



March 11, 2020

CMO MEMO to All Rare Disease Foundation Stakeholders

RE: COVID-19 Coronavirus pandemic

After consulting with colleagues and reviewing the emerging data on the Coronavirus pandemic, I have come to the conclusion that we must err on the side of caution to protect our patient population. I am thus recommending we suspend all in person events such as P2P groups, Rare Finds events, the Backyard Ultra and Outrun Rare until the pandemic is under control.

P2P groups, board meetings and team meetings can be held virtually while all in person events should be postponed until we get some clarity around this rapidly evolving problem and how it might affect vulnerable rare disease populations. Canada has robust public health system that is on the ball, vigorous case finding and case contact tracking capacity so I expect we will get clarity on where we are before the end of May. There are also 80 clinical trials in progress and the world is slowly mobilizing so I have great hope that we will overcome this challenge soon.

In Service,

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