REPORT: CORD Economic Business Panel Event & Roundtable Discussion

SCAGO-Eastern Ontario/SCDAC was in attendance at the roundtable discussion about rare diseases; it was hosted by the Canadian Organization of Rare diseases (CORD).

The forum consisted of four panelist (Durhane wong-rieger, Mr.Fred Horne, Mr. Sean Thompson, and Dr. Alex Mackenzie), all of whom discussed topics that covered the scope of healthcare (with respect to rare diseases). Canadians have benefitted from public health strategies in Chronic/common diseases (diabetes, cancer, heart disease and mental illness) whereas the approach to rare diseases has remained less than progressive.

This in turn causes Canadian families to endure many challenges including misdiagnoses, unnecessary surgeries, social isolation, financial hardship, lack of treatment options and early death.

Canada is lagging behind other countries in its approach to rare diseases. That is why CORD has developed and introduced the Canada's Rare Disease Strategy, which is a plan for collaborative action to achieve five goals:

- Improving early detection and prevention
- Providing timely, equitable and evidence-informed care
- Enhancing community support
- Providing sustainable access to promising therapies, and
- Promoting innovative research.

With this strategy they can decrease unnecessary delays in testing, wrong diagnoses and missed opportunities to treat. CORD has begun a series of Economic Club of Canada panels to discuss and improve the strategy. Ottawa was the third of five discussion panels held across the country. After the forum, a small roundtable discussion took place at which SCAGO-Eastern Ontario/SCDAC participated in. This roundtable covers topics such as:

- How can we arrive at a pan-Canadian evidence-based list of core primary conditions for newborn screening, using bloodspot and other tests?
- How can we arrive at an evaluative framework to assess the benefits, harms and costs of the implementation of new screening modalities and strategies?
- How can we develop guidelines for sharing and use of the results from newborn screening that protects the rights of families and optimize timely intervention
- How can we develop an approach for implementing available (state-of-the-art) next-generation (targeted panel, exome, genome) testing to enable diagnosis and inform patient management of rare diseases?
- How can we facilitate national collaboration to share best practices for integration of genomic data into care of patients with rare diseases, including new informatics systems for data sharing?

- How can we develop a process to introduce and integrate new sample types (e.g. metabolomics) into the care pathways for patients with rare diseases?
- How can we develop guidelines to assure healthcare professionals and families have the necessary information to make well-informed decisions about genomic testing?
- How can we enable provincial and territorial governments to collaborate to implement early detection and preventive services across the country that includes comprehensive next-generation strategies and appropriate approaches to diagnose rare diseases with no genetic link?

As of now CORD is focused on getting their strategy approved through government legislation, as well as improving their strategy with the help of patient advocacy organizations.

Report provided by the Regional coordinator for the South Eastern Ontario-Sickle Cell Awareness Group of Ontario, Rachid Barry

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