

The Linking Hand

Across Australia and New Zealand

Autumn 2005



Our Motto

A life is not measured by the number of days, months
or years that it is lived,
but by the effect that life has on other people who touch it.
It is not measured by the length of its days or the height
of its achievements,
but by the breadth of its influence.

Anonymous

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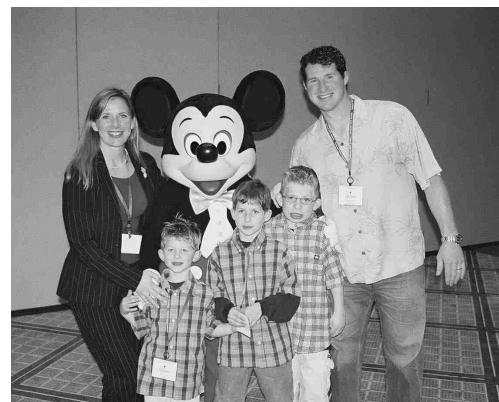
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MPS I - A Canadian Experience

By Kirsten Harkins

Our son Nicklas was diagnosed with an attenuated form of MPS I in the Spring of 2001 - just weeks after the phase II clinical trial for Aldurazyme had begun. While we were excited to hear about this hopeful new treatment, we were devastated that he could not be included in the trial and waited two agonizing years for the trial to be completed while Nicklas's health gradually deteriorated. Finally, in August of 2003, Nicklas had his first infusion of Alurazyme at BC Children's Hospital and we were overwhelmed with relief and joy when the synthetic enzyme dripped down the IV tube and into his body for the first time. Since that day, Nicklas's health has stabilized, and he has continued to lead an active, happy, and "normal" life. Aldurazyme was licensed by Health Canada on May 31, 2004, and is currently being funded through various children's hospitals across the country. We are extremely grateful to everyone involved in bringing this amazing, life-saving treatment to the market, and thank them for giving our son his life back.

Kirsten Harkins is Executive Director with the Canadian Society for Mucopolysaccharide & Related Diseases Inc.



At the Disney Conference in Florida - Kirsten, Jonas, Jansen, Nicklas and my husband Todd with Mickey Mouse

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