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Recordati Rare Diseases aims to be a trusted partner in helping patients with rare diseases reach diagnosis and appropriate care sooner

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Rapid access to innovation alone does not solve the rare disease challenge in Germany. Despite being one of Europe's most advanced pharmaceutical markets, patients still face long diagnostic journeys shaped by a highly decentralised healthcare system, fragmented care pathways, and increasing pressure on reimbursement and clinical development. This interview explores how Recordati Rare Diseases is working to support earlier diagnosis, strengthen collaboration across the healthcare ecosystem, and help more patients access appropriate care across the DACH region.

How has Recordati Rare Diseases Germany evolved in the last five-years, and what has driven the organisation's growth in recent years?

Recordati Rare Diseases Germany has evolved significantly. Notably in 2022 hema-oncology was added as a key focus area, alongside metabolic and endocrinology, through the acquisition of EUSA Pharma – contributing an ever increasing specialised deep disease expertise across the team. Together, we've built a strong patient-centric culture, with agility, focus, and the ability to execute effectively in specialised markets. This combination created a strong foundation for a more integrated organisation focused on supporting patients with rare diseases more effectively.

The organisation has been focused on expanded its capabilities across Germany, Austria, and Switzerland by aligning around a clear strategic direction and a focused set of operational

priorities. A simple but effective framework helped translate ambition into execution, ensuring that teams remained aligned while the rare disease environment around us grew in scale and complexity.

Three priorities have been central to that evolution. The first is patient detection. In Germany's decentralised healthcare system, patients with rare diseases often move through multiple care settings before reaching the right expertise, which can delay diagnosis significantly. The second is supporting timely treatment decisions. In many rare diseases, progress depends not only on the availability of therapy but also on awareness of when intervention may be appropriate. The third is long-term patient support. Once patients are diagnosed and on treatment, helping them stay engaged in care and benefit from therapy over time remains essential. Across all three areas, the goal is to reduce delays, improve the patient journey, and support better outcomes.

Alongside these priorities, the organisation operates in a highly specialised and complex environment. Recordati Rare Diseases manages a broad orphan portfolio while remaining focused and agile, and that requires disciplined execution across multiple therapeutic areas and stakeholder groups. Success depends on identifying where meaningful value can be added along the patient pathway and ensuring that specialised therapies reach the patients who may benefit from them.

Talent and culture have also been important to this development. Recordati Rare Diseases values an entrepreneurial mindset, cross-functional collaboration, and a strong sense of purpose. In a focused rare disease organisation, impact often comes from people who are willing to take ownership, work closely across teams, and remain committed to improving the patient experience. Building that culture has been an important part of strengthening the organisation over time.

How does Germany's decentralised healthcare system shape the rare disease patient journey, and where can digital tools help close the diagnostic gap?

Germany's decentralised healthcare system presents particular challenges for rare disease diagnosis because expertise is often dispersed across multiple specialties and care settings. While the country established a national framework through NAMSE and introduced a National Action Plan in 2013, implementation has been less coordinated than in some other European markets. As a result, identifying patients and helping them navigate the system remains a significant challenge.

Digital tools and data can play an important role in closing this gap. One example is Recordati Rare Diseases' work in Cushing's syndrome together with CompuGroup Medical, its subsidiary Intermedix, and the German Society of Endocrinology. Together, the partners developed a digital symptom-recognition tool integrated into physician practice software used across approximately 60,000 practices in Germany. The system identifies combinations of symptoms and diagnostic codes that may indicate Cushing's syndrome and directs physicians towards appropriate diagnostic resources. In rare diseases, where symptom patterns are often complex and dispersed across multiple specialties, such tools can help support earlier recognition and diagnosis.

Recordati Rare Diseases is also increasingly engaged in the broader discussion around rare disease diagnosis and care pathways. In Cushing's syndrome, for example, available data suggest that diagnosis in Germany can take considerably longer than in several comparable markets, leaving patients without clarity or appropriate management for extended periods. Working together with medical societies, patient organisations, and policymakers can help raise awareness of these challenges and support earlier diagnosis and more coordinated care.

Data represents one of the greatest opportunities in rare diseases. In a healthcare system as decentralised as Germany's, scalable digital approaches can help physicians recognise highly complex symptom patterns and identify patients who might otherwise remain undiagnosed for years. If used effectively, these technologies have the potential to shorten the diagnostic journey and improve outcomes for patients with rare diseases.

How does Germany balance rapid access to innovation with the reimbursement challenges surrounding rare disease therapies?

One of the major strengths of the German healthcare system is the speed at which patients can access innovation. Once a medicine receives approval, patients in Germany can often access it relatively quickly while reimbursement discussions continue. From a patient perspective, this remains an important advantage compared with many other European markets, where access can be delayed significantly. At the same time, reimbursement discussions for rare disease therapies are becoming more challenging, particularly when evidence expectations increase in situations where patient populations are small and suitable comparators may be limited. This creates a complex environment in which rapid access and long-term recognition of value must both be addressed. The question to ask is how can the system continue to support innovation in rare diseases while recognising the realities of evidence generation in very small patient populations?

Germany also plays an important role beyond its own borders because decisions made there are closely watched in other markets. As a result, how value is assessed in Germany can influence access discussions more widely across Europe. More than a decade after the introduction of AMNOG, important questions remain around how best to balance evidence, value recognition, and patient access for rare disease therapies.

Beyond its importance as a commercial market, what makes Germany strategically valuable within Recordati's broader rare disease activities?

Germany remains strategically important for Recordati not only because of its market size and relatively rapid access to innovation, but also because of the depth of its scientific and clinical expertise. The country continues to be a major source of research, specialist knowledge, and academic collaboration in rare diseases. At the same time, translating scientific excellence into clinical development and patient access can be challenging in a sometimes-fragmented system, particularly when study activation and coordination are more complex than in some other markets.

Germany also continues to generate highly influential thought leadership in rare diseases. This is reflected in collaborations with leading experts involved in areas such as neuroblastoma and cold agglutinin disease, where scientific advances have helped shape treatment approaches for patients with high unmet need. For Recordati, Germany therefore matters not only as a market, but also as a source of expertise that can help translate scientific progress into meaningful patient benefit.

What is Recordati Rare Diseases Germany's long-term ambition in the market?

Recordati Rare Diseases' long-term ambition in Germany is to be a trusted partner in rare diseases. In practice, that means helping physicians diagnose patients earlier, supporting better-informed treatment decisions, and working to ensure that patients benefit from therapy over time. This has become increasingly important as access to physicians in Germany, particularly in highly specialised areas such as oncology and haematology, has become more challenging. In an environment where every interaction competes directly with patient care time and clinical workload, relevance must come from bringing meaningful value. Ultimately, the objective is not simply organisational growth, but building long-term trust and relevance within the rare disease community by supporting patients and healthcare professionals across critical points of the treatment journey.

How would you describe the entrepreneurial culture Recordati Rare Diseases is building in Germany?

At Recordati Rare Diseases, entrepreneurship begins with understanding the challenges physicians, patients, and healthcare stakeholders are facing and turning those challenges into practical solutions. Across field teams, medical affairs, and leadership, the culture is built around asking how the organisation can contribute meaningfully to better care for patients with rare diseases. In this environment, impact often comes from creativity, speed, accountability, and a strong sense of purpose.

At the same time, this kind of culture needs to be sustainable. Recordati Rare Diseases values people who want to make a difference and who are motivated by patient impact, but long-term success also depends on creating an environment where that commitment can be maintained over time. The aim is therefore to build a culture that is entrepreneurial, focused, and collaborative while remaining grounded in purpose and long-term responsibility to patients and partners.

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