in June and its results will be presented at the annual meeting of the American Thoracic Society in May 2010. The second study, known as the *PANTHER* trial, will look at current therapies including Prednisone, Azothiaprine and the supplement, N-Acetyl Cysteine (NAC), to see if there is therapeutic benefit to the drugs or combination therapies. “NAC has to be studied. Does it have an impact on PF or is it fighting drug side effects?” Dr. Reynolds asked the group. The study, he says, is nearing its start and a third study will soon begin, as well. Called the *ACE* trial, it will review the use of the anticoagulant therapy, Warfarin, as a potential treatment for PF.

One of the spin-offs of clinical trials in which the patients are well characterized [define], is that they spark a lot of interest in research, Dr. Reynolds said. They also attract young researchers. “The future is here,” Dr. Reynolds said. “Young investigators are funded off of some of these [IPFNet] dollars and that is the future for PF.”

New Research Study for Patients with IPF

Researchers at the University of California at San Francisco (UCSF) are studying the role of microaspiration in patients with idiopathic pulmonary fibrosis (IPF). Microaspiration occurs when stomach fluid travels up the esophagus and abnormally enters the lungs without the patient recognizing it. Some studies suggest that microaspiration may be involved in causing IPF or in the progression of IPF. This study aims to diagnose microaspiration in patients with idiopathic pulmonary fibrosis and identify conditions that are associated with microaspiration. All patients with a diagnosis of idiopathic pulmonary fibrosis will be considered for this study. Patients must also be able to make three visits to UCSF (these visits can be coordinated with clinical visits to see the doctor). Subjects will be paid up to \$400 for their participation in this study.

For more information, please contact Jane Berkeley, Study Coordinator, at (415) 353-1071 or email: jane.berkeley@ucsf.edu.

Study Finds Certain Protein Levels Significantly Higher in PF Patients

A recent study published in *Respiratory Research* shows PF patients have significantly higher levels of two chemokines, or protein cell families, than patients with collagen vascular diseases and healthy individuals. The study also found there was significant correlation between levels of macrophage-derived chemokine (CCL22) and thymus activation-regulated chemokine (CCL17).

The researchers examined the expression of a specific receptor for CCL22 and CCL17, CCR4, in bronchoalveolar lavage (BAL) fluid cells as well as the levels of CCL22 and CCL17.

The researchers concluded that locally overexpressed CCL22 may induce lung dysfunction through recruitment and activation of CCR4-positive alveolar macrophages.

Source: Respiratory Research 2009, 10:80

Save the Date: B.I.G. Ball – Carle Place, New York Friday, February 26, 2010



To learn more about the event or for sponsorship opportunities, please visit www.coalitionforpf.org

Newly Developed Sphere Helps Understand Two Types of Lung Cells

Using animal and human cells, Duke University Medical Center scientists have demonstrated that a single lung cell can become one of two very different types of airway cells, which could lead to a better understanding of lung diseases.

From this single “basal” cell, a small, squat stem cell that divides to replenish the lung lining layer, scientists created 3-D hollow spheres that were lined inside with both ciliary and secretory cells. This 3-D model can be used to study dynamic processes underlying lung diseases, including cancer, said Brigid Hogan, Ph.D., chair of the

Duke Department of Cell Biology and senior researcher of the study.

“Now that we have this 3-D model and information about the gene expression ‘signature’ of basal cells, we are in a strong position to see what happens when lung-cell behavior goes awry,” Hogan said. “We might, for example, be able to activate an oncogene (a cancer-causing gene) or other factors to see how lung cancer might develop in the airways. Amazingly, almost nothing is known about lung basal cells, which are so important to health and make up nearly a third of the cells in the human airways.”

Normally, basal stem cells maintain the airways by turning over slowly into new ciliated cells and secretory cells. Ciliated cells resemble waving brooms that sweep along particles and distribute secretions that are needed in the airways, and secretory cells provide the antibacterial and lubricating secretions. These two types of cells are neatly arranged in equal proportions in healthy lung airways. However, when lungs are affected by maladies like cancer, chemical damage, cystic fibrosis or asthma, the balance of these cells can be thrown off.

Source: Duke University Medical Center; article shortened for space

Researcher Dr. Brigid Hogan, of the Duke Department of Cell Biology, developed a spheric 3-D model that can be used to study lung diseases. The CPF recently asked Dr. Hogan about the implications this new tool might have for PF research. She also shared with us news that a clinical fellow with a major interest in PF will soon join her lab.

With her [new fellow] enthusiastic input I will be learning more and extending my basic research in that direction. One of the directions I think will be important is to extend our 3D sphere assay to discover new ways in which epithelial cells in the delicate air sacs of the lung interact with the surrounding mesenchyme - the connective tissue and blood vessels that probably produce the fibrotic material that causes such terrible clinical problems. We think that the epithelial cells and the mesenchyme normally “talk” to each other and that this “conversation” goes badly wrong in pulmonary fibrosis so that the mesenchyme cells go awry. But precisely what molecular signals are involved is not known.

— Dr. Brigid Hogan

Blood Biomarker Spots At-Risk Pulmonary Fibrosis Patients α -defensin Levels Found Higher in Patients with Exacerbations Versus Stable Disease

A newly discovered blood biomarker could help clinicians identify patients with idiopathic pulmonary fibrosis (IPF) who are at risk for acute exacerbations, according to a study in the July 15 issue of the *American Journal of Respiratory and Critical Care Medicine*.

Kazuhisa Konishi, M.D., of the University of Pittsburgh School of Medicine, and colleagues extracted ribonucleic acid from 23 patients with stable IPF, eight patients with acute exacerbations (IPF-AEx), and 15 patients with normal lungs. The investigators analyzed gene activity profiles for the three groups to determine the signature gene expression for IPF-AEx compared to stable disease.

Though gene expression in IPF and IPF-AEx were similar for the genes that distinguished diseased lungs from normal lungs, the investigators identified 579 genes that were expressed differently in patients with stable disease and those with

acute exacerbations. In particular, the investigators discerned high activity in the CCNA2 gene, as well as high plasma levels of a protein called α -defensin, in patients undergoing an exacerbation, making it a possible biomarker in a blood test to identify patients at risk for sudden lung function deterioration.

"Our results indicate that IPF-AEx is characterized by enhanced epithelial injury and proliferation, as reflected by increases in CCNA2 and α -defensins and apoptosis of epithelium. The concomitant increase in α -defensins in the peripheral blood and lungs may suggest their use as biomarkers for this disorder," the authors conclude.

Three of the investigators are involved in a patent application for the use of peripheral blood proteins as disease biomarkers, and another has received study grants from pharmaceutical companies.

Source: HealthDay

Patients with Interstitial Lung Disease Need Not Avoid Air Travel

Patients with interstitial lung disease (ILD), of which PF is one, are often concerned about the occurrence of pneumothorax (collapsed lung) or other life-threatening events during air travel. However, new research shows that, even in ILD with a high prevalence of spontaneous pneumothorax, such as lymphangiomyomatosis (LAM), there is a relatively low risk of these events occurring. Researchers from the National Institutes of Health reviewed records and imaging studies of 449 patients with sarcoidosis, idiopathic pulmonary fibrosis, and LAM, who made a total of 816 trips by airplane and 416 trips by land. Results showed that the frequency of pneumothorax in patients with LAM was 2.9 percent in those who traveled by airplane and 1.3 percent in those who traveled by ground transportation. No patients with IPF or sarcoidosis had a new pneumothorax while traveling. Researchers conclude that, in patients with LAM, the presence of pneumothorax associated with air travel may be related to the high incidence of pneumothorax from the disease itself and not to travel. This article is published in the September issue of CHEST, the peer-reviewed journal of the American College of Chest Physicians

Source: 2009 issue of CHEST (journal of the American College of Chest Physicians); copy edited for space



H1N1 Information for Pulmonary Fibrosis Patients

For all PF patients and their caregivers, we have excerpted important information on H1N1 from the Department of Health and Human Services' Secretary Sibelius' office. We understand there is limited availability of the vaccine at this time. Patients need to ask their doctors for information on local access. Following are key questions for PF patients and those involved in their care.

When will the 2009 H1N1 flu vaccine be available? The 2009 H1N1 flu vaccine is now available.

Do I need both the seasonal flu vaccine and the 2009 H1N1 flu vaccine? Yes, especially if you are in one of the target groups for the 2009 H1N1 flu vaccine.

Who should get the seasonal flu vaccine? The seasonal flu vaccine is recommended for anyone who wants to reduce their risk of becoming ill with flu. It is particularly important for persons at increased risk of severe illness or for spreading the infection to persons who are at high risk. These people include:

- People aged 6 months through 18 years or age 50 years or older
- People with underlying medical conditions, such as chronic heart or lung diseases or diabetes (a longer list can be seen at www.flu.gov.)
- Residents of long-term care facilities.

If you are unsure about whether you should receive the seasonal flu vaccine, contact your healthcare provider.

Where will the 2009 H1N1 flu vaccine be available? The Vaccine will likely be available in healthcare provider offices, health departments, schools, and other settings, including pharmacies, workplaces, and community centers. Every state is developing a vaccine delivery plan. For more information about obtaining the flu vaccine, go to www.flu.gov.

To avoid spreading the flu:

- Cover your face when you cough or sneeze. Throw the tissue in the trash after you use it. If a tissue is unavailable, cough or sneeze into your shoulder or elbow instead of your hands.
- Wash your hands often or use hand sanitizer.
- Avoid touching your eyes, nose, or mouth.
- Get the seasonal flu vaccine and/or the 2009 H1N1 flu vaccine, if recommended
- Try to avoid close contact with sick people.

If you have flu-like symptoms (fever with cough or sore throat), stay home for at least 24 hours after you are free of fever without the use of fever-reducing medications.

To find a clinic near you, visit www.flu.gov/individualfamily/vaccination/locator.html.

CPF Named Finalist for National Advocacy Award

The CPF has been named a finalist for a national advocacy award for its efforts on Capitol Hill. PR News notified the CPF that it had been selected as a finalist for its "CPF National Pulmonary Fibrosis Awareness Week – Changing Lives, Changing the Future" campaign in its fiercely competitive national PR News Nonprofit Awards. The awards will be announced at the National Press Club in Washington D.C. on November 3. Other finalists in the category with the CPF are American Heart Association, Deveney Communication-Faubourg Marigny Improvement Association, Farm Aid/Vanguard Communications and the U.S. Postal Service's Corporate Communications.

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New Support Groups

Montgomery, AL

Location: Montgomery Cardiovascular Institute,
Cardiopulmonary Classroom, First Floor

Address: 2119 East South Boulevard
(on the Campus of Baptist Medical Center South)

Meeting Day/Time: The group meets quarterly. The next meeting is December 17, 2009.

Contact: Maryluz Fuentes, M.D., email: fuentesm@charter.net, phone (334) 451-5273.

Ann Arbor, MI

The CPF Announces The Quest For Breath IPF Support Group in Partnership with The University of Michigan

Location: The University of Michigan Pulmonary Rehabilitation Program

Address: 250 W. Eisenhower Parkway, Ann Arbor, Michigan

Meeting Day/Time: 10 a.m. -12 p.m. Saturdays,
the second Saturday of each month

Contact: Julie Hyzy, MSW, e-mail: juliehyz@med.umich.edu, phone: (734) 657-6605

Your Legacy Gift Can Help Change the Future!

Joe Atchison was a PF patient who had turned to the CPF for information and support in dealing with his disease. Determined to help in the fight to stop PF, he allocated a generous estate gift of \$100,000 to the organization to support its ongoing efforts. Sadly, Joe is gone, but his legacy lives on in the wonderful contribution this legacy represents.

Gifts like Joe's will keep the CPF in the forefront of the battle. Please consider an estate gift, a gift of property or stock, which can reduce taxes for you or your heirs, while having a huge impact on the PF fight. Please talk to your financial advisor or call the CPF for more information today!

CPF and Beth Israel Deaconess Medical Center Hold Successful Patient Event in Boston

More than 150 patients and family members gathered for a patient education day at Beth Israel Deaconess Medical Center (BIDMC) on a rainy day in Boston to hear experts speak about PF. Doctors from BIDMC/Harvard University Medical Center presented the latest information on PF diagnosis and treatment and discussed current treatment trials as well as lung transplantation. Drs. Joe Zibrak and Peter LaCamera hosted the event along with the CPF. The CPF's Teresa Barnes gave patients an overview of the CPF's services and encouraged attendees to get involved in raising awareness of PF in their own towns and communities and participate in advocacy efforts to support H.R. 1079, The Pulmonary Fibrosis Research Enhancement Act.

CPF, University of Chicago to Host Free PF Patient Education Seminar

The Coalition for Pulmonary Fibrosis (CPF) in partnership with University of Chicago in Chicago, Ill. is hosting a free seminar on November 14th, 2009 for patients and families living with pulmonary fibrosis (PF). The seminar will feature nationally recognized experts in the treatment and study of PF and will address PF diagnosis, current standards of care, lung transplantation, oxygen management, pulmonary rehabilitation, and resources and support services. This is a unique opportunity for patients, family members, caregivers — anyone affected by PF to learn about the latest in PF research and treatment from leading PF researchers and pulmonary experts. Also, it's a unique opportunity to meet the specialists, ask questions and to meet other patients and families fighting PF.

For more information, or to register, please contact the CPF at (888) 222-8541, ext. 702 or email Teresa Barnes at TBarnes@CoalitionforPF.org to register or for further information.

What: PF Free Educational Seminar
When: Saturday, November 14 - 2009
9:00 a.m. – 10:00 p.m.- Registration
Program: 10:00 a.m. – 3:30 p.m.
*Complimentary lunch provided
Where: Wyndham Lisle Chicago Hotel
3000 Warrenville Road
Lisle, Ill. 60532

Sponsored by



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



Education. Support. Hope.

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Supporting the CPF

The Coalition for Pulmonary Fibrosis (CPF) relies on the contributions of individuals, corporations and associations who share our commitment to improving awareness and education of PF, and improving the quality of life for patients fighting PF nationwide. Through your generous support, the CPF will continue to provide information, resources and support to more than 128,000 PF patients, caregivers and families, and to the health care professionals who treat them.

To contribute by phone using any major credit card, please call the CPF at (888) 222-8541.

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

Coalition for Pulmonary Fibrosis
Suite F, #227
1659 Branham Lane
San Jose, CA 95118-5226

Contributions are also accepted online by using any major credit card safely and securely through our Web site. Please access our contributions page at www.coalitionforpf.org/AboutUs/contribute/contributenow.asp, or click "Contribute Now" from our home page. If non-U.S. residents wish to donate, please use your credit card by calling us or donating online. We are not able to receive foreign checks at this time.

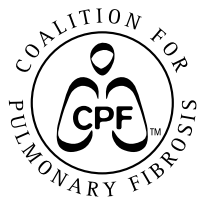
If you have any questions about your contribution to the CPF, or if you would like to make a restricted donation to advance specific CPF programs or research efforts, please contact us at (888) 222-8541, or by email at info@coalitionforpf.org.

About the Coalition for Pulmonary Fibrosis

The Coalition for Pulmonary Fibrosis (CPF) is a 501(c)(3) nonprofit organization, founded in 2001 to accelerate research efforts leading to a cure for pulmonary fibrosis (PF), while educating, supporting, and advocating for the community of patients, families, and medical professionals fighting this disease. The CPF funds promising research into new

approaches to treat and cure PF; provides patients and families with comprehensive education materials, resources, and hope; serves as a voice for national advocacy of PF issues; and works to improve awareness of PF in the medical community as well as the general public. The CPF's nonprofit partners include many of the most

respected medical centers and healthcare organizations in the U.S. With more than 19,000 members nationwide, the CPF is the nation's largest nonprofit organization dedicated to advocating for those with PF. For more information please visit www.coalitionforpf.org or call (888) 222-8541.



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