

Rare Disease Day 2025: New Podcast Series Supports Those Affected



February 28 is dedicated to Rare Disease Day, a global initiative to raise awareness about the challenges faced by people living with rare diseases. Around 400,000 Austrians are affected by rare diseases. The new podcast series in German language "Ab jetzt ist alles anders? Leben nach und mit einer schwerwiegenden Diagnose." ("Will everything be different now? Life after and with a serious diagnosis.") takes an empathetic look at the reality of those affected, bringing visibility to their concerns, which often remain hidden.

According to the EU definition, rare diseases affect fewer than one in 2,000 people. Currently, more than 6,000 different rare diseases are known, impacting approximately 300 million people worldwide. In Austria, around 400,000 people live with a rare disease, accounting for six to eight percent of the population—making them the largest patient group compared to other conditions. More than half of them are children. For approximately 95% of these diseases, no approved treatments are available.

A Long Road to Diagnosis

Cystic fibrosis, epidermolysis bullosa, Angelman syndrome, primary immunodeficiencies, mucopolysaccharidoses, or pulmonary arterial hypertension – all of these diseases are so rare that general practitioners may only encounter them once a year or even less frequently. The symptoms vary widely from disease to disease and can manifest differently even among patients with the same condition. The journey to a correct diagnosis is often long and arduous. Many patients endure years of diagnostic uncertainty, receiving incorrect or no treatment, facing misunderstanding, and sometimes even being dismissed as hypochondriacs.

Data from the Rare Disease Barometer Survey conducted by EURORDIS, the European Alliance of Patient Organizations for Rare Diseases, in May 2024 highlight these struggles. A total of 10,453 individuals from 42 countries with 1,675 different diseases were surveyed. The results show that 60% of patients were initially misdiagnosed, either with another physical condition or a mental health disorder. Women, in particular, face longer diagnostic journeys, averaging 5.4 years for a correct diagnosis, compared to 3.7 years for men.

New Podcast Series: Will everything be different now?

Receiving a serious diagnosis is an unexpected blow for many patients. Their daily lives are turned upside down, and they find themselves in a new, unfamiliar reality. Newly diagnosed patients often feel alone and helpless.

The podcast series in German language „[Ab jetzt ist alles anders? Leben nach und mit einer schwerwiegenden Diagnose](#)“ ("Will everything be different now? Life after and with a serious diagnosis."), produced by AOP Orphan Pharmaceuticals GmbH ("AOP Health") in collaboration with Vienna-based podcast agency Sisigrant, provides a new source of support for patients and their families. The audio series marks the start of the AOP Health Rare Disease Campaign 2025, which aims to increase visibility for rare diseases. The five episodes address key questions and challenges following a diagnosis, covering topics such as coping with the initial shock, informing loved ones about the diagnosis, the importance of psychotherapy, and strategies for integrating a chronic illness into daily life. Additional episodes focus on the experiences of family members and a special spotlight on Myeloproliferative Neoplasms (MPN), a rare, chronic blood cancer.

The Soul Needs Time: Coming to Terms with a Diagnosis

A major focus is on coping with the mental burden of a diagnosis. Many patients hesitate to seek psychological support, even though it can significantly aid the healing process and improve quality of life. Psychologist Maria Resch, who supports individuals diagnosed with serious chronic illnesses, explains in the podcast: "One does not immediately accept a diagnosis. The mind needs time to process and understand things." While some self-help books suggest that illness can be an opportunity for a better life, Resch emphasizes: "It will be a different life. Whether it is better, I cannot say. But perhaps it will reveal new and fulfilling dimensions." Feeling optimistic doesn't necessarily mean seeing only the bright side. Rather, it is about rediscovering hope and gradually accepting the new reality. "It's a process of highs and lows, often repeating in cycles," Resch explains. "The sooner you seek support to work through these phases, the more helpful it can be.

Advancing Hope Through Research and Therapy

Because each rare disease affects only a small number of individuals, medical expertise, healthcare resources, and research funding in this area remain limited. People with rare diseases are often referred to as the "orphans of medicine" because they receive insufficient attention in healthcare systems and scientific research. Due to these challenges, pharmaceutical companies have been reluctant to invest in this field. However, AOP Health is one of the few companies that has been dedicated to the research and development of treatments for rare diseases for nearly 30 years, striving to improve the lives of those affected.

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