



**2018 Global Respiratory Summit Report
1 October 2018**



Introduction:

On 13 September 2018, COPD Global and the Global Asthma and Allergy Patient Platform (GAAPP) convened more than 35 stakeholders from around the globe in Paris, France for the first-ever Global Respiratory Summit. Participants included persons with chronic respiratory disease, caregivers and family members, nonprofit organization leaders, healthcare providers and industry partners. The one-day event was designed to introduce evolving best practices and stimulate discussion among attendees, leading to concrete action upon returning to home organizations. The three established objectives for the day were to:

1. **Share best practices.** Attendees were encouraged to share both what is working in their roles as patient advocates and what lessons they have learned to inform the approaches of others.
2. **Build organizational capacity.** Participants were asked to share tactics and resources that have enabled them to manage their organizations, expand their impact and measure their results.
3. **Leverage our collective voice.** While more than one billion individuals are living internationally with chronic respiratory disease, we do not have the proportionate funding, surveillance data or attention these numbers demand. Attendees were called upon to work in disease-specific teams to determine discrete areas of focus and next steps to achieving goals in these areas.



Overview of the Day:

The summit included a combination of presentations from leading experts divided into three categories (awareness, education and policy) and two workshops designed to enable participants to network, strengthen connections and discuss topics of importance to them. Both groups reported out on the topics from their workshops and from this, critical topics were selected to serve as the foundation for future discussions and future outputs.

Session Highlights:

Isaack Sunte, Kenya:

- Environmental factors play a substantial role in not only the development of respiratory disease but its diagnosis, treatment and maintenance. In countries like Kenya, we must consider the structure of homes, proximity to environmental factors such as fire and smoke from cooking stoves, and access to care (e.g., Mr. Sunte learned about spirometry from his biology teacher).
- Stigma for respiratory diseases is quite high. In Mr. Sunte's case his frequent coughing led many he came into contact with to think he had contracted tuberculosis.
- Transportation issues create substantial obstacles in similar environments.
- Petitioning regulatory authorities to put basic structures in place for diagnosis and treatment of respiratory disease is paramount to begin a process of effecting change and bringing respiratory out of the shadows and into plain view.

AWARENESS

Rabiya Toak, Lebanon

- Exercise is a crucial component of her life and work. While rehabilitation is not encouraged in Lebanon, it is something she is trying to promote widely.
- There is considerable stigma to her illness in Lebanon. While there is no menu for tackling issues of advocacy, Ms. Toak finds it helpful to conduct her awareness efforts with healthy residents of her home country. She also believes firmly in promoting positivity and support within online and other communities as well as working with celebrities and politicians to increase awareness.
- Misdiagnosis was a problem for Ms. Toak and others. Physicians misdiagnosed her; she indicates they did not want to listen to her concerns regarding comorbidities and blamed all issues on her COPD. She encourages strong personal patient advocacy: you know your body better than anyone. Ms. Toak has contacted physicians who misdiagnosed her. She is effecting positive change for others like her; would these healthcare professionals like to join her in this movement?

Gustavo San Martin, Brazil

- Information equips people to move to acceptance and sharing. There are multiple ways to increase awareness. Determine what pillars you will work with in the community.

- Amplify your voice through multiple platforms: YouTube; blogs (41 MS bloggers). including patient and HCP testimonials (e.g., a Day in the Life); Facebook Live.
- Celebrities, awareness ambassadors (everyday people doing special things); contributing to patient charters for medical societies; local support groups on the ground; awareness days; sustainability (keep reinventing your approach); monthly press releases for regional media; developing relationships with media over time so they develop knowledge base and can reject non-evidence-based information.

EDUCATION

Shane Fitch, Spain

- They want to bridge gaps and bring resources to their network, to use technology to help patients to better manage their care in their own homes.
- Workshops, webinars, videos, digital/devices, including wearables, activities in pharmacies and with physicians.
- Partner with others in well-organized teams to drive change and work together in scalable models.
- We all have a responsibility to be good stewards in how we collect, use and manage data.

Ilkay Nargaz, Turkey

- At Turkish Association for Patients with Lung Disease, they use a variety of approaches to educate patients and the community, including:
 - Mobile apps (air quality, pollution); workshops; symposia; allergy diaries
 - Booklets for asthma, air pollution, PR
 - World COPD Day activities
 - Radio, TV, video, billboard ads
 - Website and social media outreach
 - Tree plantation with branding
 - Partnership with their national thoracic society and funding from the government
- Education of pulmonologists and PCPs in early detection of disease and prevention of progress.
- Partnerships with organizations locally and internationally.

Javiera Corbalan, Chile

- Dr. Corbalan participates in an initiative with children, low SES
- Wood stoves are main heating source
- Gaps in access to effective therapy in addition to under diagnosis and suboptimal management of lung disease
- Something is missing!
- Psychosocial impairments play a key role in asthma, including:
 - Parental stress
 - Chronic stress, war

- Stressful life events: death of family member
- Being from an ethnic minority
- Violence in communities

How she tries to adapt this to her own clinical practice:

- Move beyond labeling patients
- Health literacy and understanding of disease
- Customs, norms, values
- Stereotyping and discrimination
- Environmental exposures – all are psychosocial determinants of asthma

Add these to usual assessments! Ask patients and carers about these issues

Engage in shared decision-making; adopt patient-centered care; comprehensive assessment; multidisciplinary team that addresses psychosocial issues too = integrated care

Primary care is ideal for integrated care: family-health team relationship; personalized advice really possible; bigger picture is appreciated; education is usually part of the treatment; community is present; possible to involve collaborate and multidisciplinary teams and approach mental health and family functioning!

POLICY

Amena Warner, Allergy UK

- Allergy Awareness Week (2x/year)
- Social media, articles in print, interviews
- 2018 Traveling with Allergy
- Legislation in 2017 to allow UK schools to buy spare adrenaline auto-injectors for emergency use
- Allergy action plans
- Partnered with Food Standards Agency
- Work with Public Health England, etc. Key strategic partnerships to increase awareness and effect change.
- Work with parliamentary group on air quality, etc.
- Educate politicians to they can understand the impact that their decisions have on families and affected individuals.
- Contribute to guidelines on indoor air quality, etc.
- Put together data to demonstrate impact of your efforts

Vanessa Foran, Asthma Canada

- Movement to keep drug costs down
- Climate change – phasing out coal use
- Canadian government interested in national pharma care
 - Advocating for biologics and patient choice
- Partner with allied organizations to effect change: Ryan's Law in Canada

Group together, include patients in the discussion, to ensure their points of view are heard. Consider economics in your arguments; this is the heart of policy. Ensure you have the right data. Strong evidence base. Approach with respect but firmness. And don't forget the personal stories. The approach is important: our power is coming together through coalitions. Patients are the voters!

WORKING GROUPS

Asthma Working Group Outputs:

1. Outreach/Awareness - align key messages for World Asthma Day & World Lung Day 2019
2. Education - align & update messaging---Asthma is not "just asthma". It is a spectrum or syndrome not a single disease.
3. Advocacy - Ensure all countries have National Asthma Plan in place by 2021. Elevate CRD in NCD discussion at WHO & United Nations.

COPD Working Group Outputs:

1. Awareness – share social media messaging for World COPD Day that can be used across countries and work with international asthma groups on promotion of World Asthma Day.
2. Outreach/Education – conduct an audit of all respiratory organizations globally and ensure COPD Global network is represented accurately on current COPD Global map. Set up COPD Global private social group to facilitate easier communications among members.
3. Advocacy – Look into setting up a deeper collaboration with FIRS so as to ensure more mobilization behind World Lung Day in 2019.

Keeping the Momentum Going:

Patient-led organizations and advocacy leaders are key to improving patient empowerment and health literacy. They are also powerful influences in addressing issues relating to awareness, screening, access to care and medication, adoption of innovation and policy-making. The emergence and success of patient advocacy organizations is accelerated where a strong framework for organization and capacity building exists. Such a framework educates and activates advocacy leaders, links them to shared resources and enables them to benefit from peer-to-peer sharing of experience.

The Global Respiratory Summit was one step forward in building an even more powerful network of patient advocates globally. Throughout the remainder of 2018, COPD Global and GAAPP will work to execute on the outputs from the two working groups so that 2019 can bring heightened awareness, education and policy efforts throughout the world.

About COPD Global, an initiative of the COPD Foundation:

The COPD Foundation was created to undertake initiatives that result in expanded services for individuals with chronic obstructive pulmonary disease (COPD) and to improve the lives of individuals affected by COPD. Within its 14-year existence, the COPD Foundation has established itself as one of the leading voices addressing the needs of COPD patients. Since its inception, the Foundation has grown both its community and strategic vision. As part of this vision, the COPD Foundation has extended its influence and work outside of the United States.

Recognizing the tremendous impact chronic obstructive pulmonary disease has worldwide with more than 300 million affected individuals, the COPD Foundation established COPD Global in 2014 by launching its first summit in Barcelona. COPD Global's mission is to establish a collaborative network of COPD related stakeholders, to promote global communication, early detection and unified access to care for the COPD community worldwide.

About the Global Allergy and Asthma Patient Platform:

In 2009, a group of local and national asthma and allergy patient groups gathered in Buenos Aires, Argentina to establish GAAPP as a network linking organizations with a common interest: the support for and improvement of the quality of life of people around the globe who have allergies and asthma. Since then they have grown into a vibrant worldwide organization with more than 30 constituent members from every continent sharing information and best practices, concerns and hopes.

While GAAPP is a patient-focused organization, they also work in concert with healthcare professionals, researchers and scientists, industry and governments to further the aspirations of people with asthma and allergies. Their mission is to help patients and their families through their journey with asthma and allergies. GAAPP's members include organizations from nearly 30 nations.

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