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PRECISION MEDICINE MEETS PRECISION PATIENT SUPPORT

In the value-driven healthcare environment, orphan drug manufacturers are becoming increasingly aware that improving adherence requires a new approach to patient understanding and support. Take for example the required lifestyle, nutritional or physical modifications often necessary for patient compliance — behaviors that are difficult to influence, track or control without proper patient insights and ongoing therapy support services.

NEW RESEARCH CALLS ATTENTION TO UNMET PATIENT NEEDS

In a recently released white paper, Precision Medicine Meets Precision Patient Support, clinical care experts, along with insights from patient advocacy leaders, highlight a more comprehensive approach to better patient understanding.

“Precision medicine has brought hope to many facing the burden of rare disease. Now we need to apply the same degree of precision-based research into our ongoing therapy support services,” says Kathi Henson, President, Patient Services at EVERSANA. “Only through that

lens can we achieve ongoing patient adherence and ultimately improved medical outcomes.”

As one advocacy expert highlights, “A better understanding, ideally, would facilitate a true partnership among patient communities and the industry. It would inform the development of support programs that would have a meaningful impact on patients’ and families’ lives. Any time a company truly understands the patient experience and journey, it is a win-win for all involved.”

PATIENT INSIGHTS INFORM NEW MODEL FOR ORPHAN DRUG THERAPY SUPPORT SERVICES

The paper highlights the EVERSANA patient understanding and clinical navigation process, which provides orphan drug manufacturers valuable insights into the medical, emotional, and physical experiences of the patient and caregivers, from pre-diagnosis through ongoing medical care. The process is then used to develop and continuously improve an exclusive speciality distribution model that offers wrap-around, coordinated care, patient education, and comprehensive support.



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When applied to multiple orphan drug support programs, the approach has resulted in 90% plus patient adherence, compared with far lower industry standards of only 58% to 65%.

Key to the EVERSANA model is the one-on-one relationship between the patient and a dedicated Patient Services Coordinator, who is continuously trained to ensure patient empathy and coordinate additional therapies as needed throughout the treatment process.

"We're not just worried about the shipment and the time and the delivery date," shares Linda Newberry-Ferguson, SVP of Clinical Navigation, EVERSANA. "That's incredibly important, but we also care about where they are and what they're facing. Those patients are more likely to do better, stick to the regime, and take medications like they're supposed to."

The approach also helps manufacturers understand potential issues with the therapy itself that could be impacting adherence. For example, patients might share that taking a drug in many small doses is challenging, and that they would stay more adherent if they could take the drug in fewer, larger doses. Manufacturers also cite fewer adverse event challenges, thanks in large part to proactive patient outreach based on research cited concerns in the therapeutic journey.

"Patients can help the company understand the reality of living with the disease—even if there is a treatment—and how a treatment could be better," advocacy experts explain.

THE ECONOMICS OF PATIENT UNDERSTANDING

While certainly complex, the global orphan drug market is expected to grow to \$262 billion in sales by 2024, as cited in Evaluate Pharma's 2018 Orphan Drug Report. Increasing reputational and payer pressures will require the industry to create more value through better outcomes. Improving adherence, through precision patient support, will lower cost while helping manufacturers recoup their investment after years of research and development – all to the ultimate goal of better rare disease patient care.

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