

3rd Annual Ashton Matheson Golf Classic

The 3rd Annual Ashton Matheson Golf Classic in support of Tuberous Sclerosis Complex through the Alberta Children's Hospital Foundation took place in Calgary, Alberta on August 13, 2012. This charity event was started three years ago by Scott and Shannon Matheson to create awareness, raise money and to never forget their story. Although the initial weather forecast looked bleak, participants were greeted by another day of sunshine and 25+ degree weather as friends and family made their way through the 18 hole Texas Scramble on the greens of Sirocco Golf Club.

In November 2008, Scott and Shannon's second daughter Taylor was born at the Foothills Hospital in Calgary, Alberta. She entered this world over seven weeks pre-mature and weighed only 3 lbs 12 oz. This grand entrance came after courageously overcoming complications caused by a mass surrounding her heart - cardiac rhabdomyoma. Sadly Taylor's twin brother, Ashton Robert, was unable to overcome these same complications and passed away in utero. After what seemed to be an endless journey of doctor visits and ultrasounds, Scott and Shannon heard the words Tuberous Sclerosis for the first time and entered a crash course in genetics, potential side effects of this rare disorder. Ashton and Taylor were then officially diagnosed with TSC; although in the weeks, months and years that passed the masses continually shrunk and eventually disappeared. After dipping as low as 3 lbs 5 oz. Taylor now weighs in at a whopping 35 lbs and is a beautiful relatively symptom free 4 year old girl. She will continue to be monitored for much of her life, but is ready to take the world by storm.

The initial goal of the Ashton Matheson Golf Classic was to host a small, fun and informal tournament for friends and family that will one day grow into a full scale sold-out tournament.



In just three short years, the tournament has donated \$14,736.05 for a dedicated TSC program within the Alberta Children's Hospital Foundation.

A portion of these funds were used to initiate and support a two day Tuberous Sclerosis Symposium at the Alberta Children's Hospital in May 2012. The symposium included educational rounds and lectures by guest speakers Dr. Elizabeth Thiele (Mass General Hospital for Children, Boston, MA) and Dr. Peter Crino (University of Pennsylvania, Philadelphia, PA); as well as a family evening for families affected by this disorder. Nearly 100 people from all over Alberta and even into Manitoba participated in this family evening; many of whom had never met anyone affected by TSC.

THE NEWSLETTER OF TUBEROUS SCLEROSIS CANADA

COMING SOON

TSC Canada
28 McGregor Drive
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www.tscanada.ca

SUMMER 2013



TUBEROUS SCLEROSIS • SCLÉROSE TUBÉREUSE

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From Worst to First:

Transforming the Rare Disease Experience in Canada

CANADIAN ORGANIZATION FOR RARE DISORDERS (CORD)

5th Annual Rare Disease Day Conference 2013
Toronto, Ontario - February 27-28, 2013

Cathy and Kimberly Evanochko attended the Annual Rare Disease Day Conference in Toronto February 27 and 28, 2013. It was a privilege to attend this conference, hear the exciting news about how far the work on the Orphan Drug Regulatory Framework has come, and to provide input and feedback into the proposed framework.

To date, most Canadians with rare disorders generally have worse healthcare than Canadians with more common diseases and worse than rare disease patients in other developed countries. Moreover, treatment in Canada depends on which rare disease a patient has, where the person lives, and how much he/ she is willing to fight. But thanks to the combined efforts of patients, caregivers, healthcare providers, researchers, policy makers, and industry, all of that is beginning to change.

Exciting news out of CORD's 5th Rare Disease Day Conference around the momentum of the Rare Disease Research Program and the announced federal Orphan Drug Regulatory Framework.

CORD has been a fierce advocate for patients who live with rare diseases, and as a result, the regulatory framework is becoming a reality. As the only nation without a regulatory framework in the developed countries, Canada has some catch up to do. Health Canada is determined that they will use the experiences of the USA and the European Union to inform their work so we can truly go "From Worst to First". The hope is that the regulatory framework will be ready to be presented in the next fall or spring sessions of Parliament. Health Canada, in conjunction with CORD, held public consultations in May and June around the proposed framework.



In conjunction with the conference, the CORD Awards Gala was a resounding success. Information about Tuberosclerosis Complex (TSC) was front and centre and Kimberly shared her story and experience with TSC. She gained many fans when she sang a song she wrote about her life journey – Just Watch Me Go.

NOTE: A video of her performance at the CORD Gala will be available on the TS Canada website soon.

There are approximately 7000 rare diseases, so 1 in 12 of us are affected by a rare disease in some way, either as a patient, family member or caregiver of someone with a rare disease. A rare disease is defined as one that affects less than 1 in 2000 people.

Many thanks go to Durhane Wong-Rieger, President of CORD, for her support and assistance in preparing the patient submission regarding Afinitor to the federal Common Drug Review Board. One more step on our journey to having a drug to treat TSC. Thank you so much Durhane!

The goal of the conference was to develop recommendations that:

- Ensure Health Canada's Orphan Drug Regulatory Framework is complete and implemented as soon as possible
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Art for Hope Charity Live Auction

A successful charity live auction, Art for Hope was held at the Dirty Martini in Oakville on September 27, 2012 to raise funds for a TSC clinic at Sick Kids Hospital.

Organized by volunteer Cathy Greco with the generous support of the management of the Dirty Martini, the event featured a live concert by Rude E. Bones and the auction of one-of-a-kind art, including jewellery, donated by local artists. TSC Canada Director Patricia Nolan attended and distributed awareness bracelets and brochures to further promote understanding of the challenges of TSC.



Website Renewal



TSC Canada's website is undergoing changes. Phase I involved updating technical aspects of the site and was completed in time for this year's May Awareness Campaign, bringing more social networking features, such as Twitter and Facebook scrolls, and an events calendar to our home page.

Phase II involves a whole new design, which will bring not only a fresh look but more functionality to the site, including, for the first time, bilingual access and content.

TSCCanadaST would like to thank Richard Kussinger, President of A Light in the Rain Ltd., which is donating the entire website design and upgrades to TSCCanadaST. His Toronto based neuromarketing firm will be working with a graphic design team, who are also donating their work, to update the current TSC Canada ST website.

Thanks also to former TSCan Chair Ron Hutchison and former TSCan Director Joe Chidley, who have volunteered to join the website team. They bring their professional perspective and long personal experience with TSC and will provide feedback on functionality and design from the perspective of TSC needs. Together, our goal is to modernize the website, improve usability, while creating a larger emphasis on the TSC community in Canada.

TSCCanada would like to include all of its members in this process. We would love to hear your suggestions on how our website can best suit your needs, now and into the future.

We also need your help. We need individuals with TSC willing to submit their photos to show people living with TSC in Canada. We need professional translators and content-providers who can finally create a French-language home for TSC on our website. We need volunteers to help manage some of the projects we will soon be able to run from the website. We need digital artists to boost our supply of icons, event posters and logos.

If you have any photos that we could use, suggestions, or would like to help out in any other way, please contact us at TSCCanadaST@gmail.com with the subject line "Website Volunteer" or "Website Photos."



TSC Families - Health Mentors!

TSC FAMILIES SERVE AS HEALTH MENTORS IN NEW UNIVERSITY OF TORONTO MEDICAL SCHOOL OUTREACH PROGRAM

TSCanada's participation in the inaugural 2012-2013 Interprofessional Health Mentor Program at the University of Toronto (UoT) Medical School was a signal success. Thanks must go to the remarkable and patient efforts of Sheri and Rodger Campbell and their son Cole and other TSC volunteers, the enthusiasm of the students enrolled in the program, and the staff who went out of their way to accommodate the extra special needs of individuals with TSC and their families. The program was so successful that the school has requested that TSCanadaST continue to provide Health Mentors for its student training in future years.

UoT's new program is designed to increase awareness among health professionals of the challenges of those living with chronic diseases by pairing small groups of students from 11 health care fields with designated Health Mentors from representative chronic diseases. Three intensive modules were designed to develop the interview skills and compassion of professionals-in-training, in sessions that focussed on the implications of chronic health challenges, the requirements of ethics and professionalism, and patient and client safety. Our TSC Health Mentors, drawn from the TSCanadaST member community, shared their experience and perspectives on living with chronic disease.

TSC Canada Director Patricia Nolan helped to facilitate the selection of the TSC community as a representative disorder for the medical program and organized participation, opening up a key opportunity to expand awareness of living with TSC amongst those in the health care community who are the first points of contact. She also pressed the program's directors to expand their definition of Health Mentor to include caregivers, whose experience, especially across the multiple disciplines common to each TSC patient, is also critical to a fuller understanding of the challenges faced by their patients beyond the doctor's office.

Special words must be given to the generosity and contributions of the Campbell family of Goderich, Ontario, who made the 3-hour trip to Toronto, and back again, sometimes in treacherous winter conditions, fortified by the knowledge of how important it is to share their experience with young medical professionals in training. The student response was warmly appreciative. Cole's contribution and that of his family was acknowledged in a special letter of recognition from Sylvia Langlois, Faculty Lead Curriculum, and Dean Lising, Curriculum Associate, of the Centre for Interprofessional Education, that highlighted their commitment and importance to the developing program.



TSC Canada looks forward to continuing its participation in the coming year. We welcome volunteers to help us train the next generation of medical professionals to better understand the particular challenges of living with TSC.

Contact us this summer at TSCanadaST@gmail.com to become the TSCan Health Mentor for the 2013-14 school year.



How can one person make a difference in TSC doing something they love? Just ask Marjolaine Lortie who dedicated this past year making and selling scarves to friends and family. Each scarf she sold came with a note educating people about TSC as well a picture of her great niece who was diagnosed with TSC at the age of 1.

Not only did Marjolaine raise over \$1200 for TSC but more importantly she raised awareness. Thank you for your hard work and dedication in raising funds and awareness for TSC.

Comment une seule personne peut faire une telle différence dans TSC en faisant quelque chose qu'elle aime. Il suffit de demander à Marjolaine Lortie qui depuis l'an dernier s'est consacré à la fabrication et la vente de foulards à des amis et à la famille. Chaque écharpe qu'elle a vendu était accompagné d'une note pour éduquer les gens sur TSC ainsi qu'une photo de sa petite-nièce qui a été diagnostiqué avec TSC à l'âge de 1an.

Non seulement Marjolaine a réussi à amasser un montant de plus de 1200\$ pour TSC, mais plus important encore, elle a informé les gens sur TSC. Un grand merci pour votre travail acharné et votre dévouement dans la collecte de fonds et la sensibilisation pour TSC.

International TSC Congress

September 6-9, 2012

By: Cathy Evanochko

The sounds of excited voices echoed throughout the cavernous setting for a get-together for families at the International TSC Congress in Naples, Italy hosted by the AST (Associazione Sclerosi Tuberosa).

I was standing in the conference venue; Castel dell'Ovo, a seaside castle built in the 15th century. The history of where I was standing was overwhelming – this building was older than my entire country. I was excited but nervous attending this international meeting where medical professionals would report on their research and experience with the medical challenges of TSC.

I could not understand most of the words behind the rhythmic cadence of the Italian language that was swirling through the rocky chamber, but as I looked around at the faces and the obvious signs of TSC, I knew I was somewhere I belonged.

My daughter Kimberly was diagnosed with TSC in 1986 at 13 months old. I was a provincial rep with a support group in the USA (then NTSA, now TS Alliance) for several years, before being involved in the creation of TSC Canada. I rejoined the board of directors for TSC Canada in 2010.

I had met a few families affected with TSC, but not in the numbers I saw before me. As I wandered through the people hoping to find someone who spoke English, I overheard two young women chatting in English. This is when I met Claudia, who explained that she was 15 years old and had TSC. She said she was learning English in school and wanted to have an opportunity to practice. I was happy to oblige, and she was a valuable translator over the next few days. We talked about the Italian support group, AST, and she described the retreat the families had been on together in a beautiful seaside resort. What fun! Claudia was also very excited about meeting an "American girl", who I later found out was Katie Smith from the TS Alliance and the secretary for TSC International.

On each morning of the conference, we lined up to pick up our translators; headsets attached to a small box that channelled the translation. Most conference sessions were conducted in English, with simultaneous Italian translation for non-English speakers and when Italian was spoken, simultaneous English translation was available through the headsets. The three – day conference was organized in sections containing 4 or 5 presentations by medical professionals, with a presentation by an individual or a family member with TSC at the beginning of each section. This had a powerful impact on the listeners; families and medical professionals alike. I heard several doctors mention how meaningful it was for them to hear the stories from families how TSC impacts their lives.

What was astounding is that these strangers in a foreign land were telling my story too. Although no one's experience with TSC is exactly the same, I heard pieces of my own story told as each family member or individual shared intimate details of their journey with TSC. Here I was, thousands of kilometres from home, listening to people I had never met describe many of my life experiences. I cannot describe how profound this was to me.

The excitement of the medical professionals was contagious. There has been much progress in understanding TSC and promis-

ing research into possible treatments. As I listened to reports on the progress, I could not help but compare this hopefulness to the time when my daughter was diagnosed with TSC and the lack of knowledge and the availability of hopeful treatment. In those days, and in some of the stories I heard the Italian families relate, there was little hope of positive outcomes for individuals with TSC. This international conference demonstrated how we can have great hope and expectations for treatment in the future, with so many brilliant researchers spending their time searching for solutions. How comforting to know of the passionate work occurring on our behalf.

The best news of all was around the collaboration of specialist from all over the world in the development of a "gold standard" for treatment of TSC. Within the next few months, papers will be published that will outline best treatment practices around the various manifestations of TSC. These guidelines will be available worldwide to medical professionals and families alike. With this information available to all, some consistency of treatment standards for TSC patients around the world is finally possible. How exciting!

Before the end of the conference, my new friend Claudia brought her mother over for introductions. "Doctor?" her mother asked. "No", I said, "Mama" pointing at myself. "Oh, Mama" she said, and threw her arms around me for the biggest hug. I did not know what she was saying to me in Italian, and she did not understand much of my English, but we both "spoke" motherhood, TSC, and caring. I truly was where I belonged.

7248 km for Tuberous Sclerosis Complex Solo – BY BIKE!

Tuberous Sclerosis Canada Sclérose Tubéreuse would like to congratulate TSC Rider Melanie Howitt on her extraordinary, world-first achievement in raising awareness for those with tuberous sclerosis complex.



Melanie's Coast2Coast4TSC cross-country biking adventure in the summer of 2012 took her along the Trans-Canada highway all the way from Vancouver on the B.C. Coast of the Pacific Ocean to St. John's, Newfoundland in the Atlantic. She is the first person to have ever attempted, never mind achieved, such a historic cross-country awareness event and fundraiser on behalf of TSC.

TSCCanadaST is immensely grateful for her efforts and hard-won success. Through her website, Melanie directed all donors to the cause via TSCCanada's donation page. TSCCanada fans followed her sometimes hair-raising, sometimes heartwarming adventure through her blog and on the TSCCanada Facebook event page. TSCCanada members proved to be strong supporters who cheered her on, at times offering her places to stay, some vehicle escorts along the way, even laundry, meals and bike repair facilities, and checked daily for her ETA in their hometown. Members of the board of TSCCanada coordinated offers of assistance, media outlets and publicized the event, at one point providing safe vehicular escort for a portion through southern Alberta.

Thank you in particular to fellow TSC Rider Kevin Howitt for accompanying Melanie through the BC route of her journey, and to Cathy Evanochko and Ray Marco (TSC Directors) and their families for providing the safety of support ride-along vehicles through Alberta and as far as Regina, Saskatchewan.

Montreal TSC Clinic holds Family Conference

On May 22, 2013, the Montreal TSC Clinic at CHU Sainte Justine mounted a family conference, "Together for Tuberous Sclerosis Complex" featuring Canadian TSC specialists on epilepsy and neurological, cardiac, renal, pulmonary and dermatological manifestations of TSC.

In attendance was a large audience of both medical professionals and TSC families from across Quebec and Ontario. Organized by Dr. Philippe Major, TSC Clinic Director and his staff, the conference also featured a guest presentation by Italian paediatric neurologist Dr. Paolo Curatolo of Tor Vergata University of Rome, who opened the formal session with an overview of the history of TSC research, a discussion of genetic factors in TSC and a review of its primary manifestations.

The specialist presentations provided a wealth of new information to conference participants, both regarding recent research findings and recommended treatment options.

very early treatment, over a three-month period, complete resolution is possible. While optimal dosage and frequency are not yet established, results suggest that an initial treatment with the much less expensive 0.1% solution, in Aquaphor to eliminate possible irritation, twice a day for two months, is an effective treatment that can be followed by a maintenance schedule of 2-3 times a week.

Dr. Genevieve Benoit reported on renal manifestations of TSC, noting that it is the third most common clinical feature of TSC and affects between 60-80% of patients. It is, she noted, the main cause of TSC-related death for those over 30. The main problem is bleeding, which is rare before age 20. She recommended that invasive intervention should be undertaken with great caution, as it can hasten the progression of the disease. A goal of treatment should be to preserve maximum kidney function for as long as possible, for which mTOR inhibitors have had some success. The prospects for new preventive options earlier in life suggest that paediatric nephrologists will play a larger role in future.



Dr. Philippe Major
Neurologist & Clinic Head



Dr. Paolo Curatolo
Neurologist (Italy)



Dr. Louis Crevier
Neurosurgeon



Dr. Nagib Dahdah
Cardiologist



Dr. Genevieve Benoit
Nephrologist



Dr. Arnold Kristof
Pulmonologist



Dr. Catherine McCuaig
Dermatologist

Dr. Major reported on treatments for epilepsy, including the particular effectiveness of Vigabatrin for TSC-linked epilepsy, given that it has also been shown to work on the mTOR pathway, as well as vagus nerve stimulation options and the highly effective ketogenic diet.

Dr. Louis Crevier discussed surgical options for drug-resistant epilepsy, recommending early surgery in such cases of unifocal epilepsy, and discussed the potential of mTOR inhibitors such as Afinitor or rapamycin in treating TSC epilepsy.

Paediatric cardiologist Dr. Nagib Dahdah noted that 95-100% of cardiac rhabdomyomas (RHM) are diagnostic of TSC. While regressing after infancy, RHMs can recrudescence during puberty, more frequently in girls, and can cause arrhythmias and other problems.

Dr. Arnold Kristof discussed the pulmonary manifestations of TSC, noting that lymphangiomyomatosis (LAM) affects over 30% of TSC patients, almost exclusively women. Treatment with mTOR inhibitors has had some success but is not ideal and in most cases, the main treatment option continues to be lung transplantation. New drug therapies being explored include chloroquine, doxycycline and simvastatin.

Dr. Catherine McCuaig provided a comprehensive description of the various dermatological manifestations of TSC and reported on recent findings regarding the use of topical rapamycin, an mTOR inhibitor. She noted that treatment with a solution of 0.1% over a 2-month period has shown marked improvement, and in cases of

Following the specialist presentations and a Q&A session with families, TSC Canada Director Patricia Nolan ended with an appreciation of the signal contribution of Dr. Major in returning to Canada, after training with leading TSC specialists in the United States, to establish Canada's first TSC Clinic in Montreal. The impressive array of expertise at the conference itself is a tribute to Dr. Major's success at multidisciplinary clinic-building and a big step forward in the provision of comprehensive care for TSC patients in Canada. After describing the great success of the our members' 2013 May Awareness Campaign, and highlighting key research and clinical fellowships recently funded by TSC Canada, Ms. Nolan invited conference participants to join with TSC Canada in promoting awareness and in mobilizing community support and funding for future research.

For conference participants, the meeting provided a rare and extraordinarily valuable chance to meet the dedicated community of TSC medical specialists in Montreal and to learn of the encouraging advances in research and treatment. It was also a chance to meet with others in the TSC community and share their experience and hope. Kudos to the Montreal TSC Clinic, to Dr. Major and his staff and to the doctors and researchers who took time out of their busy schedules to share their expertise with the TSC community.



TSC International Meeting

September 8, 2012 - Napoli, Italy

As membership in TSC International (TSCi), a worldwide association of TSC organizations, continues to grow, over three dozen representatives from Europe, North America, Africa, Asia and the South Pacific gathered in Naples on September 8, 2012, to review progress since the 2011 TSCi meeting in Washington, D.C. and to chart future directions and priorities in the coming year.

Principal achievements of individual organizations and of the association as a whole were reviewed. The decision at the 2011 TSCi meeting to establish May 15, 2012 as the first TSC Global Awareness day was lauded as hugely successful, as was the 31 Daily Facts Campaign linked to TSC Awareness Month.



The 2012 meeting noted, as a major achievement, the substantial progress of the TSC worldwide community in developing a 'Gold Standard' of medical care for TSC to disseminate to physicians worldwide. This had been the top priority established at the 2011 TSCi Washington meeting, its urgent need pressed upon the global TSC experts gathered then, resulting in the successful 2012 Clinical Consensus Conference. As a consequence of the work of over 60 health care professionals, including Canada's Dr. Ute Bartels (Neuro-Oncology, Hospital for Sick Children in Toronto), not only have the TSC Diagnostic Consensus Guidelines been updated for the first time since 1998, the world's first Treatment Consensus Guidelines were established. They await imminent publication for release to clinicians and their patients worldwide.

The 2012 TSCi meeting concluded with an effort to establish priorities for the upcoming year. A call for volunteers for a TSCi Working Committee elicited commitments from Poland, Portugal, Australia, US, Canada and Columbia. Portugal and Canada are collaborating on producing "take-aways" such as a TSCi business card and brochure for distribution at global medical conferences.

Discussion of the upcoming 2nd International Global Awareness Day led to a consensus on the need to generate a new campaign to add to the 31 Daily Facts initiative of the previous year. The focus chosen for 2013 TSC Global Day was a focus on positive achievements in TSC, on the new medical guidelines, should they be ready for publication by then, and more children's stories and photos. Delegates also proposed that future awareness campaigns be linked to slogans each year and include an increased emphasis on fund-raising. One suggestion for a future slogan that was well received was "Leading a Positive Life with TSC." Other suggestions called for the more effective use of social media to reach the largest possible audience.

The next meeting of TSCi will be held this coming June in Washington, D.C. One of the primary topics on the agenda is identifying the means of implementing, as appropriate to each member country, the new TSC Treatment Consensus Guidelines, whose publication is expected soon.

Watch our website and Facebook pages for this announcement.

New Adult TSC Clinic Opens in Toronto

TSC Canada is delighted to announce that Canada's first multidisciplinary adult TSC clinic has opened at Toronto General Hospital under the direction of nephrologist and TSCCanadaST medical advisor Dr. York Pei.

Dr. Pei is a Professor of Medicine at the University of Toronto and a Staff Nephrologist at the Toronto General Hospital, University Health Network, where he currently directs the Hereditary Kidney Disease (HKD) Clinic. Dr. Pei is the site Principal Investigator for a randomized controlled trial of mTOR inhibitor in tuberous sclerosis complex. He is a member of the Scientific Advisory Committee for the Kidney Foundation of Canada and Polycystic Kidney Disease Foundation, USA.

The TSC Clinic will operate out of the premises of the existing HKD Clinic, on the 12th floor of the Norman Urquhart Wing. A temporary website has been set up at the address below. TSC-specific pages will be added to the clinic link at a later date.

Thanks to a Clinical HKD Fellowship co-funded by TSCCanadaST and PKD Foundation, nephrologist Dr. Moumita Barua will be joining Dr. Pei and the clinic team this summer, where she will see both PKD and TSC patients and conduct research into the nephrological manifestations of both disorders.

Temporary HKD (TSC) Clinic website:
http://temp.uhn.ca/MCC/PatientsFamilies/Clinics_Tests/Hereditary_Kidney_Disease/



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TSC Landscape Profiled

at TSCanadaST Patient and Family Forum

On June 26, 2012, Dr. Darcy Krueger, a leading specialist on epilepsy and neurological manifestations of TSC, addressed a large audience of TSCanadaST members on the subject TSC Landscape: Where We've Been, Where We're Going, followed by an audience Q&A session. TSCanadaST sponsored the breakfast social and members' forum, with the generous support of the International Society for Paediatric Neuro-Oncology (ISPNO).



Dr. Krueger outlined progress to date and future issues facing the TSC community, including updates on his own research in various clinical trials, especially the current clinical trial of Afinitor for epilepsy, of which he is head, and his experience at the TSC clinic in Cincinnati, a model for TSC patient care and advances in research.

Fresh from organizing and participating in the international TSC Clinical Consensus Conference, which was held in Washington just 10 days prior to his Toronto appearance, Dr. Krueger also reported to TSC Canada ST members on its most significant developments. These included the first update to the TSC diagnostic criteria since 1998, and the first international treatment consensus for TSC.

TSCanadaST would like to thank Dr. Krueger for the generous donation of his time and for his thoughtful presentation and sensitive engagement with our member families.

Dr. Krueger has provided TSCanadaST with a copy of his published article "Current Management of Tuberous Sclerosis Complex." If you would like a copy, please contact us by email at TS-CanadaST@gmail.com



Personal story submitted by Elise Bridges from Vancouver, B.C.

Hello, my name is Elise Bridges. I have TSC - Tuberous Sclerosis Complex.

I was 6 months old when I started having seizures. I had epilepsy brain surgery on April 11, 2000 and I'm still seizure free. I have been off anti convulsants since May 10, 2012. I know that if I start to have seizures I will need to go back on anti convulsants.

Learning disabilities, skin lesions and kidney involvement started May 26, 1996. I have five tumours on my right side and six tumours on my left side. Unfortunately, the rest of my kidneys are covered in cysts.

The left side kidney problem was for seven years. Since Sept. 20, 2003 it's both sides. I had to get the government to get me an electric wheelchair because of my kidney pain. I got it on March 18, 2003. I used to use my wheelchair when I go outside, but since Aug. 20, 2010 I now use my wheelchair inside my house and outside, too. I'm always in pain.

I used to use the Fentanyl Pain Patches from Nov. 15, 2000. I used to be okay, but since Aug. 20, 2010 I had to stop using those because they changed the way they're made. Now I'm lucky if I get anywhere from 18 hr. to 30 hrs. sleep per week because of my pain. There are a lot of times all I do is bleed. It's so red I don't see the color of the water at all.

My lungs have been affected with TSC. There are times that all I do is cough, cough, cough, not being able to breathe. My doctors call that cylindrical bronchiectasis and there are times I need to use my nebulizer machine.

I had to get all my teeth out because I just kept getting gum infections and the doctors said that's why my kidney function kept going down.

I would like people to contact me. My phone number is 604.731.3686 My address is: 309-2060 West 10th Ave., Vancouver, B.C. V6J 2B3

TSC Global Awareness Day

May 15



May Awareness Month and Global TSC Day

For over twenty years the month of May has been TSC Awareness Month in Canada. Tuberosus Sclerosis Canada Sclérose Tubéreuse and its members were busy all month with events that took the message of hope in research and awareness of the needs of people with TSC further than ever before.



In addition this year, May 15 was the 2nd Global TSC Day. TSC organizations around the world worked together to extend the reach of the TSC message throughout as many countries as possible.

For the first time, two major cities in Canada helped us get the word out. In Toronto, the CN Tower lit up TSC BLUE! and declared the day on its website, with live coverage on its webcam. In Calgary, the Langevin Bridge also lit up TSC BLUE! and introduced TSC on its website. Mayor Norm Boucher proclaimed May 15 official Global TSC Day in Medicine Hat, Alberta.

Companies such as Search Engine People, and entire neighbourhoods and schools in Ontario joined our Be a Hero-Wear Blue for TSC campaign. In Georgetown, Silver Creek Public School campaigned with blue ribbons and posters all month. In Ajax, over 80 neighbours living on and near Bolland Crescent bought up every blue light bulb and put on a show each night. Alexander Graham Bell Public School and Duffin's Bay Public School students wore blue for May 15. Meanwhile, on a ranch in Alberta, a cattle branding gathering of over 60 people was an opportunity to hold a TSC themed awareness event and fundraiser on May 17.



Media also helped us to raise awareness as never before: breakfast television coverage interviewed TSCCanadaST Directors in Ottawa and Calgary on May 15. A radio station in Windsor, Ontario, interviewed a former TSCCanadaST Chair on May 16. Local papers in Georgetown and Ajax reported extensively on the campaign events and on TSC.

On May 22, Canada's first TSC Clinic in Montreal hosted a TSC Family Conference, with TSC specialists from Canada and around the world.

On May 25, TSC families in the GTA region gathered for an informative TSC BBQ in Etobicoke, Ontario, while a family in Smithers, BC held a TSC fundraiser.

TSC individuals from Canada and around the world came together, with joy and pride, in the first TSC Global Photo Album as part of TSC International's Global Day campaign, "Where in the World is TSC?"



TSCCanadaST continues to receive photographs of these amazing events from the month of May and will post them for all to see. Drop by often and plan to stay in touch with our future events and activities on our website pages, on our Facebook fan page, and follow us on Twitter. Contribute to TSC research and community support when you donate to the cause, and most important of all, join us at Tuberosus Sclerosis Canada Sclérose Tubéreuse. Together we are making a difference. The TSC message is being heard, across Canada and the world, all year round!

Thank you to all of our members for a wonderful May Awareness Month and Global TSC Day.



Canadian Doctors Attend International TSC Meeting in Naples

Canada was well represented among the world's medical TSC experts attending the International Symposium on Tuberous Sclerosis Conference in Naples, Italy in September 2013.

Among the Canadian specialists attending the conference were:



Dr. Alan So, Associate Professor of Uro-Oncology at the University of British Columbia in Vancouver

Dr. Ute Bartels, Neuro-oncologist at the Hospital for Sick Children in Toronto and a member of the TSC Canada Medical Advisory Board

Dr. Luis E. Bello-Espinosa, Specialist in Paediatric Epilepsy and Child Neurology at Alberta Children's Hospital in Calgary.



3rd Annual Waverly Golf Tournament

Jamie and Angel Neill are the parents of seven-year-old Waverly Neill who has tuberous sclerosis complex. Waverly was diagnosed with TSC at the age of 3 months; she was having seizures.

Jamie and Angel wanted to do something for TSC so they started "The Waverly Open," a golf tournament that has been successfully raising funds for TSC for two years, benefitting TS-CanadaST, Sick Kids Hospital and The Children's Wish Foundation.

This year is "The 3rd Annual Waverly Open" on Thursday September 5th at Sleepy Hollow in Stouffville, Ontario. Registration starts at 11am. The package includes golf with cart, BBQ lunch and dinner. Former NHLer hockey player Troy Crowder has supported TSC at the past two golf tournaments. Please come out and support TSC.

For more information please see the TSC Canada website events calendar.



Thank you to all our Volunteers!

Don Evanochko,
Kimberly Evanochko
Andrew Duffy
Sheri, Rodger and Cole Campbell
Deanna Soules
Cathy Greco
Ellen van Steenburgh and Ross Doughty
Angel & Jamie Neill
Taryn Stone
Katrina Evanochko
Genevieve Dupont
Joe Chidley
Ron and Nicole Hutchison
Lee-Ann Longlade Poff
Ian Spaa
Linda Chartier
Scott Matheson

Special Thanks to Colleen and Connie for their assistance with our Calgary events, and our Medical Advisors

Clinical Care for Adults with TSC Expands in Canada

TSC Canada is proud to announce the appointment of Dr. Moumita Barua as the inaugural recipient of a one-year fellowship in Hereditary Kidney Disease at the University Health Network.



After four years of post-doctoral work in Boston on the genetics of kidney disease at the Beth Israel Deaconess Hospital and Harvard University, Dr. Barua, a graduate in internal medicine and nephrology from the University of Toronto Medical School, returns to Toronto where she will broaden her research interests with a focus on tuberous sclerosis complex.

Dr. Barua will work closely with Dr. York Pei, a distinguished specialist in hereditary kidney disease, at the new Adult TSC Clinic located on the premises of the Hereditary Kidney Disease Clinic on the 12th floor of Toronto General Hospital. She will develop strong clinical expertise in both diagnostics and therapeutics of hereditary kidney disease, with a major focus on ADPKD and TSC renal manifestation. Dr. Barua will also acquire translational research methodological expertise in both diseases and contribute to ongoing research at the clinic.

The primary goal of the fellowship is to strengthen Canadian capacity to provide expert clinical care and undertake research for TSC and PKD. TSCCanadaST and PKD Canada, in a mutually supportive initiative that is an innovative first for both organizations, have provided fellowship funding equally.

TSCCanadaST would like to thank PKD Foundation, Dr. York Pei, and the volunteers and directors from TSCCanadaST who worked hard over the last few years to make this project a reality, thus expanding adult nephrology care and research into both disorders at once.

Welcome back to Canada, Dr. Barua!



Volunteers Don Evanochko and Connie Randal share information and raise awareness at Alberta Children's Hospital. Global TSC Awareness Day 2013

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: _____

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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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