

Creating Sky High Level Interest in Rare Diseases

Frontline Medical Communications conducted a groundbreaking study to evaluate the challenges in educating stakeholders about rare diseases. Then they applied their learnings to employ a plan of attack that increased awareness about rare diseases across all stakeholders.

By JoAnn Wahl and Elizabeth Katz

Discussions with multiple pharma companies confirmed the need to better understand physicians' knowledge about the awareness, experience, and challenges that clinicians face in identifying, diagnosing, and treating patients with rare diseases and how to meet the educational challenges. Approximately 7,000 rare diseases have been identified, but only 500 are common enough to be in any physician's repertoire for diagnosis. Additionally, rare diseases affect fewer than 200,000 Americans.

The Marketing Challenge

Stakeholders in the market include: Patients and caregivers, patient advocacy groups, rare disease organizations, the FDA, other government agencies, rare disease experts, some practitioners, and pharma. Each stakeholder has their own unique challenge related to the point of view they represent and the resources they have available. But, they all see the extreme need and are especially passionate about their goals. Plus, they all talk. This passion is the unifying factor, and the common goal is educating practitioners about rare diseases in order to shorten the time to diagnosis and accelerate treatment. The biggest challenge was coordinating the communication effort and developing the right platform.

Background

Stakeholders realized that what they were missing was access to the practitioners who were evaluating patients with rare diseases. Lack of knowledge and resources was a factor in time to diagnosis; and, once diagnosed, clinicians did not know best practices for (genetic) testing, treatment, and management or whom to refer the patient.

Specifically, marketers of rare disease products have small target audiences and limited budgets. But, they also have

a tremendous amount of information ranging from disease state to clinical trial info/data and best practices for diagnosis, treatment, and management of the disease. And, they want to share it!

Research Results

Frontline Medical Communications (FMC) conducted a groundbreaking survey among 400,000 healthcare professionals across 14 different therapeutic specialties to address these challenges. The survey identified what resources and information clinicians currently turn to and what educational programs need to be developed.

The survey uncovered significant learning gaps among practitioners and called for immediate action. The association, pharma, the advocacy groups, etc., needed a powerful leader and platform to coordinate the educational campaign for healthcare providers and FMC was called upon to do it.

As a prologue, 88% of HCPs agree there is a need for more professional content on rare diseases with most rating the following channels as extremely/very valuable: Medical journals online, disease-state websites, symposia at medical conferences, on-demand audio/video, KOL speaker programs, and print journals. Respondents agreed there is a lack of networking opportunities, access to experts, clinical information, training, education, and a means to collaborate with knowledgeable colleagues on diagnosis and treatment to coordinate care.

Plan of Attack/Tactics and Campaign

Given FMC's 33 specialty-specific medical publications and websites, its validated database of 1.2 million healthcare providers, and more than 200 key opinion leaders on

The response to the outreach was outstanding. A post-campaign survey uncovered that nearly 20% of practitioners treated more than 10 patients with a rare disease in the last year!

its advisory boards, FMC is well positioned to integrate many of these goals, beginning with the creation of a proprietary database of stakeholders in this market.

The company started with a handful of key markets (neurology, endocrinology, oncology/hematology, and pediatrics) to accomplish the following:

1. Worked with a rare disease association to promote rare disease awareness and create meaningful content for eNewsletters distributed to target audiences.
2. Created physician self-assessment quizzes to gauge knowledge.
3. Created rare disease sections on the journal websites.
4. Created clinical supplements on specific rare diseases and some products.
5. Provided conference coverage of rare disease meetings and symposia.

FMC initiated a print and digital pilot in the neurology market where there was an especially strong and well-positioned journal, *Neurology Reviews*, which had existing relationships with rare disease experts—and set out to educate practitioners. NR created a *Rare Disease Special Issue*, an annual issue now in its third successful year, containing a compilation of articles on various rare diseases that features information on incidence, prevalence, demographics, and diagnostic criteria related to selected rare diseases. The effort pulled together more than 20 pharma companies, patient advocacy groups, professional medical associations, academic institutions, government agencies, and practitioners to educate, create awareness of clinical trials, and to help connect the dots between patients and providers. Since all of these groups talk, rumors spread quickly about

the opportunities.

This created an excellent and rare opportunity for pharma marketers. They now had a dedicated vehicle run by a reputable journal and access to their target audiences. FMC worked with product managers, pharma advocacy, medical affairs, and others to help identify opportunities for greater education and develop strategies and tactics to implement. These range from simple advertising to custom supplements to interactive quizzes sponsored by pharma.

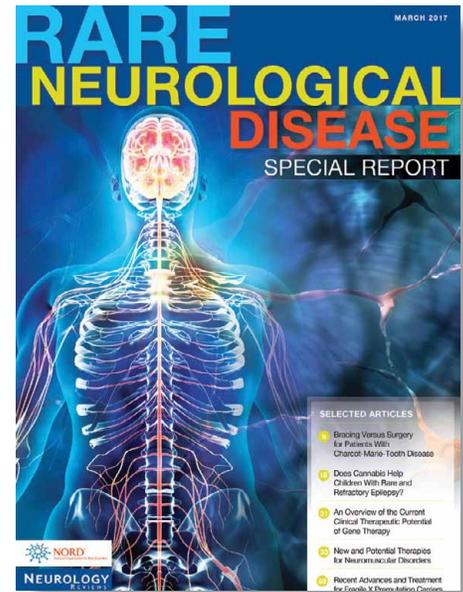
The Result

After each issue was distributed (via mail and electronically), FMC conducted a readership survey to assess physician engagement, solicit opinions, and learn more about unmet needs.

The most recent survey found a notable increase in practitioner awareness of rare diseases and access to an established resource:

- 93% of practitioners surveyed indicated that the content was very helpful and effective and that it would help them improve patient care.
- 90% said it helped them screen patients more proactively and treat more effectively.
- 45% said it made them aware of new products and services and visited a website.

A few of the ads and articles covered clinical trials allowing pharma companies in early research stages to target specific populations for clinical trials. The response to the outreach was outstanding. The response to the clinical supplements, quizzes, and reporting was outstanding too. The survey uncovered that nearly 20% of practitioners treated more than 10 patients with a rare disease in the last year!



The annual Rare Neurological Disease Special Report from *Neurology Reviews* provides an unique opportunity for marketers to get in front of HCPs who treat rare diseases.

Epilogue

Upon final assessment, the interest level in rare diseases was sky high—physicians actively sought information, networking opportunities, and clinical best practices. The ROI revealed how engaged the physicians, patients, caregivers, pharma, and other stakeholders were. And they keep coming back. ●

To learn more about the groundbreaking research or to obtain a copy of the 2017 rare disease special issue please contact: Elizabeth Katz (ekatz@frontlinemedcom.com) or JoAnn Wahl (jwahl@frontlinemedcom.com).



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