THE EVOLUTION OF SOCIAL MEDIA FOR RARE DISEASES AND ORPHAN DRUGS

WHAT DOES THE FUTURE HOLD?

Social media has evolved at an astonishing rate and biopharmaceutical companies are finding ways to participate. But by their very nature, online media are always changing and improving how we communicate. It’s important to understand where your audience is building community—and to learn how you can be part of their conversations.

RARE DISEASE PATIENTS ARE THE SUPERUSERS OF SOCIAL MEDIA

“…the internet is like a secret weapon for these healthcare superheroes, allowing them to reach across time and space to gather, share and create health information. People living with rare disorders, however, take it to a whole new level. They have honed their tools to a sharp point—and been honed themselves as they find themselves squeezing through the tightest spaces, finding a way forward where there had previously been no path.”

Susannah Fox
Associate Director, Digital Strategy
Pew Internet & American Life Project

This is consistent with Siren’s six insights for rare disease patients, caregivers and healthcare professionals derived from more than a decade of focus in this niche:

1. Patients dealing with rare disorders feel alone and isolated.
2. Patients/caregivers seek a connection with others like them.
3. Patients/caregivers use the internet to educate and support each other.
4. Physicians do not have the time to educate themselves about rare disorders they may never see in their practice.
5. Patients/caregivers are often the primary drivers of diagnosis and treatment.
6. Patients/caregivers expect biopharmaceutical companies to have a shared sense of urgency, communicate openly and transparently, be collaborative and responsive.

This is why social media has particular importance to biopharmaceutical companies with orphan drugs.

SOCIAL LISTENING AND LEARNING

With the advent of social media, patient populations that were previously confined to dark, unsearchable corners of the Internet began migrating to central social media networks such as Facebook. Platforms specific to health conversations (such as PatientsLikeMe and Inspire) were created to facilitate these interactions. An increasing number of patients and caregivers began sharing their personal journeys on blogs.

This was a monumental shift; biopharma companies gained unprecedented access to their audiences and opportunities to understand the patient’s challenges and perspectives in real time. Knowing where to find the right patients and understanding their language, terminology and unmet needs are essential for developing an effective media strategy that drives action. This was particularly valuable for orphan drug companies.
By participating in social listening, biopharma could gather data straight from the source: the patients. The end result of effective social listening is not only a better understanding of patient needs but also a familiarity with the social channels they use and the ways they interact. These insights are now frequently used to shape education and support programs and inform therapeutic improvements.

SOCIAL ENGAGEMENT

After waiting in vain for the U.S. Food and Drug Administration (FDA) to issue social media guidance and with non-regulated industries leading the way, biopharma eventually created two-way channels of communication by actually joining the conversation. What ensued was a period of transition with industry shifting from the position of listener and observer to a role of engagement.

Social media has made it easy for orphan drug companies to meet rare disease patients (and other target audiences such as potential employees and investors) where they are already spending their time and foster the growth of community within specific disease populations. The industry started utilizing the most popular social networks—Facebook, YouTube and Twitter—for corporate reputation/brand and disease awareness.

CASE STUDY:
BUILDING COMMUNITY FOR CAREGIVERS ON FACEBOOK

About 25,000 people in the US have Huntington's disease (HD), which is a rare, neurodegenerative disease characterized by a triad of progressive motor, cognitive and emotional symptoms without a cure. In particular, HD patients are looking for biopharma companies to play a supportive and engaging role.

“We did an initial landscape assessment and found that while the advocacy organizations were doing a wonderful job, there was a still a need, in particular, for HD caregiver support,” notes Katie White, communications manager at Lundbeck. “HD is an incredibly isolating disease, and HD patients and caregivers have a need to share their experiences and connect with people who understand what they are going through. You often see community members interacting and helping each other in the conversation streams.” Using social media also provided an opportunity for Lundbeck to highlight fundraising events, education days and other resources that are available to the HD community.

White explains that to be compliant with existing FDA guidelines, the page focuses only on disease awareness. Lundbeck has work instructions to manage the entire Facebook page process, and the team is committed to a prompt turnaround for approval of posts and comments.

The Facebook page has successfully created engagement between Lundbeck and the HD community. White notes, “the HD community wants a voice, they want help raising awareness for this little known and often misunderstood disease. It’s important to have a two-way dialogue because we want feedback to ensure that the resources we are providing are useful and relevant.”

“We continually use our learnings to better meet the community needs.” White says that Lundbeck is also moving into collaboration, “for example, we are developing an HD infographic based on feedback from our patient ambassadors and from the Facebook community.”
SOCIAL COCREATION

What makes today’s most successful social media sites so appealing is that they facilitate the process of cocreation.

Social media will continue to provide the channels for open, two-way dialogue and user-generated content between both sides to meet patient needs. A few biopharma companies are privately and publicly asking for feedback on new and existing programs. Current crowdsourcing includes efforts to design more effective clinical trials, gather research data online and provide input on support programs. When developing a cocreation project, know where your target audience communicates, what sorts of things they like to share and how they like to participate.

Applying this principle to develop collaboration between biopharma and advocacy groups can be a win/win for all involved. The idea of cocreating content with audiences may be intimidating for an industry that has carefully controlled all messaging. But you can cocreate safely.

SOCIAL MEDIA AND CONTENT MARKETING

Content marketing is currently a hot marketing trend, but in the rare disease space it’s been an essential tactic for years. If a biotech/pharmaceutical company can offer value to patients, they will gain trust, develop a relationship over time and ultimately obtain brand loyalty. In the rare disease space the way to add value is with information. Patients, families and healthcare professionals want accurate information on symptoms, diagnosis and treatment. Unlike with more common diseases, these resources are not available. Consequently, rare disease patients, caregivers and HCPs look to industry to provide them.
PROVIDING VALUE YIELDS BRAND LOYALTY

This valuable content can be shared by biopharma companies on social media—it will also be shared by patients via their social networks.

SHAREWORTHINESS™

If you create content of value to your target audience and make it easy to share, then your audience will share it socially. This expands the reach of this information beyond the available brand channels. When your audience shares your material, they are also endorsing it, which adds a layer of trust for their recipients.

Social media allows one person to have tremendous influence. The 1-9-90 rule posits that of the people using social media approximately 1% are creating the content, 9% are commenting/sharing it and 90% are observing the content. So it is important to remember that impressions will far outpace actual shares.

Source: Jake McKee & 90-9-1.com.

IF CONTENT IS KING, IMAGES ARE THE CROWN PRINCE

The type of content marketing is also evolving. As technology and social media have advanced, so too has our ability to easily create and share photos, videos and graphics. The online space, once dominated by the written word, has changed. This progression has been enabled by the growth of broadband which makes videos and large images quickly accessible. With
smartphones offering the ability to shoot photos/videos and create graphics, the technology is widely available. Smartphones also provide a way to perform these functions on the go, as well as instantly share the results via the internet. Social media sites such as YouTube and Facebook enable showing this type of content to friends and, if desired, the world. The real-time capture and sharing of events has become commonplace. Online you can find almost as many images as words.

The recent growth and popularity of Instagram and Pinterest attest to this desire to create and share images. Instagram, an app to filter and share photos, reports there are more than 90 million monthly active Instagram users worldwide sharing 40 million photos per day. Pinterest is a “virtual pinboard” which allows users to organize and share Internet content (typically images) by pinning it to virtual boards. Of the approximately 11 million users, 80% are women between the ages of 25 and 55, according to comScore. Facebook is also a key site for image sharing. Research from PageLever showed that photo posts on Facebook get 20 times more engagement than text.

It’s important to understand how to make your images searchable. While people may prefer images, if they aren’t tagged properly search engines can’t tell what they are about. Consider search when creating these images and ensure that they have the appropriate keywords associated with them.

**POPULARITY OF INFOGRAPHICS**

Infographics are perfect for sharing in this new world of images. Infographics (short for information graphics) are graphically interesting representations of data. Ideally, infographics present complex information in an easy-to-understand visual format. This format is perfect for users who are multi-tasking and scanning the web. For example, infographics are an excellent way to explain the complexity of a rare disorder or a drug’s mechanism of action.

To stay relevant and to continue to appeal to users, marketers need to add photos, video and infographics into the content mix. A comprehensive content marketing plan should include a variety of different types of content.

**KEY TAKEAWAYS**

1. Social media is constantly changing; for orphan drugs it’s essential to understand these changes and take advantage of the channel.

2. The most successful use of social media by biopharma companies is to take advantage of the power of cocreating materials with a target audience.

3. Orphan drug brands need to offer valuable content; increasingly this includes video, photography and infographics.
CONTACT
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ABOUT SIREN INTERACTIVE
Siren Interactive is a rare disease marketing agency with unmatched expertise in addressing the challenges and unmet needs of patients, caregivers and physicians dealing with the over 7,000 rare diseases affecting over 300 million people worldwide. For more than 15 years, across more than 30 different disease states, we’ve had 1 focus: finding rare disease patients and connecting them to our clients’ brands. As trailblazers in recognizing that patient-driven decision making is central to successful orphan drug commercialization, we are constantly innovating to meet patients and caregivers where they live. To learn more about our proprietary approaches to building trust relationships with rare disease stakeholders visit sireninteractive.com. Siren Interactive is a subsidiary of Dohmen Life Science Services. More information can be found at DLSS.com.

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