



*Rebecca Run for SMA*

# News Release

**For immediate release**

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## **2008 ESSO Rebecca Run in Newmarket Raises \$160,000 in support of SMA research**

**Holland Landing (Ontario), July 11, 2008** -- Organizers of the Esso Rebecca Run for SMA confirmed today that the 7<sup>th</sup> annual event set another record for funds raised for SMA in Canada.

Fairy Lake, Newmarket was busy with activity as runners and walkers came out in record numbers to help raise awareness and research dollars. Toronto's Bruce Raymer, 41, one of Canada's premier runners won the event in a blistering 15:40. Winning the overall women's 5km event was Angela Quick (age category 15-19) from St. George, Ontario in 20:32. "We were thrilled to see Bruce at the start line of our race. We continue to attract high quality runners and walkers as well as fitness and casual level athletes. It's really an event for everyone." says Race Director Louise Smith. "We attracted participants from all over Ontario and even the USA and Europe again this year. It's quite exciting to see so many familiar faces in the crowd, all helping us find a cure for SMA", says Louise Smith. "Raising \$160,000 in one year, with a 7-year total of \$1,160,000 is very rare with a small family-oriented event," says Louise, "This year, we were supported by over 30 corporate sponsors including Imperial Oil and a large group of their Independent Dealer Owners."

Announcing the grand total of funds raised took second fiddle to the more exciting news of a breakthrough in SMA research.

Over 200 international SMA researchers gathered in Chicago in June 2007 to discuss research progress and future. It is there the announcement was made that research has reached breakthrough. Thanks to funds raised in previous years, researchers identified and studied many possible treatment compounds. With the support of funds from events including the Rebecca Run for SMA, researchers are now taking the most successful compound to the 12-month FDA approval stage. Following this researchers will commence 1st phase human trials. This particular compound alleviated all symptoms of SMA disease in mice. All signs point to this being an effective drug treatment to eradicate all symptoms of disease for those living with SMA. The Rebecca Run for SMA is proud to be a part of this exciting discovery, giving 100% of the funds raised to the charity Families of SMA Canada.

Families of SMA Canada is volunteer-based and allots over 95% of its donations to research. "This is such an exciting time in SMA and in medicine," says Louise. "The speed at which SMA researchers have advanced is incredible considering that race namesake Rebecca was diagnosed with SMA 7 short years ago and at that time there was no cure, no treatment and no hope. Rebecca's parents were told that 50% of children diagnosed before the age of 2 would die before their 2<sup>nd</sup> birthday. Rebecca's parents were advised to take their daughter home, love her and make her life as comfortable as possible knowing that the degenerative disease would painfully slow her ability to crawl, hold her head up, swallow and breathe. Now look – we have a treatment within our grasp. I can't even imagine the joy if Rebecca were ever able to get out of her wheelchair and actually walk!"

The 2008 event was dedicated to Max Yorke Vallender, a beautiful little boy who was born July 16<sup>th</sup>, 2006 and passed six weeks later on Aug. 31.

The 2008 Rebecca Run saw over 600 people participate in the 1km SMA scamper, the 3km walk/run and the 5km run. All events went like clock work.

The day's activities included music from Wayne Jones DJ Service, who along with MC Chris Giles, kept the energy pumping and the participants focused on the reason they were there. A post-race barbecue for everyone kept bellies full. The highly skilled volunteers at the face painting area were swamped all day long. With over 125 random draw



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prizes, everyone was in high spirits. The 2008 Silent Auction featured over 200 items valued from \$5 to \$400. Folks from all ages were bidding on everything from garden items to fridges.

"It is the commitment from Esso, Running Room, our 100 sponsors and the amazing volunteers that has allowed the Rebecca Run to become the largest SMA event in all of Canada. Esso in particular has come on strong with the Esso Community Program that encourages independently owned Dealerships to promote and assist with local community events. We have over 20 Dealers from across the GTA that dedicated time and money to help in raising funds for the Rebecca Run. The Imperial Oil Corporation matches the funds raised by their Independent Dealers. Now THAT'S community involvement at its best." said Ms. Smith. "The Rebecca Run has become synonymous with highlighting the FUN in fundraising."

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### **About the Esso Rebecca Run for SMA**

Rebecca van Fraassen, the niece of Race Director Louise Smith, inspired the Esso Rebecca Run for SMA. This devastating neuromuscular disease affects Rebecca, who was diagnosed 7 years ago with SMA Type 2. This annual event raises funds for research through Families of SMA Canada. In 6 years this event has raised over \$ 710,000 for cure and treatment research. More information is available at [www.rebeccarun.com](http://www.rebeccarun.com)

### **About Spinal Muscular Atrophy**

Spinal Muscular Atrophy (SMA) is the number one genetic killer of children under the age of two. It is a group of inherited diseases that destroy the nerves that control voluntary movement, which affect crawling, walking, head and neck control, swallowing and breathing. One in 40 people carry the SMA gene; one in 6,000 babies from around the world is born with SMA and some 15,000 children die from the disease each year. 50% of the children diagnosed before their second birthday will die before they turn two. Because SMA is autosomal recessive, a child must inherit the defective gene from both parents and then has a one in four chance of being affected by the disease. More information is available at [www.CureSMA.ca](http://www.CureSMA.ca). More information about the breakthrough in research is available at <http://www.fsma.org/splash.htm>

### **About Families of SMA Canada**

Families of Spinal Muscular Atrophy Canada (FSMAC) is a not-for-profit organization dedicated to eradicating SMA by promoting and supporting the best possible Canadian research for a treatment or cure. FSMAC is volunteer-based and dedicates more than 95% of its income directly to funding research.

In addition to its fundraising activities, FSMAC helps families and individuals who are affected by SMA through national and international programs and support. It currently represents affected and interested families and individuals from Canadian provinces. FSMAC also works to educate the public and professional communities about SMA.

FSMAC was founded 2000 and achieved charitable status the same year. Its head office is located in Brandon, Manitoba. FSMAC is one of 20 international chapters affiliated with Families of Spinal Muscular Atrophy (FSMA) in the United States, which itself has raised more than US\$10 million dollars since its inception in 1984 to aid research around the world. FSMA also sponsors the annual International Spinal Muscular Atrophy Research Group Meeting, where scientists, researchers and clinicians gather to exchange research findings and ideas.

[www.CureSMA.ca](http://www.CureSMA.ca)  
[www.rebeccarun.com](http://www.rebeccarun.com)



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