

## Global Respiratory Summit – Oct 1, 2019 – Madrid, Spain

- Reasons for attending
  - Learn best practices/learn from each other
  - Bring patient voice to scientific conversations
  - Collaborate with other organizations
- Overview of GAAPP
  - Many organizations/regions presented
  - Founded 2009
  - Recent name change; goal is to expand scope to include other airways diseases and rare diseases
  - Vision: build a world without allergy, airways and atopic diseases
- GRS logistics, agenda and sponsors
- Burden/prevalence of diseases
  - WHO Global NCD Action Plan 2020—one of the guiding documents for GAAPP
  - Want to bring respiratory to the discussion globally; most attention goes to cancer, heart, etc. and respiratory gets little attention
- Personal story shared by patient (Juliëtte Kamphuis, Netherlands)
- Panel discussion: building effective partnerships between patients and industry (Hanna Saul, AstraZeneca, UK and Ilana Tabak, Regeneron, US)
  - How does industry identify patient groups to work with?
    - If entering a new disease area, a landscape analysis will be done. Industry is looking for groups' strengths. Introductions are made; industry gets a sense of the group's priorities, unmet needs, etc.
    - Industry first looks online to get to know the groups in the space; digital presence is increasingly important.
    - Partnerships with influencers are often approached/treated differently than with formal patient groups.
  - Regulatory landscape varies country by country and region by region.
    - Additionally, interpretation of policies/regulation can differ from company to company.
    - Advice to patient groups: have conversations with industry about what types of projects/partnerships they are comfortable with.
  - General timeline to start a partnership varies significantly; dependent on history, precedent and complexity
  - Navigating tricky situations:
    - Relationship between patient groups and industry is sometimes scrutinized by public/media

- Sometimes there are tricky situations to navigate between patient groups and medical societies; need to have honest conversations
    - Coalitions are good but can be challenging as well
  - Many industry companies support core funding and project-based funding based on priorities
  - Industry can also help with non-monetary support
  - Finding the right person at industry can be challenging; this is a value of being part of an umbrella group like GAAPP
    - Action item: GAAPP to build a spreadsheet of industry contacts for GAAPP member orgs
- GARD update: October 25-27 in Beijing
  - Action item: develop one statement from GAAPP/COPD for GARD
- Breakout Session
  - Creating Awareness
  - Engaging Government
  - Generating Evidence
  - Digital Health Technology
  - Advancing R&D
  - Strategic Planning
  - Driving Patient Engagement
- Convening after breakout sessions: what we learned.
  - Creating Awareness: we thought out awareness campaigns were very basic, but learned that we might even need to take a step back (e.g. some areas don't even understand that asthma is chronic)
  - Engaging Government: national practices are important when it comes to accessing government reps; discussion of main challenges and value of being active at the EU level.
  - Generating Evidence: need to raise awareness of evidence generation/data among patient groups
  - Digital Health Technology: discussed best practices for digital infrastructure; some groups still don't know how to handle and need support/training/advice
  - Advancing R&D: role of patient groups to translate scientific findings to patients
  - Strategic Planning: need for diverse representation on boards, including at-risk groups like low income
  - Driving Patient Engagement: if you're starting out, need to focus on being strategic; focus on highest impact, prioritize. (look into Google grant program)
- Action item: GAAPP to consider creating a central repository of resources/tools/etc.

## Global Respiratory Summit Breakout Session Summaries

**Presenter:** Lynda Mitchell

**Presentation Topic:** Online Patient Engagement

**Summary:** The people attending varied from those who worked for pharma with large digital teams and one-person organizations with no online presence, or with a demographic that was largely not online (such as for the elderly populations). I asked for intros from each group member and asked them to briefly discuss what kind of online communications they worked on at present and any challenges they were facing. I had a few conversation starter questions. And I had handouts (attached) for the attendees to explain components of digital strategy, the patient engagement funnel and a tool to use to think strategically regarding prioritizing what is most important and impactful.

The first group was the most engaged in the discussion with lots of sharing of personal experiences and tips for other attendees. The second group was only two people, so it was a very informal, personal discussion. The third group was still a worthwhile discussion with five people, but one or two people who were not involved with building a presence instead changed the subject to what they were doing offline. It was nice to hear how they are reaching folks offline, but I'm not sure if it was helpful to the others who had come to the roundtable to seek ideas to help them with **\*online\*** engagement.

I received good feedback from the groups overall. I think two roundtable sessions were enough. The third timeslot would be better with a presentation on a good topic that would be useful for everyone (strategy, marketing, etc).

**Presenter:** Sara Latham

**Presentation Topic:** COPD Breakout Session

**Summary:** During the 2019 Global Respiratory Summit held in Madrid, Spain, a group of dedicated advocates gathered to discuss how best to elevate conversations around chronic obstructive pulmonary disease (COPD), a disease affecting more than 250 million people worldwide.

During the beginning part of the session, advocates shared what they were doing in terms of awareness, education, advocacy and research. Towards the end of the session we agreed on three action items to work on for 2020.

The lack of awareness about many of the facets of COPD was a topic of discussion. One advocate from Austria noted the rising number of individuals affected by COPD who never

smoked and the increasing number of women being affected. There is still lack of awareness about Alpha-1 Antitrypsin Deficiency (Alpha-1) which is a genetic form of the disease.

One of the common themes discussed was that one can “never have too much knowledge” and that knowledge can be a powerful force for shaping change. In particular, the group felt strongly that the incorrect use of inhalers is contributing to suboptimal treatment and maintenance of COPD. We should not underestimate how much patients, caregivers and family members want to learn about COPD and the importance too of personal, inspirational stories.

Examples include J-Breathe which creates a printed bimonthly newsletter on respiratory diseases that is distributed to patients and providers in Japan. The French Federation of Associations of patients with respiratory Insufficiency or Handicap (FFAAIR) will celebrate World COPD Day with a social media campaign encouraging individuals impacted by COPD to join a virtual “Tour de France” stationary bike challenge. Last year 451 patients traveled more than 8100 kilometers in three days – more than two times the distance of the actual Tour de France! One advocate’s group in Reykjavik, Iceland convenes a knitting support and social group for individuals impacted with respiratory disease. In the United States Better Breathers clubs give members a sense of belonging and empathy along with educational talks. The Wigan Warblers in the United Kingdom show that singing can make a huge impact on quality of life.

The group committed to three goals for 2020 1) 1) drafting of a document from the patient perspective regarding the proliferation of treatment devices and potential improvements to medication delivery to coincide with the European Respiratory Society Conference in 2020; 2) publishing international patient and caregiver profiles that represent the uniqueness of these individuals experiences across the globe 3) continuing the conversation through the creation of an online private forum within the COPD Foundation’s 360 architecture.

The group concluded with recognition that “**we are one but are unique.**”

**Presenter:** Shane Fitch

**Presentation Topic:** Rare Disease on some key feedback from the ERS Congress on Rare Disease and a few slides which gave us a snapshot of where we are both on social outreach and impact, research, integral care support and treatment access & future innovation in new therapies.

**Summary:** We had a lively debate about registries, data and research for innovative therapies or therapies which are affordable for rare disease.

Participants expressed great interest and understanding about the benefits for the future in data-sharing through digital platforms as the best way to change our health outcomes and speed up therapy development.

Treatment safety is paramount and some patient representatives have a high-level experience through working on research committees, through their role and advisory capacity in the direction of future research.

Alpha-1 Foundation has 8 products pending approval with the FDA which shows the level of acceleration which can be achieved particularly by the biotech industry.

The difficulties in approval faced by countries such as the UK for AAT Augmentation therapy, should reduce as the FDA for example, has just introduced a more relaxed stance as far as the design of clinical trials is concerned by not enforcing placebo to be prescribed to control groups which reduces the burden of cost and difficulty in recruitment of people with rare disease, often very dispersed across many countries.

Including PROs as valid for measurable results from patient participation is very much a plus factor, so systems where this information is transparently collated by patient organizations is very important. This is of key interest for Health Technology Assessment in many European countries.

The ERN-Lung Disease session at the ERS, stated Shane Fitch from Lovexair, has highlighted however, the still very low funding levels in rare disease orphan drug treatments: less than 1%, as presented by L. Fregonese from the EMA. We went over how we could address these barriers and evidently we need the EMA and FDA to facilitate suitable ways to accelerate studies without compromising safety and achieve much better patient engagement in data-sharing for research, to improve the situation.

Patients should co-publish when they are highly involved in studies and be compensated for their participation which often requires great personal sacrifice on top of their disease. This was also another key topic under consideration during the session.

We mentioned how this compensation could reach patients: perhaps in the form of better care support for those patients & not necessarily a direct financial compensation, but one which benefits their health outcomes.

To this end we mentioned how we had seen an example of this through the Respiratory Disease Research Centre in México City and at Lovexair how the HappyAir integral care plan model is designed to provide this support, as a benefit in kind, for sharing data for research.

The new trend of using social media analytics to better understand who and where people are located, is also now very much in our minds as a key resource, for organizations planned activities and communications policy.

This may be achieved through working in new environments: both digital and physical networks, such as shopping malls etc . Additionally it is extremely valuable, when we can

interact with partners who already have experience in IT resource networks or marketing know-how to facilitate better onboarding & engagement.

We must also learn from data analytics, how to improve our outreach to people, design appropriate communications campaigns and engage people more effectively in a targeted manner.

This includes social profiling of people with rare diseases, so that the content we create is focused to meet that persons needs and expectations and we can select or develop social influencers who can help us improve our engagement methods with younger people or specific profiles.

**Presenter:** Shane Fitch

**Presentation Topic:** Digital Health breakout sessions.

**Summary:** Shane Fitch presented some key aspects about digital health and used the HappyAir Smart Community model for further information as a case study when required, to help orient or support people who were participating and had questions or needed to explore specific points.

Participants are positive about the benefits of digital but not all are sure how to build these resources or capabilities, into their own organizations activities depending on their own organization structure or role: patients, healthcare professionals.

They feel however, that they are useful to resolve patients main concerns and issues which are largely unmet: on better disease-management, data- sharing with their clinicians and improving research.

A number of participants, already had experience of apps: a gaming tool for the Italian Paediatric Asma Association, to learn about symptom management: a Longfonds app for children with a similar approach; and Aircoach from EFA, as a research project for improving inhaler use, measuring adherence, with an adapted device which was supported by EU funding from Horizons 2020.

HappyAir platform appealed to participants, across the 2 breakout sessions, mainly for helping patients to learn how to disease- manage, connect and share relevant information with doctors as well as contribute to research in the future.

The coach support for working together with patients to facilitate this service for clinicians: helping people with their physical activity plan, keeping up with pulmonary rehab exercise programs, learning by doing about disease and learning more from the healthcare professionals' monitoring panel, were of interest.

Doctors working with paediatric asthma and allergy, as well as cystic fibrosis are especially interested in using the platform either in studies, private practice or research networks. Enabling support and ongoing contact with patients in dispersed populations is a key attribute, particularly in countries such as Latin-America and being able to personalise peoples' care or monitor their progress in key aspects of care or clinical indicators were considered to be an advantage.

Training people as coaches to facilitate patients' usage or adaptation to digital is a necessary step to enabling our transformation in the digital era.

Providing evidence on outcomes or insights through a well-managed digital environment supports all our advocacy goals.

A number of participants, 8 requested follow-up information and support to determine how to implement HappyAir or learn more how to train someone in their organization or network to set up a project management from their own country or clinical centre, organization.

**Presenter:** Panagiotis Chaslaridis

**Presentation Topic:** Engaging Government

**Summary:** In the breakout sessions on "Engaging government", Panagiotis Chaslaridis, Policy Officer at the European Federation of Allergy and Airways Diseases Patients' Associations - EFA briefly discussed the dynamics that enabled, since the early 1990s, patient organisations to become a trusted advocacy pole actively engaging with authorities at the EU level. In this respect, the relationship between patients and policymakers shall be seen as a 2-way process: on the one hand, patients develop organizationally and engage at the highest political level; on the other hand, policymakers acknowledge the added value of discussing with patients, as a source of real-life insights of how it is to live with the disease. However, the majority of patient groups face organizational difficulties, as a result of lack of funding, understaffing and many being based on voluntary work, which might sometimes affect their credibility vis-à-vis the authorities.

Moving on, the discussion revolved around some of the elements that should feed into any advocacy initiative: a clear definition of the problem and the audience, the search for like-minded actors, but also the development of relevant narratives and messages, based on the use of reliable data as well as personal stories. Then the presenter gave an overview of some of the EFA advocacy initiatives: the European Parliament Interest Group on Allergy & Asthma and the report on Access, resulting from a survey of asthma and COPD patients in 7 countries. Both aim at providing input into the institutions' work, including relevant data and policy recommendations for the way forward.

Most importantly, the participants of the breakout sessions had the opportunity to discuss about their own experience engaging with national authorities on various policy areas e.g. air quality,

chemicals, access to medicines, pricing etc. In this respect, the need for engagement continuity was highlighted, based on the development of long-term working relationship with relevant policymakers and authorities. Moreover, the effectiveness of EU-level initiatives was addressed, in light of the limited competence of EU on health policy. It was illustrated that patient organizations are able to provide added value by way of identifying public health aspects where EU can take action, but also by highlighting a horizontal approach of health-in-all-policies, especially given the wide variety of policies affecting asthma and allergy beyond just health.

**Presenter:** Vanessa Foran

**Presentation Topic:** Strategic Planning

**Summary:** During the GAAPP summit in Madrid, the strategic planning sessions were well attended by both senior level staff and volunteer board members. Engaging conversations took place on the definition of strategic planning, the importance of this work from an organizational perspective, different approaches to planning, culminating with a case study presentation provided by Asthma Canada. Great discussion between global leaders on the challenges and opportunities of strategic planning provided important learning for all who attended.

**Presenter:** Allie Bahn

**Presentation Topic:** Define Your Asthma Feedback Workshop

**Summary:** Overall, all of the organizations were very positive about the campaign and thought that it did represent what life can be like with severe asthma. It seems that many of the organizations need campaigns that get even more basic than what we have already done with DYA. Depending on the country, there were different challenges with the campaign because of how little asthma is understood culturally. For example, in Brazil, asthma is not considered a chronic disease. There is also a lack of awareness that asthma is a spectrum of disease. They could relate to the workplace issues and challenges at school and liked those vignette examples.

Some topics that were raised that could be helpful for future campaigns included the need for continuous follow up with your doctor, the importance of adherence, understanding that asthma is a chronic disease, that quality of life will improve with the right treatment, and the need for educating on comorbidities and risk factors and to make these well-known and more easily recognized.

Some other ideas that were discussed were a video series of a “Day in the life” to show more of the patient journey as well as a request for more story vignettes like we’ve done with DYA, except to reach other audiences with more everyday scenarios.



**Presenter:** Tonya Winders  
**Presentation Topic:**

**Summary:**