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NEWSLETTER · IN CONVERSATION WITH JURATE LASIENE

\$400 and a one-way ticket

Jurate Lasienne — rare-disease clinical operations leader — on the patients who'd never met anyone else with their condition, why rare disease chose her, and the neuroscience that shaped how she leads.

Jurate Lasienne's career began at an airport in newly independent Lithuania, with \$400 in her pocket and a one-way ticket to America — courage mixed, as she puts it, with ruthless pragmatism. Two decades later she's an operational compass for small biotechs navigating early rare-disease trials, with a PhD in neurobiology that started, improbably, with an English literature degree and two books: Alexander Luria on brain-damaged soldiers, and Oliver Sacks.



Some of my patients had never met another person with their disease.

— Jurate Lasienne, on Pharma Prescribed

Why rare disease chose her

She's honest that it happened by accident. Covering many therapeutic areas as a CRA and project manager, it was rare disease that drew her in — the warmth of the physicians, the grace and gratitude of patients waiting for treatments that may or may not come. There's no personal family

connection; it's an emotional fit. Where a cardiovascular trial has hundreds of thousands of patients and no personal touch, rare disease has faces.

What makes rare, rare

Regulators define rare and ultra-rare by occurrence per population, but the number that stays with you is human. Jurate describes working in a disease area where patients had never met another person with their condition — until a trial brought them into the same room for the first time. That's the texture the statistics miss, and it's why these patients identify as genuinely different.

The patients are the experts

Her case for patient advocacy follows directly. In diseases this rare, the people living with them hold practical, day-to-day expertise no textbook captures — and for the very rarest, where barely anyone studies the condition, that lived knowledge may be the best evidence there is. Designing trials without it isn't just impolite; it's uninformed.



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Jurate Lasiene is a clinical research leader and biotech consultant specialising in rare-disease clinical operations, with a PhD in neurobiology.