

FOR RELEASE: 3/8/2016

CORD joins MIT NEWDIGS consortium to accelerate biomedical innovation

Rare diseases advocacy coalition advances international effort to accelerate healthcare innovation

BOSTON, TORONTO, 8 MARCH 2017—MIT's NEW Drug Development ParadIGmS (NEWDIGS) program announced today that the Canadian Organization for Rare Disorders (CORD) has joined its international effort to accelerate discovery, development, and delivery of better therapeutics to patients safely and affordably. NEWDIGS brings together pharmaceutical and biotech companies, regulators, insurers, patient advocacy groups, and other healthcare stakeholders to design modern systems connecting scientific discovery to patient care.

“CORD will be a strong ally in our system-wide effort to advance adaptive biomedical innovation,” said Dr Gigi Hirsch, Executive Director of NEWDIGS and the MIT Center for Biomedical Innovation. “NEWDIGS is deeply committed to advancing patient-centered innovation in ways that work for all stakeholders, and CORD represents the perspectives of a diverse community whose values are well-aligned.”

Durhane Wong-Rieger, President & CEO of CORD, said, “Joining MIT NEWDIGS gives us a strategic opportunity to collaborate with global leaders in health technology and healthcare innovation. It provides a powerful platform for Canadian stakeholders to contribute to the evolution of new practices that will benefit our rare disease community in Canada as well as those in the rest of the world.”

A disease is considered rare if it affects no more than 1 in 2,000 persons, but there are more than 7,000 rare diseases. Altogether there are about 2.8 million Canadians, 30 million Americans, and 30 million Europeans with rare diseases. As many as 300 million people globally are affected. Almost 50% are children, and as many as 30% of these will die before their fifth birthday. But because the population with any given rare disease is so small, the costs of developing and delivering therapies can be prohibitively expensive.

Consequently, CORD currently pursues a range of initiatives to improve health for patients with rare diseases. It represents the rare disease community in the development of Canadian Orphan Drug Policy, including the proposed Expensive Drugs for Rare Disorders program within the National Pharmaceutical Strategy. It is also working to promote state-of-the-art newborn screening in all provinces and territories, and to ensure Canada's Clinical Trials Registry works effectively for those with rare disorders.

Press contacts*MIT NEWDIGS*

Deborah Young

Operations Director

debyoung@mit.edu

+1 (617) 324-7756

CORD

Angela Covado

Managing Director

angela@optimizinghealth.org

+1 (416) 969-7464

About MIT NEWDIGS

MIT NEW Drug Development ParadIGmS (NEWDIGS) is an international “think and do tank” dedicated to helping biomedical innovation benefit all healthcare stakeholders faster and reliably. NEWDIGS designs, evaluates, and initiates advancements that are too complex and cross-cutting to be addressed by a single organization or market sector. Its members include global leaders in research, development, insurance, regulation, and patient advocacy. For more information, visit newdigs.mit.edu.

About the Canadian Organization for Rare Disorders (CORD)

CORD is Canada’s national network for organizations representing all those with rare disorders. CORD provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders. CORD works with governments, researchers, clinicians and industry to promote research, diagnosis, treatment and services for all rare disorders in Canada. Follow [@raredisorders](https://twitter.com/raredisorders) or see the [CORD Facebook page](#). For more information, visit www.raredisorders.ca.

###