Open Letter to NACI:
Reduce the timing between doses for patients with neuromuscular diseases

April 27, 2021

Dr. Caroline Quach-Thanh
Chair of the Secretariat of the National Advisory Committee on Immunization (NACI)
Via email: phac.naci-ccni.aspc@canada.ca

Dear Dr. Caroline Quach-Thanh

We are a group of physicians, health care workers and stakeholders who care for patients with neuromuscular diseases across Canada. We are writing this open letter to request for patients with neuromuscular diseases to be eligible for vaccination doses earlier than the currently scheduled 4-month interval in patients receiving vaccines requiring dual administration.

We are aware that vaccine supply is limited, however, our responsibility as clinicians and stakeholders lies in informing the public and policy makers on the importance and urgency on this matter. Similar to patients with cancer and transplant, some patients with neuromuscular disease have been included as a priority in many areas in the country, however unlike these at-risk groups, a shorter time frame for second dose vaccination has not been granted to date. This should ideally be at the recommended 28-day interval which was studied in clinical trials and which offers the highest upfront protection against COVID-19.

Patients with neuromuscular diseases include not only older adults at risk, but also young patients with Duchenne and Becker muscular dystrophies, spinal muscular atrophy, myasthenia gravis, and chronic immune nerve conditions such as CIDP. These individuals may have respiratory involvement, require immunotherapy and are particularly vulnerable to severe and life-threatening effects from contracting COVID-19 infection. Partial protection for some of the most vulnerable and high-risk patients in the country from this devastating disease is not acceptable, particularly as the virus and variants surge across the country.

We urgently ask that you further nuance the list of those who should be prioritized for their second dose to include patients affected by neuromuscular disease and that this is reflected in NACI’s recommendations.

Thank you for your consideration and support during this incredibly trying period for our patients and their families.

Sincerely,

Hans Katzberg, MD, FRCPC, FAAN
Neurologist, University Health Network
Clinical Investigator, Krembil Brain Institute
Associate Professor of Medicine, University of Toronto
hans.katzberg@utoronto.ca

Hanns Lochmüller, MD, FAAN
Professor of Neurology | Canada Research Chair in Neuromuscular Genomics and Health
CHEO Research Institute | The Ottawa Hospital | Brain and Mind Research Institute | University of Ottawa
Lead Investigator | Neuromuscular Disease Network for Canada
hlochmuller@toh.ca | hanns.lochmuller@gmail.com | https://lochmullerlab.org | +1 613-737-7600 ext. 4014

Stacey Lintern
Chief Executive Officer
Muscular Dystrophy Canada
stacey.lintern@muscle.ca

Perry Esler
Executive Director
Jesse’s Journey
perry@jessesjourney.com