

## **Pulmonary Fibrosis ‘Fast Facts’ to consider including in your call, e-mail, or letter ... but Remember ... YOUR STORY is more powerful than these facts!**

- Pulmonary Fibrosis (PF or IPF) impacts the lives of more than 200,000 Americans
- The incidence or prevalence of PF has increased 150% since 2001 and is expected to continue to increase as the ‘baby-boomer’ generation ages
- As of Feb 2018, there are only two FDA-approved treatments for PF which merely slow the progression of the disease in less than 1/3 of the PF population. There is NO CURE.
- PF claims 40,000 lives annually ~ 1 life every 13 minutes (*about the same death toll as breast cancer*)
- Nearly 80% of patients diagnosed with IPF die within 5 years of diagnosis ~ for IPF patients, time is literally of the essence!
- At the National Institutes of Health (NIH), funding for PF research remains well below that for other diseases with similar prevalence and mortality statistics. The average for FY’s 2010-2015 was \$37.8 million (*compared to the NIH overall Congressional appropriation of approximately \$31 Billion/year*) ... PF research currently receives only 0.13% of the NIH budget!
- One study estimates the annual cost to “treat” PF patients (*even though there are only modest FDA-approved treatments available for a small percentage of the PF patients*) costs the US healthcare economy between \$4.3 & \$6.7 Billion annually. Finding an effective treatment would save lives AND dollars

### **Sample Script for phone calls, e-mails or letters**

There are 327 Million Americans and only 535 Members of Congress. They receive hundreds of calls, e-mails and letters daily ... thousands each week ... on a wide variety of topics/concerns. To register your PF concerns, **you must be Persistent, Patient and Persuasive!** Be calm, polite and **as brief as possible.** Share **YOUR PF STORY** and any facts that you feel are important. Finally, ... 2 things: 1) remember to say *Thank You* at the end of your message, and 2) remember to follow-up with more calls, emails or letters – **REPEAT - REPEAT!**

**Good Morning. My name is \_\_\_\_\_.** I am a voting constituent of [*Senator or Representative \_\_\_\_\_*] and I would like to speak to his/her **Health Care Legislative Assistant** regarding pulmonary fibrosis.

*If the HC-LA is not available, ask to leave a message to have him or her call you back; if someone else in the office takes your call – no problem (all contacts are tallied by topic)*

*Whomever you wind up speaking with, introduce yourself again ...*

**My name is \_\_\_\_\_.** I am a voting constituent of [*Senator or Representative \_\_\_\_\_*]. I am also a patient (*or family member, or caregiver of a patient*) with a terminal disease called **Pulmonary Fibrosis.** I understand that [*Senator or Representative \_\_\_\_\_*] has previously supported research for Pulmonary Fibrosis by supporting funding for the National Institutes of Health. I am calling/writing to thank him/her – and you as a legislative staff member - for that past support.

But, more importantly, I am also calling to let him/her know that I want to ensure that he/she continues ... or even **increases** that support in the current session of Congress. Pulmonary fibrosis research is important to me personally – and to my family – because ... **[TELL YOUR PF STORY! – be brief, but “personalize” your request for action to make it more persuasive]**

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Finally, thank you for taking the time to consider my comments. And, please tell [*Senator or Representative \_\_\_\_\_*] that if he/she has suggestions for anything that we can do to help him/her regarding PF research initiatives or significantly increasing NIH funding by Congress, we will help any way we can. We are grateful for his/her continued, thoughtful and aggressive support of any Congressional action that will help to speed the discovery of an effective treatment for this cruel and tragically lethal disease.