

Patient advocacy at work: one man's contributions to the COPD community

Read how one caregiver established an association to provide resources for both COPD patients and caregivers.

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The power of patient-centric events stems from the dialogue that takes place – dialogue with the power to effect positive change. This was particularly true of the second Chronic Obstructive Pulmonary Disease (COPD) Global Patient Leadership Summit in Paris, as patients from around the world gathered to discuss the issues closest to the heart of the COPD community. For more information on COPD Global, proudly supported by Novartis, visit: <http://www.copdfoundation.org/Global.aspx>.

One attendee, Mert Yilmaz, made an impact we won't soon forget. Yilmaz is a passionate COPD advocate and acts as a caregiver for his father, who is living with COPD. He also helped found the Turkish Association for Patients with Lung Disease. Here, he shares his inspiration with us.

Inspired by my father

As a caregiver for my father who has COPD – and having spoken to other people about their experiences with the condition – it became clear to me that patients need to be able to have better conversations with their healthcare professionals, and better access to greater support from their community. These conversations and resources help them face important issues such as social understanding and treatment needs. We have seen the success of similar patient groups in other countries, which inspired us to set up the Turkish Association for Patients with Lung Disease.

As a newly -established association, we hope to be able to gain support from other patient groups and adapt their best practices in Turkey. We believe we can do more, and make a bigger difference to the COPD community if we collaborate with physician associations and other stakeholders from the healthcare sector.

Overcoming challenges

There were a number of challenges we faced when founding the aAssociation, including ensuring we had all of the finances we needed and finding a suitable, convenient location. It was also difficult to find members who could speak foreign languages, who would be able to communicate with advocates from other countries.

Attending the global summit: progress

Our attendance at the global summit helped us to realize we are headed in the right direction and on our way to making a real difference in the lives of people affected by COPD in our community. The summit also showed us how many successful patient organizations around the world have developed a professional way of working that was driven by passion and motivation – the key factors contributing to their success.

Advice for others setting up advocacy groups

Start by asking yourself, “What can we do to make a positive difference and improve the lives of people affected by COPD?” To find answers to that question, you have to listen to the community, develop relationships and build networks that will allow you to understand the unmet needs of patients. Finally, being passionate about the cause is essential. I can see firsthand how patient advocacy can have a positive impact on the well-being of my father and others affected by the condition, and it motivates me to keep doing more.

Life as a COPD caregiver

Being a caregiver for someone with COPD is a very rewarding job. It makes me happy to be able to help my father and offer him my support, particularly when he is faced with challenges difficult to overcome on his own.

How I would change life for COPD patients

If I could change one thing about COPD (from my perspective as a caregiver), it would be COPD patients feeling that they need to explain their respiratory devices to others in public. Patients often find that people stare at them when they are using these devices in public, which can be very humbling. I would love to see current devices replaced with ones that are lighter, smaller, easier to use and more discreet.

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