# **THEPERFORMERS**

#### X CANADA'S INFLUENTIAL THOUGHT LEADERS X

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Annual drug spend per claimant is rising more rapidly for specialty drugs, such as high-cost gene-based therapies, than for traditional drugs, with two per cent of claims representing 33 per cent of spend in 2019, according to Express Scripts Canada's 2020 Prescription Drug Trend Report. As a result, treatments for rare diseases, which are often genebased and costly, pose a significant challenge for plan sponsors. However, Jeff Boutilier, Express Scripts Canada's general manager, pharmacy, and chief clinical officer, says many available tools can improve health outcomes and help control benefits plan costs.

#### How "rare" are rare diseases?

Typically, a rare disease is classified as a serious, life-altering, often catastrophic condition that affects fewer than five people out of 100,000. That's quite rare. However, when you look across the spectrum of all rare diseases, approximately one million Canadians currently live with one. So, they're more common than you might think. And while some are associated with a life expectancy in the 40s (for cystic fibrosis, for example, it's about 44 years), more than half of patients with a rare disease are children, and many unfortunately don't live to see their teenage years. The challenges in this space go beyond

quality of life and length of life. Rare diseases are a very severe and very important public health issue.

## What impact can rare diseases have on a benefits plan?

Because each individual rare disease is so uncommon, it is often very expensive to research and to treat. For example, low prevalence makes it difficult to find enough people for a clinical trial to see if a specific medication works, and that can drive up costs for these therapies. Despite the research challenges, more than 30 new rare disease treatments are on the horizon. That's great from a treatment standpoint, but these treatments come with extremely high prices that will continue to put a lot of pressure on private drug plan spend. Consider that about 80 per cent of rare diseases have a genetic component, and gene-based therapies are among the most expensive drugs offered by plans. Some of these medications cost millions of dollars a year, so even one case can put significant pressure on a benefits plan for the plan sponsor.

## How can benefits plans manage that impact?

Comprehensively managed drug plans have quite a few tools - some old, some new – that can both improve care and help bend the cost curve. When we look at plan design, we start with a clinical approach, looking at clinical guidelines and the latest health research. Then we overlay proactive management, leveraging tools such as formulary management (deciding which drugs are included in a formulary), utilization management (for example, prior authorization and step therapy) and channel management (such as preferred pharmacy networks). More important, we also look at patient health management. Express Scripts Canada's Therapeutic Resource Centre is a dedicated team of pharmacists whose sole purpose is to support patients with complex conditions, providing them with continuing follow-up and counselling that helps manage treatment of the condition and the associated drug therapy.

## How do pharmacy services help people with rare diseases better manage their conditions?

Healthcare needs are often very specific to the individual – like a fingerprint. Pharmacy services is a multi-pronged approach that includes support from various different healthcare professionals, clinicians and patient care advocates to help patients start therapy quickly, make sure there's no lapse in therapy, and provide regular follow-up, including both clinical care and education. This type of intervention can be very helpful for people with complex chronic conditions, as well as rare diseases. Patient care advocates, in particular, can help patients struggling with a stressful diagnosis to access the medication they need and explore coverage or reimbursement options, including public reimbursement mechanisms and compassionate care programs.

Pharmacists are trusted professionals and often a main point of contact for patients and family members. So why not leverage a pharmacist's expertise not just on medication management but also as a resource who can refer patients to other healthcare professionals when there is a need?

### What impact can pharmacy services have on a benefits plan's bottom line?

There's an increasing cost associated with providing prescription drug benefits to employees, and this reality is exacerbated by the high cost of treatments for rare diseases. Pharmacy services and medication management can focus both on delivering specific health outcomes and better managing costs - and it's important to note that those two things are not mutually exclusive. Overall, there's a lot of room for plan-management tools and strategies to help benefits plans. I encourage plan sponsors to talk to their insurance professional and learn about all the various tools that can have a significant positive effect on an organization's bottom line.

