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# Action Alert

*The Quarterly Publication of the Coalition for Pulmonary Fibrosis*

## Coalition For Pulmonary Fibrosis and American Thoracic Society Award \$100,000 Pulmonary Fibrosis Grant to Massachusetts General Hospital Researcher

### CPF and ATS Jointly Fund Two-Year Study Investigating Key Trigger of Lung Injury

The Coalition for Pulmonary Fibrosis (CPF) and the American Thoracic Society (ATS), the world's leading professional organization for pulmonary, critical care and sleep physicians, announced that they have jointly funded a \$100,000, two-year research award to Andrew M. Tager, M.D. from Massachusetts General Hospital (MGH) in Boston.

"We are excited to continue this important partnership with ATS," said Marvin I. Schwarz, M.D., chairman of the CPF and the James C. Campbell Professor of Medicine at the University of Colorado Health Sciences Center in Denver. "Dr. Tager's research is certainly exciting in that it represents a potential new clinical pathway to understanding how IPF progresses in humans, which could lead to new treatments."

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## CPF Appoints Mishka Michon Chief Executive Officer

The Coalition for Pulmonary Fibrosis (CPF) announced the appointment of Mishka Michon as its new Chief Executive Officer. Michon has more than 25 years of experience overseeing all aspects of development, a key area of importance in leadership for non-profit foundations such as the CPF. Michon will lead the CPF's next phase of growth, including expanding CPF fundraising capabilities and driving its overall mission to

*Continued on page 3*

## CPF and National Jewish Announce Partnership to Provide Genetic Counseling Program for Familial Pulmonary Fibrosis Patients

### Genetic Counseling, Medical Information, and Support Program First of its Kind in U.S.

The Coalition for Pulmonary Fibrosis (CPF) and National Jewish Medical and Research Center today announced the launch of the first genetic counseling program for patients and families affected by familial pulmonary fibrosis. The telephonic counseling program will be operated by National Jewish and is funded by CPF.

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## IPF Philanthropist, Family Member and Hospital Management Entrepreneur Supports Work of the CPF

When Dave Steffy was CEO of Ohio State University Medical Center more than 30 years ago, he couldn't have imagined the course his professional and personal lives would take to intertwine in such an ironic but interesting way. Nor could Steffy have known he would support efforts to change things in idiopathic pulmonary fibrosis (IPF), a disease that was barely recognized at the time.

Steffy has spent most of his career in hospital management with some of the largest hospital companies in America. He started two of the most successful hospital management companies, Republic Health and Community Health Systems. In the mid 1990s, Steffy started Odyssey Healthcare, a hospice organization, and now serves on the company's board of directors as well as the boards of six other private companies.

He'd spent his entire career managing the care of patients and understood well the challenges related to death and dying. But it was his father's tragic illness and death from IPF that would lead him on a new path that would make him a key supporter of the efforts to understand IPF.

"My father passed away in the ER (emergency room) ripping out his breathing tubes. He died a very unpleasant death," said Steffy. "That experience got me interested in the care of the terminally ill."

Just a few years ago, Steffy's brother also died from IPF. His passing caused Steffy to think even more about how he could help people suffering from the disease. "I'd been aware of IPF and because of my professional background, I had seen enough to know it affects a lot of people and there is no effective way of dealing with it. I've experienced firsthand what this disease does and how it works its way. It is horrible - and it has compelled me to do something."

Steffy reached out to investigate ways he could financially support efforts to find treatments and a cure for IPF. Though he considered supporting research at specific medical research centers, he was looking for a way to make a much larger impact. That is when Deirdre Roney, a founding member of the CPF's Board of Directors, who has lost several family members to IPF, called Mr. Steffy. She asked if he'd be interested in talking with her about the efforts of the CPF and ways to increase fundraising for the foundation and the disease. He was.

"My involvement is to support the CPF's development mission. I prefer to be behind the scenes," Steffy said. "My goal is to get more and more people looking at the disease and doing more research. I give as much support as I can to the CPF to increase funding of research and awareness." Through his relationship with the CPF dating to 2005, Steffy has become one of the foundation's largest private donors. Steffy says it is going to take a lot of money and a lot of hard work to build the necessary amount of awareness and interest in the disease that it needs. "There isn't anything easy about it," he said.

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*The CPF's 2007 Butterfly Garden Party, held in Malibu, CA this past September, raised more than \$200,000 for the CPF.*

"As an individual whose family has the genetic form of IPF, I cannot begin to express how grateful I am for Dave's incredible support of our work and his endorsement of our research mission. We are very proud that he is a member of our CPF family,"

*– Deirdre Roney, CPF Board Member*

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Steffy chose to become a donor to the CPF after researching the organization extensively. He asked important questions such as: Is the mission significant? Does the foundation have a committed staff? Is it logical to assume that by raising the appropriate amount of resources, the foundation can accomplish their mission?

“That is where I think the CPF qualifies,” Steffy said.

“The CPF is the best interdisciplinary, most transparent organization doing this. If I wanted to support a university, I could do that, but the foundation is more of a clearinghouse of continuing support of investigators throughout the country. We share the outcomes of projects that we fund and make it available to everyone. That is unique and different than other approaches to it,” he said.

“It is important that the foundation be supported. When a treatment or a cure comes, the CPF will be involved. I feel strongly that the CPF is the most likely vehicle that will lead to hope for IPF patients and researchers in the United States.”

Steffy would like others to follow his lead in supporting the CPF. “I hope those who care and might be capable of being generous, and also be a fearless warrior for the cause”, he said. “The way to be a warrior is to ask people for their support.”

## *CPF Appoints New CEO...continued from cover*

accelerate research efforts into the deadly, incurable lung disease.

“Mishka brings a wealth of proven experience and success in the non-profit fundraising community into her new role as CEO,” said Marvin Schwarz, M.D., Chairman of the CPF Board of Directors. “Mishka’s leadership will be critical to the long term growth and success of the CPF and her vision will help the foundation expand its role as a major source of research funding in the fight against Idiopathic Pulmonary Fibrosis (IPF).” Michon joined the CPF in June 2006 as Executive Vice President of Development. Her work helped increase the foundation’s charitable contributions and staffing and she led its efforts to increase visibility amongst corporate and individual donors.

*“I am committed to the success of the CPF and to helping take the Foundation to its next phase of growth and beyond,” said Michon. “I have seen firsthand the people who have been touched by IPF and realize the great need and opportunity that exists for helping to find treatments and a cure for this devastating disease.”*

*- Mishka Michon, CPF CEO*

Mr. Shreve is remaining with the foundation as Founder & Chief Operating Officer, focusing on the day to day operations of the CPF and expanding its grantmaking capabilities. He decided to step down from the role as CEO to allow him the time to better attend to the growing needs of his family, “This change comes at a time where the CPF’s financial condition is excellent, and our reputation in the community is unrivaled”, said Shreve. “That stability gives me every confidence that this is the right time to assume a new role within the organization. I look forward to working with Mishka to continue building on the great progress we’ve made on behalf of patients and researchers.”

Before joining the CPF, Michon served as a consultant to non-profit organizations in building development programs and events in Southern California. She was director of development for the west coast division of the Museum of Television and Radio and the director of major gifts for the Shoah Visual History Foundation. She has been affiliated with top tier universities, including UCLA and USC, where she served as a director of major gifts. Along with running a college development program, she served as interim director of corporate and foundation relations for California State University, Northridge. Her experience also includes positions as development director for the ERAS Center for Children with Learning Disabilities and the John Tracy Clinic. Michon received her Bachelor of Arts degree from UCLA.

## A Note from the CEO



*As the incoming CEO of the CPF, I am pleased to inform our membership that we are greeting 2008 with a heightened sense of excitement about the growing attention to IPF. There is more research, more discussion about IPF in the medical community, public awareness of the disease is increasing, and we have also seen growing support from our generous community of friends who want to help cure IPF.*

*It is important to emphasize that continued progress and success depend on each of our CPF members actively participating in our work. With the launch of our brand new Web site in the Spring, we will be able to enlist your help, on a regular basis, in lobbying for research funding for IPF. When enough people make noise, attention is paid!*

*I'd like to share some newsworthy information about the upcoming year: we will launch our new interactive Web site with that will tremendously improve our ability to communicate with our members in real time and will constantly update users with event information, research breakthroughs, drug trial announcements, and more; we are working with the U.S. Congress to authorize up to \$100 million in new funding for the National Institutes of Health for IPF research and education; there is a welcome increase in 2008 regional fundraising events in support of the CPF; we will award new research grants in partnership with the American Thoracic Society and their rigorous peer review process.*

*The CPF remains committed to running its business as efficiently as possible so that every dollar possible can be spent on new research, patient services, physician education, national advocacy, and public awareness efforts. That's a long menu of services and I cannot stress enough how much we depend on the community of patients, friends, caregivers, families and supporters to keep this work moving forward.*

*We will continue to help patients by the thousands deal with the everyday challenges of IPF. Side by side with that effort, we will work tirelessly to raise new funds for research so IPF specialists around the country can be armed with the funding they need to advance new approaches to treat and cure this disease.*

*Lastly, I want to reassure you that the foundation is here to serve you in whatever capacity you may need. We are committed to providing you the support, education, resources, and hope that you need in your fight. Please do not hesitate to be in touch with us if we can be of assistance to you or your family.*

*My best for a happy and successful 2008,*

*Mishka A. Michon*



## Congressman Norwood's Family Makes Contribution to CPF

The late Congressman Charlie Norwood's family donated \$60,000 to the CPF. Congressman Norwood was a dedicated advocate for IPF patients and a friend to the CPF and his gift will support the ongoing search for answers to the disease. Congressman Norwood passed away on Feb. 13, 2007, at his home in Augusta, Georgia. His work on behalf of the IPF community remains an inspiration for the many patients and families who have since come forward to help the CPF.

"Obviously, IPF is a little known, incurable disease that affects so many Americans. Ongoing research is critically important. Anything I could do in Charlie's memory to honor his memory and help with research is one of the best uses for the funds that I could possibly think of," said Gloria Norwood, Rep. Norwood's widow.

*National Jewish continued from cover page*

Pulmonary fibrosis is a disease characterized by progressive scarring of the lungs, which robs patients of the ability to breathe. Most cases are of unknown cause, and are called Idiopathic Pulmonary Fibrosis or IPF. IPF affects an estimated 128,000 patients in the United States with about 48,000 new cases diagnosed each year. There is no approved treatment for IPF and it is ultimately fatal.

An estimated 10-15 percent of IPF patients, have a form of the disease that runs in families. Recent research has identified two genetic mutations that are associated with familial pulmonary fibrosis, and tests for those mutations have recently become available to the public.

The genetic counseling program will provide a qualified genetic counselor, who has expertise in familial pulmonary fibrosis, to discuss by phone various issues surrounding familial pulmonary fibrosis. 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.

"With a disease that has no FDA approved treatment and no cure, it is incredibly difficult for patients to deal with the diagnosis. When entire families are threatened by the disease, it is an even more devastating experience," said Mishka Michon, Chief Executive Officer for the CPF. "This counseling program will help patients and families to better understand what is known about familial pulmonary fibrosis and to make informed decisions for

themselves and their family members with regards to their overall care, including genetic testing. We are pleased to support this important service."

"This is a groundbreaking program in pulmonary fibrosis, and we are so pleased to be working with the CPF on it," said Kevin K. Brown, M.D., Vice Chair of Medicine at National Jewish. "Genetic counseling is often important for patients and families at risk for pulmonary fibrosis. Right now, there are few known genetic mutations that may cause familial pulmonary fibrosis, but in the future, more of these mutations will be identified. A genetic counseling program is a critical resource that will help patients and families now and into the future."

*Editor's Note: New data supporting the role of genetics in the development of FPF have recently been published and testing for these mutations have become available. However, the CPF joins with National Jewish in strongly recommending counseling before tests are performed.*

For further information on the FPF Genetic Counseling Program at National Jewish or to speak with a genetic counselor, call (800) 423-8891, ext. 1022.



Janet Talbert

## National Jewish Genetic Counselor Provides Answers, Support for Families with Pulmonary Fibrosis

Janet Talbert, Genetic Counselor & Research Coordinator at the Interstitial and Autoimmune Lung Disease Program National Jewish Medical and Research Center, sat down with the CPF's Teresa Geiger to discuss the program in more detail.

### What are your goals for the new FPF Genetics Counseling Program?

My goals are to be available for patients and family members to provide answers on the most recent genetic information for FPF as well as to help them make informed decisions about research and genetic testing. I want to guide patients and family members through the risks, benefits and options of genetic research and genetic testing so they may make the best decision for themselves. I'll also be providing basic medical information on the disease and how hereditary factors may contribute. We also plan to provide referrals to medical care if needed. We counsel patients on what the tests and results of tests mean to them.

### Is there a cost to the patient/family for the counseling service?

There is no cost for this service. We're grateful that the service is being supported through a gift from the CPF.

### Why is counseling important before and after genetic testing?

Genetic testing is very unique from other kinds of testing, and can be quite complex. While genetic testing may appear to be exact, there are also times when it is not exact. For example, a negative result does not always imply that the individual is risk-free from disease. There are inconclusive results many times, especially with chronic diseases such as IPF. Prior to genetic testing, it is important to determine who, if anyone needs to have genetic testing. Many times it is important to test someone with the disease first to see if they carry the known disease-causing gene before testing other asymptomatic family members. For this reason, it is important to discuss these and other issues before performing genetic testing.

Depending on the results of testing, counseling after genetic testing provides a framework for personalized medicine to that individual, what their results mean for their health as well as how it

impacts other family members (i.e. do others now need to be tested?). The individual can then take action to make decisions regarding their healthcare. Also, the results can be comforting if they relieve emotional distress or anxiety about the condition being tested for.

### What is being done to protect patients and families from those who would use their genetic information against them?

Not only does genetic technology outpace the education out there, but it also outpaces our legislation. Currently, genetic information gained from testing is protected somewhat through the federal law of HIPAA (Health Information Portability and Accountability Act), and other laws exist state to state. This leaves spotty protection at the moment. For the last ten years, bills have gone before Congress to create a federal law to protect genetic information, collectively known as the Genetic Information Nondiscrimination Act, or GINA. To date, the Act has not passed though."

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"With the help of the Coalition for Pulmonary Fibrosis we are able to establish the genetic counseling position here at National Jewish. We are delighted to be able to provide individuals with Familial Pulmonary Fibrosis and their family members access to a qualified Genetic Counselor skilled in all aspects of Pulmonary Fibrosis."

— Dolly Kervitsky, CRT, CCRC, manager of the Interstitial and Autoimmune Lung Disease Program

What is the importance of collecting genetic information with regards to finding treatments and a cure for IPF or FPF?

This is extremely important. In diseases such as IPF/FPF, it is most likely an interaction of different genes and the environment, and it may differ family to family, individual to individual. So it is important to continue research for discovery of more genes that may be implicated in the disease process.

What are you most excited about regarding the FPF Genetics Counseling program?

I am excited that this is going to be the first service of its kind that offers genetic counseling to families and patients with IPF/FPF. It is an honor to be part of this endeavor and my hope is that it benefits everyone who calls in with questions. I am also excited to work with the patients and families that are members of the CPF.

What would you say to hesitant patients/families who may want to call?

I would say that there are no questions too big or too small to ask. If I do not have the answer right away, I will find out and get back to them at a later point. I listen well and I am responsive to the needs of the callers. My hope is that callers will feel better once they have an improved understanding of the implications of a genetic form of FPF and patients and their families will be able to better manage their fears and expectations.



## UCSF to Host Interstitial Lung Disease CME Course for Medical Professionals April 5, 2008

The University of California San Francisco's (UCSF) Division of Pulmonary and Critical Care, Department of Medicine, and School of Medicine are offering a continuing medical education (CME) conference entitled, "Update in Interstitial Lung Disease: Effective Diagnosis and Management" on Saturday, April 5, 2008.

The conference is designed to provide clinicians and other healthcare professionals with a practical approach to the diagnosis of Interstitial Lung Disease (ILD), an understanding of the importance of accurate and timely diagnosis, and a treatment approach that is broad and evidence-based.

This CME conference is being co-chaired by Harold R. Collard, M.D., Assistant Clinical Professor of Medical Division of Pulmonary and Critical Care, and Jeffrey A. Golden, M.D., Professor of Clinical Medicine Division of Pulmonary and Critical Care, both from UCSF. Both physicians serve on the CPF's scientific advisory board.

CME Course: *Update in Interstitial Lung Disease: Effective Diagnosis and Management*

When: Saturday, April 5, 2008  
7 a.m. Registration and Continental Breakfast  
Course concludes at 4:35 p.m.

Where: Sir Francis Drake Hotel, San Francisco, CA

Contact: To register, call the UCSF CME registration office at (415) 476-5808 or visit [www.cme.ucsf.edu](http://www.cme.ucsf.edu)



## CPF Working with Congress to Introduce Legislation to Increase Federal Funding for IPF, Create National Patient Registry

Patients, Families and Medical Professionals Encouraged to Show Support for Effort

For the first time in the history of IPF, Congress is being asked to review and pass a substantial authorization of monies for the funding of research, a national patient registry and a public awareness campaign. This action represents a dramatic movement forward for all IPF patients, physicians, researchers and caregivers. The CPF will need the participation of all its members through letters and phone calls to Congressional representatives. The CPF membership is the organization's most powerful weapon in Congress!

Working with Congressmen Brian Baird (D-WA) and Mike Castle (R-DE), the CPF is preparing to introduce an IPF Bill during the first quarter of 2008. In earlier Action Alert newsletters, the CPF has already received the support of more than 20 members of Congress who have agreed to co-sponsor the Bill, and with the help of our members, we will increase that number dramatically.

The CPF is encouraging ALL patients and their families and friends affected by IPF to write their member of Congress to express their support for this effort. Please visit our Web page for more information, or contact Teresa Geiger at (888) 222-8541 to learn how you can help!"

*EDITOR'S NOTE: The CPF's campaign ACT national advocacy efforts resulted in the first legislation passing Congress recognizing IPF and the need for increased research funding and public awareness of the disease in 2007. The CPF has continued to build relationships in Congress and, with the help of its many volunteer advocates from around the United States, will garner significant ongoing attention to IPF from the federal government. Since November, 2007, the CPF has been working with Members of Congress to draft an authorizations bill that, when passed, will provide a substantial infusion of new funding to the National Institutes of Health (NIH) for IPF research, public education, and the creation of the first national IPF Patient Registry.*

### Sample Letter of Support

Dear Congressman/Congresswoman,

As someone among the hundreds of thousands personally affected by idiopathic pulmonary fibrosis (IPF), an ultimately fatal disease that annually takes as many lives as breast cancer, I am writing to ask you to support legislation to help us stop this dreaded disease. A bill will be introduced to the Congress this year that calls for increased federal funding to step up the work to find answers to IPF.

IPF is a debilitating disease marked by progressive scarring of the lungs that gradually and cruelly robs people of their ability to breathe. IPF yields a median survival rate of fewer than three years and affects more than 128,000 people in this country each year. In fact, 40,000 people die each year from IPF, the same number as are lost to breast cancer. Despite its prevalence, very little is known about IPF and there is no known cause or FDA-approved treatment.

As your constituent and as someone who has been personally touched by this terrible disease, I respectfully request that you consider supporting this legislation and becoming a co-sponsor. It is time to get serious about a disease that is steadily on the increase.

Please consider co-sponsoring the bill - we need your support. Brian Baird's office is leading the effort and they will appreciate your letting them know you support the request.

Sincerely,  
[insert your name, address and phone number]

Your letter or email is important to the success of the CPF's legislative efforts on your behalf. This bill is expected to be introduced on the floor of the House of Representatives as early as April. An online version of the sample letter on this page will also be available for members to email their Representatives directly. The CPF appreciates your voice and your help!

## CPF Supports Effort to Prevent Medicare Oxygen Services Cuts that Threaten Patient Care

The CPF partnered with the Council for Quality Respiratory Care (CQRC) in early 2007 to help advocate for Medicare issues important to our patient community. As part of this partnership, the CPF endorsed the CQRC's recent advertising campaign aimed at preventing Medicare cuts to home oxygen services for patients. CQRC, a coalition of more than 20 oxygen suppliers, medical professionals and patient groups is asking Congress to resist cuts that threaten patient care by reducing or restricting oxygen equipment and oxygen services. The ad for the CQRC campaign is below.



### MEDICARE'S HOME OXYGEN BENEFIT ALLOWS HER TO STAY AT HOME

MEDICARE'S HOME OXYGEN BENEFIT gives more than one million Americans with irreversible lung disease the ability to breathe easier, live at home and remain independent. Home oxygen also saves taxpayer dollars by reducing expensive hospitalizations and nursing home stays.

The House of Representatives recently voted to cut this critical benefit by approximately \$2 billion over 5 years. If enacted, nearly one out of every two seniors who receive oxygen therapy at home will be affected.

**We're counting on our leaders in Washington to protect this important benefit.**

**"Reduced reimbursement will lead to increased hospital costs and human suffering."**

*— Dr. Thomas Petty, Professor of Medicine, University of Colorado and Rush Presbyterian St. Luke's Medical Center, Chicago*



**THE MEDICARE HOME OXYGEN BENEFIT: PRESERVING INDEPENDENCE. SAVING TAXPAYER DOLLARS.**

## Rancho Murieta, California Woman Educates Others About Deadly Disease

By John Motsinger, River Valley Times Staff

Rancho Murieta resident Sandra Rock is lucky to be alive. Diagnosed with idiopathic pulmonary fibrosis (IPF) in 2001, she was given between three and five years to live.

Six years later, she is one of the lucky few to survive this menacing, unknown disease. However, Rock has seen many others from her support group come and go who were not so lucky, and she has dedicated herself to educating people about the disease.

On Dec. 1, it was IPF and not some horrific motorcycle crash that took the life of Evel Knievel. And on Oct. 30, singer Robert Goulet died of the same disease while awaiting a lung transplant.

Despite the death of a few high-profile celebrities, Rock says there is very little awareness of IPF. "Forty-thousand people die each year from pulmonary fibrosis - that's the same as from breast cancer," she says, yet few have ever heard of the fatal lung disease.

"There's no current FDA-approved treatment and no cure," Rock said. That's why she's been traveling to Washington, D.C. for the past five years to help increase awareness and pursue funding for research and treatment programs.

Teresa Geiger, vice president of Patient Outreach and Advocacy with the Coalition for Pulmonary Fibrosis, said they've just passed the first legislation in Congress recognizing the disease and the need to increase funding for research. She called it "a watershed event," but realizes there's still a long way to go.

"I think we are reaching a tipping point, but we aren't there yet," Geiger said. It will take the persistence of people like Rock who are willing to tell their stories to legislators who control research dollars, she said, in order to make a difference.

With a median survival rate of three years, Rock didn't expect to be around this long. Fortunately, she has been in the 10% of IPF cases that respond well to steroid treatment, which has allowed her to lead a somewhat normal life.

It has been no cakewalk though, and she often gets winded at the slightest exertion. "You don't think about bending over to empty the dishwasher or



*Rancho Murieta, Calif. residents Sandra and Jim Rock are shown in Washington, D.C. where they traveled in September during National Idiopathic Pulmonary Fibrosis (IPF) Awareness Week to help pass legislation recognizing the need for research regarding the fatal disease. Sandra Rock was diagnosed with IPF in 2001.*

getting out of a car," she said, "but even those relatively innocuous movements can be exhausting."

Rock leads a support group of more than 70 IPF sufferers who get together once a month at the Sutter Cancer Center. She tries to schedule a speaker for each meeting to talk about coping strategies, treatment programs, clinical trials and ways to increase awareness.

For information on the Rancho Murieta IPF support group and other CPF support groups across the country, visit the CPF Web site at [www.coalitionforpf.org](http://www.coalitionforpf.org) or call (888) 222-8541.

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## NIH Leaders Warn of Flat Funding

By John Reichard, CQ HealthBeat Editor

The day after Congress shot down legislation providing a real increase in funding to the National Institutes of Health (NIH), the heads of two of the world's largest medical research enterprises warned against continued flat funding of the agency.

NIH Director Elias Zerhouni and Billy Tauzin, head of the lobby representing the U.S. brand name drug industry, said at a Washington conference that such funding would threaten medical breakthroughs based on what Zerhouni called the recent "harvest" of molecular research discoveries.

Zerhouni, as head of the NIH, and Tauzin, as president of the Pharmaceutical Research and Manufacturers of America (PhRMA), represent much of the world's medical research muscle. NIH accounts for about \$28.5 billion in biomedical research spending, while PhRMA says its members spend about \$43 billion. While PhRMA's dollar total may be higher, NIH funds much more basic research - which the private sector relies on heavily to develop marketed products. "We do most of the 'R', and the industry does most of the 'D'," Zerhouni said.

Spending legislation passed by the House and Senate would boost the NIH budget by \$2 billion, to a total of \$30 billion in fiscal 2008. The increase would follow several years of flat funding after Congress completed a doubling of the agency's budget in 2003. However, President Bush vetoed the Labor-HHS-Education bill of which the NIH increase is a part. A House vote Thursday to override the veto fell short of the two-thirds majority required.

Because of inflation in the costs of conducting biomedical research, level funding means a decline in real research dollars, they said. "That's a danger signal for every patient who continues to wait for the next great discovery," Zerhouni said.

Zerhouni said the doubling of NIH funding contributed to a harvest of recent insights into what happens at the molecular level to trigger various diseases. That makes it possible to develop products to interfere early on with molecular processes that otherwise would lead to lethal diseases.

The "enormous harvest" of molecular findings poses a problem - "how are you going to study all this?" Zerhouni asked. "We have enormous opportunities but enormous needs at the same time."

"What's the sense of saying you really want to double research, and then cut it every year by a little bit, a little bit, a little bit?" Zerhouni likened that to building "a formidable discovery engine and then cutting the gas . . . that's just ridiculous."



Source: CQ Healthbeat News 11/16/07;  
Content edited for space.



## Hollywood Takes Notice of Little Known Deadly Lung Disease

### Recent Deaths of Well-Known Celebrities, Hit TV Shows Help Spread the Word About Pulmonary Fibrosis

As many people die each year of pulmonary fibrosis as of breast cancer, yet the disease is vastly unknown. Due to the recent deaths to the disease of high profile celebrities such as Evel Knievel and Robert Goulet, Hollywood is beginning to take notice and hit TV shows are spreading the word, as well.

HBO's Thursday night hit new show, *Autopsy*, focused on pulmonary fibrosis in a recent episode by telling the real-life story of a 9/11 responder named Frank Maisano, a New York City police officer forced to take early retirement, who is dying from the deadly, incurable lung disease. Cases of pulmonary fibrosis have been diagnosed amongst 9/11 workers including in James Zadroga, a first responder who died in 2006 from the disease.

The recent controversial Michael Moore film, *Sicko*, featured pulmonary fibrosis patients including Vito Valenti, a 9/11 responder and CPF volunteer and advocate.

Other hit but fictional TV shows have featured pulmonary fibrosis in their plots in recent months. Fox TV's *House* medical drama aired two shows last season that included pulmonary fibrosis diagnoses or suspicions. TNT's *Heartland* medical drama features actor Dabney Coleman whose character suffers from pulmonary fibrosis and uses supplemental oxygen in the series.

"When Hollywood takes notice of something and celebrities are associated with a cause, things really start to happen," said CPF CEO Mishka Michon. "We are thankful for the work being done in TV and film to raise awareness and increase interest in pulmonary fibrosis. It is this kind of interest, as with AIDS and breast cancer, that takes a disease from terminal to treatable."

Other Hollywood celebrities to die from pulmonary fibrosis include actors Marlon Brando, James Doohan (Scotty of Star Trek) and Gordon Jump (Maytag Repairman, *WKRP in Cincinnati*). *Jaws* author Peter Benchley also died from the disease.

## Evel Knievel Lost to Pulmonary Fibrosis

### Urgent Need for Increased Awareness of Disease, Funding for Research

Famed stuntman Evel Knievel was known for his death defying stunts and his recovery from life threatening injuries due to those stunts. It is ironic the disease that claimed his life was one that has no treatment and no cure. Knievel was unfortunately one of 40,000 people in the U.S. who will lose their lives to idiopathic pulmonary fibrosis (IPF) this year, the same number as will die from breast cancer. Yet, most people have never heard of IPF.

"Our sympathies go out to the Knievel family. We know first hand the tragedy of IPF," said Mark Shreve, COO of the CPF. "It is devastating news to IPF patients and their families that viable treatments for IPF still do not exist. We desperately need to increase awareness of IPF and fund research that will lead to new treatments, and ultimately a cure."



Following the passing of Evel Knievel on November 30, 2007, the CPF paid tribute to Evel, recognizing his extraordinary life and contributions to raising awareness of IPF.

ATS Continued from page 1

“I am deeply honored to be selected as the recipient of the 2008 CPF/ATS grant in Idiopathic Pulmonary Fibrosis. I am devoted to increasing our understanding of the mechanisms of progression of IPF, and hope our work will lead to new effective therapies for this dreadful disease,” said Dr. Tager.

The objective of Dr. Tager’s study - entitled *“Mechanisms of Fibrosis Driven by Lysophosphatidic Acid (LPA) and its Receptor LPA1”* - is to investigate the role of Lysophosphatidic Acid (LPA) and its cognate receptor LPA1 in lung injury and fibroproliferation following bleomycin treatment. Preliminary data has identified LPA as a potentially important mediator in IPF, functioning as a signaling molecule that triggers the proliferation of scar tissue. The research aims determine the role of LPA/LPA1 in fibroblast recruitment induced by lung injury, determine the role of endothelial cell LPA1 in vascular leak induced by lung injury,

and investigate the role of LPA/LPA1 in fibroblast migration in IPF.

“This research proposal was selected from an incredibly strong portfolio of applications” said Thomas R. Martin, M.D., past president of ATS and chair of the ATS Research Program. “Through our partnership with the CPF and the ATS Scientific Review Committee we’re extremely pleased to be able to provide this funding to Dr. Tager.”

Dr. Tager is an Assistant Professor at Harvard Medical School in the Pulmonary and Critical Care Division at MGH. His study was chosen by ATS/CPF Scientific Advisory Committee through a rigorous peer review application process. The award was selected from a series of applicants who submitted proposals in the areas of basic, clinical and translational research that focused on identifying new approaches to understand or treating idiopathic pulmonary fibrosis (IPF).

The *ATS/CPF Partnership Grant for Pulmonary Fibrosis* was established in 2006. The first grant through this partnership was a \$100,000, two-year award to Sonye K. Danoff, M.D., Ph.D. at Johns Hopkins University. Dr. Danoff is currently in year two of her research entitled *“VEGF: Marker or mediator of lung injury in pulmonary fibrosis?”* Her research is currently testing the hypothesis that locally elevated levels of vascular endothelial growth factor (VEGF) in the lungs of patients with autoimmune pulmonary fibrosis contribute to disease progression.

CPF and ATS intend to continue growing this important partnership by establishing new, \$100,000, two-year grants to be awarded in December, 2008 to advance pulmonary fibrosis research efforts in the United States. Details will be announced during the American Thoracic Society’s annual meeting in May 2008.



## IPF Researcher to Lead New University of Cincinnati ILD Clinic

Brent Kinder, M.D., director of the new University of Cincinnati Interstitial Lung Disease (ILD) Clinic, is researching the implications of new findings that neutrophils (white blood cells) are found in larger numbers in the lungs of IPF patients. The testing is performed with Bronchial Alveolar Lavage (BAL) and Kinder feels that BAL will become standard practice in treatment of IPF patients. Kinder received his degree from Emory and has worked with such high profile doctors in IPF as Talmadge King, chairman of the Department of Medicine at UCSF, and Marvin Schwarz, M.D., James C. Campbell professor of Pulmonary Medicine, University of Colorado Health Sciences Center.

To learn more about the ILD Clinic at the University of Cincinnati, please call (513) 475-8523 or visit their website at [www.uclungfibrosis.com](http://www.uclungfibrosis.com).

# Mass. General Hospital Researchers Identify Pathway That Appears Crucial in Development of IPF

A study led by Massachusetts General Hospital (MGH) researchers may have found a key mechanism underlying idiopathic pulmonary fibrosis (IPF).

The investigators found that a specific molecular pathway appears responsible for key aspects of the scarring of lung tissue that characterizes IPF, the cause of which is currently unknown. The results will appear in the January, 2008 issue of *Nature Medicine* and have received early online release.

“Identifying the key role of this pathway in the development of fibrosis gives us an exciting new target for devising treatments,” says Andrew Tager, M.D., of the MGH Pulmonary and Critical Care Unit, who led the study. “An agent that blocks this pathway is already being developed as a potential cancer treatment, and we’re hoping to be able to test it in our animal model of IPF to determine whether it might be a candidate for trials in patients.”

The primary characteristic of IPF is scarring (fibrosis) of the lung surface, rendering it unable to transmit oxygen into the bloodstream. In any part of the body, scarring occurs when cells called fibroblasts, an important part of normal wound healing, make collagen to reinforce the healing matrix that forms over damaged tissue. Normally scarring is limited, but if too many fibroblasts travel to the site of an injury, large amounts of collagen can be deposited, producing excessive, fibrotic scarring. Fibroblasts are known to be present in affected lung tissue

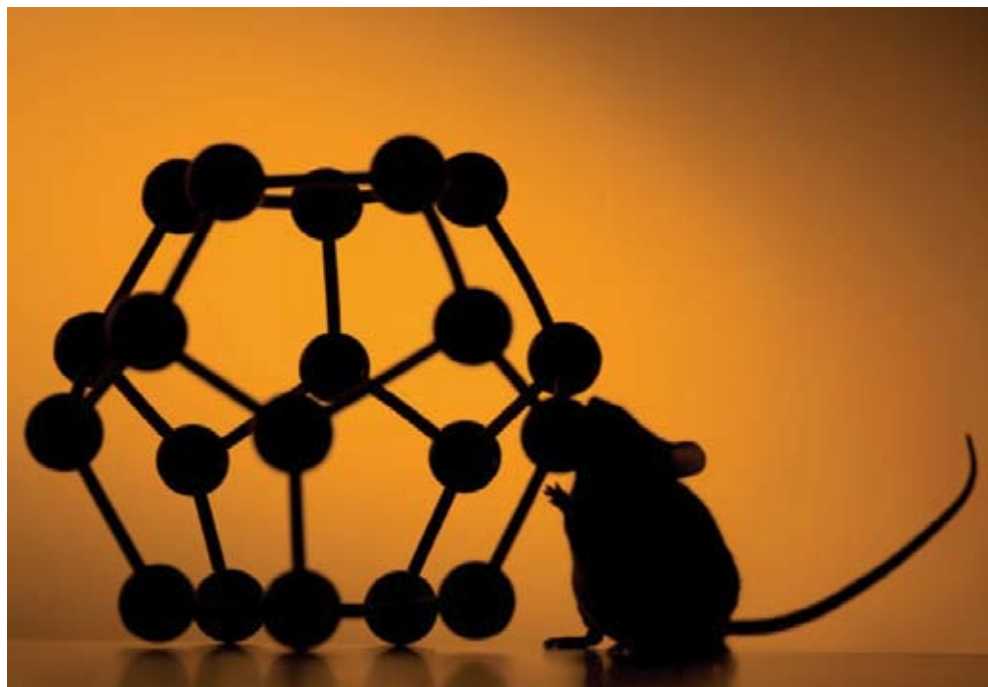
in IPF, and previous studies showed that the activity of factors that attract fibroblasts to the site of an injury rises with the severity of the disease. The current study was designed to determine which specific “chemoattractants” were associated with IPF, something not previously known.

Analysis of fluid from the lung surfaces of a mouse model of pulmonary fibrosis suggested that the activity of lysophosphatidic acid (LPA), acting through its receptor LPA1, was responsible for attracting fibroblasts in the disorder. This association was supported by the fact that a strain of mice lacking the gene for LPA1 did not develop pulmonary fibrosis when treated with a compound that usually causes the disease in the animals. Lung fluid samples from human IPF patients not only had significantly higher levels of LPA than control samples,

laboratory tests showed that patient samples attracted fibroblasts while fluid from controls did not. In addition, an agent that blocks the LPA1 receptor eliminated the ability of fluid from IPF patients to attract fibroblasts.

“These results indicate that the LPA-LPA1 pathway is responsible for the abnormal migration of fibroblasts into the lungs in IPF, an absolutely crucial step in the development of fibrosis,” says Andrew Luster, M.D., PhD, senior author of the study. “This pathway appears to be involved in several steps in the development of fibrosis, including the leaking of blood vessels, which is why the LPA1 knockout mice are so dramatically protected. If we’re right, then targeting this pathway should be a very exciting new therapeutic strategy for IPF.”

*Source: Massachusetts General Hospital Press Release; Content edited for space.*



## Smoking Belies Milder Disease But Worse Prognosis For IPF Patients

Smokers and ex-smokers with idiopathic pulmonary fibrosis (IPF) have a worse prognosis than non-smokers, according to research from London. Previous research had counter-intuitively suggested that current smokers with IPF might live longer than ex-smokers, but the new study establishes that the data likely reflected a healthy smoker effect.

The study appears in the second issue for January of the *American Journal of Respiratory and Critical Care Medicine*, published by the American Thoracic Society. "Smoking is associated with a higher mortality in IPF, and an earlier finding, suggesting the contrary, was almost certainly due to the fact that smokers tend to stop smoking when

disease becomes more severe—and so current smoking is linked to milder disease," said Athol U. Wells, M.D., of the Interstitial Lung Disease Unit at the Royal Brompton Hospital in London, who headed the research.

The investigators studied the medical records of 249 patients with IPF, and analyzed the extent and severity of their disease, smoking history and survival. Their initial findings, unadjusted for disease severity, were similar to the earlier study—namely that smokers had longer survival times than ex-smokers. But when they adjusted their data to reflect the extent and severity of the disease at presentation, their findings shed a new light on the previous finding.

"We established that current smokers live longer, but this is mostly because they have much milder disease. Clearly, many patients stop smoking precisely because their disease is getting worse. This is the 'healthy smoker' effect: that current smoking is a marker for milder disease because advancing disease causes smoking cessation," said Dr. Wells.

"The next step is to pursue the idea that mechanisms linked to smoking cause progression of pulmonary fibrosis," says Dr. Wells. "If we can then understand these mechanisms better, this may give us new treatment options."

*Source: American Thoracic Society and Medical News Today. Content edited for space.*

## Rare Lung Disease Cells Indicate Higher Mortality Risk

Large numbers of certain cells in the lungs of patients diagnosed with idiopathic pulmonary fibrosis (IPF) may increase their chance of death, University of Cincinnati (UC) researchers have discovered.

According to a new study, increased numbers of neutrophil (pronounced new-tro-fil) cells—a type of white blood cell—in patients' lungs were associated with a 30 percent increased risk of mortality in the first year following diagnosis with IPF.

"A measure of cell types in the lungs of IPF patients at the time of diagnosis may allow us to determine their risk of death in the following year," says Brent Kinder, M.D., assistant professor of medicine at the UC College of Medicine and pulmonologist with UC Physicians.

"This even takes into account other well-known measures of disease

severity like age, whether or not the patient smokes and how well his or her lung functions during breathing tests," he adds.

Kinder co-authored the study, which is featured in the January issue of the *Journal Chest*, with Talmadge King, Jr., M.D., chair of internal medicine at UCSF and senior author of the study; Kevin Brown, M.D., Marvin Schwarz, M.D., and Alma Kervitsky from National Jewish Medical Center; and Joachim Ix, M.D., from the University of California, San Diego. The study was funded by grants from the National Heart, Lung and Blood Institute.

The team evaluated the cell count of 156 people with IPF at the time the disease began to make its appearance.

"With this information, we can now work to identify neutrophil cells in patients' lungs and provide detailed information for more accurate diagnosis," says Kinder, who is also director of the newly established Interstitial Lung Disease Center at UC.

"It is our hope that this accurate prognostic information will become even more useful as effective treatments become available."

*Source: ScienceDaily.com 01/19/08; article adapted from materials by University of Cincinnati. Content edited for space.*

“The risk from a single CT, or computed tomography, scan to an individual is small. But we are very concerned about the built-up public health risk over a long period of time.”

— Eric Hall, Columbia University medical physicist

## Study: NEJM Study Indicates CT Scans Could Raise Cancer Risk

Millions of Americans, especially children, are needlessly getting dangerous radiation from “super X-rays” that raise the risk of cancer and are increasingly used to diagnose medical problems, a new report warns.

In a few decades, as many as 2 percent of all cancers in the United States might be due to radiation from CT scans given now, according to the authors of the report. Some experts say that estimate is overly alarming. But they agree with the need to curb these tests, particularly in children, who are more susceptible to radiation and more likely to develop cancer from it.

“There are some serious concerns about the methodology used,” but the authors “have brought to attention some real serious potential public health issues,” said Dr. Arl Van Moore, head of the American College of Radiology’s board of chancellors.

The risk from a single CT, or computed tomography, scan to an individual is small. But “we are very concerned about the built-up public health risk over a long period of time,” said Eric J. Hall, who wrote the report with fellow Columbia University medical physicist David J. Brenner. It was published in the *New England Journal of Medicine* and paid for by federal grants. A previous study by the same scientists in 2001 led the federal Food and Drug Administration to recommend ways to limit scans and risks in children.

### Millions of CT scans

But CT use continued to soar. About 62 million scans were done in the U.S. last year, up from 3 million in 1980. More than 4 million were in children. CT scans became popular because they offer a quick, relatively cheap and painless way to get 3D pictures so detailed they give an almost surgical view into the body. But they put out a lot of radiation. A CT scan of the chest involves 10 to 15 millisieverts (a measure of dose) versus 0.01 to 0.15 for a regular chest X-ray, 3 for a mammogram and a mere 0.005 for a dental X-ray. The dose depends on the type of machine and the person — obese people require more radiation than slim ones — and the risk accumulates over a lifetime.

### Higher risk for chronic illnesses

The authors stressed that they were not trying to scare people who need CT scans away from having them. In most cases, the benefits exceed the risks, especially for diagnostic scans. However, using the scans to screen people with no symptoms of illness — like screening smokers for signs of lung cancer — has not been shown to save lives and is not currently recommended. Both doctors and patients need to be more aware of radiation risks and discuss them openly, the researchers said.

Source: CNN. Content edited for space.



## No Link Between Acid Reflux and Survival, Study Finds

Gastroesophageal reflux disease (GERD), often known as acid reflux, is a common problem that has been associated with cancers, asthma, recurrent aspiration and pulmonary fibrosis. A new study examines whether GERD sufferers may have shorter lifespans than those without the disease.

Drawing on over 50,000 person-years of data, the study provides reassuring evidence that people with acid reflux symptoms do not have an increased risk of death, finding no difference in survival rates between sufferers and non-sufferers.

In fact, the study finds that people with infrequent acid reflux may actually have better survival rates than those with either daily symptoms, or none at all. "It may be that occasional reflux symptoms are a reflection of potential protective behaviors that are associated with reflux, such as regular exercise or modest amounts of alcohol ingestion," suggest Nicholas J. Talley and G. Richard Locke, III, co-authors of the study from the Mayo Clinic College of Medicine.

The study adds perspective to the risk of acid reflux symptoms. While there are a large number of acid reflux sufferers in the U.S., incidences of related cancer are extremely rare. "Although extraesophageal manifestations occur in some people with reflux disease, our results suggest that this disease is a benign condition in the vast majority of sufferers," say the authors.

*Source: Science Daily, January 4, 2008: Adapted from materials provided by Blackwell Publishing Ltd. Content edited for space.*

*Journal Reference: The American Journal of Gastroenterology 103 (1), 12-19. doi:10.1111/j.1572-0241.2007.01546.x*

## Gilead and LG Life Science Announce Agreement to Advance Novel Drug Candidates for Treatment of Fibrotic Diseases

Gilead Sciences, Inc. and LG Life Sciences, Ltd. announced that the companies have entered into an exclusive license agreement focused on the development of caspase inhibitors for the treatment of fibrotic diseases. The agreement grants Gilead commercialization rights to LGLS' caspase inhibitors, including LB84451, LGLS' lead compound.

Caspases are cellular proteases involved in processes such as apoptosis (cell death) and inflammation. By inhibiting various caspases, it may be possible to slow or stop the progression of fibrosis in the liver for patients with chronic viral hepatitis and non-alcoholic steatohepatitis (NASH), as well as

potentially in other fibrotic diseases such as idiopathic pulmonary fibrosis (IPF).

"We look forward to working closely with the LG Life Sciences team to advance their clinical program for patients with hepatic fibrosis and to explore other potential indications," said John C. Martin, PhD, President and Chief Executive Officer of Gilead Sciences. "Treatment of fibrosis represents an area of significant unmet medical need and one that we believe aligns well with our interest and experience in both liver and pulmonary diseases."



### About LB84451

LB84451 is an oral, once-daily pan-caspase inhibitor that demonstrated safety and tolerability in healthy volunteers in a 14-day Phase I study. A Phase IIa study designed to assess the safety, tolerability, efficacy and pharmacokinetics of the compound among hepatitis C infected individuals is currently ongoing in Europe. For further information, please visit [www.gilead.com](http://www.gilead.com)

*Source: Gilead Sciences, Inc. Press Release. Content edited for space.*

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## ImmuneWorks receives \$1.5 million grant to Fund PreClinical Development of IPF

ImmuneWorks, LLC announced today that it has been awarded a \$1.5 million grant from the Indiana 21<sup>st</sup> Century Research and Technology Fund to fund certain pre-clinical and Phase I clinical trial expenses. ImmuneWorks will use these funds to complete preclinical development of its lead product in the treatment of idiopathic pulmonary fibrosis (IPF) and submit the Company's Investigational New Drug Exemption (IND) in 2008. Additionally, the funding will provide partial support for ImmuneWorks first clinical trial in IPF patients.

ImmuneWorks is a biotechnology company developing novel therapeutics and diagnostic tests for patients with autoimmune conditions. Based in Indianapolis, IN, the company is initially developing treatments for pulmonary diseases such as idiopathic pulmonary fibrosis and prevention of lung transplant rejection.

*Source: ImmuneWorks, LLC Press Release. Content edited for space.*



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*Education. Support. Hope.*

## Bracelet Campaign Helps Raise Awareness of IPF and Support the CPF!

Purchase a unique bracelet in your favorite color to help spread the word about IPF. A percentage of the proceeds of each sale are donated to the CPF. Cost is \$12 per bracelet without shipping.

For further information, or to order IPF bracelets and obtain shipping costs, please contact:

Tracey Jean St. Cyr  
1327 Bound Tree Rd.  
Contoocook, NH 03229  
Email: [tbandgeo@tds.net](mailto:tbandgeo@tds.net)  
Phone: (603) 496-6654

Payments can be made by cash or check and mailed to the address above.



Are You an  Fanatic?

Did you know that you can support the great work of the CPF when you sell items on eBay? That's right, through an innovative partnership with MissionFish, eBay sellers can list any item they wish, and designate up to 100% of the sale price of an item to the CPF! If the item sells, the seller gets paid by the buyer and ships the item - same as always. eBay collects the donation from the seller, sends a check for the designated percentage to the nonprofit, and provides a tax receipt for the seller. It's as simple as that! So the next time you list an item, select the CPF!

To learn more about this unique program, which has raised more than \$96 million for nonprofits to date, please visit [www.missionfish.org](http://www.missionfish.org)

## 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 IPF, and improving the quality of life for patients fighting IPF nationwide. Through your generous support, the CPF will continue to provide information, resources and support to more than 128,000 IPF 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](http://www.coalitionforpf.org/AboutUs/contribute/contributenow.asp), or click "Contribute Now" from our home page.

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](mailto: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 idiopathic pulmonary fibrosis (IPF), while educating, supporting, and advocating for the community of patients, families, and medical professionals fighting this disease. The CPF funds promising research into new

approaches to treat and cure pulmonary fibrosis; provides patients and families with comprehensive education materials, resources, and hope; serves as a voice for national advocacy of IPF issues; and works to improve awareness of IPF 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 15,000 members nationwide, the CPF is the nation's largest nonprofit organization dedicated to advocating for those with pulmonary fibrosis. For more information please visit [www.coalitionforpf.org](http://www.coalitionforpf.org) or call (888) 222-8541.



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