

IMPACT COPD

*Engage, Educate
& Inspire Action*

June 18-19, 2019 • Washington, DC



Introduction

In June 2019, more than 40 patients, caregivers and healthcare professionals converged on Washington, DC, for IMPACT COPD. This interactive, two-day workshop for COPD champions consisted of training, relationship-building and advocacy, including networking opportunities and visits with Congressional offices on Capitol Hill.

On day one of this inaugural event, COPD champions, most of whom are longtime COPD State Captains, were joined by experts from the National Institutes of Health (NIH), the US Food & Drug Administration (FDA), our own COPD Foundation team and others to cover topics ranging from early stage discovery science to clinical research, access to care challenges and how to effectively apply storytelling in advocacy work.

Morning Sessions Recap



The COPD Foundation's own Bill Clark, a COPD patient himself, kicked off the day with his perspectives on the importance of community engagement. Bill reminded everyone that our founder, John W. Walsh, started the COPD Foundation to improve the lives of all those affected by COPD and that he had a fierce belief in the power of the community to create change if given the information and the resources to act.

Dr. Tony Punturieri from the NIH's National Heart, Lung, and Blood Institute (NHLBI), highlighted ways NHLBI works to achieve the NIH's mission to seek fundamental knowledge about the nature and behavior of living systems and apply that knowledge to enhance health, lengthen life and reduce illness and disability. Dr. Punturieri shared an example of how research in one condition, Marfan syndrome, has led to a potential discovery for treating COPD. He highlighted select NHLBI-supported studies that have yielded important findings for how we diagnose and treat COPD and stressed that NHLBI funds research from the early stages of basic science all the way through to studies that look at how we better deliver care to ensure patients benefit from what we know works now.

NHLBI-funded Trials Impacting Clinical Care:



▪ Studied the role of Azithromycin for prevention of exacerbations of COPD:

Azithromycin taken daily for 1 year, when added to usual treatment, decreased the frequency of exacerbations and improved quality of life.

CCRN [Azithro NEJM 2011](#)

▪ Investigated role of Statins in COPD exacerbation prevention:

Simvastatin did not affect exacerbation rates or the time to a first exacerbation.

CCRN [Simva NEJM 2014](#)

▪ Tested test whether long-term treatment with supplemental oxygen vs. no use would result in a longer time to death or hospitalization among patients who had stable COPD with moderate resting desaturation: Long-term supplemental oxygen did not result in a longer time to death or first hospitalization. LOTT [Oxygen NEJM 2016](#)

Susan Chittooran from the FDA's Office of Patient Affairs gave examples of how the FDA is engaging patients in their work. She emphasized that patients have a role to play in guiding the treatment development and approval process. FDA initiatives such as the Patient Representative Program, Patient Focused Drug Development initiatives, the Patient Engagement Advisory Panel and others across the FDA help ensure that new devices and drugs are treating what matters to patients, are tolerable and have considered appropriate risk versus benefit calculations.

FDA Patient Representative Program SM



FDA Patient RepresentativeSM consultants provide direct input to the Agency's decision-making process in over 300 diseases and conditions and participate on FDA Advisory Committees and in review division assignments.

After spending the first session talking about the discovery, development and approval of new treatments, we transitioned to barriers getting those treatments out into the community. This included how we assess if a treatment is valuable, ongoing treatment access issues, the role of public health and what comprehensive care means in COPD.

Dr. Julia Slejko from the University of Maryland educated participants about the concept of value assessment and why patients must be involved in determining what aspects of treatment are most valuable. Value assessments are increasingly being used to guide health insurance coverage decisions, so it is imperative that the patient's voice is represented from the beginning of the process. Dr. Slejko discussed a pilot study she is conducting to create COPD treatment attributes for value assessments.

COPD Foundation team member Jamie Sullivan, updated participants about critical access issues facing patients who use supplemental oxygen and an emerging threat to non-invasive ventilator access, both issues that advocates raised in their Congressional meetings the following day. She explained that a group of patient and medical professional organizations have been working to identify regulatory and legislative options to help ensure people with lung disease get the appropriate oxygen equipment for their needs, with an immediate focus on preserving access to liquid oxygen for high-flow users.

Dave Zook, Foundation policy consultant from Faegre Baker Daniels, explained the important role that the Centers for Disease Control and Prevention (CDC) plays in disease awareness, prevention strategies, public health research and other chronic disease management efforts and why we must get CDC funding in the federal budget to address COPD, the priority issue addressed in the Congressional visits.

Foundation Chief Science Officer Dr. Barbara Yawn, closed the morning with an informative session on what she considers comprehensive care in COPD and



how the COPD Pocket Consultant Guide can be a tool in closing the quality gap faced by patients across the country, the majority of whom do not have access to pulmonologists in their area. Dr. Yawn also previewed the Foundation's upcoming patient track addition to the COPD Pocket Consultant Guide App which will feature more educational content, the MyCOPD Action Plan, inhaler instructions and more. The patient track is expected to be released in fall 2019.

Elements of Comprehensive Care:

- **Correct and confirmed diagnosis**
 - Spirometry
 - Imaging
 - Oxygen status (pulse ox is good start)
- **Non-pharmacologic treatment**
 - Influenza, pneumococcal and shingles immunizations
 - Pulmonary rehabilitation
- **Selecting pharmacotherapy**
 - Symptom burden
 - Exacerbations
 - Inhaler selection and teaching
- **Co-morbidities**
 - Considered and evaluated

Afternoon Sessions Recap

Following lunch and an interactive listening session, the workshop focus shifted to storytelling, community outreach and advocacy. IMPACT participants received training in the basics of storytelling prior to the workshop and were asked to complete a worksheet to aid them in structuring the story about their COPD journey. We were joined by experts from Spitfire Strategies who facilitated an interactive session where advocates practiced their story and received feedback. All State Captains will get this important training in the coming months so that they feel empowered to share their story in a way that moves their audience and achieves whatever goals they set, whether it be to raise awareness, inspire others to report their symptoms or move policymakers to act on COPD issues.



Getting out into the community to raise awareness about COPD, one of the most important roles of a State Captain, is critical. As such, after presenting tips for hosting successful community awareness events, two volunteers demonstrated how they handle tough questions from the public and patients. Additionally, participants got an overview of resources available to them in the State Captain Meetinghouse, a private section on the COPD Foundation's website, and what printed materials are available to order for these events. The role-playing and lively discussion that followed highlighted that people's needs often go beyond basic information about COPD, as some may just need



someone to listen, allowing them to realize they are not alone in their COPD journey. Anyone can play a role in meeting these needs, whether you are a healthcare professional, patient, family member or friend.

Dave Zook closed out the workshop with a session to prepare advocates for making the most out of their Congressional visits the following day and when they are back home in their communities. Dave gave an overview of the "noise" in Washington, DC, that COPD is up against and reminded participants that the goal is to build a long-term relationship with elected officials AND their staff who play an important role in championing action on issues that their constituents bring forward in letters, calls and meetings. Participants learned more about the status of key NIH and CDC funding requests, how to conduct their in-person meetings and what to do back in their home districts to continue the progress.

Shifting to Capitol Hill

At the end of day one, the group's focus shifted to Capitol Hill where participants engaged with Congressional staff at an evening reception. Staff of all ages and tenure had the chance to engage in conversation with participants, learning from the experts why their offices should become COPD champions. Former Indiana Congressman, Luke Messer, energized the crowd by reinforcing the difference made by in-person visits with Congressional offices. Linda Walsh, daughter of COPD Foundation Founder, John Walsh, and current COPD Foundation team member, spoke about her life as a caregiver and family member of someone with COPD and Alpha-1. Linda reminded us that her father believed in the value of advocacy and in the ability of the COPD community to come together to create change and inspire action.



The following day it was time to descend on Capitol Hill once again, this time for a series of meetings with members of Congress and their staff. Over 80 offices were visited by IMPACT COPD participants who advocated for COPD research funding at the NIH and a COPD program at CDC, two important requirements for progressing the implementation of the COPD National Action Plan. They also urged Congressional members to address critical issues such as access to supplemental oxygen and the need for the Centers for Medicare and Medicaid Services to drop their proposal to include non-invasive ventilators in the competitive bidding program moving forward.

Feedback from the Congressional visits showcased a growing awareness of COPD, surprised reactions as staff and members of Congress learned more about the impact of COPD in their state along with the lack of federal funding for COPD research, prevention and management initiatives, and several offices that were eager to join the Congressional COPD Caucus to get more involved in the future.

Moving Forward

IMPACT COPD 2019 is just the beginning. If we truly want to achieve meaningful progress towards these important goals, as well as the implementation of the COPD National Action Plan, we must continue to speak up and get involved. The generous contributions from our corporate partners - Boehringer Ingelheim, GlaxoSmithKline, Grifols, Pfizer and Sunovion - made it possible for the COPD Foundation to host this inaugural event. We hope the broader community will join in their support to continue to enable us to mobilize the community, provide training and resources and facilitate meaningful in-person events such as IMPACT COPD.



You do not have to travel to Washington, DC, to be an effective advocate - your voice can make a difference from anywhere! Check out the IMPACT COPD workshop sessions by clicking [here](#), join the [State Captain program](#), contact your [members of Congress](#) or simply use your voice to spread awareness of these important issues to anyone who will listen. Together, we can make a tremendous impact!