PALs UNITED
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Patient Advocacy Leaders
United for Lung Health

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 Foundation
Barbara Jordan Conference Center | Washington, DC

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United for Lung Health

Contents

Executive Summary

This ***Patient Advocacy Leaders United (PALs United),*** event is affiliated with the ***Patient Advocacy Leaders Summit (PALS)*** program, which has been in existence since 2002 and involves patient advocates from around the country who are committed to improving health and healthcare in our communities. PALS strives to improve the capacity of advocacy leaders and identify ways to work collaboratively to develop policy and advocacy solutions to improve the lives of those affected by disease and chronic health conditions. For more information about PALS, click here.

Patient Advocacy Leaders United for Lung Health brought together a select group of national lung health advocates, thought leaders, and other key stakeholders for the first ever disease-specific ***PALs United*** leaders' forum, on October 23, 2017. There were 40 people in attendance, representing 29 different organizations (from non-profit, public and private sectors) interested and invested in lung health.

Margaret Anderson, Managing Director at Deloitte Consulting, and formerly Executive Director at FasterCures, moderated the day's discussions. For more about Margaret, click here.
She was very well-received by the attendees.

The comment below is reflective of what many attendees shared.

"Margaret is a very skilled moderator. She really got people to actually talk and she drew out different perspectives. She made participating feel very comfortable."

Margaret Anderson @MargaretAinDC · Oct 23
Pleased to moderate #palsunited mtg today to id common #lung health goals-powerful lineup of speakers & participants #research #patients

PALs United for Lung Health was developed and executed by a Steering Committee and Planning Team comprised of national lung health advocates and other key stakeholders, adhering to a key PALS principle, that programming is created "By Advocates, For Advocates". It was designed to raise and accelerate the dialogue and development of strategies for improving mutually important policy priorities in lung health and identify common goals and action steps to collaboratively advance patient-centered solutions relating to access to care, services, and innovations in lung health. By the end of the session, participants converged around two key areas for future action and collaboration: raising the profile of lung diseases and advancing patient-centered principles.

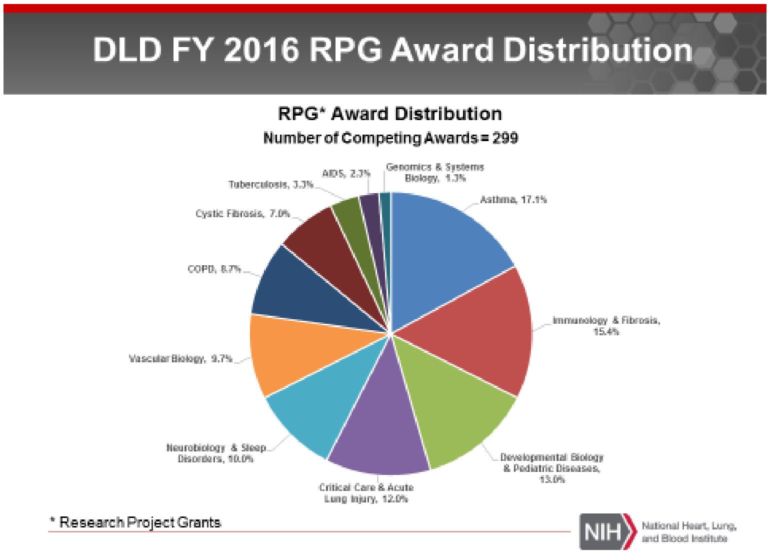
PALs United for Lung Health Steering Committee/Planning Team:

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

**PALS Advisory Board Members*

Update on Lung Disease Research at National Heart, Lung, and Blood Institute

Dr. James P. Kiley, Director of the Division of Lung Diseases (DLD) at the National Heart Lung and Blood Institute (NHLBI) at the National Institutes of Health (NIH), began his presentation by stating that so much can be done when we work together, especially around a common agenda. He provided a broad overview of the mission, strategic vision, goals and objectives of NHLBI, along with his Division. He shared information about NHLBI Funding, Research Program Grant Award Distribution within the DLD and types of Lung Disease Research. He also talked about the importance of strategic multi-stakeholder partnerships, highlighting specific examples and best practices.



DLD FY 2016 RPG Award Distribution

RPG* Award Distribution

Number of Competing Awards = 299

* Research Project Grants

NIH National Heart, Lung, and Blood Institute

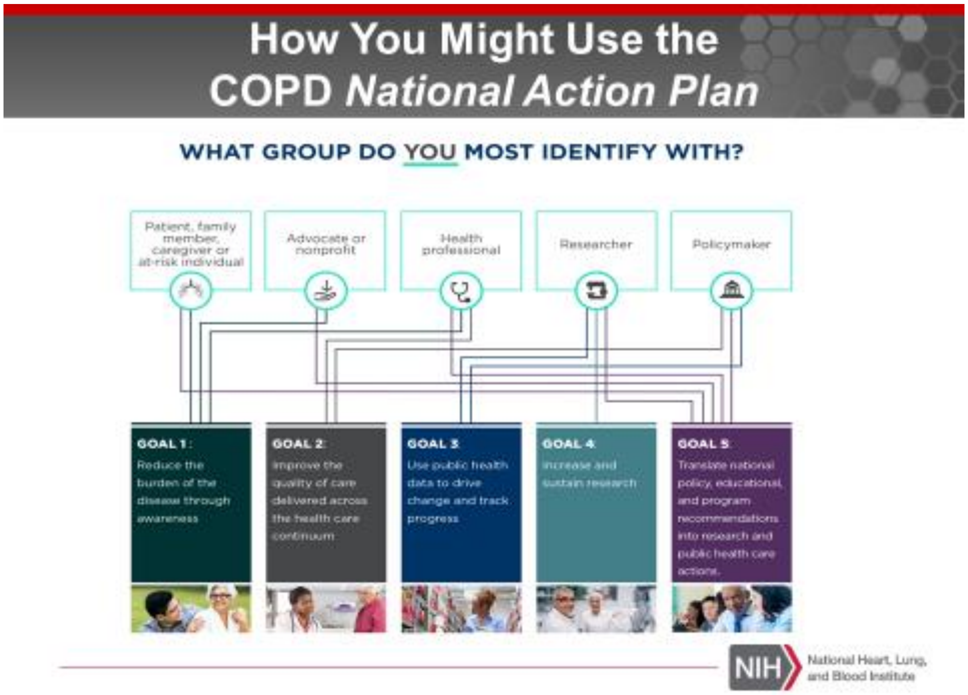
The DLD's research identifies treatments that improve care today, lays the groundwork for better treatments, and works toward preventing and curing lung diseases. To that end, the DLD awarded $677 million in 2016 through approximately 1,350 grants. Many of these grant applications were solicited through funding opportunity announcements – this vehicle allows the DLD to strategically fund specific areas of research. Other successful grant applications were not in response to specific funding opportunities and reflect the priorities of the research community.

NHLBI's activities are guided by the compelling questions and critical challenges outlined by their strategic plan. Current priorities include studying how to better use approved drugs with regard to adherence, timing, and combinations, as well as identifying approved drugs that can be repurposed for a new indication. This type of research transforms the face of medical care and shortens the time needed to translate research from the lab bench into a clinical setting.

The three strategic partnerships and related best practices he highlighted included:

- COPD National Action Plan
- National Asthma Education and Prevention Program (NAEPP)
- Lymphangioleiomyomatosis (LAM) Foundation

The COPD National Action Plan (US-CNAP) was developed through consultation with over 200 individuals – including patients, caregivers, patient advocates, healthcare providers, industry leaders, academic leaders, and **14** federal partners. The end product is a living document that can be used by patients, advocates, health professionals, researchers, and policymakers. He said the key word is “Together”. The entire community owns this plan. He provided actionable ways that individuals can help promote the US-CNAP (see COPD.nih.gov for Outreach Toolkit, videos, social media resources, fact sheets and more). This plan could serve as a framework for collaborative advocacy by the organizations participating in this event.



How You Might Use the COPD *National Action Plan*

WHAT GROUP DO YOU MOST IDENTIFY WITH?

Patient, family member, caregiver or at-risk individual

Advocate or nonprofit

Health professional

Researcher

Policymaker

GOAL 1: Reduce the burden of the disease through awareness

GOAL 2: Improve the quality of care delivered across the health care continuum

GOAL 3: Use public health data to drive change and track progress

GOAL 4: Increase and sustain research

GOAL 5: Translate national policy, educational, and program recommendations into research and public health care actions.

National Asthma Education and Prevention Program and the Lymphangioleiomyomatosis (LAM) Foundation were also discussed as best practice examples of progress and collaboration. He closed with a review of essential partnerships in research, involving multiple stakeholders. For more information see his slide deck.

Nelly Ganesan @NGanesanAvalere · Oct 23
Partnerships are key! #palsunited

Attendees appreciated Dr. Kiley, his comprehensive overview and emphasis on the importance of partnerships. Ninety-three percent of survey respondents rating his presentation as “Excellent” or “Very Good”.

> *“Excellent presentation; great opportunities to implement, disseminate plan, and move to community actions. Helpful to have information on NHLBI’s priorities/resources.”*

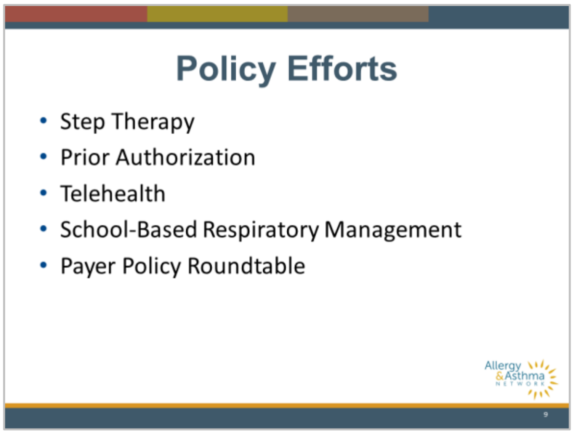
Leader to Leader Dialogue

Part I – Promoting Awareness and Access to Care Through Multi-Stakeholder Frameworks and Shared Decision Making

Identifying Gaps and Addressing Barriers

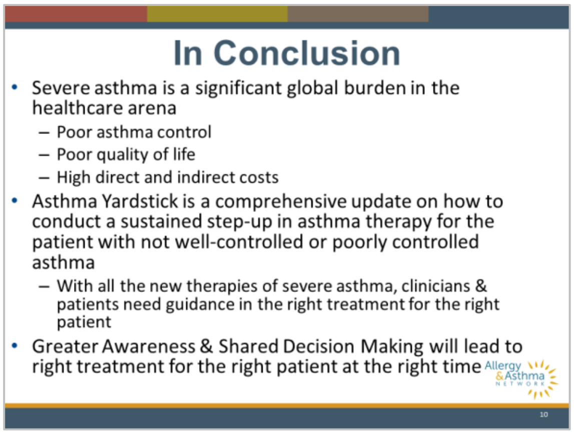
Tonya Winders, the President and CEO of the Asthma and Allergy Network and President of the Global Allergy and Asthma Patient Platform, spoke about barriers to care. Her organizations have worked with other advocacy groups to advance the asthma “yardstick” algorithm, standardize definitions and messaging, and roll out a multichannel asthma awareness campaign.

Tonya emphasized key policy priorities, which include access to effective care and insurance, funding for research, and efforts to address health disparities. With these in mind, she emphasized the need for action on specific legislation currently before Congress. One such bill seeks to establish certain exceptions to medication step-therapy, another enables schools to stock albuterol, and a third recognizes the role of respiratory care therapists in telehealth. These bills have implications beyond the allergy and asthma communities and serve as opportunities for future collaboration.



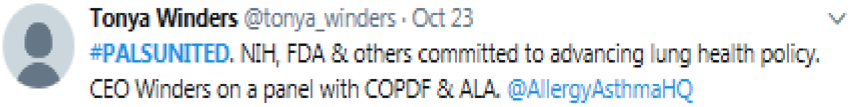
Policy Efforts

- Step Therapy
- Prior Authorization
- Telehealth
- School-Based Respiratory Management
- Payer Policy Roundtable



In Conclusion

- Severe asthma is a significant global burden in the healthcare arena
  - Poor asthma control
  - Poor quality of life
  - High direct and indirect costs
- Asthma Yardstick is a comprehensive update on how to conduct a sustained step-up in asthma therapy for the patient with not well-controlled or poorly controlled asthma
  - With all the new therapies of severe asthma, clinicians & patients need guidance in the right treatment for the right patient
- Greater Awareness & Shared Decision Making will lead to right treatment for the right patient at the right time



Tonya Winders @tonya_winders · Oct 23

#PALSUNITED. NIH, FDA & others committed to advancing lung health policy. CEO Winders on a panel with COPDF & ALA. @AllergyAsthmaHQ

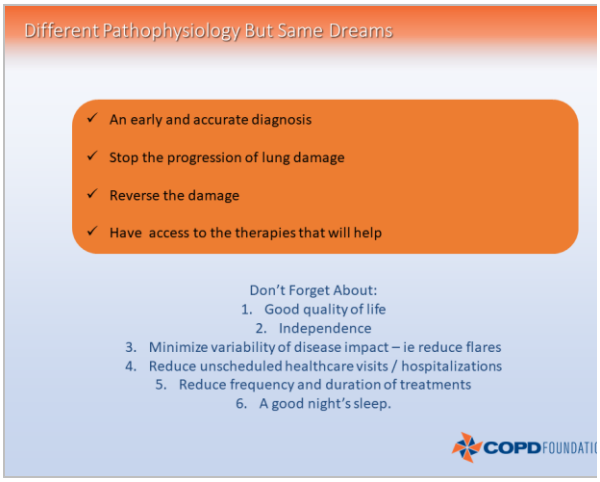
A Health Crisis Goes Unnoticed

Jamie Sullivan, the Vice President of Public Policy and Outcomes at the COPD Foundation, drilled down into four goals that unite the lung health community:

- ✓ An early and accurate diagnosis;
- ✓ Stop the progression of lung damage;
- ✓ Reverse existing damage;
- ✓ Ensure patient access to the therapies that help.

Jamie underscored that the long road leading to the COPD National Action Plan did not end with its publication – the work to carry out the vision it outlined is just beginning.

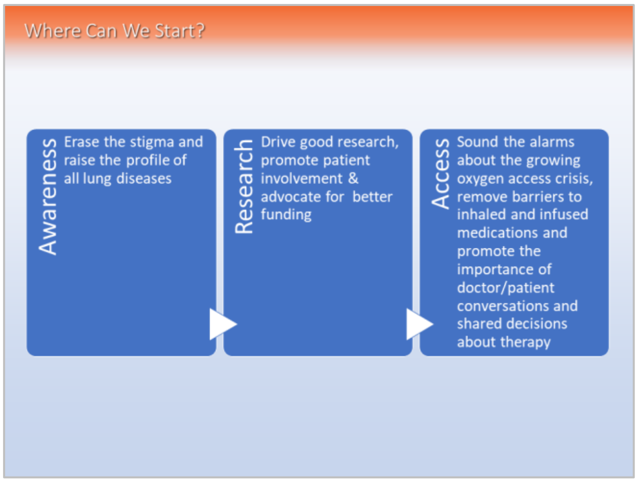
Now, the COPD Foundation and their partners are working to raise awareness about the disease; improve clinical outcomes and patient experiences; and accelerate research into prevention, treatment, and cures. There is progress to be made on several policy issues, including access to care, quality of care, healthcare payment and delivery, and medication and device regulation.


Different Pathophysiology But Same Dreams

- ✓ An early and accurate diagnosis
- ✓ Stop the progression of lung damage
- ✓ Reverse the damage
- ✓ Have access to the therapies that will help

Don't Forget About:

1. Good quality of life
2. Independence
3. Minimize variability of disease impact – ie reduce flares
4. Reduce unscheduled healthcare visits / hospitalizations
5. Reduce frequency and duration of treatments
6. A good night's sleep.


Where Can We Start?

Awareness Erase the stigma and raise the profile of all lung diseases

Research Drive good research, promote patient involvement & advocate for better funding

Access Sound the alarms about the growing oxygen access crisis, remove barriers to inhaled and infused medications and promote the importance of doctor/patient conversations and shared decisions about therapy

Jamie ended her presentation by serving up 3 areas where she felt the lung health community could collectively come together to make an impact. She indicated that opportunities exist in 1) Raising Awareness 2) Research and 3) Access.

Healthy Air Campaign

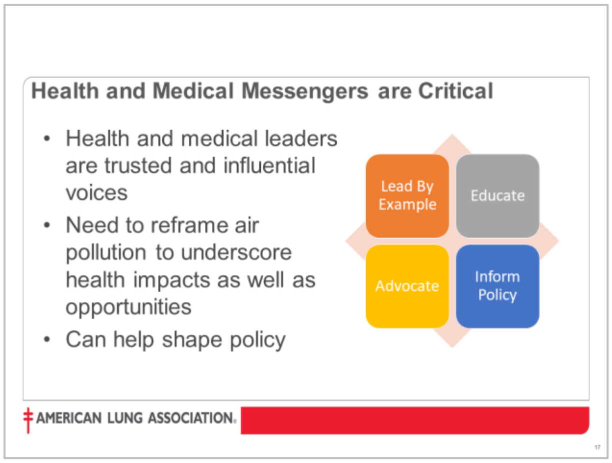
The American Lung Association's Executive Vice President for the Mid-Atlantic Region, **Deborah Brown**, brought the broad impact of air quality into the discussion. More than half of Americans live in regions with dangerous pollution levels; vulnerable populations are disproportionately impacted. While air quality is often considered an environmental issue, it has profound effects on lung health. Unfortunately, patients and providers cannot control air quality or climate change as they relate to individual health – larger, coordinated efforts are necessary to ensure that our communities can breathe easy.

Deborah reiterated that it's important to be vocal on these issues, as advocacy groups often provide the cover that enables policymakers to stand up. To help those at risk of air pollution, Deborah recommended joining the American Lung Association's efforts to fight for healthy air, spreading the word about the impact of air quality exposure, and sharing personal stories with policymakers to achieve maximum impact.

More than half of Americans still live where pollution levels are dangerous, and climate change threatens to make the situation worse. That is just one of the reasons it has been important to build and support both national and state-based coalitions.

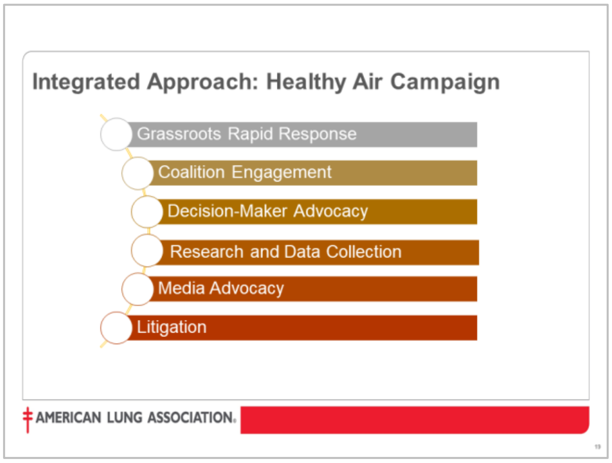
Deborah highlighted the Healthy Air Campaign, its framework and supporting tactics, which could be replicated for other campaigns. It is a science-based campaign for clean air and climate protections, made up of a coalition of health and medical organizations. Some of the advocacy and community engagement tactics utilized are listed below:

- Host weekly calls to help partners track policy development and identify strategic opportunities for response;
- Draft technical comments and letters for statewide sign-on;
- Draft letters for health professionals from all 50 states to sign-on;
- Create media advocacy opportunities;
- Coordinate meetings with the Administration and Congress.



Health and Medical Messengers are Critical

- Health and medical leaders are trusted and influential voices
- Need to reframe air pollution to underscore health impacts as well as opportunities
- Can help shape policy



Integrated Approach: Healthy Air Campaign

- Grassroots Rapid Response
- Coalition Engagement
- Decision-Maker Advocacy
- Research and Data Collection
- Media Advocacy
- Litigation

Healthy Air PA @HealthyAirPA · Oct 23

.@Dbrownala talks about how #ClimateChangesHealth at the #PALSUnited for Lung Health Summit in D.C.

Survey results reveal that 100% of attendees rated this overall session, involving Tonya Winders, Jamie Sullivan and Deborah Brown, as “Excellent” or “Very Good”. A comment from one attendee:

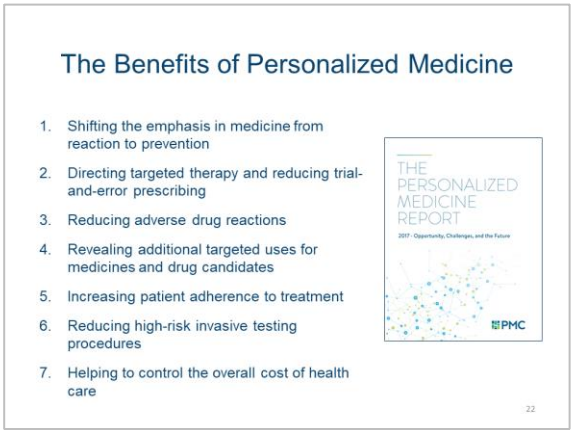
“I have a note on every single one of these presenters about how excellent the slide decks were. Looking forward to sharing with colleagues! The example campaigns highlighted by each speaker were very relevant and enlightening.”

Part II – Infusing the Patient Voice in Patient-Centered Solutions to Advance Lung Health

Personalized Medicine

Personalized medicine is the combination of precision medicine with shared decision making. **Cynthia Bens**, Vice President of Public Policy at the Personalized Medicine Coalition, provided an overview of personalized medicine’s transformative impact on care. Personalized medicine pushes for targeted therapies that align with the patient’s values and needs, in turn improving adherence and controlling overall health costs. For example, genetic testing can determine which patients will respond to the breast cancer drug Herceptin, the use of which saves $24,000 per patient on average.

While personalized medicine may lead to the development of novel drugs and therapies in the future, substantial barriers exist in terms of product development, the regulatory environment, insurance coverage and reimbursement, and clinical adoption. Perhaps most importantly, as a policy initiative, realizing the full potential of personalized medicine involves changing the paradigm of healthcare coverage and investing heavily in diagnostic tests and treatments that pay off over the long term.



The Benefits of Personalized Medicine

1. Shifting the emphasis in medicine from reaction to prevention
2. Directing targeted therapy and reducing trial-and-error prescribing
3. Reducing adverse drug reactions
4. Revealing additional targeted uses for medicines and drug candidates
5. Increasing patient adherence to treatment
6. Reducing high-risk invasive testing procedures
7. Helping to control the overall cost of health care

What are the Barriers to Realizing Personalized Medicine?

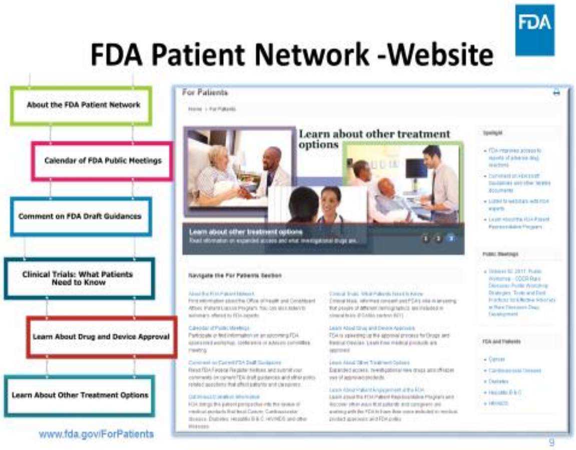
- Scientific and product development challenges
- Regulatory
- Coverage and reimbursement
- Clinical adoption, especially:
  - Public and health care work force education
  - Patient engagement and patient protections
  - Evidence generation to demonstrate the value of personalized medicine technologies
  - Programmatic infrastructure and information management
  - Evolving medical culture from one-size-fits-all, trial-and-error practice to targeted, personalized care

Patient Engagement

The Office of Health and Constituent Affairs at the U.S. Food and Drug Administration (FDA) is an office of patient engagement and assistance that works across the agency – drugs, devices, biologics – and is charged with advocating for patients within the agency and including the patient voice in regulatory activities and decision making.

Steve Morin, Health Programs Coordinator for this office and Director of the FDA Patient Network, covered the myriad ways the FDA works to integrate the patient perspective into the agency's efforts. He shared that the most meaningful participation and input from patients comes from those who understand the regulatory framework and processes.

Much of Steve's work has centered on enhancing outreach through the [FDA Patient Network]() website, which features a calendar of public meetings, opportunities to comment on FDA draft guidance, and tips for engaging with the FDA.



FDA Patient Network -Website

About the FDA Patient Network

Calendar of FDA Public Meetings

Comment on FDA Draft Guidances

Clinical Trials: What Patients Need to Know

Learn About Drug and Device Approval

Learn About Other Treatment Options

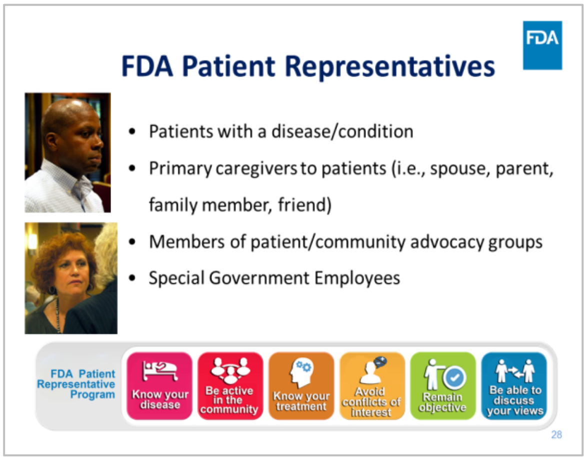
www.fda.gov/ForPatients

For Patients

Learn about other treatment options

Learn about other treatment options

9



FDA Patient Representatives

- Patients with a disease/condition
- Primary caregivers to patients (i.e., spouse, parent, family member, friend)
- Members of patient/community advocacy groups
- Special Government Employees

FDA Patient Representative Program

Know your disease

Be active in the community

Know your treatment

Avoid conflicts of interest

Remain objective

Be able to discuss your views

28

The FDA primarily works with patient representatives who have the condition, are the primary caregivers to patients, belong to a patient advocacy group, or are special government employees. They have expanded their efforts to train patient representatives. The goal is to educate broader patient communities about FDA, respond to questions, keep them apprised of opportunities to comment, and encourage appropriate participation in medical product development.

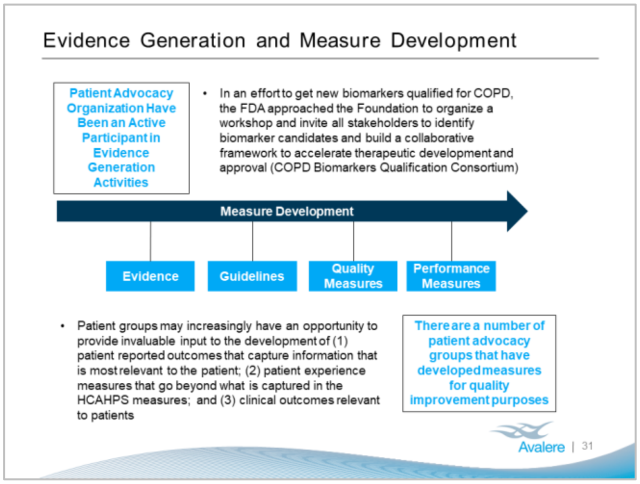
Steve highlighted six tips for effective patient engagement, which are applicable across all organizations interested in furthering the involvement of their constituents in advocacy initiatives.

1. Know your disease
2. Be active in the community
3. Understand your treatment
4. Avoid conflicts of interest
5. Remain objective
6. Be able to discuss your views

Development and Implementation of Patient-Reported Outcomes Measures

Nelly Ganesan, Senior Director at Avalere Health, discussed the impact of value and quality measures on healthcare. Patient advocacy organizations have an opportunity to advance patient care through various approaches: Quality Measures, Payment & Delivery Models, Treatment Options, Individual Care Plans, Promotion of Evidence-Based Medicine, Patient Education. They have a critical role to play in developing patient reported outcomes that capture patient priorities, patient experience measures, and clinical outcomes important to patients.

For example, The FDA, COPD Foundation, and other stakeholders partnered to identify biomarker candidates for COPD. In another instance, Minnesota Community Measurement solicited feedback from patient groups on COPD patient reported outcome measures; this input provided guidance into patient priorities.



Evidence Generation and Measure Development

Patient Advocacy Organization Have Been an Active Participant in Evidence Generation Activities

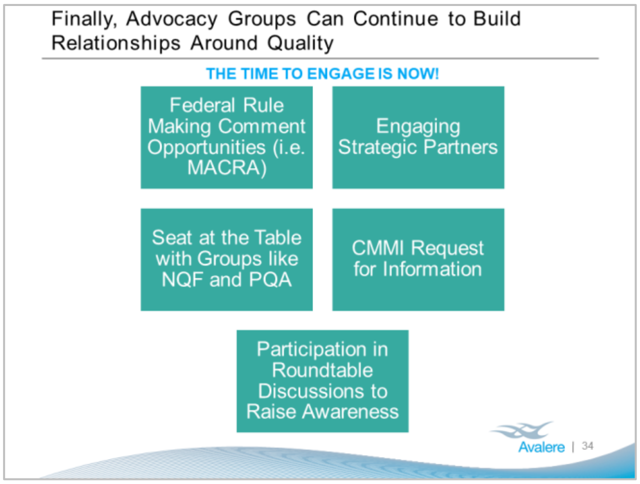
- In an effort to get new biomarkers qualified for COPD, the FDA approached the Foundation to organize a workshop and invite all stakeholders to identify biomarker candidates and build a collaborative framework to accelerate therapeutic development and approval (COPD Biomarkers Qualification Consortium)

- Patient groups may increasingly have an opportunity to provide invaluable input to the development of (1) patient reported outcomes that capture information that is most relevant to the patient; (2) patient experience measures that go beyond what is captured in the HCAHPS measures; and (3) clinical outcomes relevant to patients

There are a number of patient advocacy groups that have developed measures for quality improvement purposes

Patient advocacy groups have the passion and a wealth of information (both data and patient population details) that can play a major role in evidence generation, measure development and better optimization outcomes for patients. The next clear step is to build successful partnership between healthcare stakeholders so that all the great work being done is not happening in a vacuum and groups like CMS, NQF and measure developers can benefit from all the valuable contributions that have been made to further this work to date.

Nelly closed by highlighting some activities that all stakeholders can participate in (including patient advocacy groups that were participating at the event) to continue to advance quality and work towards achieving a value-based system.



Finally, Advocacy Groups Can Continue to Build Relationships Around Quality

THE TIME TO ENGAGE IS NOW!

Federal Rule Making Comment Opportunities (i.e. MACRA)

Engaging Strategic Partners

Seat at the Table with Groups like NQF and PQA

CMMI Request for Information

Participation in Roundtable Discussions to Raise Awareness

Avalere | 34

Survey results reveal that 100% of attendees rated this overall session, involving Cynthia Bens, Steve Morin and Nelly Ganesan, as “Excellent” or “Very Good”.

“Interesting to hear all of these perspectives with a focus on patient engagement.
Very interesting slide about barriers to realizing personalized medicine from Cynthia Bens and regulatory obstacles about developing a regulatory framework.
Definitely thought-provoking! Nice questions for Q&A.”

Raising the Profile of Lung Disease Through Stories

The day concluded with an inspiring speech from Chris Draft, who spent 12 years playing professional football in the NFL. He is now Founder, President, and CEO of the Chris Draft Family Foundation whose mission has been to empower families to lead healthy lifestyles. He is also the Co-Founder of Team Draft, leading the creation of a national campaign that is changing the face of lung cancer. He is an internationally recognized speaker, community leader, and family and character advocate who serves as an NFL Ambassador and a national spokesperson on many health-related issues, including the care and treatment of asthma, from which he suffer; and lung cancer, the disease that claimed the life of his wife, Keasha in 2011. Chris and his story has an impact on just about everyone he meets.

He has realized that his life and work have positioned him to be a catalyst for change, and that telling his story and sharing with others is the platform that allows him to reach others most effectively. Chris is passionate about raising the profile of lung diseases such as asthma and lung cancer. He advocates strongly for increased funding for early detection and lung disease treatment, with an ultimate goal of improving survivorship and quality of life. He told attendees to “look at which communities are winning, and try to do what they are doing.” The attendees very much enjoyed him, shared many positive comments and seemed to appreciate ending the meeting on a high note, feeling motivated and inspired.

Consensus Areas

Raising the Profile of Lung Diseases

Attendees agreed that efforts to raise awareness about lung disease among policymakers would benefit the community as a whole and lay the foundation for future advocacy initiatives. The COPD National Action Plan was proposed as a springboard to engage in broader lung health conversations. Participants recommended numerous strategies for connecting with policymakers on Capitol Hill, including showing the faces of lung disease, collaborating with relevant Congressional caucuses to host briefings, and including local patients in conversations to drive home the impact of lung illnesses on individuals and their families. Many emphasized the need to act on/visit local government offices in order to build relationships and further a movement that could resonate on the national scale.

While raising the profile of lung diseases at large helps the community, the need to coalesce around specific goals remains. Suggestions included advocating for payers to cover therapy options, encouraging reimbursement models that promote quality care, and supporting legislation that enables the expansion of telehealth services. Future conversations will further define these goals.

Advancing Patient-Centered Principles

The community of participants also places high priority on working to incorporate the patient voice throughout the medical ecosystem. There are many opportunities to engage with this theme, from developing patient reported outcome measures to collaborating with the Centers for Medicare and Medicaid Services, to promoting coordinated care.

Participants emphasized the need to better understand the current landscape and outlined two tools that they would find useful: a matrix that maps out the priorities of different lung advocacy groups and where their policy and advocacy initiatives overlap; an overview of existing quality measures within the lung health space and sharing results of collaboration with providers, payers, and professional societies.

Potential Next Steps

The Steering Committee and Planning Team that created this event are working on distilling all the information from the meeting, and coming up with actionable next steps. A webinar is one of the first follow-up activities that is in development. Continuing the connection among the participants in a PALs United for Lung Health network is another suggestion that is being considered.

As part of the evaluation, attendees were asked what specific actions they may plan to take as a result of attending this event. Below are some of the suggestions.

- *"We need to do more to raise awareness of the COPD National Action Plan."*
- *"1) Investigate which "communities are winning" in terms of case studies and 2) I will be connecting with some participants regarding collaboration."*

- *"A bit TBD, but I believe that groups like this one are the only way to get traction on big issues like Access and Reimbursement. Engaging conversation and more to explore but a great start."*
- *"We are focusing on building our Advocacy program so this was timely."*
- *"Increased consideration of COPD/ACOS (Asthma-COPD Overlap Syndrome) in our asthma efforts."*

Overall Program Feedback from Attendees

How would you rate this PALs United for Lung Health Overall?
93% of attendees rated it as "Excellent" or "Very Good" and 7% as "Good"

How useful, in your day-to-day work, was attending this PALs United for Lung Health event?
93% of attendees rated it as "Excellent" or "Very Good" and 7% as "Good"

Overall feedback on your experience at PALs United for Lung Health:

▸ *"This was my first PALS meeting. I was impressed. The topics were good and speakers very good. It was also a great networking opportunity. Finding common ground with other lung disease groups was valuable."*

▸ *"The meeting raised awareness of timely and important issues around lung disease with a group of diverse stakeholders in patient advocacy – awesome."*

▸ *"Thank you for putting on this program. It was very informative and interesting."*

▸ *"I really enjoyed this meeting and will look forward to what comes out of it."*

▸ *"I think Anne Easter did a spectacular job with a very difficult task. It's a bit unclear how to move forward from here. I think it would have been wonderful to put some thoughts on the white board, but still, extremely well done. Margaret did a really good job."*

What did you like Best?

- *“Powerhouse group of people with unique but complimentary perspectives.”*
- *“Gaining knowledge of issues around lung disease that I wasn’t familiar with. It was an excellent forum overall.”*
- *“1) Meeting Others and*
  2) Focus on Lung Health”
- *“Diverse audience – multiple perspectives; asthma yardstick.”*
- *“The examples and shared discussion at the end was great in identifying opportunities to act on.”*
- *“I think that Chris Draft was really great! Inspiring and conveyed terrific advice!”*
- *“Meeting new contacts.”*
- *"The opportunity to attend!"*

Suggestions for Improvements?

- *“Expand invitation to more lung disease advocacy groups.”*
- *“I don’t have any suggestions for improvement. The format was very effective.”*
- *“Be more specific to issues – some of it was just information about Departments. Very good but should have been more lung disease specific.”*
- *“No mention of impaired health literacy and its impact on patient awareness. How to reconcile patient awareness and interaction with decreasing time /availability with prescribers.”*
- *“No discussion of ethnic/ socioeconomic status – very important in outcomes, compliance, disease presentation & understanding.”*

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.
For more information about PALS, contact Anne Easter, Director, PALS, at healthadvocacy@nc.rr.com.

PATIENT ADVOCACY
LEADERS SUMMIT

Appendix A – Agenda

PALs
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Patient Advocacy Leaders
United for Lung Health

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.*

<u>Key Objectives</u>:

- 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

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**

Appendix B – Registered Attendees

Last Name	First Name	Title	Organization
Anderson	Charmayne	Director of Advocacy	Allergy & Asthma Network
Anderson	*Margaret*	Managing Director	Deloitte Consulting LLP
Bens	*Cynthia*	Vice President, Public Policy	Personalized Medicine Coalition
Bowman	C. Michael	President-Elect and Advocacy Chair	Association of Asthma Educators
Brown ★	*Deborah*	Executive Vice President	American Lung Association - Mid-Atlantic
*Bryan** ★	*Deborah*	Program Manager, Mothers & Others for Clean Air	American Lung Association – Southeast
Carino	Tanisha	Vice President, Public Policy	GlaxoSmithKline
Cohen*★	Michael	Principal Consultant	MJC Health Solutions, LLC
Crews*	Clint	Associate Professor	Eastern Virginia Medical School
Dehoney★	Ellie	Vice President, Policy and Advocacy	Research!America
DeMatteis^	Candace	Policy Director	Partnership to Fight Chronic Disease
Draft	*Chris*	President & Founder	Chris Draft Family Foundation
Easter	Anne	Director	Patient Advocacy Leaders Summit (PALS) @ The AIDS Institute
Eftekhari	Sanaz	Director, Corporate Affairs	Asthma and Allergy Foundation of America
Ewart	Gary	Chief, Advocacy & Government Relations	American Thoracic Society
Flowers	Derek	Manager	Alliance for Patient Access
Fruchterman	Emily	Science Policy	Research!America
Ganesan	*Nelly*	Senior Director	Avalere Health
Gibb	Emily	Senior Director, Public Policy & Patient Assistance	GlaxoSmithKline
Hale	Laura	Program Manager	American Lung Association
Harman*	Chuck	Chief Development Officer	National Alliance on Mental Illness
Hummel	Anne Marie	Associate Executive Director	American Association for Respiratory Care

Last Name	**First Name**	**Title**	**Organization**
Kephart	Craig	Chief Executive Officer	COPD Foundation
Kiley	*James*	Director, Division of Lung Diseases	National Heart, Lung and Blood Institute/National Institutes of Health
Kochman	Fran	Director, Advocacy and Alliance Development	GlaxoSmithKline
Krofah	Esther	Director, Public Policy	GlaxoSmithKline
Kroner	Katie	Policy Director	Pulmonary Hypertension Association
Latham	Sara	Chief Operating Officer	COPD Foundation
Leong*	Amye	President & CEO	Healthy Motivation
Maloney	Matt	Director of Health Policy	Respiratory Health Association
Mascia-Rand	Marie	Managing Director/Co-Founder	Phaware Global Association
Miniter	Paul	Strategist	American Association for Respiratory Care
Morin	*Steve*	Health Programs Coordinator, Office of Health and Constituent Affairs	U.S. Food & Drug Administration
Niles	Amy	Vice President, External Affairs	Patient Access Network (PAN) Foundation
Pannu	Jasmine	Business Development Manager	Asthma and Allergy Foundation of America
Ruppal	Michael	Executive Director	The AIDS Institute
Silverman	Jennifer	Director, Operations	Transition to Success ®
Sullivan ✶	*Jamie*	Vice President of Public Policy & Outcomes	COPD Foundation
Traxel	Pam	Senior Vice President	ACS CAN
Winders ✶	*Tonya*	President & Chief Executive Officer	Allergy & Asthma Network

✶PALs United for Lung Health Steering Committee Member
^ PALs United for Lung Health Advisor
** PALS Advisory Board Member*
Speakers in Italics