Why We Need to Work Year-Round to Reduce the Burden of Rare Respiratory Diseases

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With February's Rare Disease Day behind us, it can be easy to forget the impact of these diseases on individuals, their families and care givers, and our communities throughout the other 11 months of the year. But if we – in healthcare, in government and in academia – are to truly make an impact, we need to identify and address the challenges those with rare diseases, and those trying to find ways to treat and cure them, face.

From lack of awareness and established standards of care, to delays in diagnosis and a dearth of robust clinical data, the struggles are myriad, but by no means insurmountable. By working together across public and private sectors, and ensuring that the healthcare community is informed, we can start to make a positive impact.

But the clock is ticking. Because for those living with rare diseases like Idiopathic Pulmonary Fibrosis (IPF) – a devastating disease that causes progressive decline in lung function and can ultimately lead to respiratory failure – these challenges are much more than theoretical. They can literally be a matter of life or death.

IPF causes scarring on the lungs, which, as it progresses, makes it increasingly difficult to breathe. By preventing the uptake of oxygen to the blood, it leads to extreme fatigue and exhaustion. The condition takes a significant toll – limiting a person's ability to work and support a family, and

making simple daily activities, like bathing or dressing, difficult. For family members and caregivers, the burden can be equally overwhelming, often meaning they need to make changes in their working lives, or even necessitating them giving up careers, all while having to witness the declining health of those they care for.

Despite its devastating impact, IPF remains a relatively unknown condition. And while the disease itself may be uncommon, its symptoms are not, leading to delays in diagnosis which can result in missed treatment opportunities and poorer outcomes for patients. Today, there is no cure for IPF, but there are medicines, known as antifibrotics, which can help slow its progression and make a meaningful difference to a patient's quality of life. But early diagnosis and access to treatment is critical, as once the disease progresses, there is no way to reverse the damage it causes.

So how can we make a difference, help ensure earlier diagnosis and improve quality of life for those with IPF, and those that care for them? The first step is raising awareness. At Boehringer Ingelheim, we are not only committed to treating rare diseases and meeting unmet medical needs, but also to working to educate our communities – from healthcare professionals to patients, to policymakers and the public – about these conditions.

Building on our 100-year heritage in respiratory care to address diseases like IPF, we are working to improve diagnosis times and access to treatment by active outreach with the medical community. Recent initiatives here in the region include our annual Interstitial Lung Disease summit for healthcare professionals which is designed to drive peer-to-peer exchange of the latest scientific information on rare respiratory conditions. This event and others like it provide real-world evidence in shaping the therapeutic landscape in clinical practice, allowing healthcare professionals to gain actionable insights from experts across multiple healthcare disciplines to identify the best treatment approach – which can significantly improve lives for those managing these rare conditions.

Given the criticality of early diagnosis for IPF and other progressive lung diseases, we are constantly striving to create ways for healthcare specialists to connect with other local and international experts across disciplines. Our Perceptorship Program is a platform that empowers local and regional specialists with knowledge and international best practices in the management of rare respiratory diseases by adopting a multi-disciplinary approach; and also enables these experts to explore opportunities for building specialist centres that are important to improving patient outcomes.

We're also exploring how emerging technologies like artificial intelligence (AI) and machine learning can support medical professionals by using predictive imaging biomarkers to improve diagnosis and treatment decisions. These tools – which we're developing globally and regionally including through our partnership with Brainomix, a spin-out from the University of Oxford – draw on anonymised data from CT scans via open-source data repositories. In accessing these datasets, and identifying specific patterns that indicate IPF or other respiratory diseases, the technology looks set to provide fast and accurate diagnoses – with the potential to improve clinical trial success, foster broader adoption of existing therapies and improve patient outcomes.

But it's not just medical professionals who need to be connected with the latest information. Those living with the condition and their families also need access to data, resources, and support to help them navigate their journey with IPF. To meet this need, we have developed educational online resources in English and Arabic which help patients understand more about their condition and the best ways to manage IPF.

But there is still more to be done, and we can only make real progress through concerted efforts across public and private sectors, and across healthcare disciplines. As part of our ongoing commitment to patient care, we will continue to strive to identify challenges and find solutions to the problems faced by those living with and treating rare diseases like IPF. By working with our peers in industry, government, healthcare and academia across the region we are determined to further our collective knowledge, enhance and standardize treatment and care, and find ways to lighten the burden carried – often needlessly – by patients and their families.

Mohammed Tawil is Regional Managing Director and Head of Human Pharma India, Middle East, Turkey and Africa (IMETA) at Boehringer Ingelheim, which specialises in developing pharmaceutical and technological treatments for unmet medical needs. The company has developed an Arabic website called Life With Pulmonary Fibrosis to provide resources for Arabic speaking patients who wish to learn more about their condition and help them find ways to enhance their mental and physical well-being.

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