

# RARE DISEASE DAY

## February 28, 2010

Rare Disease Day 2010 marks the beginning of a year that will lead to a decade of unprecedented opportunities for rare diseases and disorders in Canada. We have much to celebrate. Most provinces now provide enhanced newborn screening for rare genetic disorders. Many patients with previously untreated rare conditions now have access to life-saving and life-enhancing therapies, including innovative medicines. The first CIHR-funded grant competition for research on rare diseases will be announced this year. And with the support of the federal government, we anticipate regulations and legislation to support rare disorders.

But we still have a long way to go. Progress and opportunities have come about only through dedicated efforts of many individuals, including those affected by rare disorders, those treating and supporting rare disorders, those doing research and drug development, and those who craft the policies and legislation.

The Canadian Organization for Rare Disorders is offering all individuals and their organizations a year's worth of activities and events that will help us continue the progress on rare disorders in Canada. Some are fund-raising projects that can be held in local communities; some will raise public awareness and support for rare disorders; some will educate and engage healthcare professionals; and all will help to opportunities for understanding and supporting rare disorders.

### Opportunities

#### Global Genes Project

Thanks to the generosity of the Children's Rare Disease Network and their sponsors, the Canadian Organization for Rare Disorders has the privilege of offering patient groups and other partners the Global Genes Project to raise funds and awareness of rare disorders. Request information and a toolkit to hold your own Global Genes denim party.

#### Café Scientifique

The Café Scientifique is an opportunity for scientists to bring to the public topics of current relevance and to engage in an exchange of view. The announcement of the 1<sup>st</sup> CIHR 5-Year Grant Competition for Rare Diseases is an opportunity for CORD to organize Café Scientifique in various communities across Canada. Sign up to co-host, to suggest a topic, to recommend a speaker (researcher, clinician or patient) and to take part. If you would like to propose a Café in your community, let us know and we are happy to organize with you.

#### Canadian Rare Disease and Orphan Drug Plan

Join CORD for consultations on proposed Canadian Rare Disease and Orphan Drug Policy. Consult the calendar for the date proposed in a city near you, or sign up for the national Rare Disease Conference in Ottawa (October 2010).

#### Extraordinary Measures [Screening Events]

CORD will be hosting a "private screening" in Ottawa in celebration of Rare Disease Day on March 1<sup>st</sup>. We hope to engage the federal Members of Parliament and their staff as they prepare to start the Legislative Session. Let us know if you are interested in attending in Ottawa. Or, organize a screening in your community. We can provide information and promotional assistance.

#### Video Project

In celebration of Rare Disease Day, CORD invites patients, families and patient groups to send us their videos of "extraordinary" people affected by rare disorders. We will provide space on our website to share your stories. Please watch the CORD website for further details.

#### **CORD will provide:**

Resource materials, access to sponsors, promotional materials and support for patient group issues

#### **Patient groups are asked to provide:**

Acknowledgement of CORD's support, awareness of issues affecting all those with rare disorders, and voluntary contribution to CORD research fund



Rare Disease Day  
28 February 2010

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

# 3<sup>rd</sup> Annual RARE DISEASE DAY



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Rare Disease Day 2010 marks the beginning of a year that will lead to a decade of unprecedented opportunities for rare diseases and disorders in Canada. Sign up today to participate in CORD's, "EXTRAORDINARY" events.

<p><b>Extraordinary Measures - Movie Screening Event</b> CORD will be hosting a "private screening" in celebration of Rare Disease Day. We hope to engage the federal Members of Parliament and their staff as they prepare to start the Legislative Session</p> <p><b>Date:</b> March 1, 2010 <b>Location:</b> Ottawa, ON</p> <p>*Other screening events will be announced soon.</p>	<p><b>Café Scientifique</b> Take part in a Café Scientifique, it is opportunity for scientists to bring to the public topics of current relevance and to engage in an exchange of view.</p> <p><b>Topic: Challenges in Diagnosing Rare Disorders</b> <b>Date:</b> March 4, 2010 <b>Location:</b> Toronto, ON</p> <p>*See calendar below for more Café Scientifiques planned across Canada.</p>	<p><b>Regional Consultations on Rare Disease and Orphan Drug Policy</b> Join CORD for consultations on proposed Canadian Rare Disease and Orphan Drug Policy</p> <p><b>Date:</b> March 27, 2010 <b>Location:</b> Edmonton, AB</p> <p>*See calendar below for more Regional Consultations planned across Canada.</p>
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- Help CORD raise funds and awareness for rare disorders through the Global Genes Project.
- Send us your video project and it will be featured on our website: [www.raredisorders.ca](http://www.raredisorders.ca)

## “EXTRAORDINARY” EVENTS FORM

<b>Name:</b>	<b>Organization:</b>	
<b>Address:</b>		
<b>City:</b>	<b>Postal Code:</b>	<b>Phone:</b>
<b>Email:</b>	<b>Website:</b>	

**I WILL ATTEND THE FOLLOWING EVENTS:**

**EXTRAORDINARY MEASURES MOVIE SCREENING EVENTS:**

March 1 (Ottawa)

**CAFÉ SCIENTIFIQUE EVENTS:**

March 4 (Toronto)

April 8 (Vancouver)

April 15 (Halifax)

May 6 (Montreal)

Sep 30 (Ottawa)

**CONSULTATIONS ON RARE DISEASE AND ORPHAN DRUG POLICY EVENTS:**

March 27 (Edmonton)

April 9 (Vancouver)

April 16 (Halifax)

May 7 (Montreal)

**PLEASE INDICATE YOUR INTEREST IN THE FOLLOWING EVENTS:**

Rare Disease Action Day: September 30, held in Ottawa

Annual Rare Disorders Conference: Oct 1-2 , held in Ottawa

**I WISH TO REQUEST MORE INFORMATION ON:**

The Global Genes Project and toolkit

Hosting my own Global Genes Denim Party

Hosting or co-hosting a Café Scientifique

Suggesting a topic or a speaker for a Café Scientifiques

Organizing an Extraordinary Measures screening in your area

## 2010 Events

### **FEBRUARY**

28th — Rare Disease Day

### **MARCH**

1st — Screening of Extraordinary Measures movie  
(Ottawa)

4th — Café Scientifique, Topic: Challenges in diagnosing  
Rare Disorders (Toronto)

26th — Café Scientifique (Edmonton)

27th — Regional Consultation on Rare Disease and  
Orphan Drug Policy (Edmonton)

Date to be confirmed — All Party Legislators Roundtable  
on Rare Diseases and Orphan Drugs

### **APRIL**

8th — Café Scientifique (Vancouver)

9th — Regional Consultation on Rare Disease and  
Orphan Drug Policy (Vancouver)

15th — Café Scientifique (Halifax)

16th — Regional Consultation on Rare Disease and  
Orphan Drug Policy (Halifax)

### **MAY**

6th — Café Scientifique (Montreal)

7th — Regional Consultation on Rare Disease and  
Orphan Drug Policy (Montreal)

### **SEPTEMBER**

30th — Rare Disease Action Day at Parliament Hill  
(Ottawa)

30th — Café Scientifique (Ottawa)

### **OCTOBER**

1st & 2nd — Annual Conference on Rare Disorders  
(Ottawa)