

Representative Erik Paulsen, MN-3



February 17, 2015

Representative Steve Cohen, TN-9

CONGRESSIONAL BRIEFING ANNOUNCEMENT & INVITATION

TO Members of Congress and their staffs
(also open to the public on a space available basis)

RE Special Congressional Briefing on Pulmonary Fibrosis

Date **Wednesday, February 25, 2015**
Time **12N – 1:30pm** (*lunch will be provided*)
Location **2103 Rayburn House Office Building**

Every 13 minutes, someone in America dies from complications of Pulmonary Fibrosis (PF) ... more than 40,000 deaths annually (the same mortality rate as breast cancer). More than 200,000 Americans have been diagnosed with PF, there are only 2 newly approved (Oct '14) treatments and no cure. 80% of PF patients succumb to this lethal disease within 3-5 years of diagnosis. They literally suffocate.

Held in conjunction with **GLOBAL RARE DISEASE DAY**, the briefing on PF (aka, IPF) will introduce you to the disease, a genuine healthcare crisis in the USA. It will highlight historical funding, ongoing research and detail the crucial roles Congress, NHLBI, FDA, and patient advocacy groups play in saving lives. PF took the life of our colleague, Rep. Charlie Norwood (R, GA-10) and two past Secretaries of the Treasury. It has impacted the lives of more than a dozen current Members of Congress. The work we do – the work YOU do – will have a meaningful impact on our constituents – patients, family members, caregivers, clinicians and researchers struggling to solve the mystery of pulmonary fibrosis.

Please confirm your registration for this special Briefing today!

Provisional Meeting Agenda:

- 11:45 – 12:00 15 Registration & Lunch
- 12:00 – 12:08 8 Reps. Erik Paulsen & Steve Cohen - Introduction
- 12:08 – 12:23 15 Dr. Craig Conoscenti, Boehringer-Ingelheim – Overview of PF
- 12:23 – 12:38 15 FDA Staff – process for streamlining drug approvals for rare diseases; update on other PF drugs currently under FDA screening
- 12:38 – 12:53 15 James P. Kiley, PhD – Director, Division of Lung Diseases, National Heart Lung & Blood Institute ~ Update on FY'14, '15 & projected '16 funding and grants for pulmonary fibrosis research
- 12:53 – 12:59 6 Paul Fogelberg – PF patient and volunteer Director, PULMONARY FIBROSIS ADVOCATES (PFA) – patient perspective
- 12:59 – 1:05 6 Douglas Jones – lung transplant recipient and 'Ambassador' for the PULMONARY FIBROSIS FOUNDATION (PFF)
- 1:05 – 1:11 6 Diane Dorman – NATIONAL ORGANIZATION FOR RARE DISEASES (NORD) **2015 Global Rare Disease Day - Living with a Rare Disease Day-by-day, hand-in-hand** [in partnership with EURODIS]
- 1:11 – 1:30 19 Additional audience Questions & Answers



**Please RSVP
by 12N 2/23/15**

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If you know of someone in your office or district touched by PF, please let us know when you register!