

Dear RemTech Delegates:



Ilsa Mae, was an angel. She had an angelic personality, laugh and smile. In her short span of time on this earth, she earned her wings by bringing a bit of joy to everyone she met.

On May 18, 1998, this little angel arrived. After a few hectic weeks with a new baby, thoughts turned to all she could accomplish. Dad was hoping to watch her excel at golf, baseball and hockey. Mom planned to introduce her to running and tap dancing.

When Ilsa reached the age of four months, this angel was not yet able to lift her head, roll over, or do much more than wiggle her toes, but everyone thought she was just setting her own timetable. At six months, Ilsa was diagnosed with Spinal Muscular Atrophy (SMA).

Only a few children with SMA type1 (the most severe form) live to adulthood and all are severely disabled. Ilsa was never able to sit up unassisted, roll over, stand or walk like healthy children. This neuromuscular disorder also affected her lungs. With little muscular strength to breathe adequately and cough, Ilsa had pneumonia numerous times. Her ability to eat was also reduced so Ilsa went through an operation to put a tube into her stomach to enable us to put food directly into her stomach.

The hardest part as parents was dealing with the uncertainty; as there was no treatment available and no cure. When Ilsa did not have pneumonia, we allowed ourselves to believe that she would be one of the few that would survive. When Ilsa was desperately ill in the hospital, we had to resign ourselves to the fact that she would not be with us tomorrow. We tried to fit as much as we could into her life and enjoyed her laughs and smiles everyday.

Ilsa was not expected to be here for her first birthday. Her first birthday came and went along

with her second Christmas. On March 28, 2000 Ilsa passed away peacefully while watching Bear in the Big Blue House, just a few months short of her second Birthday. This little angel endured much in her short life without complaint.

Ilsa, our little angel, continues to touch many people's lives as she teaches them how precious life is when we tell them our story.

After Ilsa's diagnosis, the organization that offered our family assistance was Muscular Dystrophy Canada (MDC). During this trying period, they provided us with information we could not have obtained elsewhere and an enormous amount of support. One of the unseen but essential components of Muscular Dystrophy Canada's goals is their contribution to scientific research. A great deal of progress has been made over the past decade. Every year, more is learned about SMA and over 100 other neuromuscular disorders and we come closer to a cure.

Following RemTech 2005, ESAA and the Chowaniec Family, (through MDC) created the ILSA MAE RESEARCH FUND. This fund has the specific goal of supporting SMA research in Canada. Money raised for Muscular Dystrophy Canada at ESAA events are donated to this fund. Since 1998, ESAA Members and the environment industry have raised over \$26,000 to support the initiatives of MDC.

Though a cure was not found in time for Ilsa, I do believe a cure is in reach. I ask that you join Muscular Dystrophy Canada in its mission to provide support and resources to people challenged by neuromuscular disorders today, while searching for tomorrow's cure.

Please give generously to Muscular Dystrophy Canada's Ilsa Mae Research Fund and help make muscles move.

Our family and MDC thank-you for your support.

Joe Chowaniec



Yes, we want to give a gift to the Ilsa Mae Research Fund

Company Name _____

Contact Name Mr. Mrs. Ms. _____

Address _____

City _____ Prov. _____ PC _____

Phone _____ Fax _____

All donations of \$20 or more are automatically registered for a tax-deductable receipt. Muscular Dystrophy Canada is a registered Charity under the Income Tax Act (Canada). Business Number 10775 5837 RR0001

Let's make muscles move

\$1000 \$500 \$250 \$100 other

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Please make cheques payable to Muscular Dystrophy Canada and

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