





To the Pulmonary Fibrosis Community

We are energized and thrilled to present ***Accelerating the Pace of Progress***, the Pulmonary Fibrosis Foundation's (PFF) Strategic Plan for 2022-2024. This plan sets out our vision and priorities for the next three years, with the overarching goal of accelerating our progress toward a cure, and a world without pulmonary fibrosis (PF). Since the creation of our first strategic plan five years ago, this community and the PFF have accomplished a great deal in our collective efforts to improve and extend the lives of people with PF. None of this would have happened without your support and engagement. Together we have set the stage for even more dramatic progress over the next three years, and beyond.

***Accelerating the Pace of Progress* lays out three strategic goals that best reflect our community's stated needs. We have also mapped out corresponding initiatives for each goal so that we can hold ourselves accountable to the community.**

There has never been a more hopeful time in this community, as we are poised to capitalize on new research insights, technology advances, and increased public support to shorten timelines for new treatments. At the same time, we must acknowledge that the current set of realities for PF patients remains unacceptable. This means we will need even deeper involvement and engagement from the community to meet our goals.

Thank you for joining our mission. We look forward to working with you to move this field forward in the coming years.

Sincerely,



George Eliades

George Eliades, PhD
Chair, Board of Directors

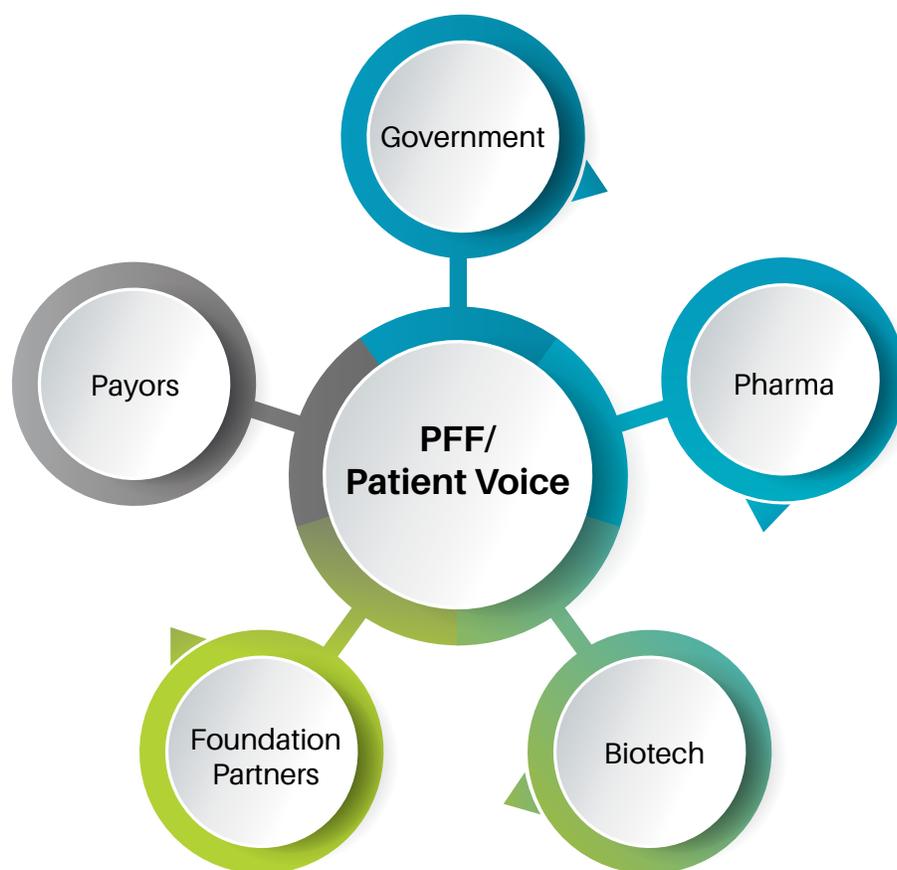


William T. Schmidt

William T. Schmidt
President and CEO

Building and Leading the Community

Since its founding in 2000, the PFF has led the charge to create a world without pulmonary fibrosis. We have done this by forging partnerships with other patient and provider organizations, research institutions, the pharmaceutical and biotech industries, and government agencies such as the National Institutes of Health, U.S. Food and Drug Administration, and U.S. Department of Defense. We estimate that over 250,000 people in the United States currently live with PF, so it is more urgent than ever for the PFF to lead a community-wide, coordinated campaign to accomplish our critical mission.



Uniting to Fight Pulmonary Fibrosis

In our mission to accelerate new treatments and a cure, improve quality of care, and provide quality support and education for all individuals affected by PF, the PFF is committed to diversity, equity, and inclusion. The PFF's strong commitment to inclusion and equity across race, gender, age, religion, identity, ability, and experience will lead to greater innovation, improved access, and more rapid progress in accomplishing our mission.



Our Vision

A world without pulmonary fibrosis.

Our Mission

The mission of the Pulmonary Fibrosis Foundation is to accelerate the development of new treatments and ultimately a cure for pulmonary fibrosis. Until this goal is achieved, the PFF is committed to advancing improved care of patients with PF and providing unequalled support and education resources for patients, caregivers, family members, and health care providers.

Our Values

In pursuit of our mission, the PFF is guided by the following core values:

- » Patient-centered
- » Urgency
- » Innovation
- » Collaboration
- » Inclusiveness
- » Evidence-based
- » Trusted information
- » Compassion

Listening to the PF Community



We developed ***Accelerating the Pace of Progress*** based on extensive feedback from an internal staff task force, the PFF Board of Directors, and the Medical and Scientific Advisory Committee of the Board. We also consulted four stakeholder groups representing a broad cross-section of the PF community: patients and caregivers, healthcare professionals, researchers, and industry partners. A professional facilitator led two discussions with

each of these stakeholder groups. Stakeholder input informed the mission, values, and key goals and initiatives in this plan.

Vision for the Future

To achieve our overarching vision of a world without PF, the PFF identified three key strategic pillars or goals with corresponding initiatives to achieve each one.

STRATEGIC GOAL 1

Accelerate new and improved treatments and, ultimately, a cure.

STRATEGIC GOAL 2

Improve care of all patients with PF.

STRATEGIC GOAL 3

Provide reliable, high-quality patient support and education.

Based on community input, we believe these three goals are the highest priorities for patients with PF and their families. In our view, these are also attainable goals. We have established metrics for each initiative over the next three years so the community can track our progress. By pursuing these goals aggressively and collaboratively, we believe we can shorten the timeline for a cure, and in the meantime, dramatically improve the lives of PF patients.



GOAL 1

Accelerate New and Improved Treatments and, Ultimately, a Cure

Currently, two FDA-approved therapies have been shown to slow the progression of pulmonary fibrosis, but there remains no cure for this deadly disease. Rapid development of more effective treatments to prevent, halt, or reverse lung fibrosis and inflammation is imperative. The PFF will pursue six initiatives to meet this goal:



INITIATIVE

Partner with researchers and industry to leverage and enhance use of the PFF Registry and PFF Care Center Network (CCN) to study key PF research questions.

With support from donors and funders, the PFF has built and developed the PFF Registry and CCN as critical research resources to stimulate new avenues of PF research. We plan to expand the scope of both assets and leverage their use to answer more questions.



KEY METRICS

- **Increase the number of studies using PFF Registry data and biosamples by 50%.**
- **Establish at least three new researcher and industry partnerships for CCN assistance in clinical trials.**



INITIATIVE

Lead an effort to work with the FDA to improve and speed up the process for approving new PF treatments.

The FDA's currently accepted endpoint, forced vital capacity (FVC), has limitations. FVC may not reliably predict symptom management or patients' functional status. In addition, new therapies will need to show they are more effective than the two approved therapies. The FVC endpoint will make it difficult to show adequate reduction of FVC decline beyond the current therapies.

As the country's largest PF-focused patient advocacy organization, the Foundation can coordinate this discussion and present independent and evidence-based perspectives. We are uniquely able to bring patient voices and other community views and recommendations to this dialogue.



KEY METRICS

- **Establish a PFF FDA Engagement working group, comprised of patients and experts in PF drug development.**
- **Develop evidence for new endpoints and drug development tools.**
- **Validate 1-2 new endpoints for PF-related clinical trials.**

*While creating **Accelerating the Pace of Progress**, we took time to review and celebrate what we've accomplished since 2016 when we wrote the previous strategic plan. These outstanding projects have laid the groundwork for what we hope to achieve during the next three years:*

PFF ACCOMPLISHMENTS

1

Created the PFF Registry, a world class research tool. Already, nearly 40 studies have been completed or are underway using the Registry's valuable data and samples, including the \$22 million PRECISIONS grant by the National Institutes of Health and Three Lakes Foundation.

2

Expanded the PFF Care Center Network from the original group of nine to the current 68 centers across the country. PFF Care Centers provide state-of-the-art care, conduct cutting-edge research, and engage in vital patient and provider education.



INITIATIVE

Increase participation of patients with PF in clinical trials.

Patient recruitment remains a major challenge across all diseases, which can slow progress in finding new treatments. As new potential treatments continue to enter the development pipeline, demand for patient participation will increase substantially. The PFF can play an even bigger role in helping to meet this demand by enhancing our patient education efforts through our Clinical Trial Finder tool and Clinical Trials Newsletter. In addition, we will work with sponsors to fully use both data sets of the PFF

Registry to identify patients who meet eligibility criteria for qualified clinical trials. We will also work to expand clinical trial enrollment among historically underserved and underrepresented communities including African Americans, Latinos, Native Americans, and multiracial, low-income, and rural people.



KEY METRICS

- **Increase the number of patients using the Clinical Trial Finder by 50%.**
- **Track the number of Clinical Trial Finder users who enroll in a trial and increase this number over time.**

3

Launched the PROLIFIC consortium, a collaboration with leading companies and research funders to boost scientific exploration and drug development in PF.

4

Established a government affairs program that advocates funding for PF research and improvements to patient care, including better access to supplemental oxygen.



INITIATIVE

Enhance public policy advocacy efforts to increase funding of PF-related research at the National Institutes of Health and U.S. Department of Defense.

The PFF will build on strong working relationships with government partners such as the National Heart, Lung, and Blood Institute, part of the National Institutes of Health, and the U.S. Department of Defense, which currently funds PF-related research through the Peer Reviewed Medical Research Program (PRMRP) of the Congressionally Directed Medical Research Programs. In 2020, the PFF retained a highly regarded, D.C.-based lobbying firm to help us better position ourselves to influence two of the world's largest funders of PF-related research.



KEY METRICS

- Achieve annual increases in PF-related research funding by the NHLBI that match or exceed the annual percentage increase in funding for the Institute overall.
- Increase the number of PF-related research proposals to the PRMRP program by 20% over three years.
- Work with NHLBI to convene a community-wide workshop to develop an updated, comprehensive research agenda for PF that emphasizes biomarker identification.

PFF ACCOMPLISHMENTS

5

Expanded our PFF Scholars program, which helps to build a pipeline of future PF researchers.

6

Expanded our patient education programs, including an educational video series that has received over 450,000 views.



INITIATIVE

Support the next generation of PF researchers by expanding the PFF Scholars program.

The PFF’s funding of investigators with an interest in PF-related research dates to our founding in 2000. The PFF’s funding focus has shifted to encourage early-career investigators to enter the PF field. Over the life of the program, we have distributed almost \$5.5 million; recipients have gone on to receive over \$100 million in support from the NIH, an impressive return on investment. The PFF will continue to seek additional financial support to increase the number of grants and award amounts while encouraging proposals from researchers of diverse backgrounds.



KEY METRICS

- **Increase the Scholars grant funding level to \$75,000 per year for two years.**
- **Secure additional funding to provide eligibility to healthcare professionals, including nurses and others.**

7

Enhanced our patient support programs and the PFF Help Center. The number of PFF-affiliated support groups has increased from 88 to approximately 150.

8

Developed a user-friendly clinical trial finder tool to help patients find and access relevant clinical trials.



INITIATIVE

Facilitate greater research collaboration among the CCN centers.

The PFF Care Center Network, currently comprised of 68 centers across the U.S. dedicated to PF research, clinical care, and education, is an important resource for the PF research community. We plan to facilitate further collaboration among CCN centers by bringing projects from individual centers to larger portions of the network. To assist, the PFF will develop a centralized clearinghouse of databases and biorepositories across the CCN that will be available to researchers.



KEY METRICS

- **Develop a centralized database and biorepository of CCN investigator-initiated studies within one year.**
- **Create a new CCN Research Working Group that will work with the CCN Steering Committee to facilitate and prioritize network-wide research using this database and biorepository.**
- **Launch research projects vetted by the CCN Research Working Group.**

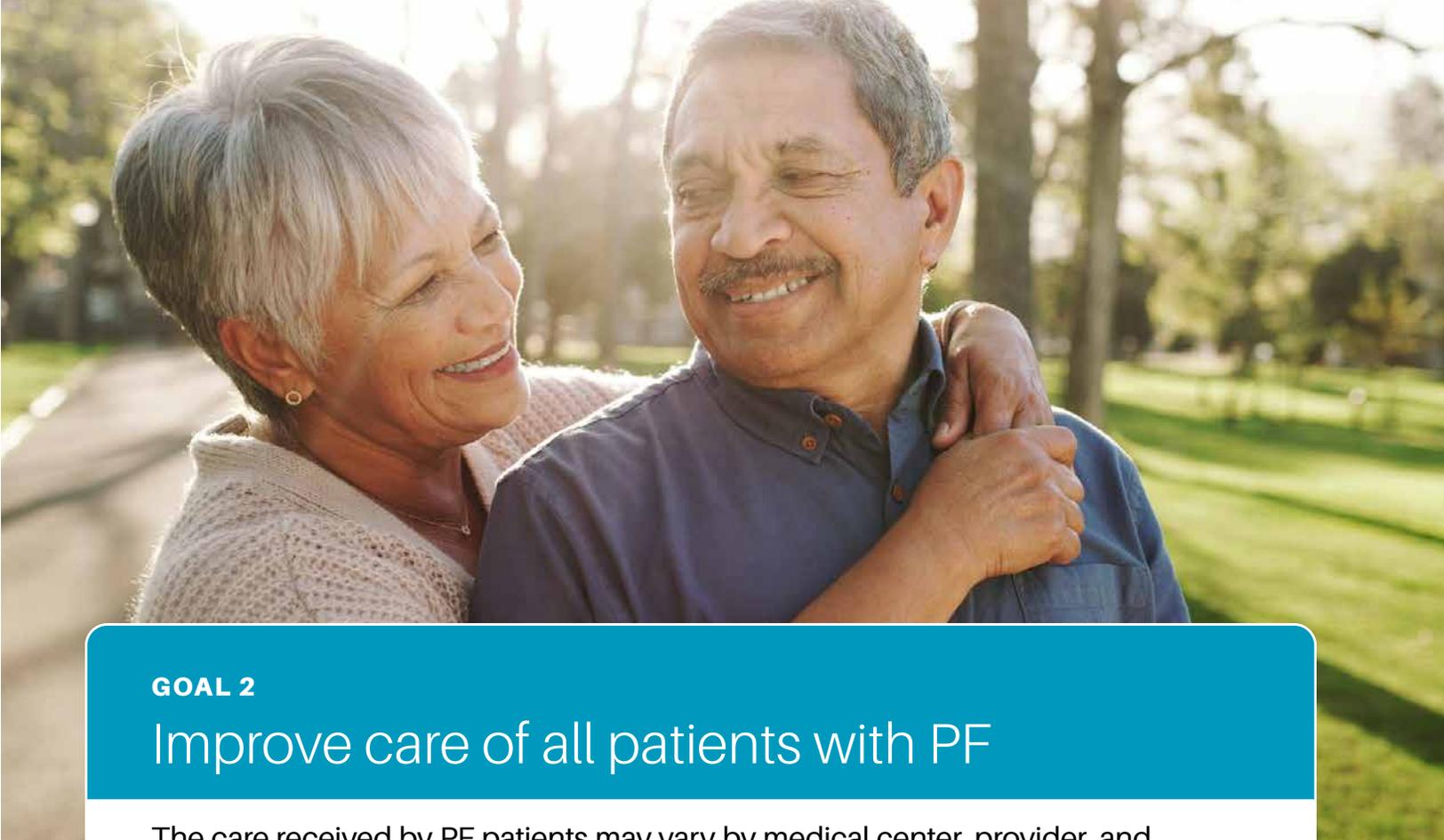
PFF ACCOMPLISHMENTS

9

Forged a formal partnership with Three Lakes Foundation to coordinate efforts and maximize resources for PF research, care, and awareness.

10

Launched a national PFF Walk program that has expanded to six cities and raised nearly \$3 million.



GOAL 2

Improve care of all patients with PF

The care received by PF patients may vary by medical center, provider, and region due to the inherent complexity of making a diagnosis and the limited access to care. People living in underserved and rural communities may be especially vulnerable to disparities in care. The PFF will expand its efforts to ensure more consistent care across the U.S.

INITIATIVE

Reduce time to diagnosis.

Reducing the time to diagnosis continues to be a major priority for the PF community. Far too often, patients and caregivers experience a long and frustrating odyssey before receiving a definitive diagnosis. According to recently published data from the Mayo Clinic, diagnoses often take three to five years. A PF diagnosis may require consensus among a pulmonologist, a pathologist, and a radiologist; even so, misdiagnosis is still too common. This ongoing quest for a diagnosis delays care that could improve and extend patients' lives.

The PFF is renewing its goal of reducing the time to diagnosis by redoubling our efforts through partnerships with Three Lakes Foundation and others.

KEY METRICS

- **Shorten the time to diagnosis from three-to-five years to two years or less.**
- **Develop a study to evaluate the diagnostic process and time to diagnosis at CCN and non-CCN centers.**
- **Implement the recommendations of the diagnostic process study.**
- **Address barriers that have been identified to shorten the time to diagnosis.**



INITIATIVE

Establish best practices across the CCN to identify PF standards of care.

The PFF will identify the CCN centers that are achieving the best patient outcomes, facilitating quality improvement, and conducting high-quality clinical research. Using CCN data, we will establish best practices linked to the optimal patient outcomes among the highest-performing sites. We will then share these best practices across the network and our community.



KEY METRICS

- Establish metrics for best practices through the PFF Care Center Network.
- Implement the best practices using these metrics and incorporate them as membership criteria for the PFF CCN.



INITIATIVE

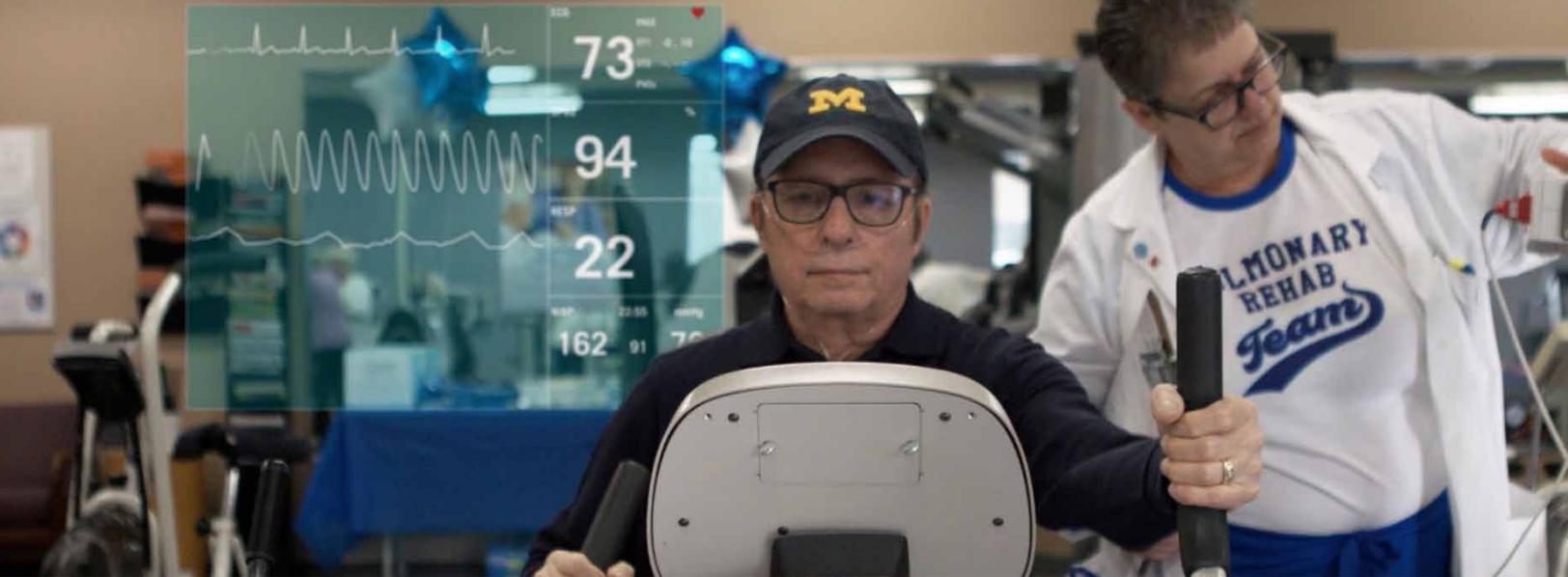
Update CCN entry criteria to expand network membership.

The PFF will create a tiered membership model to welcome top community-based providers into the CCN to increase the reach of PFF resources. The PFF will develop criteria for CCN membership based on patient needs, quality of care, and research potential. These community centers may not meet every criterion but will provide quality care while referring patients to tertiary centers for services they cannot provide.



KEY METRICS

- Use the CCN Steering Committee and various working groups to develop new criteria.
- Add at least three new CCN members.
- Evaluate all centers using the new criteria.



INITIATIVE

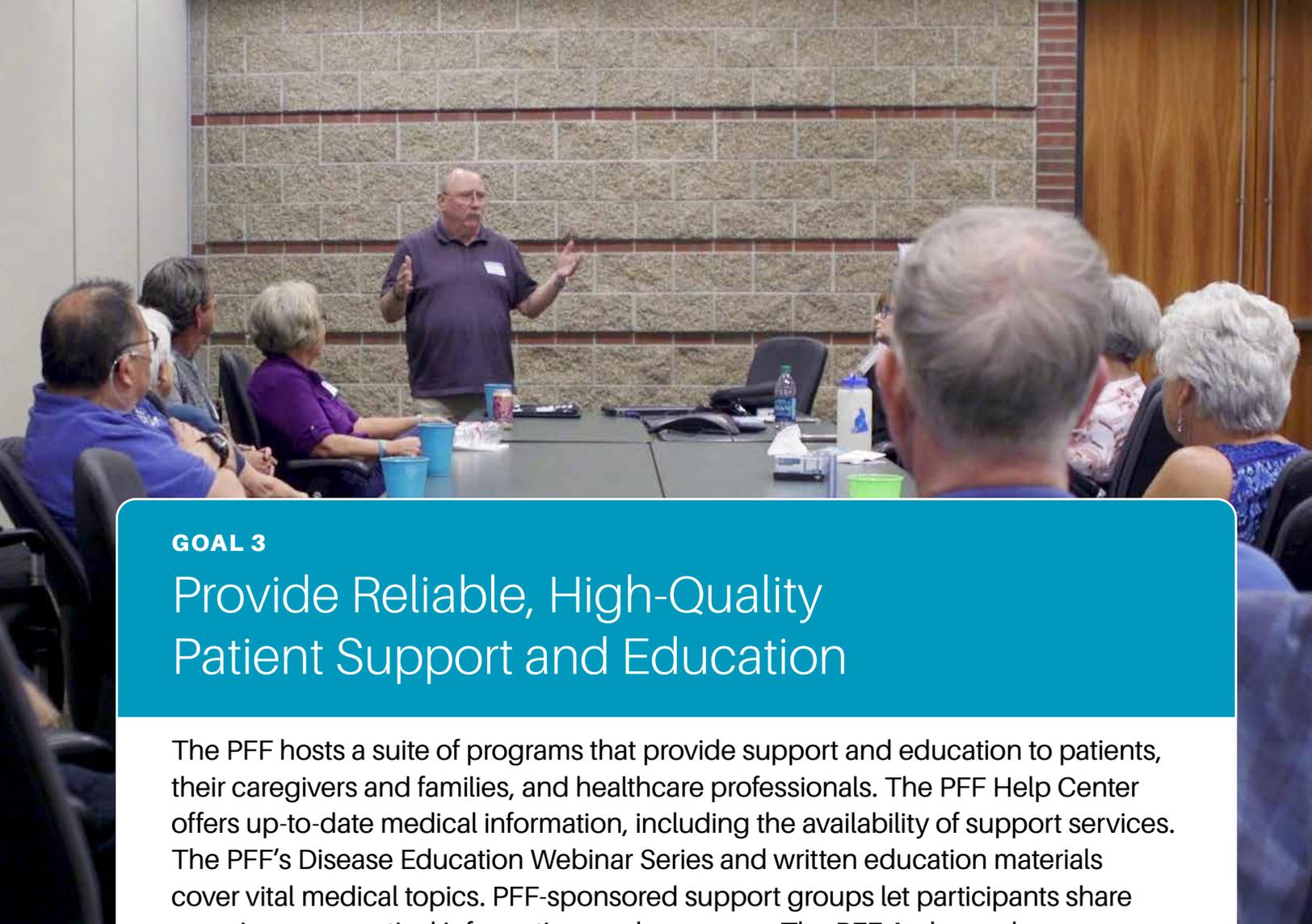
Improve access to supplemental oxygen and pulmonary rehabilitation.

Patients with PF continue to have difficulty getting and keeping access to lifesaving oxygen through Medicare. Overall, the Medicare competitive bidding program has significantly obstructed access to oxygen therapy. Many parts of the country do not have a single participating supplier that will provide prescribed liquid oxygen. In general, patients face difficulties and delays in getting supplies and equipment serviced or repaired. The PFF will continue to work with other pulmonary health advocacy organizations to find a legislative and regulatory solution.

The shortage of pulmonary rehabilitation (PR) centers means that many people do not have a center nearby. The PFF will advocate for Medicare reimbursement improvements and build community awareness of the importance of PR. We hope to ultimately increase the number of PR centers nationally.

KEY METRICS

- **Participate in pulmonary community advocacy efforts to develop comprehensive access to supplemental oxygen legislative and regulatory proposals, and work to introduce legislation in Congress.**
- **Partner with the American Association for Respiratory Care, the American Association of Cardiovascular and Pulmonary Rehabilitation, and other advocacy organizations to improve access to PR services.**



GOAL 3

Provide Reliable, High-Quality Patient Support and Education

The PFF hosts a suite of programs that provide support and education to patients, their caregivers and families, and healthcare professionals. The PFF Help Center offers up-to-date medical information, including the availability of support services. The PFF’s Disease Education Webinar Series and written education materials cover vital medical topics. PFF-sponsored support groups let participants share experiences, practical information, and resources. The PFF Ambassador program empowers patients, caregivers, and healthcare professionals to become spokespeople for the PF community. These programs are all available to the community free of charge.



INITIATIVE

Redirect general awareness efforts to creating greater awareness of the PFF and its resources.

We learned during recent focus groups that patients and caregivers would like more guidance in connecting with the PFF and how to access resources. Far too many patients with pulmonary fibrosis and their families are unaware of the PFF and the resources it has to offer. To address this critical need, the PFF will focus on efforts to

help more newly diagnosed patients find the Foundation early in their disease journey. We will partner with others on general disease awareness activities and continue to capitalize on free media opportunities to educate the broader public. We will also continue to work with pulmonary fibrosis support groups to share the PFF’s resources.



KEY METRICS

- **Ensure availability of PFF educational materials and PFF Support Kit in all 68 CCN centers.**

 **INITIATIVE**

Create a more focused, tailored support and education path for newly diagnosed patients.

Based on feedback from patients and caregivers, the PFF will redouble its focus on newly diagnosed patients, developing an orientation program for those who are new to the PFF. This orientation will introduce the PFF's educational materials, support resources, and opportunities to get involved. Participants will receive guided modules both digitally and as a printed PFF Support Kit. Additionally, PFF staff will hold regular "New to the PFF" virtual meetings that welcome patients and families, including sharing ways to engage with the PFF. Additionally, the PFF will increase engagement with Care Center Network sites and community providers to raise awareness of PFF resources available for newly diagnosed patients.

 **KEY METRICS**

- **Create and implement "New to the PFF" orientation program and PFF Support Kit.**
- **Have at least 75% of program participants report a better understanding of pulmonary fibrosis upon completion.**
- **Increase annual inquiries to the PFF Help Center by 50%.**
- **Increase new-patient referrals from the CCN to the PFF Help Center by 50%.**

Aspirational Goals

In developing Accelerating the Pace of Progress, we identified additional goals as important, but beyond the scope of our current staffing capacity and financial resources. These include:

- **Educate primary care providers about PF and how to identify and refer patients promptly.**
- **Create a PFF-operated clinical trials network.**
- **Enhance awareness of PF among the public at large.**



Organizational Development Goals

To make the PFF as effective as possible in accomplishing its mission, we will focus efforts on the following organizational issues and improvements:

ENHANCING DIVERSITY

To maximize our effectiveness as an organization, we need myriad perspectives, experiences, and professional backgrounds.

Research has shown that more diverse organizations produce better results, so implementing a Diversity, Equity and Inclusion plan will be a top short-term priority. This plan will touch every aspect of the organization. Highlights include:

- **Increase Board and Board committee diversity.**
- **Broaden staff diversity.**
- **Enhance outreach to diverse communities for all our support, education, and research programs.**
- **Lead a study of access to PF care in Black and Latino communities.**

FUNDRAISING

The PFF's ambitious goals and initiatives will not come to fruition without expanded fundraising. Without adequate support, we cannot continue to deliver our programs. Fortunately, the PFF has grown its revenues dramatically over the past five years, and we are grateful to our many donors, sponsors, and partners. But improving the lives of PF patients requires us to focus on enhancing performance in several fundraising programs:

- **Individual giving, including major gifts**
- **Planned giving**
- **Events**
- **Commercial partnerships**

Our goal is to increase overall revenues by 10% per year over the next three years.

Hope for the Future

From day one, the PFF has maintained a laser focus on the needs and aspirations of PF patients and their loved ones. The PFF exists as the leading agent for bringing the entire community together to eradicate this dreaded disease, and to assist patients and caregivers until we reach that outcome. We dream of the day when we can declare victory over PF and close our doors forever. Simply stated, we want to put ourselves out of business. This intensity and focus on behalf of patients drives everything we do. Please join us in this quest.



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