

A Tribute to Auntie Louise

Nine years ago, our daughter, Rebecca, was diagnosed with Spinal Muscular Atrophy Type 2 at twenty months of age. SMA is a progressive disease whereby the nerves controlling muscles slowly die off. The result is the inability to walk, crawl, hold one's head up, swallow and eventually, breathe.

The doctor told us there was no treatment, no cure and to take Rebecca home and love her. We were lost. There was no care manual, no support network and we thought, no hope.

Help often comes in unexpected ways. In our case, it was through Louise Smith or "Auntie Louise" as she is known in SMA circles. Auntie Louise was training for a marathon at the time of Rebecca's diagnosis. The same strength and commitment it would take to run a marathon was used to plan the first "Rebecca Run for SMA."

We were a sad, lost, rag tag bunch who met in the parking lot of the Newmarket municipal building. But, it provided the backdrop for people that we loved and cared for to all come together to help us and Rebecca. We met other SMA children and families for the first time. We connected, commiserated and we started to raise money to find a cure.

Since the inception of that first run, it has morphed into the Esso's Rebecca Run for SMA now held at Fairy Lake in Newmarket, ON. Events sell out every year. There are usually about 1,000 people in attendance. **\$1.7 million dollars** has been raised for research to find a cure through the Rebecca Run and the Angel Gala for SMA.

Pictures of SMA children here and gone line the race route. It gives people the opportunity to see that SMA is a real disease that affects real people. It gives families struggling with SMA a way to honour and to remember their children.

And, it was all made possible by the efforts of one, remarkable woman. Louise's friends often talk about getting caught in the "vortex" that is Auntie Louise. She has inspired so many people to volunteer and get involved with the Rebecca Run. Imagine the countless hours that it would take to organize an event like the Rebecca Run?

Louise's exceptional work for the Families of SMA Canada charity has not gone unnoticed. John Stanton, who is the owner and founder of the Running Room store has made her this year's "Volunteer of the Year". Louise was honoured at the Good Life Toronto Marathon on Saturday October 16/10 for her outstanding, tireless commitment to SMA.

Auntie Louise, we love and thank you.