

The Value of Online Support Groups in Rare Disease Communities – and the Role Pharma Marketers Can Play

Online support groups for patients and caregivers living with rare diseases have grown tremendously in number and size over the past 10 years. Often closed to the general public, these semi-private groups are usually started by one or two motivated individuals, then extend throughout the world to include others living with the same condition. The reach and impact of these groups can be extraordinary, and the value to rare disease patients and their families, life-changing.

Through my own personal experience, as well as in working with rare disease families for many years, I've identified just three of the many ways in which online support groups provide value to those within the rare disease community, and what that can mean for orphan drug marketers.

Online Support Groups Help in the Creation of a “New Normal”

Living with a rare disease means facing unique and difficult challenges every day. From logistical challenges and physical disabilities, to emotional burdens and financial implications — nothing seems “normal” for these families. Yet, being connected to so many other families that are dealing with these same challenges and talking or posting about their experiences makes it all feel less overwhelming, less daunting, and surprisingly, more normal. Having this regular and consistent ability to connect with others who are so similar and are dealing with the same issues can make some of the most unique challenges seem more commonplace.

Online Support Groups Are Excellent Means for Crowdsourcing

Patients and caregivers living with a rare disease can be greatly comforted by the fact that any uncertainties or questions can be quickly and easily posed to thousands of “experts” who will give their honest answers or share similar experiences within minutes. This can be incredibly helpful in accelerating time to diagnosis, and in certain situations such as starting a new medication or therapy, finding experienced specialists, or even just looking for tips on how to make life with a rare disease more manageable.

The existence of online support groups is changing the way people deal with rare diseases. They give patients the ability to overcome the isolation and unknown aspects of their disease and enable them to live more manageable and fulfilled lives. Orphan brands, in turn, should strive to do the same.

There is an implicit level of trust in many support groups. Nothing seen or discussed in a closed group should be shared publicly, and members can feel free to ask whatever they want to, regardless of how personal the topic may be. There also exists an absence of judgement that sometimes occurs in other areas of mainstream life. Regardless of what question is asked, members can be assured it will be answered with honesty, acceptance, and understanding.

Online Support Groups Add Levity to Heavily Burdensome Situations

Faced with an uncertain and unpredictable future, it is common for many caregivers to feel varying levels of worry, anxiety, and depression, sometimes on a daily basis. Dealing with a rare disease is not for the faint of heart. It requires commitment and resilience, and yes, humor. Online support groups offer incredibly valuable support and knowledge, but one of the most important things they do for us is to make us laugh.

Often, our ability to laugh at ourselves and our situations is the only way we know how to make it through the toughest of times, and who best to make us laugh than the people who understand exactly what we are going through? So, for all of the advice, experience, and information that comes from being in a rare disease support group, connecting with others on an emotional and



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human level is by far the most valuable service it provides.

The Role Pharma Marketers Can Play in Online Support Groups

First and foremost, it is our job to learn from them. We can seek to understand what patients and caregivers are getting out of these groups and how we can augment that support with our own efforts. We can try to build the same level of trust, transparency, and understanding, and we can help make connections where there may not be any, whether that is in finding undiagnosed patients and guiding them to the right care, or uniting diagnosed patients with those that can provide consistent, ongoing support. Online support groups are changing the way people deal with rare diseases. They give patients the ability to overcome the isolation and unknown aspects of their disease and enable them to live more manageable and fulfilled lives. Orphan brands, in turn, should strive to do the same. ^{PV}

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WHY UNIFY

In specialty and rare disease communities, HCPs do not always see the totality of a patient's disease burden or the benefits that new therapies may provide. Likewise, patients often struggle to express their needs or be their own advocates for treatment.

It is our belief that only by uniting these audiences—through empathy, understanding, and shared responsibility—can we help specialty brands reach their true potential.

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