

January 24, 2017

RDLA Rare Disease Week ~ February 25th through March 1st 2018

PULMONARY FIBROSIS ADVOCATES – Wayzata MN

- Former US Rep. Brian N., Baird, Ph.D. (D, WA3)
- Paul A. Fogelberg, Esq., Patient-Advocate & Director

PULMONARY FIBROSIS FOUNDATION – Chicago IL

Staff

- William (Bill) Schmidt, President & CEO
- Kate Gates, Director of Programs

Volunteers

- Cindy Solimino Chandler, Webster NY
- Douglas Jones, St. Louis MO

EVERYLIFE FOUNDATION FOR RARE DISEASES

and

RARE DISEASE LEGISLATIVE ADVOCATES

- Julia Jenkins, Executive Director
- Rachel Klein, Senior Director of Advocacy & Strategy
- Sabah Bhatnagar, RDLA Program Director

- Andy Russell, Associate Director, Government Relations & Advocacy
- Lisa Schill,

WEBSITE: <http://rareadvocates.org/rdw/>

RDLA local HQ = **Washington Court Hotel**, 525 New Jersey Avenue NW, Washington DC, 20001 • 800.321.3010 • 202-628-2100 RDLA rate \$219/nt expires 1/27/18

<u>Sunday Feb 25th</u>	5:30 – 9:30pm	Cocktail Reception & Rare Disease Documentary Screening ~ ➤ US Naval Heritage Center, 701 Pennsylvania Av NW
<u>Monday Feb 26th</u>	9:00 – 4:15pm	Legislative Conference <i>[mandatory for those participating in Tuesday's Hill Day]</i> ➤ Ronald Reagan Bldg., 1300 Pennsylvania Av NW
	5:30 – 7:30pm	Responsum Reception
<u>Tuesday Feb 27th</u>	7:30 – 8:30am	Lobby Day Breakfast ➤ Washington Court Hotel on Capitol Hill 525 New Jersey Ave NW
	9:00am – 5:00pm	Scheduled meetings with Members of the Senate & House or designated staff (arranged by Soapbox Consulting according to State (for Senators) and Zip Codes (for Representatives))
<u>Wed. Feb 28th</u>	9:00am – 4:00pm	PFA & PFF meetings with Congressional Champions
	12:30 – 1:45pm	Rare Disease Congressional Caucus Briefing ➤ Russell Senate Office Building Room 325
	2:00pm	RDLA Group Photo ➤ US Capitol (facing First Street NE)
	7:00pm	Rare Artist Reception ➤ Russell Senate Office Building Room 325
<u>Thursday, March 1st</u>	8:30am – 4:00pm	Rare Disease Day at the National Institutes of Health ➤ 9000 Rockville Pike, Bldg. 10, Masur Auditorium