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The Rare Journey Needs a Special Pharmacy Partner

Today's guest post is from Bansi Nagji, Chief Executive Officer at PANTHERx Rare.

Bansi argues that rare disease pharmacy is a fundamentally different model built around precision, speed, and hyper-personalized care. He suggests how manufacturers and stakeholders must rethink their assumptions to effectively support the unique demands of rare disease patient journeys.

Hear from PANTHERx patients and their caregivers about what it's like to live each day with a rare disease.



Read on for Bansi's insights.

The Rare Journey Needs a Special Pharmacy Partner

By Bansi Nagji, Chief Executive Officer, PANTHERx Rare

When people outside the rare disease community try to understand rare pharmacy, they often reach for an analogy: It's traditional specialty pharmacy (SP), just for smaller patient populations.



An understandable shortcut, yet deeply misleading. The functions a rare disease pharmacy performs may sound familiar to anyone who has worked in SPs, but the way a rare pharmacy approaches each of those functions is fundamentally different—not incrementally, but at the level of its core operating philosophy (Table 1).

Below are five areas in which rare pharmacy is distinct from traditional specialty.

1) Tiny Patient Populations Change Everything

More than **10,000 rare diseases collectively affect over 30 million Americans**. This is roughly the prevalence of diabetes, yet rare populations are very small and extremely heterogeneous. This changes the entire algorithm of care.

Small populations also mean that the usual mechanisms for iterative learning simply don't exist. In diabetes care, with millions of patient interactions occurring every year, clinicians and health systems can absorb errors, refine protocols, and steadily improve outcomes over time. In rare diseases, we often have only one opportunity with one patient to get it right.

Most rare conditions are genetic and chronic, with patients managing a lifelong journey. A missed dose or incorrect titration can lead to hospitalization, irreversible disease progression, or a crisis that undoes months of careful therapy management.

2) The Nature of Rare Therapies Demands More

Rare disease therapies are among the most complex. Many involve cold chain and other precision logistics, intricate titration schedules, routine safety monitoring, and regular laboratory assessments. This is why rare pharmacy, in partnership with a patient's physician, can be a critical part of the care team providing a safety net and personalized, expert support and education throughout the patient journey.

Prescribers are frequently hyper-specialized experts with a handful of patients with a given rare condition in their practice. The relationship between a rare pharmacy and these prescribers is necessarily more collaborative and more intensive than the transactional one that characterizes many traditional SPs.

3) Speed-to-Therapy Is a Clinical Imperative

People living with rare diseases typically face a prolonged 'diagnostic odyssey' that often takes **more than six years and nearly 17 doctor visits** from the onset of symptoms to an accurate diagnosis. Every delay can have disproportionate consequences, and patients don't have alternatives or redundant care pathways. They simply can't wait.

Speed matters. Consider a **newborn with hypophosphatasia**, a devastating condition that can impair the mineralization of the skeletal system, leading to soft, fragile bones and potentially fatal respiratory complications. When treating infants with hypophosphatasia, removing access barriers and initiating therapy soon after birth can make the difference between improving survival and reducing the risk of irreversible harm.



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Dimension	Traditional Specialty Pharmacy	Rare Pharmacy
Primary Focus	Broad mix of chronic & complex conditions	Narrow rare disease portfolio
Average Annual Therapy Cost	\$15K–\$100K for GLP-1s, biologics & monoclonal antibodies	Rare disease therapies can be 3-5X traditional specialty, and 10-50X for cell & gene therapies
Therapy-specific Experience	Rare therapy dispenses make up small share of total volume	High volume & repetition with a focused set of rare therapies
Care Coordination	Usually non-dedicated central teams with more limited care coordination capabilities	Actively orchestrates among patients, HCPs, manufacturers, payers & advocacy groups
Time from Rx to First Fill	Longer for atypical or rare regimens due to unfamiliarity	Shorter on average for target rare indications due to repeatable workflows
Prior Auth Support	Handles high PA volume, but with broad, generalized protocols	Deep PA playbooks for specific drugs, payers, and plans; proactive re-auth tracking

Table 1: Comparison of traditional specialty pharmacy with rare-focused pharmacy.

4) Access Is Narrower and Far More Complex

The high cost of rare therapies narrows access. Yet the cost of poor adherence, incorrect dosing or missed doses is also high if they lead to increased utilization, hospitalization, and serious complications like organ failure or transfusion. Prior authorizations (PAs) for some of these therapies can fill 150 pages. PAs can also take longer, be more clinically demanding, and more frequently challenged than for typical specialty medications—and the consequences of a denial are far more severe when a patient has no alternative.

Manufacturers of rare therapies often choose exclusive or limited distribution pharmacy relationships for consistently reliable data, highly coordinated care, and pharmacists who can engage payers as clinical partners presenting a complete picture of a patient's journey. The move from transactional benefits investigation to end-to-end access solutions aligns payers, prescribers, patient advocacy groups, and manufacturers around measurable outcomes.

5) Frequent Patient Interactions Are Hyper-Personalized

The volume and nature of interactions per patient by dedicated rare pharmacy teams are not comparable to the generalist call center model of traditional SPs. Across PANTHERx's current portfolio we interact with patients an average of eight times before dispensing their first script, and up to 14 times for some therapies. Traditional SPs average fewer touchpoints, according to multiple sources.

Rare touchpoints consist of education; monitoring interactions and safety labs; coordination with prescribers, caregivers, payers, and hubs; and follow-ups to help manage therapy initiation, side effects, risk evaluation and mitigation strategies (REMS) criteria, and more.

Rare Disease Needs its Own Ecosystem

Rare pharmacy is not simply a subset of specialty pharmacy. It requires a different ecosystem entirely: journeys are longer, populations are smaller, and every breakdown in care is magnified. Infrastructure that works at scale for chronic, high-volume conditions was not built for rare and cannot adequately adapt. That is why a dedicated rare pharmacy model—built around depth, not volume—exists.

I encourage you to [experience PANTHERx patient stories](#) that show what rare disease pharmacy and our hyper-personalized RxARECARE® approach looks like in practice, and what it means to get it right for patients and their families.

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