

Patients, Caregivers, Doctors Meet with FDA about Deadly Lung Disease

Listening Session Held to Help Inform Regulatory Decision-Making in Pulmonary Fibrosis

IRVING, TX, UNITED STATES, April 9, 2026 /EINPresswire.com/ -- [PF Warriors](#), a global non-profit support network for patients and caregivers affected by [pulmonary fibrosis](#) (PF), shares that the U.S. Food and Drug Administration (FDA) today held a listening session on the topic of pulmonary fibrosis. The agency heard from patients, caregivers and doctors about their experiences with the deadly lung disease, providing insights that may help inform regulatory decision-making.

The FDA Public Engagement Staff, along with the Reagan-Udall Foundation, hosted the virtual event that was moderated by Aviva Strategies. The listening session provided a direct connection between the agency and the PF community allowing for better understanding of disease burden and experiences and providing key insight into what's important to patients.

PF community non-profit representatives were invited to the private virtual meeting representing these organizations and the PF community at large: PF Warriors, The Pulmonary Fibrosis Foundation, Wescoe Foundation, Three Lakes 12-20 Pulmonary Fibrosis Research Foundation, Hermansky Pudlak Syndrome Network, The American Thoracic Society and The National Scleroderma Foundation.

"Patients' and caregivers' testimonies provided direct insight into the devastation PF represents," said Teresa Barnes, Chief Executive Warrior, PF Warriors, who has lost five family members to the disease. "Having a chance for them to share personal perspectives about their lives with this illness that greatly diminishes their quality of life and life expectancy can help FDA to better understand the patient journey with PF."



Max Bronstein, CEO of Aviva Strategies

Doctors delivered important information to the FDA about their work and expertise in the disease area as well as the challenges they face in providing care for their patients. In addition, they shed light on clinical trial access.

“Despite recent FDA approvals, PF remains a universally fatal disease that robs patients of quality of life – we need disease-modifying medicines in this community,” said Max Bronstein, CEO of Aviva Strategies and caregiver to his late mother, a PF patient. “This listening session gives the FDA insight into the challenges facing patients and the importance of ensuring clinical trials remain available to patients in the U.S.”

Barnes requested the patient-led listening session on behalf of PF Warriors with the needs of the entire pulmonary fibrosis community in mind for a direct route of communication for patients, advocates and medical experts. FDA then agreed to facilitate and hold the virtual private meeting.



Teresa Barnes, Chief Executive Warrior, PF Warriors

Prior to today’s meeting, it had been more than a decade since the last direct formal communication between the PF Community and the FDA via a Patient-Focused Drug Development Workshop on Pulmonary Fibrosis in 2014. The first two drugs in the disease were approved the same year.

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FDA Patient Listening Sessions are private, non-regulatory and non-binding virtual meetings. In the weeks following today’s meeting, a patient listening session summary will be provided by the PF Community to the FDA that will ultimately be made public on its website.

Pulmonary Fibrosis (PF) is a serious lung disease marked by irreversible scarring that impairs oxygen exchange and normal breathing. Life expectancy for patients with the disease is three to five years, and there are only three FDA approved pharmaceutical therapies that slow the progression of PF. The only cure is lung transplantation, which is available to fewer than one percent of patients.

About PF Warriors

PF Warriors is the largest nonprofit patient support network for individuals and families affected by fibrotic lung diseases, serving more than 25,000 members across the U.S. and 14 other countries. The organization provides multilingual education, expert-led webinars, peer support groups, and advocacy programs that empower patients and caregivers. Membership is free at <https://www.PFWarriors.org>.

Teresa Barnes

PF Warriors

+1 303-521-4080

[email us here](#)

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Pulmonary Fibrosis WARRIORS

PF Warriors is a global support network that provides education, inspiration and hope to individuals and families affected by pulmonary fibrosis. Our mission is to help people facing a life-altering progressive lung condition to live their best possible life.

This press release can be viewed online at: <https://www.einpresswire.com/article/904627466>

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