



PULMONARY FIBROSIS FOUNDATION

Breathe

BULLETIN

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Our Mission

The Pulmonary Fibrosis Foundation mobilizes people and resources to provide access to high quality care and leads research for a cure so people with pulmonary fibrosis will live longer, healthier lives.

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

DISCLAIMER:

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

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Letter from our President and CEO

DEAR FRIENDS,

When I joined the Pulmonary Fibrosis Foundation (PFF) in August, I came into a dynamic organization powered by the progress of the last few years. I'm honored and inspired to build on and accelerate that momentum as we move into the next phase of accomplishment.

Our community has some special achievements and advancements to celebrate as 2017 winds down. The PFF Patient Registry, which has reached more than **1,500** enrollees, is now open for research studies that will use the data and samples collected by the registry and biorepository to expand our understanding of PF.

Determined *Team PFF* leaders hosted walks, runs, golf outings, and other activities to make this June a record month in both proceeds and attendance. These volunteer-organized events benefiting the PFF are key to raising both funds and awareness of this deadly disease.

Our inaugural PFF Walk in Chicago's Lincoln Park this September was a stellar success. 850 families, caregivers, and friends gathered for a one- or three-mile walk on the city's magnificent lakefront. Many others across the globe joined us for a virtual walk. We look forward to rolling out the first national PFF Walk — perhaps in a city near you—in 2018.

These volunteer-organized events benefiting the PFF are key to raising both funds and awareness of this deadly disease.

Throughout September, your *Team PFF* events, social media posts, correspondence with legislators, and other spread-the-word projects contributed to another outstanding Pulmonary Fibrosis Awareness Month. With every year's observance, we raise more awareness and motivate more people to contribute to programs that improve diagnosis, treatment, care, and support for families living with PF.

I hope you'll also join us in "Dancing Toward a Cure," our year-end campaign, by sharing a video of your dance skills to help raise awareness and funds for PF. Your gift to the PFF brings us ever closer to a world without PF. Thank you for your courage and commitment — you are an important and valued part of the PF community.

Sincerely,



William T. Schmidt

PRESIDENT AND CHIEF EXECUTIVE OFFICER



New Chief Executive Officer & Board Chair Look to the Future

With a joint vision for moving the organization forward, the Pulmonary Fibrosis Foundation (PFF) welcomes new President and CEO William T. Schmidt and incoming Chair of the Board of Directors, George Eliades. Both began their new roles this summer.

SCHMIDT BRINGS STRONG HEALTH CARE ADVOCACY BACKGROUND

"After a comprehensive search process, the board is pleased to have found the best individual to lead the PFF," says Eliades. "Bill is a leader in healthcare advocacy, particularly in the areas of strategic planning, public policy, and fundraising. His expertise with volunteers and donors is already maximizing the impact of important initiatives like our biennial *PFF Summit* in Nashville and inaugural PFF Walk. We're poised for our next level of growth — and we think Bill will help us get there."

On working with Eliades and the board, Schmidt comments, "By nature, I'm someone who likes to collaborate, and I'm looking forward to working with the board to implement the strategic plan, track how we're doing, and make any needed adjustments as the medical research field changes rapidly."

Schmidt says that expanding and diversifying sources of revenue is one of the PFF's most important efforts for the foreseeable future. "You can have the best ideas, but if you don't have funding for them, they don't become a reality," he explains. "The PFF is a young organization and it's to be saluted for what it's accomplished in a relatively short period of time. We have the opportunity to build on that great work with our marketing and fundraising efforts."

Schmidt also sees further development of the PFF Care Center Network (CCN) and PFF Patient Registry as significant goals. "We know from other disease research communities that these are critical elements to speeding treatments and cures to patients, as well as reducing time to diagnosis," he says.

In his first several weeks on the job, Schmidt met with virtually every PFF staff member and some key volunteer leaders. "I've really been impressed with the staff's talent, commitment to patients and collaborative spirit," he says. "And the energy level and passion among volunteers is extremely high."

"I'm honored and grateful to the board for the opportunity to lead this exceptional organization," Schmidt adds. "Working with ambitious patient-led groups to eradicate disease has been my life's work. Together with the board, staff, and community, we can move toward a world free of the devastating impact of pulmonary fibrosis."



Bill Schmidt
President and CEO,
sets up his work space
and wears a Breathe
Bracelet on his first day
in the PFF office.



George Eliades,
Partner in Bain &
Company's San
Francisco office, has
joined the PFF as
board chair.

PATIENTS, CAREGIVERS

When the PFF reached out to Eliades several years ago, he immediately discovered that the work of the foundation marries a couple of his deep interests. "I've been working for a long time at the intersection of patient care with therapeutics, diagnostics, and data: what works and doesn't work," Eliades

says. "I got very passionate about what the PFF is doing, and became extremely interested in working with a foundation that's looking to transform patient outcomes through its own patient registry, a unique and powerful tool." Comments Schmidt of Eliades's new leadership role, "One of the reasons I became interested in the PFF was meeting George. He's a very smart guy who knows the biotech and pharma world very, very well. And his passion for what we do here is obvious."

The diverse individuals serving on the board "are incredibly committed and generous with their time and money," Eliades says. Working with Schmidt and the staff, Eliades sees the board's role as "enabler of the PFF strategy."

He explains, "We have a great, accomplished staff, and I want to make sure they have the resources they need to deliver on the strategic plan." Among the tasks he sees as most pressing: further developing the CCN and registry, stepping up advocacy for issues such as insurance coverage of oxygen, and continuing to encourage development of new drugs.

"I also want us to stay highly focused on our patients," Eliades adds. "Some parts of our work, like the PFF Patient Communication Center, don't get as much notice and attention, but they're amazing resources that are vitally important to our patients and their caregivers."

Eliades continues, "We've accomplished so much already, and I think we'll truly move the needle on this disease in the next five years. Moving the ball forward, making sure patients and caregivers are as healthy and supported as possible, is what gets us up in the morning."

“Working with ambitious patient-led groups to eradicate disease has been my life’s work. Together with the board, staff, and community, we can move toward a world free of the devastating impact of pulmonary fibrosis.”

WILLIAM T. SCHMIDT

PFF President and CEO

- Veteran health care advocacy executive with more than 25 years of experience
- Most recently served as CEO of the Foundation Fighting Blindness, Inc. (FFB), where he managed the largest non-governmental source of funding for retinal degenerative disease research in the world, grew annual revenues from \$16 million to \$40 million, and helped lead a major gifts campaign that raised over \$110 million for vision research
- Has held senior executive roles at several health advocacy organizations, including the Epilepsy Foundation of America and the Juvenile Diabetes Research Foundation
- Received a JD from DePaul University College of Law; completed the Kellogg Graduate School of Management’s Executive Development Program; graduated with honors from Amherst College
- Originally from Evanston, Illinois, and calls his return to Chicago “a nice homecoming”

GEORGE ELIADES

Chair, PFF Board of Directors

- Partner in Bain & Company’s San Francisco office, expert in Bain’s healthcare practice
- Nearly 15 years of management consulting experience
- Primarily advises clients in biotech and pharmaceuticals sectors; his work spans commercial and development organizations and multiple therapeutic areas, with extensive experience in oncology, neurology, endocrinology, ophthalmology, and many other specialty products
- Expertise in products relating to multiple cancer indications, biosimilars, and diagnostics, including next-generation sequencing strategy from both pharma and diagnostics business perspectives; has also advised nonprofit clients in the healthcare sector
- Received an MA and PhD from Harvard University; graduated *magna cum laude* with highest honors from Harvard College
- Member of the PFF Board of Directors since 2016

A WARM THANKS TO MIKE HENDERSON

As Eliades succeeds Michael C. Henderson, board chair from 2014-17, both he and Schmidt have very positive reflections on Henderson’s service. Founder and chair of Albina Community Bank from 1995 until his 2009 retirement, Henderson was diagnosed with idiopathic PF in 2004 and received a double lung transplant in 2006. He’s a facilitator of PF and lung transplant support groups in Seattle and Portland.

“Mike gave enormously of his time and talent as board chair,” says Schmidt. “The PFF had a lot of significant growth during his tenure; a nice foundation has been laid from which we can really take our organization to the next level.”

“As board chair and vice chair, Mike has helped the foundation flourish for years,” Eliades says. “Under his and Patti Tuomey’s stewardship, the PFF established the Care Center Network, enrolled 1,000 patients in the PFF Patient Registry, merged with the Coalition for Pulmonary Fibrosis, and established itself as the most important advocacy group for PF.

“He’s also one of the most level-headed, thoughtful guys you’ll meet,” Eliades continues. “I’ve been grateful that he’s offered his mentorship during the transition, and I know he’ll continue his valuable service on the board.”

PFF Patient Registry Open for Studies

With its first acceptance of study proposals from researchers, the Pulmonary Fibrosis Foundation (PFF) Patient Registry meets a major milestone.

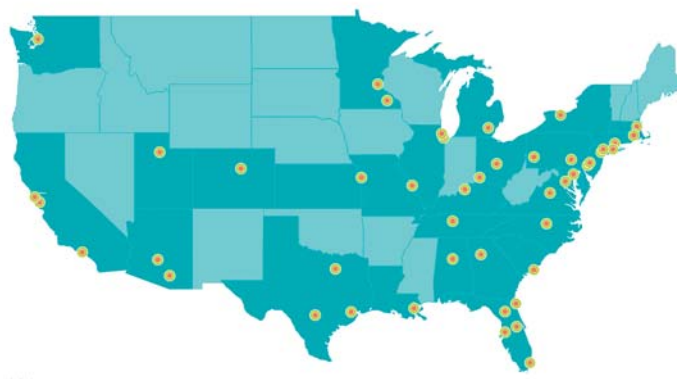
An invaluable research tool available in the fight against PF, the registry invites people living with pulmonary fibrosis (PF) to share detailed medical information that will be used for research. The registry contains information about how each person's diagnosis was made, symptoms, medical test results, the use of medications, and will even capture information about how people are doing years after enrolling.

All registry data comes from patients seen at PFF Care Center Network (CCN) sites, ensuring standard collection of high-quality information. The information is always de-identified for patient anonymity. Enrollees may choose to contribute a blood sample to be stored in the registry's biorepository for future research. When combined with the information in the registry, these samples will help scientists better understand the causes of PF, improve the ways doctors diagnose and manage people living with PF, and help discover new treatments.

ROBUST RANGE OF RESEARCH TOPICS

The first round of study submissions drew seven proposals. Most are from investigators working within the CCN, but other researchers may apply as long as they partner with a CCN investigator.

"There's a great deal of enthusiasm out there among researchers," says Rex Edwards, PFF Vice President, Care Center Network and PFF Patient Registry, adding that the first round of proposals touched on a wide cross-section of data aspects from the registry and biorepository.



Research topics in the initial group included patient characteristics driving use of anti-fibrotic medications and confidence in diagnosis, how the distance patients live from CCN sites affects diagnosis and care, prognostic biomarkers in biorepository samples, and more.

"It's still early in the life of the registry, and it's important to remember that much research requires a longer patient follow-up period," Edwards says. "But we're really impressed by the number and thoughtfulness of the proposals we've received. We expect a fairly dramatic uptick in the number of proposals we'll review in the next round."

Proposals are reviewed three times a year. Acceptance decisions are made within about 12 weeks, with an aim of research abstracts being ready for major conferences like the American Thoracic Society Conference, ERS Lung Science Conference, and CHEST Annual Meeting.

The next window for submissions will be in or near January 2018. Visit pffpatientregistry.org for details on submitting a research proposal.

“There’s a great deal of enthusiasm out there among researchers”

PFF REGISTRY AT A GLANCE

As of October 30, 2017

Total enrollment	1,506
% participating in biorepository	89
Average follow-up time of participants	8 months
Approximate data completion	96

Patient diagnosis (% of enrollments)

IPF	56.7
Idiopathic interstitial pneumonia (other than IPF)	11.6
CVD/Autoimmune	17.3
Hypersensitivity pneumonitis	9.2
Drug or occupational exposure	1.2
+ other	4.0



MEETING OTHER MILESTONES

In addition to opening for research studies, the registry has met other significant targets for size and quality.

“Our CCN sites have done an excellent job of enrolling patients,” says Edwards. “We get 100 new patients every 30 to 45 days, which is tremendous.”

In addition, “we are building a significant amount of follow-up data on our enrollees” Edwards adds. “On average, we have eight months of follow-up, and over a year for some patients. We’re building a longitudinal data set that allows investigators to conduct meaningful research.”

The registry asks CCN sites to complete a set of detailed informational forms for each patient, and “sites are staying on top of this,” Edwards reports, explaining that an impressive 97% of requested forms are being submitted.

The registry is actively seeking funding to take its enrollment from the initial goal of 2,000 patients to 6,000 and beyond. “We expect to have an even larger registry as soon as that expansion is funded,” Edwards says.

If you’re a patient being treated at one of the CCN sites and would like to enroll in the registry, speak to your care team about your interest.

“We’ve made exceptionally good progress, but we’re not there yet,” Edwards says. “Participation takes very little effort on patients’ part, but it makes a huge difference in our understanding of PF.”

Inaugural PFF Walk Unites Pulmonary Fibrosis Community from Across the Nation

On September 9, 2017 during Pulmonary Fibrosis Awareness Month, the pulmonary fibrosis community (PF) united to lead the way toward a world without PF at the inaugural PFF Walk.

This milestone event was held in Chicago's beautiful Lincoln Park on a sunny and breezy morning. More than 850 patients, caregivers, healthcare providers, and friends of the PF community came together to unite in the fight against PF.

"The Walk was definitely a positive experience for me," said Doug Wright from Battle Creek, Michigan, a PF patient who participated in the walk in Chicago. "I'm not in an area with a local PF support group, so, besides the doctor's office, I haven't been around other PF patients in any sort of group or organized event."

At the PFF Walk, members of the PF community had the opportunity to share their stories and build connections with other individuals and families—many of whom have similar experiences. The event welcomed special guests Mary Ann Ahern (NBC 5 Chicago), Tom Johnson (Director of Public and Board Relations, Better Business Bureau of Chicago and Northern Illinois), Dr. Sangeeta Bhorade (pulmonologist, Northwestern Memorial Hospital), and Heather Kagel (PFF Ambassador, patient) as speakers in the opening ceremony that also aired live on the PFF's Facebook page.

Participants could choose from a one- or three-mile route. The one mile route led walkers through the scenic pathways of Lincoln Park, and the three mile walk extended onto the lakefront with a beautiful view of Lake Michigan and the Chicago skyline. The Foundation also offered a special route called the Lung Distance Lap. The lap provided a more accessible option for patients and circled the event site with easy access back to the celebration area at any point during the lap.

"When I saw other patients packing their oxygen support, [I understood] that there is a significant amount of solidarity and a quality I've called *stick-to-it-iveness* among patients stricken with this disease," Doug continued. "It was great to see them out there."

After the walkers returned from their routes, participants gathered back at the walk site to celebrate their accomplishments with lunch.

More than 200 additional walkers participated in the walk virtually, representing 40 states and four countries, including Belgium, France, Ireland, and Australia. The Foundation encouraged those who could not be present in Chicago to register as virtual walkers and to participate by raising funds, building a team, and walking in their own community on September 9, or on a day that worked best for them.

"For me, the virtual walk gave me the opportunity to do something that felt productive," said Katie Howard from Overland Park, Kansas, who participated in the virtual PFF Walk. "When my mom called to tell me my dad had been diagnosed with idiopathic pulmonary fibrosis, it was a shock because I had never heard of PF before. Since my dad's diagnosis in April 2017, I have felt like there was nothing I could do to help "fix" him. The walk allowed me to focus some of that energy on raising awareness among my friends and family members."

"The team I started had walkers from at least five states and it was so uplifting to see so many people come together to show my family support and love!" said Katie.

The PFF wishes to extend its deepest gratitude to the PF community for making the inaugural PFF Walk a milestone success. The PFF Walk will return to Chicago in September 2018, and is expected to branch out to even *more* U.S. cities next year—stay tuned for more information.

For more information or to be added to our newsletter, please contact Amy Kozyra at akozyra@pulmonaryfibrosis.org or 312.878.2351. Mark your calendars and lead the way with us in 2018!

BOTTOM LEFT:

Mary Ann Ahern of NBC 5 Chicago welcomes guests to the PFF Walk.

TOP RIGHT:

Heather Kagel, patient and PFF Ambassador, tells her story and encourages others to share their own.

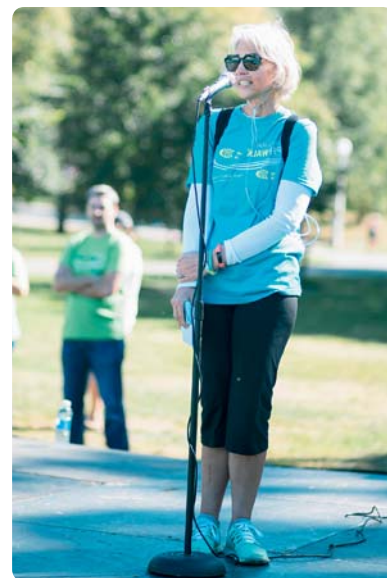
BOTTOM, THIRD ROW, TOP:

Doug Wright, PF patient from Battle Creek, Michigan, traveled to Chicago to participate in the inaugural PFF Walk.

BOTTOM, THIRD ROW, BOTTOM:

Walkers from Belgium participate in the virtual PFF Walk. Participants from three additional countries, including Australia, France, and Ireland also participated.

“More than 850 patients, caregivers, transplant recipients, those who have lost a loved one, healthcare providers, and advocates of the PF community came together to unite in the fight against PF.”



The Foundation's original goal was to raise a total of \$70,000 from the PFF Walk. But through the dedicated fundraising efforts of more than 117 teams, participants of the PFF Walk raised a groundbreaking \$238,000 and counting!



PFF Summit 2017

Nashville, Tennessee • November 9-11

Presented by the *Pulmonary Fibrosis Foundation*

What happens when patients meet scientists? *PFF Summit 2017* proved once again to be the pulmonary fibrosis (PF) community's premier event to connect patients, researchers, and industry professionals.

This year's *Summit*, held November 9-11 in Nashville, Tennessee, opened its doors to more than 800 attendees from throughout the United States and internationally—our largest *Summit* attendance to date!

Started in 2011 and held biennially, the *PFF Summit* welcomes anyone who has been affected by pulmonary fibrosis. At the *Summit*, patients, caregivers, transplant recipients, and those who lost a loved one are joined with a diverse group of physicians, researchers, allied health professionals, and industry representatives to collaborate, learn, and drive the need to find a cure for this devastating disease.

PATIENTS FIND THEIR VOICE AT PFF SUMMIT

For patients, some of the most notable activities at the *Summit* are the breakout sessions. This year, non-industry attendees were categorized into three groups based on their experiences: recently diagnosed patients and their caregivers, those who have been living with PF, and those who are currently transplant recipients or have lost a loved one.

Attendees were encouraged to participate in sessions that were tailored to their experiences and interests. Sessions included a wide range of topics, such as understanding PF, treatment options, how the Foundation can help them throughout their journey, and how to get involved in advocacy and fundraising. To view the full program and sessions from *PFF Summit 2017*, please visit:

pffsummit.org/program.html.

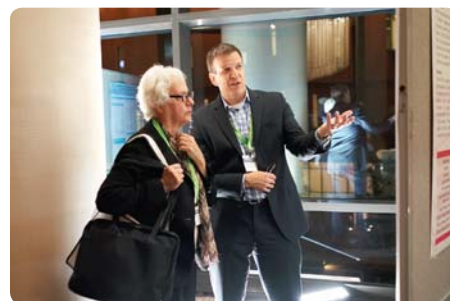
"I wanted to go to the *Summit* so I can find out as much as I can about PF and IPF," said Glenda Rouland, a PF patient from Mountain Brook, Alabama. "I want to be educated on what my diagnosis is about, talk to my doctor as an empowered patient, and hear about what treatments are in the pipeline."

While all attendees were welcome to attend any session at *Summit*, the tailored sessions provided a platform for learning, dialogue, relationship building, and ultimately, emotional healing.

POSTER PRESENTATION: VISUALIZING THE LATEST RESEARCH

As part of the Foundation's commitment for collaboration, the *Summit* held a scientific poster presentation, an ideal opportunity to see a snapshot of 78 current research projects and speak with researchers who are working tirelessly to help improve understanding of PF.

Academic posters were evaluated by the Foundation's Scientific Advisory Committee selection panel. The top six poster presenters were recognized at the Networking Dinner, and briefly presented their research during sessions in the following days. In addition to cash prizes, travel awards were granted to all six presenting authors.



View Recorded Sessions

Did you miss the *PFF Summit 2017*? You can watch recorded sessions and coordinating slide decks of the event right on your computer, mobile phone, or tablet! Each recorded session will be available after the new year at pffsummit.org/archive.html.

“The Summit fosters a collaborative environment to improve education and awareness of PF”

TOP THREE WINNERS

Taylor Adams

Yale University, School of Medicine

Single cell RNA-sequencing of thousands of cells from IPF lungs reveals cellular diversity of distinct cellular populations

Cecilia Gonzalez Sanchez, PhD

Tulane University Health Sciences Center

Chaperone Mediated Autophagy, a Critical Modulator of Pulmonary Health and Fibrosis

Lida Hariri, MD

Massachusetts General Hospital

Endobronchial Optical Coherence Tomography for Low-Risk Microscopic Assessment and Diagnosis of UIP/IPFs

HONORABLE MENTIONS

Ankita Burman

Vanderbilt University Medical Center (VUMC)

ER stress effector CHOP augments AEC apoptosis and worsens lung fibrosis

Justin Hewlett

Vanderbilt University Medical Center (VUMC)

Clinical features and outcomes associated with telomere pathway mutations in Familial Interstitial Pneumonia

Susan S. Jacobs, RN, MS

Stanford University Medical Center

Patient Perceptions of the Adequacy of Supplemental Oxygen Therapy: Results of the American Thoracic Society Nursing Assembly Oxygen Working Group Survey

Posters were kept on display until completion of the conference on Saturday.

The Poster Presentation was made possible by our presenting sponsors, and by a generous donation made by Hales Family Foundation.

CONTINUING EDUCATION FOR HEALTHCARE PROFESSIONALS

Each year, the *Summit* provides continuing medical education (CME/CE) for healthcare professionals in accordance with the Essential Areas and policies of the Accreditation Council for Continuing Medical Education (ACCME). Concentrating on the science and disease mechanisms of PF, this year's sessions examined genetics, environmental influences and advances in diagnosis, and therapeutics. CME/CE credits for this program were offered to physicians, researchers, registered nurses, and allied health professionals. This year, the PFF was proud to include respiratory therapist and pharmacist credits based on an increased interest from the 2015 conference.

Another unique offering in CME/CE this year is a series of multiple CME/CE certified enduring activities jointly developed in partnership with Global Academy for Medical Education and Post Graduate Institute for Medicine. These activities, which will launch in early 2018, will provide conference highlights and key takeaways to a broader audience of practitioners. Activities will include onsite interviews with faculty speakers, an audio-recorded roundtable discussion of clinicians, patients and caregivers focusing on improving clinician-patient partnering, and an enduring print and digital conference highlights activity to *CHEST Physician* derived from *Summit* sessions, which will extend the reach and accessibility of the conference's education far beyond, and long after, the end of the meeting.

All enduring CME/CE activities are supported by educational grants from Boehringer Ingelheim Pharmaceuticals, Inc. and Genentech, Inc.

THE PFF COMMUNITY IN MUSIC CITY

Nashville was the perfect destination to capture the spirit of the *PFF Summit 2017*. The PFF's strong tie to our Care Center Network site at Vanderbilt University, and the proximity of so many active support groups nearby made Nashville the perfect destination for the *Summit*.

Want to make sure you're the first to know about the next *PFF Summit*? Sign up for our newsletter at pulmonaryfibrosis.org, and be sure to follow us on Facebook, Twitter, and Instagram at [@pfforg](https://twitter.com/pfforg).

Stay tuned for the announcement of *PFF Summit 2019*!



PFF Summit 2017

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PFF Volunteer Strategic Plan Lights a Path to Future

“As the PFF has experienced exponential growth over the past few years, we’ve realized we could do even more to be sure the volunteer programs are run effectively for both volunteers and the PFF”



In the most successful organizations, all stakeholders — board, staff, and volunteers — are working together toward common goals. Building on the Pulmonary Fibrosis Foundation’s (PFF) strategic plan, PFF2020, the new Strategic Plan for Volunteer Engagement 2017-2020 is bringing clarity, guidance, and inspiration to PFF’s valued volunteers.

“As the PFF has experienced exponential growth over the past few years, we’ve realized we could do even more to be sure the volunteer programs are run effectively for both volunteers and the PFF,” says Kate Gates, PFF Director of Programs. “The Strategic Plan for Volunteer Engagement 2017-2020 ensures that volunteers have a clear understanding of how they fit into the organization, that staff understand how much all volunteers are contributing, and that we have a process to periodically review volunteer roles and opportunities and adjust them as needed.”

Created with substantial input from different volunteer constituencies, plus PFF employees and board members, the plan “is broad-based and works for all our volunteer groups,” Gates says. Efforts are divided into three areas:

- **Culture and Commitment**—Build capacity by embracing a culture of collaborative, high-impact volunteer engagement across the PFF and the PFF Care Center Network.
- **Best Practices**—Enhance impact through consistent volunteer engagement best practices across all departments and programs.
- **Training**—Increase staff and volunteer competency, effectiveness, and impact through enhanced training.

The emphasis on training is of particular interest to both current and potential volunteers, Gates says. “We heard at our last volunteer meeting that volunteers really enjoy and get a lot from our training, so we’re enhancing our efforts, providing more and in some cases different training.”

For each of the three areas, the plan includes specific goals and objectives that define how those goals will be achieved. For example, one of the **Culture and Commitment** goals is building organizational support for volunteer engagement; an objective to help reach that goal is developing PFF staff standards for engaging and supporting volunteers. **Best Practices** goals include maximizing volunteer impact by supporting volunteer success; a supporting objective is creation of a PFF Volunteer Handbook. Ensuring volunteers are competent and empowered is one of the **Training goals**; an associated objective is developing and providing role-specific training.

“Through the collective goals and objectives of the plan, the PFF will gain access to skills, talents, networks, and resources of a community of volunteers committed to helping those affected by pulmonary fibrosis,” Gates says.

For more information on the Strategic Plan for Volunteer Engagement, 2017-2020, contact Kate Gates at kgates@pulmonaryfibrosis.org or 312.224.9820.

VOLUNTEER ENGAGEMENT VISION

Mobilizing volunteers through impactful service to work as partners with the PFF to build a world without pulmonary fibrosis.

THE VOLUNTEER PLAN’S VALUES

- **Appreciation**
- **Commitment**
- **Compassion**
- **Integrity**
- **Positivity**
- **Professionalism**
- **Respect**



Pulmonary Fibrosis Community Rallies to Create Legislative Change

From meeting with legislators' staffs, to promoting healthcare policy awareness on social media, to testifying before a federal agency, the Pulmonary Fibrosis Foundation (PFF) staff and volunteers are active in advocacy efforts for the pulmonary fibrosis (PF) community.

PFF REPS HIT THE HILL

As part of a push to increase the PFF's presence in legislative issues, PFF staff and volunteers visited Capitol Hill in Washington, DC, on May 22 for the inaugural PFF Hill Day. The 22 participants held 56 meetings with congressional staffers to spread awareness and support for PF research funding.

"We had three asks: increase funding for the National Institutes of Health by \$2 billion in fiscal year 2018, provide a total of \$2.8 billion in funding for the U.S. Food and Drug Administration (FDA) in FY2018, and increase awareness of PF among members of Congress," says Kate Gates, PFF Director of Programs. Through a simultaneous social media campaign, volunteers who weren't able to travel to Washington communicated the same requests to their legislators from home.

The PFF has participated in previous Hill trips focusing more generally on rare diseases, but this is the first time a visit has been devoted solely to increasing awareness and action for PF. "This was an exciting milestone for us, the first chance we had to go in and speak about the specific issues and effects on our community," Gates says.



ADVOCATING FOR ACA PROTECTIONS

This summer, the Graham-Cassidy plan and the Better Care Reconciliation Act (BCRA) were proposed with the intent to repeal and replace the Affordable Care Act (ACA). As the plans were debated in the U.S. Senate, the PFF stepped up its advocacy efforts in this area.

"Members of our community are really dependent on their health care services, and vulnerable members could be strongly affected if they lost some of those services," Gates explains.

With the support of the PFF medical team, "We sent messages, mostly through social media, encouraging our constituents to contact their senators to advocate for keeping the basic protections in the ACA, including pre-existing conditions and Medicaid expansion."

POSSIBLE PATH TO MORE SUCCESSFUL TRANSPLANTS

Pulmonary fibrosis is one of the leading reasons for lung transplantation — but, although about 1,200 PF patients receive transplants each year, more than 40,000 die of the disease. Many are eligible for a lung transplant, but getting healthy lungs to patients in time for successful surgery is a continuing challenge.

“This was an exciting milestone for us, the first chance we had to go in and speak about the specific issues and effects on our community”

“When a lung is removed from a donor, there’s a time limit to how long it can be utilized,” says PFF Chief Medical Officer Gregory Cosgrove, MD. “It would be great not to need transplants, but until that day arrives, we have to make use of all donor lungs, so that every patient who’s able to have a transplant can do so.”

Dr. Cosgrove was invited to participate and testify on May 17 before that agency’s Gastroenterology and Urology Devices Panel, advocating for interventions that could improve the lives of patients with PF. The focus of the panel was the TransMedics Organ Care System (OCS) Lung System, a new, portable system that maintains lungs in a warm, functioning state.

“This device has the potential to improve the lives of patients with IPF. It increases the time from explantation to implantation without significant degradation of the lung. That’s especially important when a lung is traveling across long distances to reach the recipient,” Dr. Cosgrove explains.

“The focus of my testimony was to provide the PF patient perspective, educate the panel on the severity of this disease, and explain the urgency of finding new ways to increase the number of lungs available to patients,” Dr. Cosgrove explains, adding that he was encouraged by the openness with which FDA representatives heard his and others’ testimony.

At this time, the FDA is recommending further study of the TransMedics OCS System prior to possible approval of the device.



Gregory P. Cosgrove, MD (left), Legislative Aide for Henry Cuellar, PhD (center), and Boehringer Ingelheim #BreathlessIPF spokesperson, Bernie Williams (right).

EXPAND YOUR OWN ADVOCACY SKILLS

To learn more about legislative and social media advocacy designed especially for volunteers please contact Kate Gates at kgates@pulmonaryfibrosis.org.

We Let the World Know!



San Francisco City Hall lit up blue on September 19.

This September, we generated awareness for those who have been impacted by pulmonary fibrosis (PF) worldwide during Pulmonary Fibrosis Awareness Month. From sharing stories on social media and hosting fundraising events, to officially declaring September PF Awareness Month in numerous cities and states, members of the PF community united to raise awareness and funds for research.

GO BLUE: #BLUEUP4PF

September was the perfect opportunity to participate in our social media campaign, #BlueUp4PF. This campaign encouraged participants to take a picture while wearing as much blue as possible, then share the image on social media. Some wore blue from head to toe, including dyeing their hair blue or wearing wigs. Participants also posed with a selfie sign of their location, reinforcing the widespread impact of PF.

Last year, the Foundation was thrilled to announce that the Wrigley Building in Chicago participated in #BlueUp4PF. This

year, we had an extraordinary 14 sites join our lighting campaign and radiate blue in recognition of PF Awareness Month. From the Willis Tower in Chicago, to Niagara Falls in New York, to San Francisco's City Hall, renowned landmarks and iconic structures nationwide helped us shine the light on PF.

PORTRAITS OF PF

The ever-popular Portraits of PF series on Facebook returned to share stories of patients, caregivers, and others in the PF community. These incredible journeys were shared every weekday of September. Because of the increasing popularity of

- Palmer House Hilton, Chicago, Illinois (9/1-30)
- Willis Tower, Chicago, Illinois (9/1-3)
- Silverline Center, Tysons Corner, Virginia (9/8)
- Capital Wheel, Oxon Hills, Maryland (9/9)
- UT Health San Antonio, San Antonio, Texas (9/14)
- City Hall, Buffalo, New York (9/15)
- Wrigley Building, Chicago, Illinois (9/16-17)
- City Hall, San Francisco, California (9/19)
- Pennsylvania State Capitol, Harrisburg, Pennsylvania (9/23)
- Parthenon, Nashville, Tennessee (9/23)
- Union Station, Kansas City, Missouri (9/23)
- Central Library of Rochester and Monroe County, New York (9/26-30)
- Peace Bridge, Buffalo, New York (9/29)
- Niagara Falls, New York (9/30)



Kathy Galdine from Bronx, New York, participated in #BlueUp4PF in memory of her father.

“Members of the PF community have worked hard to raise awareness and funds”

Portraits of PF, we have begun a new campaign, Share Your Story, in which individuals can share their stories with us all year long. You can read the stories from Portraits of PF on our Facebook page, and submit your own story to us at socialmedia@pulmonaryfibrosis.org.

TWIBBON AND THUNDERCLAP

On September 1 at approximately 9:00 a.m., we kicked off PF Awareness Month with a Thunderclap and Twibbon campaign that helped ignite awareness of pulmonary fibrosis on social media. Thanks to more than 280 participants in the Thunderclap, our message, *“This September for Pulmonary Fibrosis Awareness Month, I’ll #BlueUp4PF in support of those living with the disease!”* reached 371,513 people on social media! Supporters also spread awareness through

Twibbon, which enabled our social media followers to proudly place a PF Awareness Month filter over their profile image.

30 FACTS IN 30 DAYS

Every day in September, the PFF posted a fact about PF on Facebook, Twitter, and Instagram. Many members of the PF community passed the facts along on social media to a wider audience.

PROCLAMATIONS

The Foundation provided sample proclamations as a starting point for members of the community to reach out to their local officials, and the community did not disappoint. This year, we received 17 city and state proclamations from all over the country, as well as a resolution from the United States senate!

PROCLAMATIONS

Mayor Frank Brocato, Hoover, Alabama

Mayor Ken Ritter, Youngsville, Alabama

Governor Daniel Malloy, Connecticut

Mayor Bob Huber, Simi Valley, California

Mayor Stan Ridgeway, Eagle, Idaho

Mayor Tammy de Weerd, Meridian, Idaho

Mayor Rahm Emanuel, Chicago, Illinois

Mayor Stewart Welch,

Mountain Brook, Louisiana

Governor Eric Greitens, Missouri

Governor Kate Brown, Oregon

Mayor Ted Wheeler, Portland, Oregon

Governor Tom Wolf, Pennsylvania

Mayor Nirenberg, San Antonio, Texas

Governor Henry McMaster, South Carolina

Governor Jay Inslee, Washington

Mayor Tom Trulove of Cheney, Washington

Governor Jim Justice, West Virginia

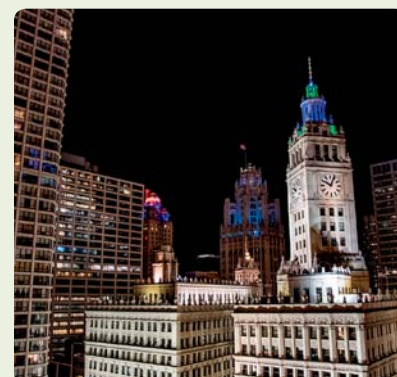
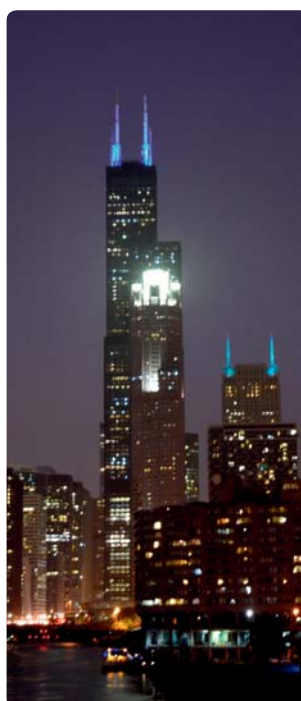
CLOCKWISE FROM LEFT:

Glenda Rouland, IPF patient from Mountain Brook, Alabama, received a proclamation declaring September as PF Awareness Month in her hometown.

The Willis Tower in Chicago, Illinois lit up blue for PF awareness from September 1-3. Chicago is home to the PFF's headquarters.

The Wrigley Building in Chicago, Illinois lit up blue for PF Awareness for the second year on September 16 and 17.

Nurses at Piedmont Pulmonology and Sleep Medicine participated in a Spirit Week during PF Awareness Month.



We Let the World Know!

PF AWARENESS EVENTS

PF Awareness Month is one of the best times of the year to fundraise. The Foundation is grateful for events that members of the PF community held in September to raise funds and awareness toward the battle against PF. Walks, barbecues and bowling tournaments were held in several states, including the 9th Annual Garden State Support Group 5K Run/Walk (New Jersey), the 7th Annual Ready.Set.Breathe! 5K (Indiana), and the 3rd Annual Jim Cormier Canal Walk for the Pulmonary Fibrosis Foundation (Massachusetts).

To read more about some of our notable Team PFF events that took place this September, please refer to page 19.

If you are interested in starting your very own fundraiser for the PFF, please contact Amy Kozyra, Director, Special Events, at akozyra@pulmonaryfibrosis.org or 312.878.2351 for tips and information about how to get started.

THE INAUGURAL PFF WALK

Our inaugural PFF Walk was a milestone success! The Foundation welcomed more than 850 walkers in Chicago and more than 200 virtual walkers. Together, we raised \$238,000 - more than triple our original goal of \$70,000. Read more about the PFF Walk on page 8.

“This year, we had an extraordinary 14 sites join our lighting campaign and radiate blue in recognition of PF Awareness Month.”



Participants celebrate PF Month and blue lighting at UT Health San Antonio.



The Dyke family from Auburn, Massachusetts participated in #BlueUp4PF.



The Capital Wheel at National Harbor in Oxon Hills, Maryland lit up blue for PF awareness on September 9.

Spotlight on Philanthropy

Team PFF Breaks Records In June

In June, Team PFF had its most successful month ever and the momentum has continued through the fall with the growth and expansion of community events across the country.

Terence Hales, a PFF board member, started the NYC Run-Walk-Hike for Pulmonary Fibrosis (PF) the year his father, Tom Hales, received a successful lung transplant. “This year’s event, our 10th, was the biggest yet in terms of participants and fundraising, with more than \$120,000 raised,” says Hales. “We’ve grown from a grassroots effort raising \$2,500 in our first year to a 10-year event total of over \$650,000.”

The annual Pete DeVito Memorial Foundation Golf Outing in Mt. Sinai, New York, was held for the seventh and last time in June. Nick DeVito, Pete’s son and the force behind the event, is transferring his volunteer energies to other areas, including serving on the PFF Board of Directors.

“Our last outing was bittersweet,” Nick DeVito says. “Celebrating the legacy of my father, Pete DeVito, was always a big part of our event, but raising awareness about idiopathic pulmonary fibrosis (IPF) was just as important. In our years hosting this event we’ve successfully done that, and we’re becoming a source of information and support for newly diagnosed IPF patients and their families on Long Island.”

The final DeVito golf outing raised \$30,000 for the PFF — funds that will be used to support a new learning track at the *PFF Summit*. Called Friends of PF, the track is designed for people who have lost friends and loved ones to the disease. Though they’re no longer caregivers, these individuals still want to be involved in the fight against PF.

Cindy Chandler, a Team PFF leader and a member of PFF Daughters Advocacy Working Group, is involved in several volunteer efforts, including legislative advocacy on Hill Day (see page 14). The 10th Annual Greg Chandler and Guy M. Solimano Memorial Golf Tournament was hosted in remembrance of her father and her husband, and attracted a record number of golfers this June. The event brought in \$27,945, the highest amount ever.

The energy, enthusiasm, and creativity of Team PFF event leaders continued through the summer. Events included the 2nd Annual Tee It Up with Twisters Golf Outing held by the Spadafore family, and two new events, Drive Fore Breathing Golf Outing in Stow, Massachusetts, organized by the Wholley- Rivers family, and the Birdies Fore Breathing hosted by Ann Wagner. Together, these event leaders raised more than \$15,000! From the Midwest to Boston, where Team PFF has notably increased its presence, event leaders are staging strong events.

Pulmonary Fibrosis Awareness Month in September also proved to be a record- breaking month with over \$333,000 in revenue!

In addition to the PFF Walk, community walks were held across the country. PFF Support Group Leader, Barbara Murphy, had a record-breaking year with \$20,000 raised at her 9th Annual Garden State 5K Run/Walk. Additionally, PFF Support Group leaders Debbie Herndon (Meridian, ID) and Beverly Wernet (Syracuse, NY) launched their walks this year with tremendous success and raised a combined \$22,500. The Cormier Family also saw significant growth in their 3rd Annual Jim Cormier Canal Walk by raising \$14,000, an increase of 40%.

“Communities are joining together and making a bigger impact as a group through Team PFF events,” says Amy Kozyra, PFF Director of Special Events. “That’s the vision we see for our future, and it’ll be a big piece of the PFF moving forward.”



TOP:
Attendees at the NYC-Run-Walk Hike gather after a successful event

LEFT:
The Annual Greg Chandler & Guy F. Solimano Golf Tournament enjoyed record attendance on a beautiful and sunny day.

RIGHT:
A little bit of rain couldn't stop the Pete DeVito Memorial Foundation Golf Outing from celebrating a successful final year.

INSPIRED TO CREATE A TEAM PFF EVENT OF YOUR OWN?

You can become a successful Team PFF leader—and the PFF can help. Visit pulmonaryfibrosis.org/get-involved/fundraise-for-team-pff for an event leader guide and welcome kit.

Spotlight on Philanthropy

Dancing Toward a Cure: Join us This December

Put on your dancing shoes — and let your smooth moves take us toward a cure for pulmonary fibrosis! Join us this giving season as we come together as a community to raise funds in our effort to eradicate pulmonary fibrosis. This December, the Pulmonary Fibrosis Foundation is calling for short videos of you and your friends, family, and colleagues “dancing toward a cure” to be shared on Facebook to raise awareness and funds for the programs our community needs most. Our goal is to raise \$125,000 and we need your help!

HOT TIPS: Even if you have two left feet, your video will raise important awareness and provide people with the opportunity to give. Get creative! Wear PFF colors (teal and green), sport your PFF Breathe Bracelets, and get wacky with signs and backgrounds! Challenge your friends, family, and medical team to join too!

If dancing's not your thing, the campaign is still an easy and rewarding way to honor a loved one, caregiver, patient base, or research facility this holiday season — all gifts made before December 31 are tax-deductible.

“It's a special time of year for many of us and our families,” says Miller. “Dancing Toward a Cure is a great way to make a big impact while honoring those closest to our heart.”

For more information, contact Amanda Miller at amiller@pulmonaryfibrosis.org.

TAKE ACTION. QUICK AND SIMPLE

- 1) Follow the campaign on the PFF's Facebook page today
- 2) Spread awareness and raise funds to support our community!
 - A) Record a 10 second video of you or your group “dancing toward a cure”
 - B) Post it to our Facebook page and include:
 - I) Why you're dancing toward a cure
 - II) How others can help – make a video themselves or donate today at pulmonaryfibrosis.org
 - III) A tag for the PFF (@PFForg) – this way we can share it too!
 - IV) The following hashtags: [#PFFdancechallenge](https://twitter.com/PFFdancechallenge) and [#pfforg](https://twitter.com/pfforg)
- 3) Share the PFF's campaign posts and emails so others can join in as well!
- 4) **Don't have Facebook?** No problem! Send your videos to development@pulmonaryfibrosis.org and we can share them for you. Campaign updates will also be made by email, so make sure you're on our email list!



“We have an amazing community dedicated to supporting each other and we can't wait to see the creative ways people will raise awareness and funds,” says Amanda Miller, the Pulmonary Fibrosis Foundation's Director of Major Gifts. “I think we'll be seeing some creative videos from our staff and medical team as well.”

Putting your Dollars to Work: PFF Researchers Make Strides

The Pulmonary Fibrosis Foundation (PFF) is pleased to announce the recipients of the 2017 Established Investigator and Junior Investigator Awards.

A key part of the PFF's mission is to fund research that will enhance pulmonary fibrosis (PF) patient care and identify potential treatments for the disease. The Research Fund to Cure Pulmonary Fibrosis was created to fund innovative grants for projects that may widen the base of knowledge about PF. The fund supports two types of grants awarded each year: the Albert Rose Established Investigator Award and the I.M. Rosenzweig Junior Investigator Award. Launched in 2012, these awards support projects that work toward an enhanced understanding of PF and encourage collaboration between industry and academic researchers.

Grants undergo a peer review process administered by the PFF's Scientific Advisory Committee. Each recipient will receive a \$50,000 grant distributed over two years. These awards are made possible by private gifts to the PFF and through the generous support of Boehringer Ingelheim & Pharmaceuticals, Inc.



ALBERT ROSE ESTABLISHED INVESTIGATOR AWARD



Cecilia Gonzalez Sanchez, PhD

Tulane University Health Sciences Center

Chaperone-Mediated Autophagy, a Regulator of (Myo)fibroblast Activation and Pulmonary Fibrosis

Dr. Sanchez is an assistant professor at the Tulane School of Medicine, Division of Pulmonary Diseases. Her laboratory focuses on understanding the mechanisms of signal transduction (cell signaling), autophagy (the degradation and recycling of cellular components), and epigenetic regulation in fibrogenesis (the development of fibers). Her goal is to develop new therapeutic paradigms for chronic fibrotic disorders, including idiopathic pulmonary fibrosis (IPF).

In this project, which is based on significant preliminary data, Dr. Sanchez will investigate the consequences of reduced chaperone-mediated autophagy (CMA)—an important process in regulating cell metabolism—in a specific type of lung cell. Dr. Sanchez's team will investigate biological samples from IPF patients and age/sex-matched controls to determine whether they are markers of progression in IPF patients.

Partnering with the Metabolomics Core at the University of California, Davis, and with experts in other fibrotic disorders, “We plan to move toward the potential use of CMA modulators

Putting your Dollars to Work: PFF Researchers Make Strides

in other models of pulmonary fibrosis and the clinical setting,” Dr. Sanchez explains. “I expect that our work will lead to a better understanding of the molecular pathogenesis of pulmonary fibrosis and provide a new therapeutic tool for its treatment.”

She adds, “My long-term goal is to understand the molecular mechanisms that regulate tissue remodeling, and to provide an intervention to prevent the development of uncontrolled pulmonary fibrosis. The PFF Award is crucial at this stage of my career to support my laboratory so that I may successfully compete for my first federal grant and continue research on pulmonary fibrosis. I expect funding from the Albert Rose Award to provide the data needed to compete at the federal level, and anticipate that future research along these lines will be sustained through this type of funding in the future.”



Steve M. Albelda, MD

The Trustees of the University of Pennsylvania

Use of T cells Directed to Fibroblast Activation Protein to Treat Pulmonary Fibrosis

DISCLAIMER: Contract is under legal review. Upon approval, this award will be funded by a grant from Boehringer Ingelheim Pharmaceuticals, Inc.

I.M. ROSENZWEIG JUNIOR INVESTIGATOR AWARD



Samuel Yoffe Ash, MD

Brigham and Women's Hospital

Quantitative Imaging Biomarkers in Early Interstitial Lung Disease: Progression and Susceptibility

Dr. Ash is a clinical/research fellow in Harvard-Brigham and Women's Pulmonary and Critical Care Fellowship Program. His research centers on quantitative analysis of CT imaging in acute lung injury as well as ongoing longitudinal analysis of CT imaging in lung transplant.

Quantitative imaging biomarkers are objective characteristics found in imaging that may indicate whether biologic processes are normal, pathogenic, or responsive to treatment — for instance, a change in tumor size for a patient with cancer or an assessment of brain atrophy for patients with multiple sclerosis. In this project, Dr. Ash will investigate whether the progression of interstitial radiographic features detected using quantitative imaging biomarkers is associated with decline in lung function, and whether those individuals who have both interstitial disease and emphysema are at increased risk of respiratory exacerbation and mortality.

The Research Fund to Cure Pulmonary Fibrosis was created to fund innovative grants for projects that may widen the base of knowledge about PF.

“A key part of the PFF’s mission is to fund research that will enhance pulmonary fibrosis (PF) patient care and identify potential treatments for the disease”

Depending on the results of the current project, Dr. Ash hopes to pursue other areas of study, including replicating his findings in other cohorts and modifying the technique to work in low-dose, lung cancer screening CT imaging. “With the rapid proliferation of lung cancer screening and the overlap of risk factors for lung cancer, emphysema, and interstitial disease, this would be an important adaptation to make,” he says.

“Funding from this grant will allow me to continue to develop this method and, more specifically, will enable me to pay for image processing and technician costs necessary to support this work,” Dr. Ash says. “I believe that this or a similar approach may someday prove an indispensable tool for grading the severity of interstitial disease, monitoring treatment response and disease progression, and identifying patients who would most benefit from early therapeutic interventions.”



Robert Guzy, MD, PhD

The University of Chicago

Mechanism of Gremlin-1 in Pulmonary Fibrosis

Dr. Guzy is an assistant professor in the University of Chicago Department of Medicine, Division of Pulmonary/Critical Care. His research focuses on the mechanisms involved in recovery from lung injury, and how aberrant recovery from injury leads to fibroblast (connective cell tissue that plays a critical role in wound healing) activation and the development of pulmonary fibrosis.

“The goal of my research is to understand the mechanisms regulating how lung epithelium, endothelium, and fibroblasts interact following injury to promote repair following lung injury and Acute Respiratory Distress Syndrome (ARDS), as well as pathological fibroblast proliferation resulting in a variety of lung diseases, including PF,” Dr. Guzy explains.

Results from his experiments in this project will be instrumental in establishing the requirement for Gremlin-1 — a protein-coding gene — in the pathogenesis of pulmonary fibrosis. These studies also will establish the role of fibroblast-derived Gremlin-1 in fibrogenesis.

This award is funding models, reagents, and preliminary data needed to pursue future independent studies on the mechanisms of Gremlin-1 signaling in PF, and will provide novel mechanistic insights and the potential to develop cell-specific therapeutics, Dr. Guzy says.

Results from this project will be the basis of future studies investigating regulation of Gremlin-1 expression, mechanisms of Gremlin-1 mediated fibrosis, and potential therapeutic interventions targeting this pathway, Dr. Guzy adds. “These studies will be the basis for establishing an independent research program and future independent (R01-level) grant applications. I anticipate that this proposal will lead to future studies that will identify fibroblast-specific pathways involved in the development of PF.”

For those interested in applying for a grant through the PFF Research Fund to Cure PF, our 2018 cycle for Letters of Intent (LOI) are now open with a deadline in late November. All LOIs and full proposals are to be submitted through online portal proposalCENTRAL at <https://proposalcentral.altum.com/>. The PFF does not accept emailed applications. For any further questions, you may email grants@pulmonaryfibrosis.org.

Andy Tager: A Legacy of PF Research



ANDY TAGER: A LEGACY OF PULMONARY FIBROSIS RESEARCH

Andrew M. Tager, MD, a significant and beloved figure in the pulmonary fibrosis (PF) research community, passed away on August 11, 2017. A member of the Pulmonary Fibrosis Foundation (PFF) Medical Advisory Board and Research Advisory Forum, Dr. Tager was Director of the Massachusetts General Hospital (MGH) Fibrosis Research Program; Principal Investigator, MGH Center for Immunology and Inflammatory Diseases; Associate Physician, MGH Pulmonary and Critical Unit; and Associate Professor of Medicine, Harvard Medical School. He was a recipient of the Marvin I. Schwarz Research Award in Pulmonary Fibrosis for his leadership in efforts to find a cure for PF, as well as the American Thoracic Society's Recognition Award for Scientific Accomplishments.

At a recent meeting of about two dozen researchers attended by PFF Chief Medical Officer Gregory Cosgrove, MD, four attendees had independently added slides honoring Dr. Tager in their presentations. "That suggests the tremendous impact he had on the field," says Dr. Cosgrove.

"Andy identified important molecular pathways, LPA (lysophosphatidic acid) and S1P-S1P1, for lung and other forms of fibrosis," Dr. Cosgrove continues. "That may have a major impact and could improve the lives of many individuals. In addition to being an intelligent and revolutionary scientist, he was a truly kind and energetic individual, passionate about everything that he did, and especially about his family. Andy made it cool to be a scientist and cool to be nice. He set that example."

Added Naftali Kaminski, MD, a PFF board member and the Boehringer Ingelheim Endowed Professor of Medicine and Chief of Pulmonary, Critical Care, and Sleep Medicine at Yale School of Medicine, "Andy Tager was a superb physician scientist, a generous collaborator, and a dedicated mentor. For IPF patients, he made a huge difference—as a scientist, by discovering new molecular pathways that are now tested in the clinic; as a physician, by caring for those patients; and as an opinion leader, by advocating for us. He was the ultimate 'mensch,' always positive and never self-serving. At a recent meeting, I almost imagined seeing him smiling delightedly and supportively — as he always did — while a trainee presented a poster, and was sad to realize this will not happen again."

Barry Shea, MD, Assistant Professor of Medicine at Brown University, was a postdoctoral fellow in the Tager lab at MGH. "Andy epitomized what it meant to be a mentor, deriving more joy and satisfaction out of his trainees' successes than his own," says Dr. Shea. "And for those of us fortunate to work in his lab, Andy provided so much more than scientific and career mentorship — he was a friend, a big brother, and a father-figure. His combination of intelligence, humility, humanity, and generosity were unmatched, and his enthusiasm for science was infectious. His impact on the field was and will continue to be profound."

Dr. Tager is survived by his wife, Carolyn Ho, his son, Sam Tager, and many extended family members. Donations may be made to the MGH Fibrosis Research Center, which has been renamed in his memory.

"In addition to being an intelligent and revolutionary scientist, he was a truly kind and energetic individual, passionate about everything that he did, and especially about his family."

Save the Date!

Save the Date for Broadway Belts for PFF! 2018

MARCH 12
EDISON BALLROOM, NEW YORK CITY

The Pulmonary Fibrosis Foundation (PFF)'s annual star-studded tribute to Broadway returns Monday evening, March 12, in the historic Edison Ballroom in New York City, New York.

Early-bird tickets to *Broadway Belts for PFF!* are available now—and make a great gift for the holidays. Treat your family and friends to a stellar evening of entertainment while benefiting the Foundation's programs to improve the lives of pulmonary fibrosis (PF) patients and their caregivers and families.

Actress, comedian, and PF advocate Julie Halston will again host this year's event, which will feature a cast of Broadway's brightest stars performing their smash hits and original pieces. Expect a glittering evening of highly acclaimed actors, actresses, comedians, impeccably crafted cocktails, and a four-course plated dinner.

Last year's sensational performances included Grammy-winner Stephanie Mills (*The Wiz*), Mandy Gonzalez (*Hamilton*, *In the Heights*), Orfeh (Tony-nominee for *Legally Blonde*), Lucas Steele (*Natasha, Pierre & the Great Comet of 1812*), James Snyder (*If/Then*, *Cry-Baby*) NBC's Gus Rosendale ("The Weekend Today in New York"), Stephanie J. Block (*Falsettos*, and Tony-nominee for *The Mystery of Edwin Drood*), Mario Cantone ("The View"), Robert Creighton (*Cagney*), and Tony-winner Randy Graff (*City of Angels*, *The Babylon Line*).

Sponsorship options, including naming opportunities, are available for this can't miss event of 2018!

For individual tickets or details about sponsorships, contact Amy Kozyra at akozyra@pulmonaryfibrosis.org or 312.878.2351.



Our 2017 event was the biggest yet, raising nearly \$250,000 for the Foundation's programs—And we hope to surpass that record!

Calendar



NOVEMBER 16

"Breathe Easier" Better Breathers Support Group

Cass City, Michigan

NOVEMBER 18

MollyK 5K Run/Walk

Burke Lake Park, Virginia

NOVEMBER 25

Elmhurst Breakfast Club Support Group Meeting

Elmhurst, Illinois

NOVEMBER 30

Piedmont Triad PFF Support Group

Greensboro, North Carolina

DECEMBER 4

Simmons Center IPF Support Group

Pittsburgh, Pennsylvania

DECEMBER 7

Mid-Missouri Pulmonary Fibrosis Support Group Meeting

Columbia, Missouri

DECEMBER 12

Joe Walsh Memorial Pulmonary Fibrosis Support Group Meeting

Denver, Colorado

DECEMBER 13

St. Luke's Hospital Pulmonary Fibrosis Support Group Meeting

Easton, Pennsylvania

DECEMBER 30

Elmhurst Breakfast Club Support Group Meeting

Elmhurst, Illinois

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