

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 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 April 2014, there is **NO FDA-approved treatment for PF**
- 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 PF die within 5 years of diagnosis ~ for PF patients, time is literally of the essence!
- At the National Institutes of Health (NIH), funding for PF research has remained essentially 'flat' since 2006 at around \$26 Million/year (compared to the NIH overall Congressional appropriation of approximately \$31 Billion/year) ... PF research currently receives only 0.0818% of the NIH budget!
- One study has estimated that the annual cost to "treat" PF patients (even though there is currently no FDA-approved treatment available) 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 317 Million Americans and only 535 Members of Congress. They receive many dozens of calls, e-mails and letters daily ... hundreds each week ... on a wide variety of topics/concerns to their constituents. Be calm, polite and as brief as possible. **Share YOUR PF STORY** and any facts that you feel are important. Finally, remember to say *Thank You* at the end of your message!

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/her call you back; if someone else in the office takes your call – no problem (all calls 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 through legislation and 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!]**

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 NIH funding, 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 tragically lethal disease.