

Dr Carole Legare  
Director, Office of Clinical Trials  
Therapeutic Products Health Canada, Government of Canada

May 15, 2020

Dear Dr. Légaré,

We hope you are well and staying safe during these unprecedented times.

We are writing to thank you for taking the time to communicate with us regarding access to Deflazacort for Canadians with Duchenne Muscular Dystrophy. We appreciate the helpful information you provided about the Special Access Programme. We would like to once again emphasize that our concerns are grounded in the perspectives and experiences of patients living with Duchenne Muscular Dystrophy; our understanding of the importance of access to Deflazacort for Canadians; and our appreciation of the importance of timely and uninterrupted access of Deflazacort in Canada. As noted in your correspondence, we also would like to see a predictable supply of Deflazacort for Canadians and we will continue to work with all parties to ensure we reach the best solution for patients.

We would also like to use this opportunity to offer input or consultation to you and your team on important medications and processes. Specifically, we would be happy to discuss mechanisms to which patient organizations can provide consultation to Health Canada Special Access Programme processes, and provide our patient perspective on current and future new drug applications for Canadians with Duchenne Muscular Dystrophy.

Thank you again for your consideration of this matter and for valuing our patient perspective.

Kind regards,



Perry Esler  
Executive Director, Jesse's Journey



Marie-Catherine Du Berger  
President & Co-founder, La Force DMD



Stacey Lintern  
Chief Executive Officer, Muscular Dystrophy Canada



Edward Worsfold  
Co-founder and Chair, Stand for Duchenne Canada