No Patient Left Behind...
Connecting Rare Disease Patients to Orphan Drug Manufacturers

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Abstract

If you have ever worked with orphan drugs, you know finding appropriate patients is a major commercial challenge. Pharmaceutical sponsors of orphan drugs often lack the infrastructure and capabilities necessary to identify physicians who diagnose, treat, and manage these rare patients. TrialCard developed a proven model for making this critical match and has helped many patients gain access to the therapy they so desperately need. In a recent 2015–2016 program, TrialCard’s “Detective Model” approach to locating patients with a specific rare disease returned tenfold more leads back to the pharmaceutical sponsor than forecasted.

Situational Analysis—The Challenges Orphan Manufacturers Face

By definition, a rare disease includes fewer than 200,000 diagnosed patients, yet many of these diseases have only hundreds to a few thousand patients. Industry reports indicate there are approximately 7,000 identified rare diseases. Many of these diseases have no therapies, however the trend is improving due to government incentives to pharmaceutical manufacturers to invest in these rare diseases. In fact, of the 44 new products approved by the FDA in 2015, 42% received Orphan Drug designation for rare diseases¹. Product approval is only the first hurdle. The commercial challenge for manufacturers is to find healthcare providers who manage these rare diseases and locate patients in need of orphan medications. There are also many other challenges facing the Orphan Drug category:

- Multiple healthcare providers and specialties may be participating in a patient’s care.
- Patients often seek multiple opinions before gaining a proper diagnosis.
- Patients are geographically dispersed across the country.
- Many specialists are often not aware of new treatment options.
- Resourcing a field sales force is difficult and expensive.

Some of these patients have been afflicted with a serious, but non-fatal condition for years. Others may die if they aren’t located and introduced to therapy within the first year. By locating patients stricken with such rare diseases and connecting them with the therapies they need, the result can improve a patient’s quality of life or even save their life. The obvious gap in this process is the cost-effective way to canvas the complex healthcare marketplace in search of physicians who diagnose, treat, and manage these rare patients.

Our Approach

TrialCard understands the complexity of finding patients with rare diseases. It takes time to learn about the brand and the disease state community. TrialCard deploys highly skilled pharmaceutical clinical specialist teams who are empowered to canvas healthcare systems in search of the healthcare professionals who manage these patients and connect them with the orphan drug manufacturer. The teams serve as healthcare detectives within complex systems.

To be successful, the detective model must include the following:

- The right team members with an incredible will and drive to save patients lives
- A customized call flow that helps team members navigate offices and healthcare systems
- Specific skills to listen and inform healthcare professionals to create deep physician engagement
- Ability to act as a patient advocate and instill spirit of polite persistence
- State-of-the-art technology to track progress and report findings

Case Study: Rare Kidney Disease

BACKGROUND

TrialCard was asked to search for patients with a rare kidney disease, which typically required them to have 10-20 or more surgeries in a lifetime. As with all genetic disorders the condition has no cure, but there are available therapies that can help prevent the need for surgery, providing a meaningful quality of life improvement. Patient diagnosis of this condition is difficult, requiring a greater knowledge of science to successfully engage the healthcare professionals on the other end of the telephone.

TrialCard customized a dual-model program, utilizing both healthcare service representatives and pharmaceutical clinical specialists. Healthcare service representatives were given a script and call flow, while the clinical specialists were given a list of leads in healthcare systems. Both teams were trained on TrialCard’s “Detective Model” and underwent a continuous team-sharing program to accelerate results.

RESULTS

In the first five months of the program, the TrialCard teams combined identified over 90 qualified leads of physicians who had patients presenting symptoms of this disease in their practice. Through the vetting process, several of those patients were connected to therapy. In this lead generation program, the pharmaceutical clinical specialists found 72% of the patients, while the healthcare service representatives found 28%. TrialCard delivered patient counts 6 times higher than original client expectations. Notable in this program was the success of both teams reaching a nurse or physician in between 30% and 50% of the calls made. These results show a more cost-effective orphan drug lead generation effort than traditional field-force initiatives, mass marketing campaigns, or traditional event lead generation.

Conclusion

Finding physicians who treat rare diseases and identifying patients under their care that would be strong candidates for orphan drug therapies is by no means an easy task. It’s one, however, that the pharmaceutical clinical specialist teams at TrialCard have repeatedly proven successful in accomplishing. In doing the “detective work” to find and connect patients, providers, and therapies, TrialCard is proud to help deliver quality of life improvements to patients.
About TrialCard Incorporated

TrialCard Incorporated provides a comprehensive portfolio of Marketing for Patient Access, Prescription Abandonment, HUB/Reimbursement, Analytics, and Customer Experience Management.

Since opening its doors in 2001, TrialCard has been awarded nine patents related to the processing and marketing of patient access programs. TrialCard is the largest provider of patient access programs in the industry, processing over $1 billion in patient benefits per year to help brand manufacturers achieve their goals with prescribers, patients, and pharmacists.

For more information on TrialCard, please visit www.trialcard.com.

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