Health Awareness

Help Coping With Rare Disease Diagnosis

(NAPSA)—It may seem strange, but rare diseases are pretty common. In fact, according to the National Institutes of Health, more than 25 million Americans—about 8 percent of the U.S. population—have been diagnosed with one. They and their families have to handle the stresses of managing it, but now there's help for some from an unusual source.

The Problem

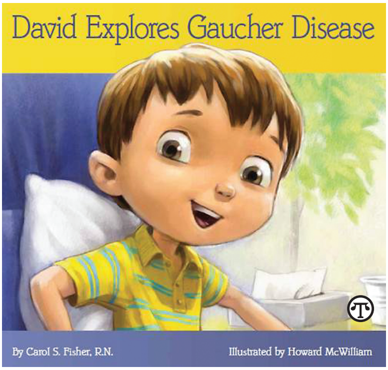
Unfortunately, a rare disease diagnosis can often take years of tests and uncertainty. Carol Fisher, a research nurse and study coordinator at the neurogenetics lab at New York University's Langone School of Medicine, who has spent the past 15 years caring for patients who are suffering from one such rare disease, known as Gaucher (pronounced go-shay) disease, has done something about it.

A Nurse's Answer

"Over the years, I've seen so many children and their families trying to come to terms with this disease," said Carol. "I wanted to find a way to make people feel better about the disease, to ease some of the concerns parents and patients may have, and to prepare them for the journey that lies ahead."

What Is Gaucher Disease?

Gaucher disease is a chronic and progressive disorder with many different symptoms that can range from patients showing no symptoms to experiencing severe disease manifestations. It's an inherited genetic disease that often strikes within an extended family and affects many of the body's organs and tissues, including the liver, spleen and bones. It's estimated that between one in 50,000 and one in 100,000 people have Gaucher disease.



A new book may brighten the lives of children diagnosed with a rare disease and their families.

When a child is diagnosed with a rare disease, it can be a very confusing and difficult time for the family. Inspired by her brave, young patients, Fisher partnered with Shire HGT, a biopharmaceutical company dedicated to helping people with life-altering conditions lead better lives, to write a children's book to help newly diagnosed children and their families understand type 1 Gaucher disease in a simple context. Through "David Explores Gaucher Disease," she hopes to ease some of the concerns the family may have and explain a little about managing the disease in easy-to-understand terms instead of medical jargon.

"Those first few visits can be scary, especially for children," said Carol. "These families are already going through so much, and my hope is that the book will give them some support."

Free Books

Free copies are available by e-mailing Shire_Program@Shire.com. To learn more about Gaucher disease, please visit www.onepath.com.