



# Happy Holidays!

From the Board of Directors of TS Canada ST

## OTTAWA RACE WEEKEND!

"Team TSC" is gearing up for Ottawa Race Weekend happening May 24-25th, 2014!

Come to Ottawa and join TSC Canada in this major fundraiser and fun family event weekend. Walk, Run, Cheer and have fun! A family event will take place May 25th – details to come!

Team  
TSC

## THE BIRTH OF A DISABLED CHILD

For Cathy and Don Evanochko, life was sweet. They had three beautiful daughters, a lovely home and professional success. Then, three years ago, the birth of their fourth daughter turned their lives upside down

By Suzanne Zwanig

# a

At the back of virtually every pregnant woman's mind is the thought: "What if my child is born disabled?" With the birth of a healthy normal child, she feels flooded with relief. There will be no terrible burden to be shouldered, no heart-wrenching sorrow because she has brought a sick or damaged child into the world.

Such thoughts occurred to Cathy Evanochko, now 30, during each of her four pregnancies. As a teen-age volunteer in a Calgary hospital, she had been horrified to see pitiful babies struggling to gain a grasp on life. "They broke my heart. I didn't know how parents could live with such a thing." With the certainty of the young, she knew she would never be able to cope with the tragedy of a flawed baby. And it seemed she would never have to: three beautiful blond babies—Amanda, now 9, Melissa, 6, and Katrina, 4—were born to Cathy and her husband, Don, now 32, who designs and sells industrial hydraulics systems.

Their fourth baby, Kimberly, looked equally exquisite when she arrived on January 20, 1985. But their luck had run out. Angelic as the baby looked, she was the victim of a



The Evanochkos (Kimberly, far right)

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## TS CANADA ST Sponsors 2014 World Conference

RESERVE YOUR SPOT!

Visit: [www.tsalliance.org](http://www.tsalliance.org)

The Tuberous Alliance (TS Alliance) is proud to announce the 2014 World Tuberous Sclerosis Complex (TSC) Conference to be held July 3-6, 2014 at the Omni Shoreham Hotel in Washington, DC.

We anticipate more than 1,100 attendees from across the globe including families and individuals with TSC; caregivers; healthcare professionals; researchers; a wide array of exhibitors; and others interested in TSC.

## TSC Family Forum

Toronto, Friday, December 13th

### Save the Date!

Children and adults with TSC and their families are invited to attend a TSC event in Toronto featuring top TSC physicians from Canada and the USA on Friday afternoon, December 13th.

#### Featured speakers include:

- Dr. Ute Bartels, Paediatric Neuro-Oncology, Hospital for Sick Children
- Dr. John Bissler, Paediatric Nephrology, Cincinnati TSC Clinic
- Dr. Peter Crino, Paediatric Neurology, Temple University School of Medicine
- Dr. York Pei, Nephrology, Toronto General TSC Adult Clinic



Watch our website and online calendar for registration information and updates.

TSC Canada  
28 McGregor Drive  
Ajax, ON L1T 3W8

## Clinical Trial for TSC Seizures opens in Montreal & Vancouver

The EXIST3 clinical trial is currently accepting patients from across the country at two Canadian centres, one at the Montreal TSC Clinic, and one at the Vancouver TSC Clinic.

EXIST3 is a three-arm, randomized, double-blind, placebo-controlled study of the efficacy and safety of two trough-ranges of everolimus as adjunctive therapy in patients with tuberous sclerosis complex who have refractory partial-onset seizures.

The primary objective is to compare the reduction in frequency of partial-onset seizures on each of trough ranges of everolimus (3-7 ng/mL and 9-15 ng/mL) versus placebo in patients with TSC.

To be eligible for the trial, patients must:

- Be between ages 2-65
- Have a clinically definite diagnosis of TSC
- Have a diagnosis of partial-onset epilepsy

For more information on eligibility and other details, see our website or contact the clinics.



THE NEWSLETTER OF TUBEROUS SCLEROSIS CANADA

# CONNECT

### YES! I WOULD LIKE TO HELP TSC Canada RAISE AWARENESS AND HELP EVEN MORE FAMILIES.

Amount of cheque: \_\_\_\_\_  Member only  Donation Only  Membership & Donation

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City/Prov/Postal Code: \_\_\_\_\_ Tel: \_\_\_\_\_

Email: \_\_\_\_\_

In Memory Of: \_\_\_\_\_

I am unable to financially support TSC Canada at this time, but I would like to receive the newsletter.

PLEASE DETACH AND RETURN TO TSC CANADA, 92 CAPLAN AVE, SUITE 125, BARRIE, ON L4N 0Z7

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[www.tscanada.ca](http://www.tscanada.ca)

NOVEMBER 2013



#### TSC Canada Board Members

Melissa Cote, Director  
Ray Marco, Director  
Karen Shulist, Director  
Mary Zilba, Director  
Jennifer Flinn, Director  
Patricia Nolan, Director  
Cathy Evanochko, Director

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Please email [kshulist@sympatico.ca](mailto:kshulist@sympatico.ca) for feedback on the current newsletter and future stories.

## Announcement

The board of directors for Tuberous Sclerosis Canada Sclérose Tubéreuse (TSCST) is happy to announce that Cathy Evanochko and Karen Shulist have agreed to serve as co-chairs of the organization for the next two years.



**Cathy Evanochko** is one of the founding board members of the organization. In the days prior to the availability of the Internet, an article about Cathy's family in the February, 1988 issue of Chatelaine magazine brought individuals together from across the country to create the Canadian organization Tuberous Sclerosis Canada Sclérose Tubéreuse. After taking a hiatus for a few years, Cathy rejoined the board in 2010. Cathy is a fierce advocate for TSC awareness, especially around the challenges adults with TSC face. Her daughter Kimberly was diagnosed with TSC in 1986 and with LAM in 2007. Cathy has recently been elected to sit on the board of directors for the Canadian Organization for Rare Disorders (CORD), a patient advocacy group for the rare disease community.



**Karen Shulist** has been a director on the TSCST board for almost nine years. She has been a part of many fundraising events and awareness raising initiatives. Karen was instrumental in organizing a medical conference in Toronto in 2007, and she looked after the 800 line for several years. She was involved with the TS Alliance organization in the USA as a Ex officio Board member, she knows how to build on relationships, which is key strength of hers. Karen has an 11 year old son who was diagnosed with TSC at 6 months, so she understands the challenges that everyone affected by TSC can face. Karen's first and foremost priorities are her family. The one message Karen would like to send out to all members, is to get involved and volunteer! To move forward we need your help.

The board has been working to update our bylaws as mandated by new laws affecting all non-profit organizations in Canada. The bylaws are currently undergoing review by a lawyer to ensure their compliance with the new legislation. The new bylaws will formalize the process for electing board members and the executive. In the meantime, we are confident that Cathy and Karen will provide consistency as we bring our processes in line with the new legislation. TSCST

directors have been actively involved in pursuing approval for the use of Afinitor in Canada for the treatment of renal AMLs and SEGA.

The TSCST board members for the next two years are: Melissa Cote and Jennifer Flinn in Ottawa, Patricia Nolan and Karen Shulist in the Toronto area, Cathy Evanochko in Calgary, and Ray Marco in Dunmore, Alberta.

Many thanks to Genevieve Dupont who looks after the 800 number and to Ray Marco who responds to the Gmail account for TSCST. You provide essential connections between families and the organization. Ray has also agreed to continue as Recording Secretary for the board. Thanks also to Andrew Duffy who continues to support the board with financial matters.

It is with sadness that the TSCST board accepted the resignation of Mary Zilba from the board. Although she felt that her professional commitments did not permit her to continue as a director, she stated that she would continue to advocate for TSC and would be a spokesperson for TSC awareness whenever opportunities arise. Thank you for all you have done for the TSC cause Mary, and we wish you well in all your future endeavours!

### TS CANADA ST - Job Opportunity Grant Writer

The Board of Directors of TS Canada ST is currently looking to hire an individual who has experience with grant writing and researching opportunities for funding. Someone who understands the medical condition of tuberous sclerosis complex is ideal. There is flexibility with this role. For more information; or to submit your resume, please email [tscanadast@gmail.com](mailto:tscanadast@gmail.com)



Please send us your email address if you would like to be kept up to date with conferences, events and research and clinic information.

Forward your email address  
(and update your contact information)  
to [TSCanadaST@gmail.com](mailto:TSCanadaST@gmail.com). Thank you!

When we come together, we make TSC less rare.

### New International Gold Standard for Treatment of TSC

TSC Canada is delighted to announce the recent publication in the October 2013 issue of Pediatric Neurology of the "International Consensus Guidelines for Diagnosis, Surveillance and Management of Tuberous Sclerosis Complex."

TSC Canada encourages all patients with TSC to become familiar with the updated diagnostic and especially with the new treatment guidelines for TSC available on our website. A copy of these guidelines should be given to each specialist and family physician involved in the care of TSC patients.



October 29, 2013

Dear TSC Patients, Families and Friends,

As many of you know, for some years Tuberous Sclerosis Canada Sclérose Tubéreuse eagerly anticipated the approval of Afinitor (everolimus) for the treatment of TSC in Canada.

The drug was approved by Health Canada – meaning doctors in Canada can now prescribe it for their TSC patients - for subependymal giant cell tumours (SGCTs or SEGAs) in June 2011 and for renal angiomyolipoma (AMLs) in spring 2013.

It was then submitted to the Common Drug Review (CDR), whose recommendation was requested in order to obtain funding through provincial drug plans, initially specifically for AMLs. Many of you responded to the feedback survey sent around earlier this year enabling patients to provide input to the CDR review process.

We are surprised and dismayed to learn that the CDR has recommended that Afinitor NOT be funded for TSC patients with AML.

Their explanation was that, even though Afinitor has been proven in clinical trials to reduce the size of AMLs, there was no DEFINITIVE evidence that reduction in AML size was related to reduction in bleeding complications, avoidance of surgery, or renal function preservation.

This is an absolutely unacceptable response for many reasons, which cannot be fully discussed in this brief message.

Members of TSCanada need to know that there is *no appeal*.

So, unless the TSC patient and professional community take strong action, we will be in a position where only those patients with private drug coverage will benefit from Afinitor. At TSCanada we believe we need to mount action now.

There are a number of opportunities available to us. To move forward, we are asking the patient and professional community to participate in a number of ways.

**First, please send us your personal stories.**

For those who are being treated with Afinitor for AML or subependymal giant cell astrocytoma (SEGA), we need your stories about the impact that Afinitor has made

**"If this treatment had been available then, I would still have my daughter."**



**Have you used Afinitor (everolimus)? Have you been denied coverage for Afinitor? If this treatment had been available to you, how would your life be different?**

#### QUALITY OF LIFE WITHOUT & AFTER AFINITOR (EVEROLIMUS)

Thank you for helping us to make available life saving treatments affordable for the TSC community.

Please include the following details, if applicable, with **EXAMPLES** of how this has made a difference in your life and in that of your family or community:

**EXAMPLES** of quality of life: please detail any changes you have noticed in the patient's life & that of family or caregivers. Some examples already provided to us below.

**Tumours**

- tumour growth & shrinkage and extent of this
- new tumour growth & prevention of this
- tumour damage, reduction or cessation
- kidney function extent and improvement
- hydrocephalus, prevention & reduction

**Lung & kidney function and seizure control**

- "can ride bike now" or "sings more"
- "more seizure-free days"
- "sleeps better or longer"
- "required constant supervision now independent"

**Access**

- prescribed for AMLs?
- prescribed for SEGAs (SGCTs)?
- prescribed but not funded?
- needed but cannot afford?

**Changes in emotional/behavioural issues**

- "gets along with siblings better"
- "calmer in school settings"
- "more sociable with strangers and friends"

**Changes in or prevention of medical risks**

- kidney haemorrhage
- loss of kidney function & dialysis
- organ removal (kidney or lung)
- hydrocephalus & SEGA-associated headaches, nausea, neurocognitive delays & behavioural issues

**Time lost to illness and medical appointments**

- "misses less school/work"

**Additional medical benefits** in other aspects of TSC if applicable

- tumour shrinkage of facial angiofibroma
- seizure reduction
- neurocognitive improvement
- behavioural and emotional improvements
- regained lung function in cases of LAM

**Neurocognitive functions**

- "smiled for first time in decades"
- "can feed self now"
- "can now speak a few words/sentences"
- "improved academic performance"

**Consequences of alternative or no treatment**

- pain: coping mechanisms & effectiveness
- brain or kidney surgery, (initial & repeated)
- dialysis, kidney/lung transplant, few organ donors
- brain shunts & hydrocephalus
- neurocognitive & behavioural setbacks and loss
- facial laser surgery
- anaesthetic risks
- anti-seizure drug effectiveness & side effects
- increasing rates of decline in health and fatality

**Facial tumours**

- "shrinkage of facial angiofibroma"
- "social effects of facial disfigurement"

**Effects on family and community**

- "whole family sleeps through the night now"
- "caregivers missing less work"
- "siblings getting more of my time and attention"
- "relationships improving"

**Other possibilities to mention if applicable**

- stress levels & caregiver health
- consequences for family income
- family & social ripple effects (health & relations)
- lost work/school time & babysitting cost

### IMPORTANT: Afinitor & TSC Stories Requested

#### Calling All Members with Afinitor Experience or Lack of Access to Afinitor

Those of you willing to share your Afinitor stories, or need for Afinitor, or lack of access to Afinitor, including how this has had an impact on your life, please contact [pnolan\\_tsc\\_canada@rogers.com](mailto:pnolan_tsc_canada@rogers.com) as soon as possible.

We need people who are willing to share their stories anonymously, as well as those who are willing to be quoted or perhaps even to speak publicly. Please write and let us know how you would like to be involved.

Thank you for your help.