

Northern Directions



Balancing Life's Tough Times™

FUNDRAISING CDS

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Families of Spinal Muscular Atrophy Canada

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Project Cure SMA Progress Report (et version française)

Multi-Center Phase II SMA trial using a combined treatment of valproic acid and carnitine (SMA-CARNI-VAL Trial).

The members of the Neuromuscular Diseases Program at Marie Enfant Rehabilitation Centre of Sainte-Justine Hospital, situated in Montréal, Québec, Canada, are proud to announce their participation in the "Project Cure SMA Phase II SMA Carni-Val trial".

SMA Carni-Val is a multi center trial involving 5 sites within the United States (Baltimore, Maryland; Columbus, Ohio, Detroit, Minnesota; Madison, Wisconsin; and Salt Lake City, Utah) and one site in Canada (Montreal, Quebec). The primary objective of this study is to evaluate the safety, tolerability, and efficacy of combined valproic acid and carnitine treatment of children with SMA. The secondary objectives are to refine both clinical and electrophysiological measures in order to enhance our understanding of the natural history of this devastating disease. Specifically, the clinical evaluation of SMA patients will provide an objective and precise measure of their functional capacity whereas electrophysiological measures will provide an assessment of the extent of motorneuron loss at different time

points of the disease. Finally, genetic studies will provide a better understanding of the genetic factors influencing disease severity.

Children participating in this study will be seen for a total of 5 site visits over a period of 12 months. At the Montreal site, each visit will involve a half-day assessment at Sainte-Justine Hospital on Day 1 and a half-day evaluation at the Marie Enfant Rehabilitation Centre of Sainte-Justine Hospital on Day 2. A number of different measures will be taken over this 2-day period and these include neurological, motor and pulmonary function evaluations as well as blood tests.

The SMA Carni-Val protocol will be reviewed by Sainte-Justine's Hospital Research Centre Ethics Committee early in September and recruitment will commence upon Ethics approval. The Montreal site will enroll 2 groups of SMA patients: 1) non-ambulatory children between 2 and 8 years of age with a confirmed diagnosis of type II SMA and 2) ambulatory children between 3 and 17 years of age with a confirmed diagnosis of type II or type III SMA. SMA diagnosis must be confirmed by neurological examination and SMN DNA testing. We expect to commence enrolling subjects at

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In Memoriam—Chelsea Hogan

April 27, 1999 - March 25, 2000

Chelsea was diagnosed with SMA type 1 at 11 months of age. She was our third child, two previous children both SMA free. She was the third grandchild in this generation to die of SMA. She loved music and lights, but loved her two older brothers the best of all. She was a special angel sent to us for such a short time and we treasure every minute we had with her.

Janine Hogan



A Record Setting \$130,000 Raised at Newmarket Event



SMA Event Attracts Participants From Across the Globe.

Newmarket, Ontario was a-buzz with activity as runners and walkers came out in droves to help raise awareness and research dollars for SMA. Jose Carvalho, who set a blistering pace and broke the finish line tape in a time of 16:28, won the 5km event. This is the 2nd time in 4 years that Jose has won this event and we're honoured that high quality runners support the race, as do the fitness runners and walkers. It's really an event for everyone.

We knew we were the largest SMA fundraising event in Ontario and were prepared for people from all over the province to participate. We were surprised, however, to have people from as far away as Calgary, Portland, Oregon and even Delhi, India arrive at Fairy Lake to walk and run in the name of SMA.

A whopping \$130,000.00 was raised at the event this year – bringing the 4-year total to over \$400,000.00. Over 100 corporate sponsors including Imperial Oil and a large group of their Independent Dealer Owners supported this year's event.

2005 was dedicated to the memory of best friends in heaven, Abigail Lynn Loebach and Jamie Olivia Haapalainen. Amazing stories have been writ-

ten about these precious angels. Please browse www.rebeccarun.com to view their videos and read their full stories.

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. Jazz the Clown painted faces of the young and young at heart and with over 200 random draw prizes, everyone was in high spirits. The 2005 Silent Auction featured over 150 items valued from \$5 to \$400. Folks from all ages were bidding on everything from garden items to mountain bikes.

We are proud that the money raised at the Rebecca Run will support Canadian cure and treatment research, especially now that we've entered the 2nd phase of human drug trials. This is incredible considering that Rebecca was diagnosed with



SMA Type 2, 5 short years ago and at that time the doctors told her parents there was no cure, no treatment and no hope. 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!

It is the commitment from Esso, Running Room, and all the other sponsors and volunteers that has allowed the Rebecca Run to become an on-going success. Esso in particular has come on strong with their Esso Community Program that encourages independently owned Dealerships to promote and assist with local community events. The Imperial Oil Corporation matched the funds raised by their Independent Dealers. The Rebecca Run has become synonymous with highlighting the FUN in fundraising.

Quinn's Quest for a Cure—Winnipeg, Manitoba

The 2nd Annual Quinn's Quest For a Cure was held on August 14, 2005 at Pineridge Hollow earning over \$51,000 for SMA research.

The inspiration for Quinn's Quest for a Cure is Quinn Orchard, born May 13, 2001. Quinn bravely endured test after test until the mystery of his life was finally unlocked. Spinal Muscular Atrophy, Type 1 was the diagnosis. On June 3, 2001, at the age of 3 weeks, Quinn peacefully left this world in the arms of his mommy and daddy. Though his life was brief he will for-

ever be remembered through his Quest for a Cure.

«It is the commitment from countless sponsors and volunteers that has allowed Quinn's Quest for a Cure to become such a successful event », says Lori Orchard. Great-West Life in particular has come on strong with support, and their staff's participation has also provided a corporate financial contribution.

Quinn's Quest For a Cure includes a 1 km Kid's Scamper for children 10 and under, a 3 km family fun race or walk and

a 5 km run for participants of all ages.

Quinn's Quest was honored to have Jeremy Bray as our 2005 race honoree. Jeremy is a 10-year-old boy with SMA Type II. Although quite shy, those that have the opportunity to get to know him better are soon captured by his wonderful personality. Jeremy has a sense of humour well beyond his years, which helps him cope with his everyday challenges. What he lacks in physical strength he makes up in strength of character.

The 2006 race is set for August 13th and the honoree this year will be Kaylan Roy, (SMA Type I, b. August 11, 2004 d. Jan., 2005).



Jeremy Bray

A New Beginning by Stephanie Woods, age 12

Her eyes blue as water.
 They sparkle like glitter.
 Her smile, sweet as candy.
 Her hair, blond as golden straw.
 She ws born today.
 I have a new cousin.
 Her name is Chelsea Patricia Hogan.
 April 1999
The News
 The parents found out Chelsea had S.M.A.
 They were also told that Chelsea

had six months to a year to live.
 They didn't tell any of us kids what was wrong with Chelsea.
 August 1999
Sick Again
 Chelsea got sick again and had to go to the hospital for another week.
 I really hope she gets better.
 When she came home she was very weak, worse than before.
 I don't understand why she's so sick.
 I keep on bringing her stuff that I

know she will like and putting it in her crib.
 October 1999
The Talk
 My Mom and Dad sat with my brother and I and told us about Chelsea's disease.
 They told us about SMA and what it was.
 They also told us that she was going to die and didn't have much time to live.
 My brother and I cried for quite awhile.

The Phone Call
 My family and I got a phone call this morning at 7:30.
 My Mom picked up the phone and she hung it up and started to cry.
 She told us that Chelsea had died.
 We all went next door as quickly as possible.
 We hugged her and kissed her and said goodbye.
 I will always remember her smiles and giggles.
 March 2000

Developing Independence by Michelle Laverdiere

My name is Michelle Laverdiere. I was born in 1968 in Edmonton. At birth I appeared to be of normal health, although slightly floppy, although my aunt, a neonatal nurse felt something was wrong.

Still, I was able to hold my head up from 3-6 months and seemed to progress averagely according to the infant charts.

When I began to have difficulty holding up my head while I was on my stomach and later while I sat in a slightly reclined sitting position my parents realized something was wrong. I started backsliding.

After one and a half years of testing I was diagnosed with Werdnig-Hoffman's disease (SMA Type II).

I'm now 37 and having out lived my early life-expectancy by 32 years I'd like to share my perspective on what it takes to live with SMA and maintain independence. I have had several debates with many people, in-

cluding those with disabilities, on what is the definition of independence. It to me is the ability to communicate your physical needs, having those needs met, making your own choices in daily life, and building your own short and long term goals.

Here are some tips on fostering independence in your child:

1. Give your child the freedom to make his or her own decisions. We learn best from making our own mistakes, but always be supportive and don't leave your child stranded.
2. Teach your child good communication skills: especially how to communicate their own care needs.
3. Be empathetic without feeling sorry for your child.
4. Teach the child to safely push he/herself forward

5. Plan ahead proactively by setting both short and long-term goals for life. (Remember! We can often live past life expectancy.)
6. It is difficult to get good grades or have fun when in pain. Learn about pain control.
7. View your child in a holistic manner. We're more than just our body and our illness.
8. Teach self-advocacy skills.
9. Encourage peer support both able bodied friends and others with progressive disabilities. Each gives a unique perspective, social development



Self-portrait: Michelle Laverdiere

- and support.
 10. Know and teach your child about their rights and what abuse is how and to report it.
- Remember:
 We want quality in our lives, and not to just have our medical and physical needs met. To do this we need to work as a team: the individual, the family, the caregivers, and society.
 Start building this team now!

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Our Mission

To fund the best possible Canadian research in search of a treatment or cure for the SMA diseases. To support families and individuals affected by SMA.

FUNDRAISING IDEAS



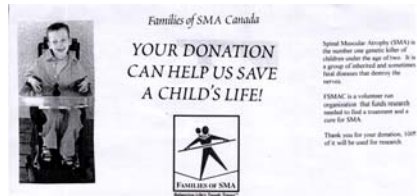
Rubber Wristbands

NEW this summer—all the rage with teens!

Rubber wristbands with CURE SMA imprinted on them. A great gift or an excellent fundraiser. They can be purchased cheaply and resold for 4 times their price.

A great idea to raise funds for SMA. They are half red and half black and would easily work for school fundraisers. This is a great opportunity to raise funds for FSMAC AND raise awareness about SMA at the same time.

Order by contacting louise@curesma.ca.



Fundraising Cans

Cans are available as well as posters and pamphlets. Please contact the FSMAC head office for more information or to place your order.

Remember:

Memberships are a tax-deductible donation! Please help us reduce costs and mail in your membership form today!

Project Cure SMA, cont'd et version française: Projet Guérison AS

(Continued from page 1)

the end of September 2005 and will continue recruiting patients until we have obtained our objective of 15 subjects: 10 patients for group 1 and 5 patients for group 2. Families who are interested in participating in this study can contact the Montreal site co-ordinator at the Marie-Enfant Rehabilitation Centre of Sainte-Justine Hospital, Monique Émond, Pht, MSc., at (514) 374-1710 extension 8278 as of August 29th, 2005.

Version Française

Les membres du Programme des maladies neuromusculaires du Centre de réadaptation Marie-Enfant de l'Hôpital Ste-Justine de Montréal sont fiers de participer au projet "Guérison AS phase II : SMA Carni-Val trial".

Ce protocole multi-centrique, impliquant 5 sites aux États-Unis (Baltimore, Maryland; Columbus, Ohio, Detroit, Minnesota; Madison, Wisconsin; and Salt Lake City, Utah) et un site au Canada (Montréal, Québec), a pour but premier d'évaluer la sécurité, l'efficacité ainsi que la tolérance d'une combinaison de médicaments, l'acide valproic et la carnitine, chez des enfants atteints d'amyotrophie spinale. Les objectifs secondaires sont de raffiner les techniques d'évaluation électrophysiologiques et cliniques afin de permettre un meilleur suivi de l'évolution de la maladie.

Ces dernières comprennent : 1) l'évaluation clinique qui aide à mesurer de façon objective et précise les capacités fonctionnelles des patients, 2) les techniques électrophysiologiques qui permettent d'étudier l'évolution de la perte au niveau des motoneurons et 3) l'étude des méca-

nismes génétiques qui influence la sévérité du phénotype. L'enfant qui participe à ce projet de recherche clinique devra être vu à 5 reprises sur une période de 12 mois. Chaque visite comprend 2 demi-journées à 2 sites différents soit la clinique de neurologie de l'Hôpital Ste-Justine et le Centre de Réadaptation Marie-Enfant de l'Hôpital Ste-Justine. Lors de chaque visite, nous procédons aux différentes mesures requises par le protocole : évaluation neurologique, tests sanguins, évaluation de la fonction motrice et de la capacité pulmonaire.

Actuellement, nous procédons aux différentes étapes requises pour l'obtention du certificat d'éthique. Nous débuterons la collecte de données dès l'obtention de ce dernier et prévoyons pouvoir évaluer le premier sujet en octobre 2005.

Nous travaillons pour cette étude avec 2 cohortes de patients : 1) des enfants âgés de 2 à 8 ans, non-ambulants, ayant un diagnostic confirmé d'amyotrophie spinale de type II et 2) des enfants âgés de 3 ans à 17 ans, ambulants, ayant un diagnostic confirmé d'amyotrophie spinale de type 2 ou de type 3. Nous devons recruter un minimum de 10 sujets pour la cohorte 1 et de 5 sujets pour la cohorte 2. Le recrutement se fera activement pendant l'automne 2005 afin d'atteindre notre objectif minimal de 15 sujets.

Les familles intéressées par le projet peuvent contacter la coordinatrice de cette étude au Centre de réadaptation Marie-Enfant de l'Hôpital Ste-Justine, Monique Émond Pht, MSc. au (514) 374-1710 poste 8278 à compter du 29 août 2005.