

## **Fact Sheet**

### **The Rare Disease Foundation**

The Rare Disease Foundation (RDF) supports people who have been diagnosed with a rare disease. Their mission is to create communities of patients, caregivers, health care providers, researchers, and supporters that work together to transform the lives of those living with a rare disease.

#### **What Is a Rare Disease? How Many People Have a Rare Disease?**

A rare disease is defined as a condition affecting fewer than one in 2,000 people. There are more than 7,000 known rare diseases in the world, and many more that have not yet been classified. About one in 12 people – nearly 3 million Canadians and 30 million Americans – has a rare disease. Most rare disorders are severe and chronic, with many being life-threatening. Half of those affected by rare disease are children, and one-third of children with a rare disease will not live to see their fifth birthday.

#### **An Innovative Approach**

The RDF is focused on linking basic science together with clinical practice to improve rare disease research. By incorporating clinician observation and parental knowledge into the various stages of rare disease research, the RDF is greatly impacting the speed of discovery and the way rare conditions are managed. The RDF's unique approach to research is invaluable, because when it comes to rare diseases, pre-existing treatments are almost never available.

#### **History of the Rare Disease Foundation**

- The RDF was started in 2007 by a group of parents and doctors in Vancouver, BC, as a means of finding answers for patients with rare and undiagnosed diseases. In 2008, the RDF became a non-profit organization and developed a concept of a cross-disease support network for the rare disease community. Through organizing meetings and events for families of affected children, the RDF has been able to complement their innovative research approach with inclusive social support.
- The RDF has partnered with the Michael Smith Genome Sciences Centre, Child & Family Research Institute, BC Children's Hospital Foundation, Partners in Care, and others to ensure the highest quality of care and research in the area of rare diseases.



**RARE DISEASE  
FOUNDATION**

[www.rarediseasefoundation.org](http://www.rarediseasefoundation.org)