Statement of Paul Fogelberg* at the Congressional Briefing on Pulmonary Fibrosis

sponsored by **Representatives Erik Paulsen** (R, MN-3) & **Steve Cohen** (D, TN-9)

and, **Pulmonary Fibrosis Advocates**, **Pulmonary Fibrosis Foundation**, **National Organization for Rare Disorders** and **Boehringer-Ingelheim**

Wednesday, February 25, 2015 – 2301 Rayburn House Office Building, Washington DC

I am honored to offer a statement on behalf of 200,000 pulmonary fibrosis patients and their families. We are grateful to Representatives Paulsen & Cohen, Senator Murphy and the other experts at this briefing for this opportunity, their insights and their optimism.

Today, I am a partially disabled, terminal pulmonary fibrosis patient … but 43 years ago I had the joy of working for Rep. Paul McCloskey (R, CA)**. My time here was some of the best of my life and I especially commend the legislative assistants here for accepting the low pay, long hours, relentless pressure and serious responsibility that is theirs.**

I am here because rare diseases afflict more than 30 million Americans … 90 - 120 million when you add family members and caregivers. I am here because pulmonary fibrosis is not simply a "*rare disease*" ~ in fact it claims the lives of 40,000 of our fellow citizens every year. Pulmonary fibrosis is a clear and present danger for America's healthcare system.

I am here because this is where citizens come for help – and hope. Pulmonary fibrosis and other rare diseases are – as a group – just as tragic and pervasive as heart disease or cancer, yet they rarely gain robust private sector engagement. Without underlying fundamental basic and translational research funding, there are no cures.

You have heard from exceptional experts about the lethal diagnosis and statistics regarding pulmonary fibrosis, as well as the promise shown by recent drug approvals and projected treatment advances. In spite of that promise, the patient's reality is that a pulmonary fibrosis diagnosis remains a death sentence. I have been blessed to cheat the mortality table and use my "extra" time to be an advocate for those whose voices have been tragically silenced … friends or former fellow PF patients like

- **LISA SANDLER SPAETH** Bethesda MD
- **WILLIAM BAIRD** Edmonds, WA
- **ROSS HOUSE** Golden Valley, MN
- **FORMER REP. CHARLIE NORWOOD**

I also have 3 amazing daughters and a significant number of PF patients are now classified as having "familial or genetically related PF". My efforts now might spare my daughters a possible outcome as unpleasant and certain as mine.

In 2007 former Rep. Brian Baird first introduced THE PULMONARY FIBROSIS RESEARCH ENHANCEMENT ACT. While unsuccessful, it was co-sponsored by 93 Members of Congress and it succeeded in significantly raising the profile of the disease. Brian's father, William, died from PF in 2001 and I am proud that Brian remains in the fight as the Chairman of the Board of the PULMONARY FIBROSIS ADVOCATES.

The traumatic, suffocating death of a pulmonary fibrosis patient plays itself out every 13 minutes … more than 40,000 times each year … more than 320,000 deaths since Rep. Baird first introduced the PFREA legislation. The optimism and hope

expressed by experts here today must be tempered by the grim scientific and legislative reality that none of us are working hard or fast enough.

The tragic fact is that researchers showing promise in the quest for a broad and effective treatment for PF and other fibrotic diseases lack sufficient funding to bring their research to fruition. Their progress in solving the basic scientific problem of fibrosis has been effectively delayed or outright stalled by insufficient basic research funding.

In the last 5 years, NIH funding for pulmonary fibrosis research has been essentially "flat" ~ at around $32.6 MILLION per year … less than 1% of the NIH's appropriations for an incurable disease that kills 40,000 Americans every year.

Over those years NHLBI has allocated only $816 per PF-related death and just $163 per PF patient each year. If someone you love were dying of a disease, and you were told you could only spend $163, or $816 to try and keep them alive, you would fight with all of your might to be able to do more. Yet, that is all we as a nation spend on a disease that kills 40,000 Americans annually. We can do better than that.

In FY 2014, NHLBI funded only 58 PF research grants, down from 75 in FY 2013 ~ a shocking 20% DECLINE in research grants for this lethal disease. That is a national tragedy and a national embarrassment. We simply MUST do better.

Today, you and the people you work for, have an extraordinary opportunity to save the lives of rare disease victims you represent. Hard working, tax paying Americans who, through no fault of their own, have a deadly disease that will kill them in less than 3-5 years unless an effective treatment is found. Pulmonary fibrosis has claimed at least 7 lives in the time allocated for this meeting. You can play an essential role in changing that tragic dynamic. That is really something … each of you CAN make a meaningful difference in this fight.

Here is what we are asking … help provide the research funds to get the job done – *Faster.* Insure that EVERY Member of Congress joins bi-partisan efforts to co-sponsor and pass legislation like …

1) the **21ST CENTURY CURES INITIATIVE** Reps. Upton (R, MI-6) & DeGette (D, CO-1)

2) **the permanent extension of the R & D tax credit,** the **AMERICAN RESEARCH & COMPETITIVENESS ACT OF 2015** **(HR 880)** Reps. Brady (R, TX-08) & Larson (D, CT-1),

3) the **PERMANENT INVESTMENT IN HEALTH RESEARCH ACT** **(HR 777)** Reps. Castor (R, FL-14) and Butterfield (D, NC-1),

4) the **AMERICAN CURES ACT** **(S. 289)** Sen. Richard Durbin (D, IL)**, and**

5) the **ORPHAN PRODUCT EXTENSIONS NOW, ACCELERATING CURES & TREATMENTS** (**OPEN Act**) **(HR 971)** Reps. Bilirakis (R, FL-12), Butterfield (D, NC-1), and McCaul (R, TX-10)

6-7) the **ACCELERATING BIOMEDICAL RESEARCH ACT** **(S.318 and H.R. 531)**
Rep. Rosa DeLauro (D, CT-3) and Sen. Barbara Mikulski (D, MD)

As patients, constituents, taxpayers and voters, we are not looking to Congress for a magical silver bullet. We want hope and we need action. You may not be a research scientist, but there is a strong personal, economic and frankly political, imperative for you to take action on the important, life-saving legislation just mentioned as early as TODAY.

Our organization, the PULMONARY FIBROSIS ADVOCATES, works closely with our friends and colleagues at The Pulmonary Fibrosis Foundation. The PFF has graciously prepared information packets for each of you. We hope that you will visit with their representatives this afternoon (Patti Tuomey, Jennifer Bulander and Courtney Firak)**.**

The PF Foundation is a remarkable and thriving resource for PF patients, family members, caregivers – and for Members of Congress. Like the PULMONARY FIBROSIS ADVOCATES, they are at your service with invaluable medical, scientific, financial and patient information. ASK US FOR HELP!

Thank you for attending

… for honoring the memory of those who have already lost their battles with PF
… for giving more than 200,000 of us a chance to breathe, and to live.

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* **Paul Fogelberg** is a pulmonary fibrosis patient who resides in Orono, MN. He is a lawyer and small business owner who also serves as the volunteer Director of the non-profit **PULMONARY FIBROSIS ADVOCATES, www.pfadvocates.org** ~
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