THANK YOU FOR BELIEVING IN A BRIGHTER FUTURE FOR CANADIANS WITH MPS

The Canadian Society for Mucopolysaccharide & Related Diseases Inc.

December 6, 2006

Dear Canadian MPS Society supporter,

In the spring of 2006 our son Trey was diagnosed with MPS II (Hunter Syndrome) and like many other parents given the same diagnosis for their child, we said, *"What is that?"* MPS II is, like all MPS diseases, extraordinarily rare – we had just won a lottery we wish we wouldn't have, and were thrust into a world we didn't know existed.

Unbelievably, my mother's neighbour in North Vancouver had heard of MPS – his son had played baseball against Nicklas Harkins (who has MPS I) and he had even won an autographed MPS CUP jersey through a radio station give-away in 2005. He gave my mom the Canadian MPS Society's phone number, and a life ring was thrown to us when we thought we would literally drown in the overwhelming sea of information and grief we were swimming in.

The booklets and information we received immediately from the Society gave us and our family the tools to deal with Trey's condition – with MPS, there are so many medical situations to deal with, many of them unique to MPS, and the advice we've received through the Society's publications and members has really made a difference in the way we have approached Trey's medical care. We would be lost without it.

And the support we received wasn't just helpful, it was *essential*. Knowing that there was a family nearby who had gone through a similar situation was a huge relief and meeting them made us feel as if we weren't alone. Although family and friends supported us as best as they could, there's no substitute for talking to someone who *really knows* what you're going through. Through information found on the Society's website, my mother contacted Simon Ibell (an adult with MPS II) and his mother, and although they live across the country, we had an opportunity to meet them in Vancouver and they have been able to share so much with us since then. Simon's full, rewarding life gave us a positive vision of how life could be for Trey, and for us.

This summer we attended the Society's national family conference in Collingwood, ON, and not only were we excited to be in the presence of so many MPS experts and families and have the opportunity to speak to them in a relaxed environment, but we were thrilled to finally meet the McFadyen family as well. Little Isaac McFadyen has MPS VI and is the same age as Trey – watching Trey and Isaac run around kicking soccer balls and swatting hockey sticks warmed our hearts and the news that Isaac would be starting enzyme replacement therapy (ERT) gave us hope that Trey would also be able to begin ERT for MPS II sometime soon.

Now that the reality of Trey's condition has set in and the waters have calmed around us, it's clear to us that while it's always important to belong to a community, it's absolutely vital when your child has a disease that's incredibly rare and you don't know if you are going to sink or swim. Now we're ready to offer a lifeline to other families, and want to ensure that when other families have children diagnosed with MPS, they will be able to access the same support and information that we did through the Society's essential services and programs.

And we share the Society's vision of a future where there are cures for *all* MPS diseases. But we need your help to fund research to make this vision a reality for kids like Trey.

Please consider giving a gift to the Canadian MPS Society this holiday season.

With thanks for your continued support,

Deb Purcell

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