



Canadian Organization
for Rare Disorders



Rare Disease Day Event Ideas

Rare Disease Day is just around the corner. Here are some rare disease day ideas for patient groups and other organizations.

Raising Awareness Activities (from rarediseaseday.org)

- Organize interviews with the media to talk about the situation of rare disease patients in your region/country (magazines, newspapers, television, and radio)
- Organize events around rare diseases and the topics important to patients in your region (conference, workshops and meetings, walks, demonstrations, sports events etc.)
- Organize a political event to advocate for rare diseases to your local authorities
- Give out awards to people who are recognized for having acted effectively or outstandingly for the cause of rare disease patients.
- Hold a competition centered on rare diseases (art competition, photo contest, essay writing challenge etc.)
- Display posters, images, or other awareness raising displays.
- Distribute stickers, flyers, or badges to people on the street, in schools, hospitals, or universities.
- Make appointments to meet with your local and national authorities, in particular those involved in research and the diagnosis, treatment, and care.
- Organize a visit by a politician or local authority to a rare disease research laboratory or centre of expertise.
- Organize fundraising events or a special fundraising campaign.

Social Media Ideas

- Families can start early in February posting about Rare Disease Day and sharing about their experiences living with a rare disease
- Change your profile and cover picture to represent Rare Disease Day (rarediseaseday.org has social media graphics that are free to download)
- Write a letter to the editor of your local newspaper

School Ideas

- Teach your child's class or entire school about rare diseases or your child's specific disease (rarediseaseday.org has a number of activities and even curriculum lessons for older students)
- Invite schools to involve children via essay writing campaigns or other educational initiatives.

Workplace Ideas

- Lunch and learn – some employers hold periodic mini seminars during lunch – ask about a seminar for rare diseases or your specific disease. This can also be a fundraiser.

Please go to www.rarediseaseday.org for a free downloadable information kit which contains useful items such as posters, infographics, social media banners, and much more!