

A Message from the President to the Annual General Meeting of the Canadian Organization for Rare Disorders

Toronto, Ontario

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Durhane Wong-Rieger, President

Every year at the AGM we look back and say that during this past year CORD has had an unprecedented amount of activities and achievements on behalf of rare diseases in Canada. Someday, we may feel we have reached that asymptote and things are leveling off but not yet this year, not yet today. CORD had a “breakout” year (of sorts) in 2015, reaching out to new audiences and engaging new stakeholders.

Following the highly successful launch of Canada’s Rare Disease Strategy in February on Rare Disease Day 2015, CORD took the Strategy on the road under the banner of the Economic Club of Canada to bring it to patients, healthcare providers, policy makers, researchers, and developers across Canada. We started in Toronto in September where we introduced our new multi-stakeholder collaboration, Rare Alliance Canada. It is bringing together academics and thought leaders and, as importantly, achievement-driven actors from patient organizations, hospitals, research units, centers of excellence, associations, review agencies, and payers.

In Toronto, we focused on Canadian innovation. We then moved to Edmonton in October where an invited Roundtable also discussed access strategies with payers and providers, with high-level agreement on principles for access, mechanisms to manage coverage with evidence development, and necessary tools for monitoring outcomes and impact. Then we took the program to Ottawa in November where screening and diagnosis took centre stage, and then to Vancouver in January 2016, where we dovetailed with the meeting of the Federal/Provincial/Territorial Health Ministers. Rare diseases, including newborn screening and access to drugs, were key issues, garnering renewed commitments.

Parenthetically, progress was not without its drama. Those of you who followed us through the social and public media will recall that we almost got

ejected from the hotel where the Health Ministers were meeting before achieving an impromptu meeting (in the corridors) resulting in an invitation to attend the final Press Conference the next day. While we were highly disappointed (but not surprised) that there were no concrete commitments on a panCanadian Drugs for Rare Diseases program, we did learn (months later) that the Ministers had agreed on recommendations for newborn screening. Apparently, they are proposing 22 core conditions to be included in all provincial screening programs. This is a first and we will need to monitor the implementation.

In the meantime, CORD has continued to support its patient members and member organizations. We were directly involved in a half-dozen submissions to the Common Drug Review and the panCanadian Oncology Drug Review. We have conducted training workshops and presented at meetings of member groups. We are active in presenting at conferences across Canada as well as internationally.



Rare Disease Day Rarity Awards Winners

In 2015, CORD joined Rare Disease International, a newly formed international network of national rare disease organizations and international rare disease associations. CORD has a position on the Governing Board and will be a key representative as RDI begins engagement with the United Nations in creating a Select Committee on Rare Diseases, which will include UNESCO, UNICEF, and the World Bank. As we contribute to the global advancement of rare diseases, the international developments will support our work in Canada.

Perhaps one of the key achievements for FY 2015-16 was our intervention at Queen’s Park in Toronto. On Rare Disease Day, Health Minister Hoskins met with the CORD patient community and announced the formation of a Working Group to implement Ontario’s Rare Disease Strategy. We have been liaising with his office toward the implementation of the Working Group. Kudos to CORD, in that Ontario decided to adopt CORD’s Canadian

Strategy, saying that it was very developed and there was no rationale to start with something else. Not only is this a reaffirmation of the Strategy itself, it will allow Ontario to move quickly to implementation rather than starting with definition. Also parenthetically, the members of Working Group are nearly all in place, with the President of CORD having one of the patient seats. We are hoping that we can use Ontario to pilot or provide a platform for many of the initiatives in the national strategy.

I would like to acknowledge the contributions of the CORD Board. As many of you know, CORD has a very small staff contingency and we rely on the board to carry out many activities. I am especially indebted to our President, Wayne Critchley, and to rest of our Executive: Cathy Evanochko, Vice-Chair, Maureen Smith, Secretary and my savior in so many situations, Riyad Elbard as Treasurer who has been a real asset to the office, and John Dyck, the Executive Member-at-Large. Ian Stedman and Patti Bryant have taken on key committee tasks. I also want to acknowledge our out-going board members, John Adams who is the longest serving, Gena Brumitt who has served CORD for several years, John Dyck who is taking a teaching sabbatical, Kelly Gorman who is our “voice of reason”, and Christine White who has promised that her daughter may step up her role with CORD.

Rare Disease Day on Parliament Hill



We of course, could not succeed without the engagement of our nearly 100 patient organizations, and our 35 (at last count) corporate partners. We also thank Bill Dempster and his team at 3Sixty Public Affairs for their consulting work. We look forward to seeing all of you at our next conference for Canada’s Expert Patients in Health Technology, on November 7-8 at the Hyatt in Toronto.

Respectfully Submitted,

Durhane Wong-Rieger, PhD
President