

HUGE SUCCESS

2014 Rare Disease Day

FIRST OF ALL, Many thanks to all of the patients, families, patient organizations, researchers, clinicians, policy makers, and industry supporters who joined the Canadian Organization for Rare Disorders in making Rare Disease Day 2014 the most impactful ever.



You were 155 strong on March 3rd for the Rare Disease Strategy Consultation in Ottawa. Huge kudos to the hard working Working Group who produced a draft strategy around five key themes. We were able to engage in significant dialogue and deliberation to generate more than 100 recommendations. These recommendations are being crafted into a Strategy that will be expanded upon in a series of Regional Forums (see information below). We will be sending the framework for the Strategy to all participants shortly.

Rare Disease Day Awards Gala Celebration

Again this year, COR.D recognized those who have demonstrated outstanding commitment and achievements in improving the lives of all Canadians with rare diseases. The champions were recognized at COR.D's 2nd Annual Rarity Awards Gala Celebration. Well deserved and heartfelt congratulations go to the winners:

Rare Disease Leadership Awards

Presented to an individual who has demonstrated outstanding leadership in the rare disease community.

Recipient: Maureen Coleman

Policy Maker Award

Presented to a policy maker whose dedication and commitment to rare diseases has made a difference to the rare disease community.

Recipient: Marlene Haffner

COR.D Volunteer Award

Presented to an individual who has made an outstanding contribution to COR.D and the rare disease community on a volunteer basis.

Recipient: Kirsten Harkins

Scientific Award

Presented to a distinguished researcher whose career represents a unique blend of scientific excellence and support of the patient community.

Recipients: Dr. Kym Boycott and Dr. Alex MacKenzie

Patient Organization Award

Presented to a COR.D Affiliate Member group making outstanding contribution in patient support or advocacy.

Recipient: Regroupement québécois des maladies orphelines (RQMO)

Corporate Award

Presented to a leading company who is dedicated and committed to developing and providing treatments to improve the lives of those with rare diseases.

Recipient: Novartis Pharmaceuticals Canada Inc.



*Rarity Award Winners (L to R):
Kirsten Harkins, Alex MacKenzie, Gail Ouellette, Janet Whitley (accepting award on behalf of Marlene Haffner), Paul Simpson & Karen Chow (accepting award on behalf of Novartis Canada)*

Action Day on Parliament Hill

On March 4th, CORd hosted another successful Action Day on Parliament Hill. It was a great opportunity for 40 patients and families to visit with over 35 Members of Parliament, Senators, and key government officials. The good news was that many were aware of the Orphan Drug Regulatory Framework and promised to write to Health Minister Ambrose to urge its implementation at the earliest opportunity this year. We received reassurances that it was a top priority.



*L to R:
Christine White, Tiffany Howell-Skladan,
Irene Mathyssen, MP London—Fanshawe,
Scott MacLellan and John Dyck*

Regional Forums

We need you at the Regional Forums to develop the Canadian Strategy for Rare Diseases. This is the opportunity to put a Strategy together and make Rare Diseases a priority in the next federal budget and election in 2015. Beginning in Toronto on May 1-2, followed by Montreal on May 29-30 and Vancouver on June 22-23. Other dates and locations will be announced soon.

To register, view the schedule or for more information go to: www.raredisorders.ca or email us at info@raredisorders.ca.

Petition to Health Minister

A public Petition calling on the Health Minister to implement the Orphan Drug Regulations had been launched the previous week and has now garnered almost 10,000 signatures.

HEY, get a few friends to sign and put us over the top so we can send to the Minister. Go to: rarepetition.ca

