The Canadian Society for Mucopolysaccharide & Related Diseases Inc.

MPS

MPS Society Welcomes New Enzyme Replacement Therapy for Rare Genetic Disease – MPS II (Hunter syndrome)

Elaprase ™ offers hope for children and adults with MPS II (Hunter syndrome)

(Vancouver, BC—June 27, 2007) – People with MPS II (Hunter syndrome) have new hope now as Health Canada has approved ELAPRASE™, a human enzyme replacement therapy, for sale in Canada, following priority review. Elaprase is the first and only treatment approved for people suffering from MPS II, a rare, life-threatening genetic condition that results from the absence or insufficient levels of the lysosomal enzyme iduronate-2-sulfatase. Elaprase, which is given as weekly infusions, replaces the missing enzyme that MPS II patients fail to produce in sufficient quantities.

MPS II is usually diagnosed in children aged 18-36 months. It is progressive, and life-limiting. There is a broad range of severity in the symptoms. Untreated, the disease may result in a thickening of heart valves, an enlarged liver and spleen and other organs, obstructive airway disease, and progressive deafness. It may also result in changes in facial features, skeletal changes including joint stiffness, and in some cases central nervous system involvement leading to potentially serious developmental delays. It is estimated that approximately 40 people in Canada and 2,000 people worldwide are afflicted with MPS II.

“Making Elaprase available in Canada will mean a world of difference for families across the country whose children are living with MPS II. This is a progressive disease, so the sooner a child is treated, the better,” said Kirsten Harkins, Executive Director of The Canadian MPS Society. “It was only in February that the first child in Canada with MPS II began receiving Elaprase through Health Canada’s Special Access Program and reimbursed by the BC government. We know there are more families waiting for the treatment to be made available so that their children can have a better quality of life. Elaprase will not cure the disease, but it is shown to have a remarkable impact on the course of this devastating illness. This is very exciting news, because now when a child is diagnosed with MPS II, he or she has the hope of leading a normal life,” said Harkins.

Trey Purcell, a three-year-old B.C. boy with MPS II, has been receiving weekly infusions since February 5, 2007, after the treatment was made available through the Special Access Program and special funding from the provincial government. “Elaprase has given us hope that Trey will live a long and fulfilled life,” said Deb Purcell, Trey’s mother. “We are thrilled with the changes we have seen in Trey in only four months. His organs are shrinking back to size, his facial features are softening, he is growing like a weed again, and these are only the changes we've seen from the outside. As a parent of a child with a progressive and life threatening disease, knowing that there's treatment and hope means everything."

Simon Ibell, an MPS II patient who lives in Toronto was part of the clinical trial for Elaprase, has defeated the odds and, at 29, is enthusiastic about this new treatment. ”Elaprase is a blessing and a life saver that I never thought would be available in my lifetime. It has provided many positive changes, such as improvements in my breathing, stamina, mobility, flexibility and decrease in the size of certain organs. All of these improvements have provided a better quality of life, even for me at my age. Also, I have witnessed the increased benefits of Elaprase for those

younger Hunter syndrome patients and I hope to see this treatment being reimbursed across Canada in order to treat the disease before it has progressed.''

“Health Canada’s approval is a very important step, but only the first step in the process. It is urgent that people with MPS II have access to this treatment within their provinces,” said Harkins. “We ask the provinces to act quickly and approve funding for this new breakthrough treatment.”

-30-

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