



***Collaborating to Raise the Profile of Lung Disease to  
Create Greater Access to Care and Better Patient-Centered Solutions***

***October 23, 2017***

***Henry J. Kaiser Family Foundation - Barbara Jordan Conference Center  
Washington, DC***

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*This PALs United event is affiliated with the Patient Advocacy Leaders Summit (PALS) program and promotes the mission of PALS: To improve the lives of those affected by disease and chronic health conditions by educating and mobilizing health advocacy leaders to work collaboratively developing impactful policy and advocacy solutions, focusing on the prevention and elimination of disease and chronic health conditions.*

**Key Objectives:**

- 🕒 Convene and engage national lung health advocates, thought leaders and other key stakeholders to raise and accelerate the dialogue and development of strategies for improving mutually important policy priorities in lung health.
- 🕒 Identify common goals and action steps to collaboratively advance patient-centered solutions relating to access to care, services and innovations in lung health.

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12:00 pm – 12:30 pm ***Registration / Lunch***

12:30 pm – 12:45 pm **Welcome to PALs United for Lung Health!**

***PALs United for Lung Health Moderator:***

***Margaret Anderson, MS***  
*Managing Director, Deloitte Consulting LLP*

12:45 pm – 1:15 pm **Update on Lung Disease Research at National Heart, Lung, and Blood Institute**

***James P. Kiley, PhD***  
*Director, Division of Lung Diseases, National Heart, Lung, and Blood Institute, National Institutes of Health*



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1:15 pm – 3:00 pm **PALs United for Lung Health - Leader-to-Leader Dialogue**

1:15pm – 2:00 pm **Part I - Promoting Awareness and Access to Care Through Multi-Stakeholder Frameworks and Shared Decision Making**

 **Tonya Winders, MBA**

*President & Chief Executive Officer, Asthma & Allergy Network and  
President, Global Allergy & Asthma Patient Platform*

 **Jamie Sullivan, MPH**

*Vice President of Public Policy & Outcomes, COPD Foundation*

 **Deborah P. Brown, MS**

*Executive Vice President, American Lung Association, Mid-Atlantic Region*

2:00 pm – 3:00 pm **Part II – Infusing the Patient Voice in Patient-Centered Solutions to Advance Lung Health**

 **Personalized Medicine**

**Cynthia Bens**

*Vice President, Public Policy, Personalized Medicine Coalition*

 **Patient Engagement**

**Steve L. Morin, RN, BSN, CDR US Public Health Service**

*Health Programs Coordinator, Office of Health and Constituent Affairs,  
U.S. Food & Drug Administration*

 **Development and Implementation of Patient-Reported Outcomes Measures**

**Nelly Ganesan, MPH**

*Senior Director, Avalere Health*

3:00 pm – 3:15 pm **Networking Break**

3:15 pm – 4:15 pm **Making It Happen! Finding Common Ground to Collaborate for Collective Impact**

4:15 pm – 5:00 pm **Raising the Profile of Lung Disease Through Stories**

**Chris Draft**

*President and Founder, Chris Draft Family Foundation*

5:00 pm **Event Concludes**



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United for Lung Health**

*This event was developed by PALS and the PALs United for Lung Health Steering Committee/Planning Team:*

Name	Organization	Title	Role
<b>Kip Adams</b>	COPD Foundation	Executive Vice President, Chief External Relations Officer	Advisor
<b>Rudy Anderson</b>	CHEST Foundation	Associate Executive Director	Steering Committee
<b>Deborah Brown</b>	American Lung Association	Executive Vice President, Mid-Atlantic Region	Steering Committee
<b>Deborah Bryan</b>	PALS Advisory Board, American Lung Association, Southeast	Advisory Board Member, Program Manager, Mothers & Others for Clean Air	Steering Committee-PALS Board
<b>Mike Cohen</b>	PALS Advisory Board, MJC Health Solutions	Advisory Board Member, Principal	Steering Committee-PALS Board
<b>Ellie Dehoney</b>	Research!America	Vice President, Policy & Advocacy	Steering Committee
<b>Candace DeMatteis</b>	Partnership to Fight Chronic Disease	Policy Director	Advisor
<b>Anne Easter</b>	Patient Advocacy Leaders Summit	Director	Steering Committee-PALS Staff
<b>Brian Kennedy</b>	Alliance for Patient Access	Executive Director	Steering Committee
<b>Grace Anne Dorney Koppel</b>	Dorney-Koppel Foundation, COPD Foundation	President, Immediate Past President and Chair of Advocacy & Public Policy Committee	Advisor
<b>Michael Ruppal</b>	The AIDS Institute	Executive Director	TAI/PALS Staff
<b>Jamie Sullivan</b>	COPD Foundation	Vice President of Public Policy & Outcomes	Steering Committee
<b>Tonya Winders</b>	Allergy & Asthma Network	President & Chief Executive Officer and President, Global Allergy & Asthma Patient Platform	Steering Committee

*PALS is convened by The AIDS Institute, a national non-partisan, non-profit organization with offices in Washington, DC / Tampa, FL / Tallahassee, FL  
PALS is guided by the National PALS Advisory Board.*



**PATIENT ADVOCACY  
LEADERS SUMMIT**

