PALs United for Lung Health Advocacy Roundtable

Collaborating to Raise the Profile of Lung Disease and Advance Better Patient-Centered Solutions: Moving from Ideas to Action

May 20, 2018

Omni San Diego Hotel | San Diego, CA

PALs UNITED

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Patient Advocacy Leaders
United for Lung Health

Contents

Overview

The PALs United for Lung Health Advocacy Roundtable was held on May 20, 2018 in San Diego, California in concurrence with the International Conference of the American Thoracic Society. In total, 30 lung health advocacy leaders from organizations throughout the U.S. and Canada registered for the Roundtable event (see Appendix A for a list of registered attendees). The meeting was developed by the Patient Advocacy Leaders Summit (PALS) in collaboration with the PALs United for Lung Health Steering Committee.

The convening was intended to carry forward the engagement that began at the American Thoracic Society Briefing in May 2017, continued at the inaugural PALs United for Lung Health event held in Washington DC in October 2017, and was further advanced at the Advocacy Roundtable held at CHEST in Toronto in October 2017. Two-thirds of 2018 Advocacy Roundtable registrants attended one or more of these previous meetings.

Key objectives of the Advocacy Roundtable were to:

- Further coalesce and collaborate around common goals and action steps to raise the profile of lung disease and advance patient-centered solutions relating to access to care, services, and innovations in lung health.

- Assess and prioritize action steps and implementation strategies to enable lung health leaders to work collectively in raising the profile of lung disease and assure patient-centered care by incorporating clinically focused values and outcomes as well as the voices of patients and their families.

The Advocacy Roundtable was focused on determining specific strategies and tactics PALs partners can work on collaboratively to achieve these objectives (see Appendix B for meeting agenda). Two small group breakout sessions were conducted, each focusing on one of the objectives listed above.

Welcoming Remarks

The meeting began with opening remarks by Deborah Bryan, President and CEO (retired) of the American Lung Association of North Carolina. Ms. Bryan welcomed guests and thanked PALS sponsors and the PALs United for Lung Health Steering Committee for their support. She introduced event moderator Louse Binder, Health Policy Consultant with the Save Your Skin Foundation in Toronto.

Ms. Binder pointed out that health policy advocacy is a long-term effort that requires dedication and optimism. She discussed the importance of remaining focused on patients' needs, and the benefits of collaboration and working together to enhance impact. She told her story about being a patient and an advocate, and how in this space we sometimes live on "fumes of hope." She reminded everyone that making such a profound difference in peoples' lives is precious and rewarding and that she was honored to be in a room full of heroes.

Ms. Binder drew on the *COPD National Action Plan*, which can serve as a best practice, providing tools that can be applied to other lung health conditions. She suggested using this document to assist in determining more specific PALs United for Lung Health efforts. She reminded attendees of the goal of reaching collective agreement on specific action steps to raise the profile of lung disease and to assure that patient-centered care includes the voice of patients and their families.

Ms. Binder introduced Nick Navatta, a local illustrator, who created a graphic recording of the Advocacy Roundtable (see page 8). She reviewed the meeting agenda and pointed out useful materials in the packet including summaries of past convenings and components of the *COPD National Action Plan*.

Small Group Breakout Sessions

Participants were pre-assigned to one of two breakout groups.

Group 1

The topic of Group 1 was "Raising the Profile of Lung Disease." This group was facilitated by Tonya Winders, MBA, President & Chief Executive Officer of the Asthma & Allergy Network and President of the Global Allergy & Asthma Patient Platform.

Group 1 key discussion questions included:

- Who are the key stakeholders and what are the key messages we need to increase awareness of lung disease?
- What are the primary unmet educational needs in lung disease and how might we partner to enhance understanding?

Ms. Winders initially led the group in a brainstorming activity to identify key stakeholders. These included:

- Patients
- Providers
- Payors
- Politicians
- Caregivers
- Media

- Teachers
- Nurses
- School nurses
- Respiratory therapists
- Multi-disciplinary treatment teams
- WHO
- Industry, including pharma and device manufacturers
- Hospitals
- General public
- Professional societies

Next, Ms. Winders facilitated a discussion about which key educational messages would best increase the awareness of lung disease for each stakeholder group. After a broad list of possible topics was created, participants narrowed down key messages that would resonate best within each group. Results of this discussion are presented below, with key recommended messages indicated with an asterisk (*).

Stakeholder Group	Messages
Patients	• *Prevention (including smoking cessation, vaccines, environmental causes, nutrition, exercise, and the importance of overall health across the lifespan) • *Self-management, adherence, and compliance • Knowing how to make/share decisions with providers and ask the right questions • Self-advocacy • Managing own environment • Research and innovation, which can provide hope • Understanding mental health and its relationship to lung health • Managing stigma
Healthcare providers / Multi-disciplinary teams	• *Importance of personalized care (e.g., treating patients as people, not merely symptoms; recognizing how lung disease impacts overall physical and mental health; focus on people, not money) • *Understanding when and how to refer patients to other resources for support (e.g., primary care referrals to specialists, educational resources, advocacy, financial support) • Assessing functional status and considering patients' individual goals • Better trust and communication between providers and patients • Providing a sense of hope for patients

Stakeholder Group	Messages
Payors	• *Value of patient-driven care and treatment (right treatment + right patient + right time = value) • *Importance of patient choice and supporting (not undermining) the patient/provider relationship • Focus on long-term care, not short-term care • Define value based on lifetime health rather than 12-month return on investment • Recognize that “one size” does not fit all patients • Simplify delivery of care and coverage options • Recognize the indirect costs of lung disease (e.g., lost productivity, absenteeism) • Develop more creative and innovative payment models
Policymakers / Politicians / WHO	• *Burden and overall impact of lung disease (e.g., cost of the disease to patients and society, potential cost savings of effective prevention and treatment) • *Prevalence, morbidity, and mortality of lung disease • Disproportionate spending for lung disease vs. other chronic diseases • Funding for lung disease should be a non-partisan, apolitical issue • Importance of accommodations for people with lung disease • Better understanding of patients’ needs • Health disparities and the importance of health equity • Importance of research and development • Better access to care including technology and innovation
Media / General public	• *Provide storytelling with purpose and direction with the message that lung disease can kill • *Focus on the connection between lung health and overall health across the lifespan (i.e., the lung health/total health connection) • Emphasize prevention • Dispel myths, stigma, and misperceptions • Reduce apathy about lung disease • Use planned events to raise awareness (e.g., World Lung Day, National Asthma Month) • Focus on lung disease prevalence, morbidity, mortality, costs, and disparities • Focus on the importance of prevention • Provide information on available resources and how to navigate the healthcare system • Create media partnerships

Stakeholder Group	Messages
Industry	*Provide better access to treatment and medications with a focus on affordability *Implement patient-driven, patient-centered protocols for research and development, technology, innovation, big data, and artificial intelligence; include the patient perspective from the very beginning of the process Communicate early with patients and the general public about new products, research and development, and clinical trials
Caregivers / Community / Support systems	*Focus on the connection between lung health and overall health across the lifespan (i.e., the lung health/total health connection) Support is needed for caregivers including emotional support Educate and equip caregivers to become advocates Caregivers need their own tailored messaging, tools, and resources Focus on the importance of community health workers Focus on the financial impact of lung disease on caregivers and families

Group 2

The topic of Group 2 was "Advancing Patient-Centered Principles." This group was facilitated by Vanessa Foran, President and Chief Executive Officer of Asthma Canada.

Group 2 key discussion questions included:

- What are the key two or three policy areas that we could focus on for lung disease across borders, co-morbidities, and disease states?
- What are the key "asks" to support these advocacy priorities?

Ms. Foran began the breakout session by pointing out that although policy advocacy can be slow and aspirational in nature, lung health advocates can raise the profile of lung disease and advance patient-driven care by working collaboratively and holding others accountable. No matter where we live, we can find a common agenda that will result in helping people.

Next, Ms. Foran led participants in a discussion to identify policy issues relevant to lung disease. Issues raised included:

- Patient-driven, patient-centered care that:
    - Impacts lung disease across the continuum
    - Addresses aspirational goals of patients
    - Allows for shared decision making regarding medications and lifestyles

    - Includes caregivers and families
- Improvements in access to care:
    - Specialists
    - Appropriate screening and diagnostics
    - Evidence-based medications and therapies
    - Equipment
    - Research
    - Education and training
    - Accurate surveillance data
    - Resources
- Prior-authorization for treatment
- Managing step therapy and non-medical switching
- Provider training on right device + right medication + right time
- Impact of cultural and language issues on utilization
- Portability of coverage
- Payment system reform to encourage/allow shared decision making
- Public-private approaches to fill gaps in coverage (e.g., medications and innovative treatment options)
- Addressing wait times for chronically ill vs. critically ill patients (Canada)
- Inclusion of rare disease diagnosis in board exams
- Expansion of pulmonary fellowships
- Changes in death certificate coding
- Better data/analysis on cost savings related to good disease management and proper treatment vs. neglect

Ms. Foran mentioned that health advocates could create synergies and coalesce around the same issues. With this in mind, the group discussed which policy options were the highest priority for advocacy efforts. Recommended areas of focus included:

- Access to care and treatment
    - Using a team approach, design a system in which all needed care is received
    - Focus on the right diagnosis at the right time with the right treatment
    - Provide better reimbursement for treatment education and more time spent with patients
    - Integrate mental healthcare into clinical care for lung health
    - Address cultural and language barriers
    - Reduce administrative burdens on medical practices
- Better care coordination
    - Integrate mental and physical healthcare capitated into reimbursement rates
    - Certify healthcare providers in disease management and education
    - Identify policies related to other chronic health conditions (e.g., diabetes, Parkinson's disease, heart disease) that can be adapted for lung disease
    - Increase use of telehealth and phone "wearables" for reporting and monitoring
- Funding for economic research
    - Combine costs of all chronic diseases for greater emphasis and impact

How to Make it Happen: Next Steps for Action

The final session brought all participants back together with the purpose of moving toward consensus on action steps. Ms. Winders and Ms. Foran provided reports and key recommendations from each breakout group. Ms. Binder pointed out that there was much synergy between the breakout sessions and provided some recommendations for possible next steps. These included:

- Dive deeper into messaging for each key stakeholder group:
    - Develop a comprehensive list of individual stakeholder categories (e.g., separate policymakers from politicians, public payors from private payors, media from general public)
    - Determine which stakeholders are decision makers and which are influencers; prioritize categories for targeted messaging and short-term opportunities
    - For each stakeholder category, create a matrix examining specific issues and relevant messages
- Develop and build on some early communication and advocacy “wins”
- Focus on developing common messaging (including talking points, media releases, etc.) in time for two upcoming events:
    - September 18—Ms. Winders will be presenting on lung health at the United Nations
    - September 25—World Lung Day

Ms. Binder closed the Roundtable by saying she was energized by the hard work, commitment, and passion of participants. She reiterated the importance of collaboration and working together and thanked PALs United for Lung Health for hosting this important meeting.

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*This **PALs United** event was part of the **PALS (Patient Advocacy Leaders Summit)** program, which involves patient advocates from around the country who are committed to improving health and healthcare in our communities. PALS is guided by the PALS Advisory Board comprised of advocacy leaders from across the country, who help ensure PALS is By Advocates, For Advocates. PALS was developed by GlaxoSmithKline (GSK) in 2002. GSK has granted The AIDS Institute exclusive rights to implement PALS in the US and provided a portion of the funding for this event.*

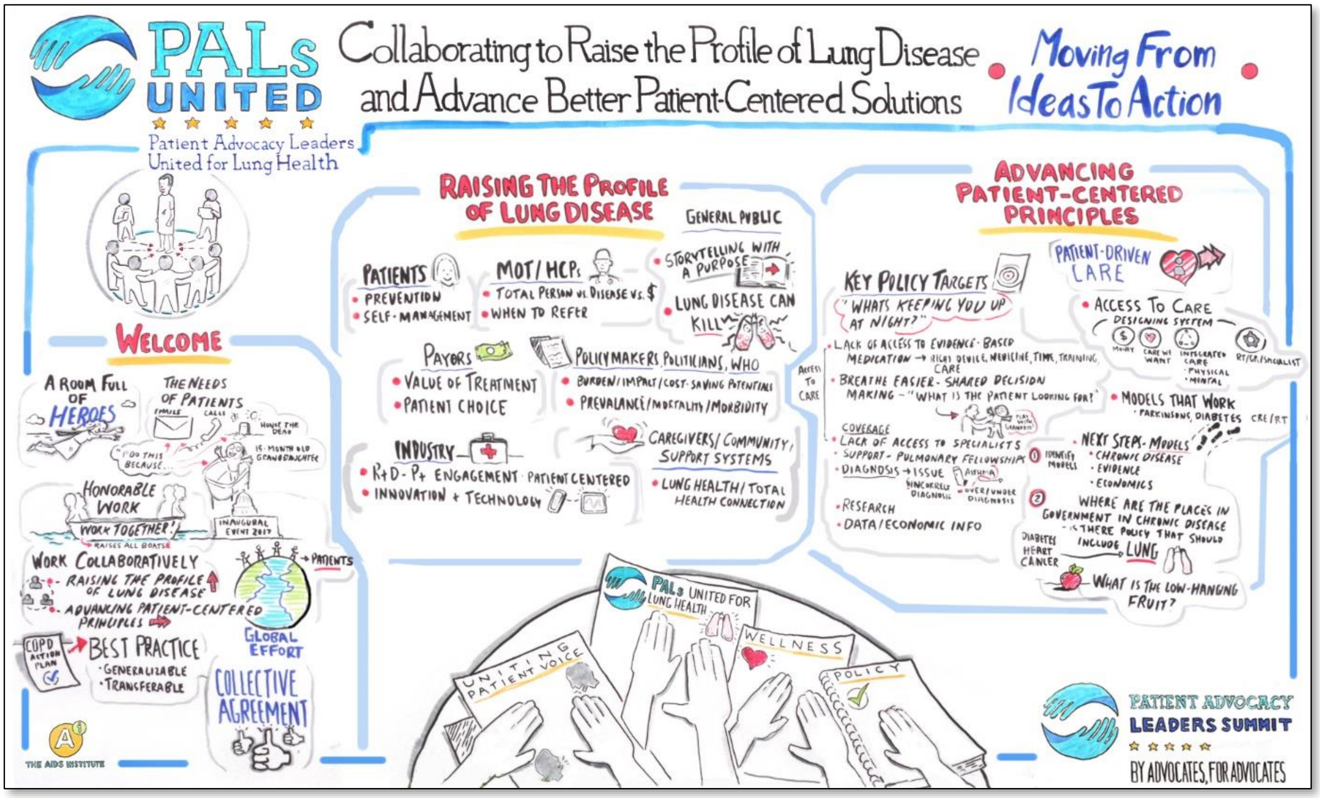
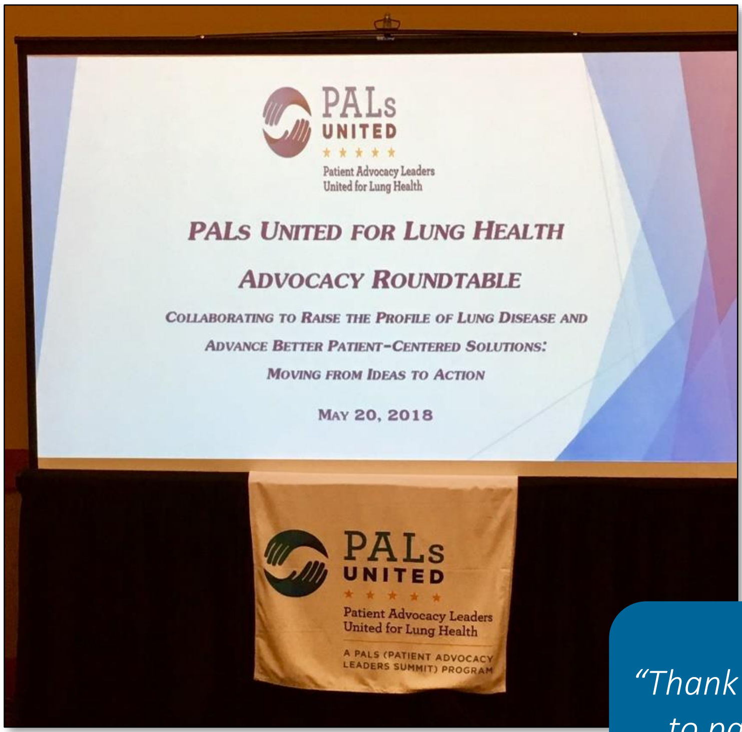

PALs UNITED
Patient Advocacy Leaders United for Lung Health
Collaborating to Raise the Profile of Lung Disease and Advance Better Patient-Centered Solutions
Moving From Ideas To Action
WELCOME
A ROOM FULL OF HEROES
THE NEEDS OF PATIENTS
EMAILS
CALLS
HOUSE THE DEAD
"I DO THIS BECAUSE..."
15-MONTH OLD GRANDDAUGHTER
HONORABLE WORK
WORK TOGETHER!
RAISES ALL BOATS
INAUGURAL EVENT 2017
WORK COLLABORATIVELY
- RAISING THE PROFILE OF LUNG DISEASE
- ADVANCING PATIENT-CENTERED PRINCIPLES
PATIENTS
GLOBAL EFFORT
COPD ACTION PLAN
BEST PRACTICE
·GENERALIZABLE
·TRANSFERABLE
COLLECTIVE AGREEMENT
THE AIDS INSTITUTE
RAISING THE PROFILE OF LUNG DISEASE
PATIENTS
• PREVENTION
• SELF-MANAGEMENT
MOT/HCPs
• TOTAL PERSON vs. DISEASE vs. $
• WHEN TO REFER
GENERAL PUBLIC
• STORYTELLING WITH A PURPOSE
• LUNG DISEASE CAN KILL
PAYORS
• VALUE OF TREATMENT
• PATIENT CHOICE
POLICYMAKERS, POLITICIANS, WHO
• BURDEN/IMPACT/COST-SAVING POTENTIALS
• PREVALANCE/MORTALITY/MORBIDITY
INDUSTRY
• R+D - P+ ENGAGEMENT - PATIENT CENTERED
• INNOVATION + TECHNOLOGY
CAREGIVERS/COMMUNITY, SUPPORT SYSTEMS
• LUNG HEALTH/TOTAL HEALTH CONNECTION
ADVANCING PATIENT-CENTERED PRINCIPLES
KEY POLICY TARGETS
"WHATS KEEPING YOU UP AT NIGHT?"
ACCESS TO CARE
• LACK OF ACCESS TO EVIDENCE-BASED MEDICATION → RIGHT DEVICE, MEDICINE, TIME, TRAINING, CARE
• BREATHE EASIER - SHARED DECISION MAKING - "WHAT IS THE PATIENT LOOKING FOR?"
PLAY WITH GRANDKIDS
COVERAGE
• LACK OF ACCESS TO SPECIALISTS
• SUPPORT - PULMONARY FELLOWSHIPS
• DIAGNOSIS → ISSUE
ASTHMA
INCORRECT DIAGNOSIS
OVER/UNDER DIAGNOSIS
• RESEARCH
• DATA/ECONOMIC INFO
PATIENT-DRIVEN CARE
• ACCESS TO CARE
DESIGNING SYSTEM
MONEY
CARE WE WANT
INTEGRATED CARE
·PHYSICAL
·MENTAL
RT/GP/SPECIALIST
• MODELS THAT WORK
·PARKINSONS, DIABETES
CRE/RT
• NEXT STEPS - MODELS
① IDENTIFY MODELS
·CHRONIC DISEASE
·EVIDENCE
·ECONOMICS
② WHERE ARE THE PLACES IN GOVERNMENT IN CHRONIC DISEASE
- IS THERE POLICY THAT SHOULD INCLUDE LUNG
DIABETES
HEART
CANCER
WHAT IS THE LOW-HANGING FRUIT?
PALs UNITED FOR LUNG HEALTH
WELLNESS
UNITING PATIENT VOICE
POLICY
PATIENT ADVOCACY LEADERS SUMMIT
BY ADVOCATES, FOR ADVOCATES

Photo Gallery



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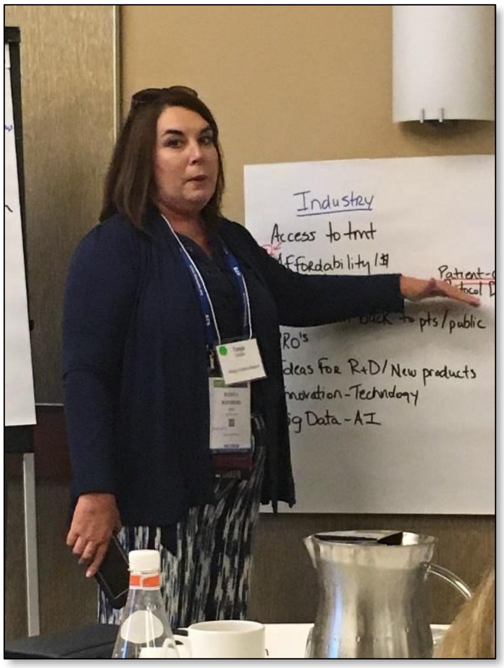
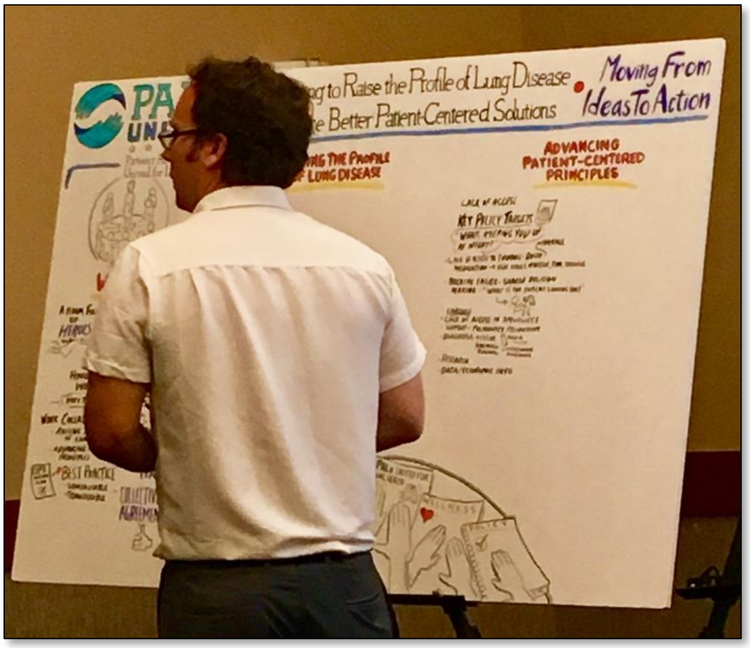
ADVOCACY ROUNDTABLE

COLLABORATING TO RAISE THE PROFILE OF LUNG DISEASE AND
ADVANCE BETTER PATIENT-CENTERED SOLUTIONS:
MOVING FROM IDEAS TO ACTION

MAY 20, 2018

> *"Thank you for including me. I am so glad I got to participate and look forward to staying connected with this group."*
> *Roundtable participant*


Industry
Access to tmt
Affordability / $
back to pts/public
RO's
deas For R+D/New products
novation-Technology
g Data - AI


g to Raise the Profile of Lung Disease
e Better Patient-Centered Solutions
Moving From Ideas To Action
ADVANCING PATIENT-CENTERED PRINCIPLES
BEST PRACTICE


Awareness
Patients
MDT-HCP
Payers
Louise Binder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Patient Advocacy Leaders United for Lung Health
A PALS (PATIENT ADVOCACY LEADERS SUMMIT) PROGRAM
Support for PALS provided by:
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