



March 14, 2017

Dear FSMAC Members,

We at FSMAC would like you to know that we understand pressures that our families are facing in terms of waiting for the regulatory approval from Health Canada of Biogen's, Spinraza. We are advocating on behalf of those affected by SMA in Canada and will keep you updated as information comes available.

In our recent communication with Health Canada officials, we have some information for you.

While it is incredibly difficult to wait patiently for the process to be completed, be aware that the internal drug approval process is very large and detailed. They are very limited by regulations about the information they are able to provide to the public of the process itself and have actually given out more information than they normally would to our community. Did you know that the same team that addresses the review process are also the people that respond to family questions and comments? They answer the same questions over and over and respond with the same replies. When we are inundating that team at Health Canada, we are actually reducing the speed at which the process takes. We are unable to increase the probability of the approval, they must go through their scientific review process. This is why we at Families of SMA Canada are requesting your stories to be forwarded to us to submit as a group. Not only are we more efficient, but we also have more impact as a unified group. Thank you to the families that have already sent your stories and photos to us for submission, if you haven't yet, it is not too late. Please send them to fsmacan@telus.net

To make comment to the process itself and the timeline we are looking at, Health Canada has expedited the application and is aiming to respond by the end of June. Now is the time to be communicating with your individual provincial governments to affect the approval of funding Spinraza after a positive response from Health Canada. FSMAC will also be communicating with the provincial health care authorities on behalf of our SMA families.

Support Research Hope

103 - 7134 Vedder Rd ~ Chilliwack, BC ~ V2R 4G4 ~ Phone 1-855-824-1277 ~ Fax 604-824-1363

curesma.ca ~ fsmacan@telus.net

This is a great time for SMA, we are on cusp of major change. It is also a time for supporting each other and presenting as a unified group. We must stay strong and continue on our quest for a cure. Even though Spinraza is the first treatment, we must continue our fight for a cure! We must remain vigilant to fund research and support our families.

Together we WILL find a CURE!!

Sincerely,

Susi VanderWyk
Executive Director
Families of SMA Canada

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