

Christmas 1999

The Miracle of Ilsa

As you are probably aware our daughter, Ilsa Mae, was diagnosed with a rare disorder called Spinal Muscular Atrophy just before Christmas last year. She was given very little time to be with us as children with SMA Level 1 rarely live to 18 months. Ilsa is still with here and is almost 19 months old. She has battled 3 separate bouts of pneumonia since March 1999 and shows no sign of giving up the fight.

Our lives have changed as her requirements change. We now spend a lot of quality time at home watching videos, playing with toys, and reading books. Her schedule is full every day with chest physiotherapy treatments, suctioning,



G-tube feedings, and leg and arm physiotherapy.

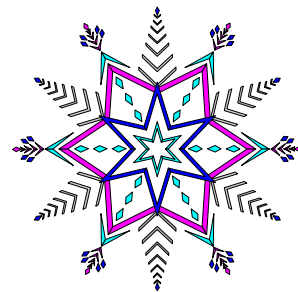
Ilsa is a very beautiful child who now talks to us all the time but still mainly in her own language. The only word we can get her to say consistently is "Hi". She does understand everything we say though as she follows our directions-- when she feels like it. She will also wave goodbye to everyone and occasionally will

even say "Bye-bye". Ilsa is constantly amazing us when she is able to do something that we never thought we'd get a chance to see her attempt.

Fundraising Efforts

The whole family has

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been involved with the Muscular Dystrophy Association of Canada to raise funds for research into SMA and for medical equipment required by children with neuromuscular disease.

The company Joe works for (ESAA) raised money at their annual golf tournament.

Our family was the corporate family for Western Canada this year. Rami wrote a letter asking for funds from various corporations throughout Western Canada. Being such a cutie-pie, Ilsa has been asked for her picture to be used extensively. Ilsa is on a poster for which is displayed in firehalls in BC and Alberta to promote awareness and



thank Firefighters for raising funds to fight Muscular Dystrophy. Ilsa was also on the local Edmonton news as a story during Muscular Dystrophy awareness month in September. She was a natural and hammed it up for the camera even though she and Rami had only slept 3 hours the night before due to teething. Odo (our cat) also received his 15 minutes of fame when he was included in the story.

Thank you!

Our entire family would like to thank everyone for their prayers, visits and extra efforts they have made to keep our spirits up during this last year.

A special thanks to:

- ◆ Ilsa's nanny Michelle -we



could not survive without you.

- ◆ Aunt Shannon, babysitter extraordinaire and Ilsa's WWF Buddy
- ◆ Uncle Erroll- Ilsa's favorite uncle
- ◆ Joe's mom for everything and just being there.
- ◆ All Ilsa's nighttime nurses-so Joe and Rami can get some sleep
- ◆ All the healthcare professionals involved with Ilsa - making our lives easier

Wishing you all a joyous Christmas and a Happy Millenium.

***Rami, Joe, Ilsa,
Kira and Odo***