



EVERSANA™



THE POWER OF WORKING TOGETHER WITH THE RARE DISEASE COMMUNITY

And the Lessons Learned to Drive Success with Gene Therapy Launch

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When thinking about EVERSANA's work in rare disease and gene therapy, I am reminded of a quote from Helen Keller: "Alone, we can do so little; together, we can do so much."

This sentiment addresses the power of working together to improve health in rare disease. I believe it's impossible to support clients launching gene therapy products without a full understanding and appreciation of the rare disease space and the importance of the different stakeholders. (As a reminder these are diseases that affect fewer than 200,000 people.)

At EVERSANA, we have developed a unique working relationship with rare disease communities. I must admit – as a former marketer who spent significant time working in the primary care general medicine space, the term community was new to me, but since joining EVERSANA, I have gained a tremendous appreciation for these tightknit groups.

The bond that these communities have are established in large part by the fact that finally these caregivers have found someone they can connect with. The rare disease patient journey often consists of fear, anxiety, depression and isolation. Families as motivated information seekers, as their path to diagnosis is often built on years of misdiagnosis. This is understandable since, many times, physicians may have never seen a patient present with these symptoms. These families form a tight bond with other patients who have been afflicted by this rare disease.

Since families are devastated by the diagnosis, they will seek support from the communities, who have significant influence with the patient journey (including treatment decisions). I have heard through our agencies' work that the community can equate to the most trusted voice regarding treatment recommendations.

Successfully working with these communities, especially in gene therapy, requires a demonstrated long-term commitment to the science and commitment to a cure. These communities are central to the health for these patients and their families.

As HCP Dr. Mark Hyman stated, "The power of community to create health is far greater than any physician, clinic or hospital."

These communities are part of a comprehensive outreach for gene therapy, which is required for a successful launch strategy. Another interesting nuance is working with opinion leaders in gene therapy. Again, drawing on my general medicine experience, there was more alignment on behalf of opinion leaders pertaining to treatment guidelines. That is not always the case in rare disease. Knowing and understanding that lack of consensus is an important point to factor in for launch planning.

In summary, our work in rare disease and gene therapy includes advocacy and caregivers along with the traditional stakeholders – patient, HCP and payers. Taking this approach with the communities and traditional stakeholders and creating a culture of working together is the best way to assure appropriate care with a goal of improving health.

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