

# Connections

The Newsletter of Tuberous Sclerosis Canada

## Two stay-at-home dads share their experiences

Paul Archer and Aldoria Caissie have a few things in common. Each has a child with a disability, and each is committed to offering his child a good quality of life. As a result, both Paul and Aldoria have left the workforce to stay at home full-time while their spouses head to the office.

Paul, a resident of Peterborough, ON, and his wife, Elaine Scharfe, knew they wanted one parent to stay home with their son, Ben, who has Down syndrome. They decided that Paul would be the one to take on that task since Elaine, a professor at Trent University, “has a much higher income than I ever will,” according to Paul.

The decision for Aldoria, a resident of Moncton, NB, to stay at home came about more by chance. About four years ago, Aldoria arrived home from a conference to hear his wife’s



Paul and Ben

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announcement, “OK, now you’re staying home.”

While Aldoria had been away, Zachary had had a seizure and his head had gotten stuck between the toilet bowl and the bathtub.

“[My wife] got scared,” recalls Aldoria. “She couldn’t get him out.” Zachary, already a big boy, required a lot of

physical strength to handle. The Caissies decided it would be better if Aldoria took over for his wife, Patricia, who had been parenting at home full-time until then.

In the three-plus years that he has been a stay-at-home parent, finding adequate support of varying kinds has not been  
*see Connecting with, pg 6*

## Homeopathy helps maximize potential in people with autism

Dr. Wei-Wei Han has had two patients who live with the effects of Tuberous Sclerosis Complex, one, a young boy, the other, a young man, both of whom experience issues of anxiety related to autism. Both patients have experienced improvement in their symptoms as a result of homeopathic therapy, says Han.

“The seven-year-old boy has a lot of rage associated with autism,” she explains in a telephone interview from her office in Toronto, Ont. “I followed him for about four months and he was doing very well on homeopathic remedies, but I lost contact with the family because of family issues.”

“The other young man experiences much less anxiety now,”

says Han. “I see remission of progression of the TS itself. You don’t see new tumour growth. Much less medication is needed. The relief for the parents is the biggest thing. He was delayed, but now has better physical and mental development.”

Han says that with homeopathic intervention, the potential people have can be maximized. “But it takes a loving, caring and committed parent who can give a good description of their child,” she says. “To have effective treatment, it would be a great help if parents are good observers.”

Anxiety can manifest itself in different ways in people who live with the effects of autism. “It can be anything from panic attacks to running and



Wei-Wei Han

throwing and breaking things, temper tantrums, or rage when becoming frightened. Or you can see obsessive compulsive behaviours, or agoraphobia where people won’t go out. It affects people in very individual ways.”

*see Good observation, pg 4*

TS Canada Newsletter  
581 Chamberlain St.  
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May 2007

Sharing innovative ideas with our families and those who support them

### Current issue is about innovation

The theme of this issue of *Connections* is “Innovation.”

When people meet, one of their most popular greetings is, “What’s new?” This issue focuses on things that are new.

Often, in the Tuberous Sclerosis community, we tend to focus on what’s new in research. Of course, research will always be of interest to the families whose lives are affected by TSC, and in this issue you will read about two studies currently underway that relate to TSC.

However, we must not forget about the other facets of a person’s life. In this issue, you will also read about an innovative program that makes it possible for young people who live with disabilities to attend integrated summer camps. You will also find out about an innovative intervention for people who live with autism, as well as an alternative school whose services may benefit people who live with the effects of TSC. And you will also read an article about the benefits of homeopathy.

Family testimonials are always an important part of *Connections*. In this issue, there are four stories that focus on innovative solutions that family members have found to various challenges.

You may have your own innovation story to tell, and we’d love to hear it. By telling your story, as the people in this issue have done, you will be helping others, and you will be raising awareness of the impact that Tuberous Sclerosis has on people’s lives.

The *Connections* team encourages you to share your story – even if you don’t think you have a story to tell, we encourage you to contact us. Sometimes it’s only during a brief discussion that your real story emerges. And our fervent belief is that every single person affected by TSC has a story that could help someone else.

The theme of the September issue of *Connections* will be “How’d They Do That?” We will be delving into how people make things happen on behalf of TS Canada.

Our goal is to take the mystery out of the various things active members do or would like to do for the organization. Our hope is that we will motivate and engage others in supporting the activities of TS Canada. Some suggestions might be: How do you go about getting payroll deductions made to TS Canada? How do you plan a conference or a workshop or an information session to raise awareness of TSC? How do you organize a fundraiser? How do you get TSC in the media? How do you get peer-to-peer support when people are spread coast to coast to coast?

We hope to speak with as many TS Canada members as possible who are doing things, large and small, to benefit families affected by TSC.

We invite you to contact us through our Web site at [www.tscanada.ca](http://www.tscanada.ca), or contact *Connections*’ managing editor directly by email at [linda.viscardis@sympatico.ca](mailto:linda.viscardis@sympatico.ca). You may also call Linda Viscardis directly at 705-742-4126.

### Connections shares story with UK

Tuberous Sclerosis Association UK has requested permission to reprint a Tuberous Sclerosis Canada article in their publication, *Scan*. The piece appeared in the September 2006 issue of *Connections*.

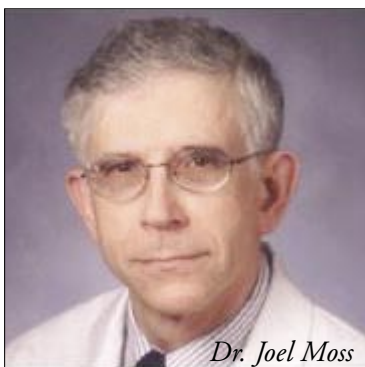
The item about Taryn Stone, entitled “A transition support group would have eased shift to adulthood, says cargo officer,” will appear in the next Spring issue of *Scan* and online at [www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org).

The request came from Corinne Swainger, who is a trustee of TSA-UK, where she helps to organize activities for adults who live with TSC.

*see Taryn Stone, pg 4*

## U.S. medical team studies skin tumours in Tuberous Sclerosis

A medical team from Bethesda, Maryland is conducting a study of skin tumours in Tuberous Sclerosis Complex (TSC). The study's objective entails "looking at what may cause skin tumours as a way of developing better therapies," says Dr. Joel Moss, pulmonary physician at the National Heart, Lung and Blood Institute, in a telephone interview.



Dr. Joel Moss

Specifically, the purpose of the study is to identify the genetically altered cells in skin lesions and to measure factors produced by these cells that induce the growth of tumours.

Moss's co-investigators, Dr. Thomas Darling, a dermatologist, and Dr. Shaowei Li, both at the Uniformed Services University of the Health Sciences, have isolated cells from skin tumours that have mutations in the TSC2 gene in several patients.

Darling, Li and Moss are now studying the effects of a drug called Rapamycin on the growth of those cells. Moss's work focuses on the lung manifestations of the disease called lymphangioleiomyomatosis (LAM) and, in the future, effects of the drug on lung manifestations. Since people with TSC are more likely to have lung lesions, some of his patients also participate in the skin tumour study, which Darling oversees.

Participants in the study undergo a biopsy of up to eight skin lesions. The tissue samples are used for examination of genetic changes and measurement of proteins that may regulate cell growth or behaviour. Tumor cells are also cultured out of the skin samples and the effects of drugs on their growth are investigated.

In-lab tests have shown that Rapamycin does inhibit growth of these cells, according to Moss. However, Darling points out that the tests conducted to date have revealed that Rapamycin "doesn't specifically kill just the tumor cells."

"That means we may need to search for better drugs or drug combinations," he says in a telephone interview.

Li, in studies supported by the Tuberous Sclerosis Alliance, is conducting in-lab research on the effects of Rapamycin in combination with various other drugs to inhibit the growth of skin tumour cells.

While these laboratory investigations are in progress, clinical trials are ongoing to investigate the effects of Rapamycin in patients with TSC and LAM.

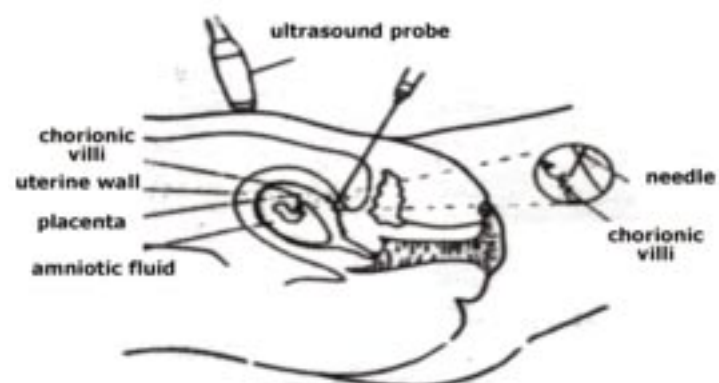
The clinical study is expected to take about three years. Participants are still being recruited for study of lung and skin lesions and may come from Canada, according to Darling and Moss. They must be over 18.

For more information, call 301-496-3632.

## Chorionic villus sampling

Chorionic villus sampling (CVS) is an alternative to amniocentesis for prenatal diagnosis. CVS is a prenatal testing procedure offered in certain pregnancies for determination of the karyotype of the fetus. The chorionic villi are part of the placenta. CVS involves removing a small sample of the placenta with a thin needle which is inserted through a woman's abdomen or with a catheter which is inserted through the vagina and cervix. The location of the placenta sometimes dictates which method is used. The procedure is carried out under the guidance of ultrasound. In most pregnancies the chromosomal content detected in the placenta is an accurate representation of the chromosomes in the fetus. CVS is performed at 10-12 weeks gestation.

There is a one to two per cent risk of miscarriage, above the background risk, associated with the procedure. That is, 1/100-1/50 women will lose the pregnancy following this procedure due to complications of the procedure. There is a potential risk of limb reduction defects associated with CVS of approximately 1 in 1000.



## New therapy tested on brain tumours

A team at the Cincinnati Children's Hospital Medical Center is conducting a study of the safety and potential side effects of an experimental drug on a person with Tuberous Sclerosis Complex (TSC) who has also been diagnosed with a brain tumour or an astrocytoma.

Five to 20 per cent of people with TSC will develop an astrocytoma, a slowly progressive brain tumour, according to a synopsis about the study.

"The tumours grow and cause damage to surrounding tissue, blockage of spinal fluid, blindness, trouble walking, seizures and brain damage," the synopsis states. If left untreated, the tumour can be fatal.

Standard treatment involves surgery to remove the brain tumour.



Jenny Leonard R.N., C.F.R.P.

"However, surgery may itself cause brain damage, bleeding, or infection, as well as other complications," the synopsis asserts.

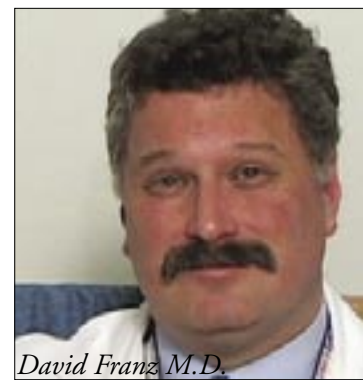
The drug being tested in this study is called Everolimus, and it has been shown to suppress the chemicals that cause tumours to grow in TSC.

The hypothesis is that the drug will cause the tumour size to decrease and may have beneficial activity separate from effects on tumours in patients.

Participants are still being recruited for the study. There are no limitations regarding citizenship as far as participation is concerned, says Jenny Leonard, certified family nurse practitioner, at the Cincinnati hospital. "If Canadians are interested, they can contact us regarding possible participation," she says in a telephone interview.

To date, four people have enrolled in the study. The goal is to recruit about 20 participants, says Leonard.

The study, called Everolimus Therapy of Giant Cell Astrocytoma in Patients with Tuberous Sclerosis Complex, is a six-month trial with two main outcomes being mea-



David Franz M.D.

sured. First, the incidence of reported and observed side effects will be analyzed as a percentage of the patients enrolled in the study and treated with Everolimus.

Second, the overall reduction in tumour volume, neuropsychological testing, and change in cognitive function will be analyzed after five subjects have completed six months on the study. David N. Franz, M.D., is the principal investigator for the study.

Leonard notes that at the time of the interview with *Connections*, enrolled participants had completed one month of the trial. She could not speak to any outcomes at that point.

For more information about the study, call 513-636-4222.

## CVS testing provides peace of mind to prospective parents

"He's the best negative thing that's ever happened to me," says Corinne Swainger about her son Cameron, age 5.

Thanks to chorionic villus sampling (CVS), Corinne and her husband Jonathan, of Pinner, North West London, UK, knew before he was born that their baby did not have TSC.

Growing up, Corinne had no idea she would one day be part of the TS community. It was not until 1993, at age 27, when the couple were planning to get married, that Corinne was told that she might have TSC, although it was difficult at that time to determine which mutation she had. No one else in her

family is affected by TSC.

After getting married in 1995, the couple decided they wanted children, but "we knew we had a 50 per cent chance of having an affected child," says Corinne. They knew they would have to undergo testing to determine the specific mutation and implications for having children.

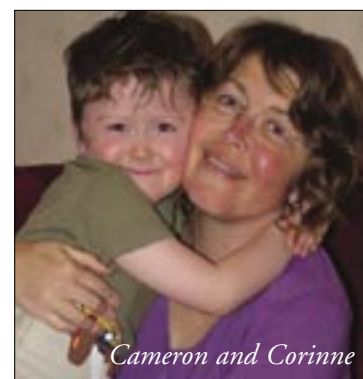
In 1998, Corinne sent samples of her blood to the TS genetics clinics in Cambridge, England and Cardiff, Wales, and then waited for them to identify her TS mutation.

"At that time, there was about a 70 per cent chance of success for finding mine," she says. "Fortunately, after two years of waiting, the clinics identified my mutation."

Knowing the mutation meant that, in 2001, Corinne and Jonathan could consider getting pregnant using CVS testing.

"In CVS, DNA is removed from the placenta at about 12 weeks gestation and examined to determine if the affected parent's TS 'fault' is also present in the fetus," explains Corinne.

Corinne and her husband nervously proceeded with



Cameron and Corinne

the procedure despite the complication of her being a transplant patient. "I've had three kidney transplants since 1986," says Corinne.

The CVS test results came back five days later – the results were negative. The baby did not have TSC. The pregnancy went well and Cameron Swainger was born in 2001, with no health problems.

"I doubt I would have attempted to have Cameron if the TS genetics test hadn't been available," says Corinne. "It is largely thanks to the support of the Tuberous Sclerosis Association [UK] in funding the genetics research and the specialist genetics clinics, as well as their ongoing support, that it was all possible."



Cameron and Jonathan

# Pediatric neurologist speaks to recent PET scanning developments

A newer brain imaging technique is being used in Detroit to identify the specific area of the brain where seizures begin. The tool, a-[11C]methyl-L-tryptophan (AMT) Positron Emission Tomography (PET), was first developed at the Montreal Neurological Institute to measure serotonin synthesis in patients with depression.

Dr. Harry Chugani, chief of pediatric neurology, as well as director of the Positron Emission Tomography (PET) Center at the Children's Hospital of Michigan, Wayne State University in Detroit, used it for his patients with epilepsy.

"We found that it shows increased activity in the seizure focus," says Chugani in a telephone interview. "Even when the patient is not having a seizure, you can still see an increase in uptake in the seizure focus."

Noting these results, Chugani decided to test "what would happen if you looked at a patient with Tuberous Sclerosis Complex, whether only the epileptic tuber would show the uptake and the other tubers would not." Subsequent study revealed this to be true.

"So AMT PET actually enables us to pick out the offending tuber, the epileptic tuber, amidst a multitude of tubers," says Chugani, adding that from that point of view, the AMT PET is very tactical for searching for the epileptic focus of the patient who is

being evaluated for surgery.

Chugani notes that the specificity of the AMT PET is 100 per cent, in that, once the area which suggests the epileptic focus is identified, it will always be the epileptic focus. However, the sensitivity of the tool is about 65 to 70 per cent.

"We are finding heterogeneity so that 65 to 70 per cent of patients have this mechanism that the PET scan picks up but the other ones don't."

Chugani says that various processes lead to epilepsy, even in TSC.

"We are now attempting to figure out why the sensitivity is only 65 to 70 per cent effective," he says. "What kind of PET scans do we have to do to pick up the other 30 per cent who are negative on the AMT [but] who continue to have seizures?"

"This is exciting research, to find out what tests we need to do to reach 100 per cent so that more patients can be helped," he says.

The AMT PET is primarily used for pre-surgical evaluation of patients who have difficult-to-control seizures. The PET Center at Children's Hospital of Michigan is widely renowned, with patients coming from across the United States, Canada and now Norway as well. According to Chugani's information, the Montreal Neurological Institute also now performs

AMT PET scans on patients with seizures, the only institution to do so in Canada.

Aside from its use as a pre-surgical evaluation tool, the AMT PET has led to some surprising and interesting findings, says Chugani.

For instance, it has revealed metabolic pathways in the brain, known as Kynurenine pathways, which lead to the formation of chemicals in the brain that are very toxic and that cause the seizures that play an important role in TSC. These pathways are not normally used much, but they are capable of being turned on and, for whatever reason, perhaps genetics, says Chugani, they became activated and make these toxic chemicals.

This finding has "taught us a lot about the mechanisms of epilepsy in TSC," says Chugani, adding that it was a surprise to all researchers.

A potential result of this revelation could be a new way of trying to control seizures, he says. Eventually a new anti-convulsant may be developed, specifically for those with TSC.

Dr. Chugani's research has been in the area of cerebral metabolism in brain development, epilepsy surgery, and brain plasticity. He uses PET techniques in children, and is also involved in basic research in which reorganization following lesions is studied using a variety of methods.

## Valerie MacLean gets a HANDLE® on Behaviour



Valerie MacLean

"Behaviour is a means of communicating what cannot be adequately expressed in words," says Valerie MacLean. "My work is about being a detective, to figure out what behaviour is trying to express."

MacLean is a neurodevelopmental educational therapist and Director/Principal of the Phoenix Alternative Learning Centre, located in Peterborough, Ont. She provides a learning environment to students within her school as well as providing service to clients through her HANDLE @ Home Programs. MacLean is one of two Certified HANDLE @ Screeners in Canada, and is now interning with Judith Bluestone, an international award-winning educator and author, and the founder of The HANDLE® Institute. MacLean is driven towards her goals to be Canada's first Certified HANDLE @ Practitioner, and a HANDLE @ Trainer.

HANDLE® is an acronym for "Holistic Approach to Neuro-Development and Learning Efficiency." The HANDLE Institute is an organization that provides an effective non-drug evaluation and treatment program for individuals with neurodevelopmental disorders, and provides training in the HANDLE @ approach. Judith Bluestone developed her approach based on 11 years of academic study and over 40 years of professional practice, according to her website, [www.handle.org](http://www.handle.org).

Although new to Canada, HANDLE @ is known worldwide. MacLean explains: "Clients have been served by HANDLE @ Providers in countries around the globe for 40 years. The organization has grown, and currently there are trained HANDLE @ Affiliates providing services in the USA, England, Ireland, Wales, Scotland, Hong Kong, Singapore, Switzerland, South

see HANDLE's, pg 6

## Is brain surgery an option?

It has been almost two years now since the Zeppieris started the process of determining whether Michael Zeppieri, 17, is a good candidate for brain surgery.

When Michael, who lives with his parents in Peterborough, Ont., began having more intense and frequent seizures several years ago, the neurosurgeon who had been monitoring him since he was nine years old suggested brain surgery.

It has been "quite a process" since then to determine whether surgery can actually be done, says Lynn Zeppieri, Michael's mother.

His history was first brought to an epilepsy conference team for their input. When they decided that his case was worth looking into, he was scheduled for an examination at the epilepsy monitoring unit at the Hospital for Sick Children in Toronto.

His medications were reduced before the examination, resulting in increased seizure activity. Physicians then tried to determine exactly where the seizures originated in the brain.

The assessment revealed that the seizures appear to be coming from two tumors related to Tuberous Sclerosis Complex, says Lynn.

Upon presentation to the epilepsy team, it was decided that the tumors could potentially be removed without affecting any of Michael's skills.

"So at this point, it's a go," says Lynn. "Everything has come back favourably to say he's a good candidate for the surgery."

While a date has not been set, the surgery is expected to be performed in late spring or early summer.

Lynn points out, however, that up until the very week of the surgery, the family will not know 100 per cent whether the tumors will actually be

removed or not.

The surgery is a two-step process. On the first day a grid with electrodes will be inserted on Michael's brain. "This will give an actual map of how to get to the base of where the seizures are coming from," says Lynn.

A conference with the medical team and the Zeppieri family will take place within a day or two of that first step. Together they will make the final decision on whether the tumors can be effectively and safely removed. If it is determined that there is too great a risk, then only the grid will be removed. Otherwise, the surgery will proceed, followed by a week in hospital for recovery and several more weeks for full rehabilitation.

Lynn says the family is prepared for either scenario—but, of course, hope that the surgery can be carried out and Michael's seizures can be eliminated.

### Revised (1998) Diagnostic Criteria for Tuberous Sclerosis Complex

Major Features:

1. Facial angiofibromas or forehead plaque
2. Non-traumatic unguis or periungual fibroma
3. Hypomelanotic macules (more than 3)
4. Shagreen patch (connective tissue nevus)
5. Multiple retinal nodular hamartomas
6. Cortical tuber<sup>a</sup>
7. Subependymal nodule
8. Subependymal giant cell astrocytoma
9. Cardiac rhabdomyoma, single or multiple
10. Lymphangiomyomatosis<sup>b</sup>
11. Renal angiomyolipoma<sup>b</sup>

Minor Features:

1. Multiple randomly distributed pits in dental enamel
2. Hamartomatous rectal polyps<sup>c</sup>
3. Bone cysts<sup>d</sup>
4. Cerebral white matter migration lines<sup>a,d,e</sup>
5. Gingival fibromas
6. Non-renal hamartoma<sup>c</sup>
7. Retinal achromic patch
8. "Confetti" skin lesions
9. Multiple renal cysts<sup>c</sup>

Definite TSC: Either 2 major features or 1 major feature with 2 minor features

Probable TSC: One major feature and one minor feature

Possible TSC: Either 1 major feature or 2 or more minor features

<sup>a</sup> When cerebral cortical dysplasia and cerebral white matter migration tracts occur together, they should be counted as one rather than two features of TSC.

<sup>b</sup> When both lymphangiomyomatosis and renal angiomyolipomas are present, other features of TSC should be present before a definitive diagnosis is assigned.

<sup>c</sup> Histologic confirmation is suggested.

<sup>d</sup> Radiographic confirmation is sufficient.

<sup>e</sup> One panel member recommended three or more radial migration lines constitute a major feature.

Call TS Canada — Toll free  
English 1-800-347-0252 Français 1-866-558-7278

## Good observation skills help – Wei-Wei Han

*continued from front*

Homeopathic medicine differs from Western medicine in that patients are treated much more individually, says Han. “We try to understand why the anxiety is there and what they are anxious about. That will determine what kind of medicine to use. I want to know the root cause of their anxiety – whether they feel frustrated because they can’t express themselves, or whether they feel abandoned or frightened. Different causes will determine different remedies. Also, I want to look at how they express their anxiety – whether they have tics or they bite themselves or attack others or if they are obsessive compulsive. Different manifestations will determine what medicines to use.”

Knowing the essence of who the person is and what is happening in their life is the key to finding the clues to the right medicine, she says. “That’s why parents who are good observers make my job much easier,” says Han. And because each patient is different from the next, the interventions will vary from patient to patient.

Once an appropriate remedy is found for an individual, the impact can be significant. “We’re looking at curing the person of anxiety,” says Han. “You will see the person no longer suffering from anxiety. They will react to things normally. They will deal with issues and move on. People who are on medication [for anxiety] can expect to be medication free.”

Han does not advocate removing her patients from pharmaceutical medications when homeopathic intervention is started. That would mask the effect the homeopathic remedy is having on the patient. However, even while taking conventional medications, patients may see clear cut improvement in anxiety levels within the first month or two of taking a properly prescribed homeopathic remedy.

“Improvement tells me the remedy is correct,” says Han. “I ask the parent to work with their medical doctor to reduce their [anxiety] medication appropriately. They know how to wean the person off their medication. But parents need to be aware that, as the [pharmaceutical] medication is being reduced, the person may start to see more side effects, because their body has too much of the medication. This is a clue that the medication needs to be reduced.”

Most people are candidates for homeopathic intervention, according to Han. “The only patient that I see who is difficult to work with is the person who does not trust homeopathic medicine,” she says. “If they doubt it, or they think they know better than the homeopath, that doesn’t work well. They often want scientific proof, which is limited out there at this time. Commonly, the problem is that these people don’t follow the instructions of their naturopathic doctor. They don’t take their medications, they don’t come back for follow-ups and they don’t carry on with treatment.”

Han explains that naturopathic and homeopathic medicine is difficult, at this point, to quantify scientifically. “It’s like years ago before germs were discovered,” she says. “They didn’t know germs existed, so they could not explain why people got sick. We can’t measure how homeopathy and naturopathy work because it’s about energy. We don’t have an efficient way to measure or quantify the energetic disturbance yet.”

*see Consider training, pg 7*

## Taryn Stone seen an inspiration to those living with TSC

*continued from front*

“As a writer, I’m always looking for good stories about individuals who live and work independently with TSC, despite challenges TSC can bring,” she said in her e-mail.

Taryn was delighted when she heard about the request.

“I would be very honoured [to have the article reprinted],” she said in an e-mail. “I am still trying to deal with having this disease and I want to help others in any way I can. That is why I am doing an Education Degree and then my Masters in Education. I was able to have a professional career with special letters from my specialists and ones who allowed me to follow my dreams.”

## Blue Jays support TS Canada for May awareness month



Saturday, May 12

Blue Jays vs Tampa Bay Devil Rays  
Game starts at 1pm, Tickets \$25

Contact Ron & Nicole

Hutchison at 905-426-3979 or  
ronhutchison@rogers.com

## Family doesn’t take ‘no’ to special needs support

When the Pervilas enrolled their daughter Liisa in junior kindergarten several years ago, they were told that she would require a full-time educational assistant (EA) in order to be integrated into the classroom.

They understood why, since the class was fairly large, and agreed to look into the matter.

“Little did we know that this process would be a grueling year-long journey,” says Laura Pervila, Liisa’s mother. Liisa lives with the effects of Tuberous Sclerosis Complex.

After speaking with the principal and special resource team at the school, the Pervilas, who live in Burlington, Ont., were told that the school had already allocated all of the EA hours available to them and that it wouldn’t be possible to provide an EA for Liisa at that time. “The reason for this was a lack of funding,” says Laura.

Nonplussed, the family, with the support of the teacher, special education resource team and principal of the school, contacted the Board of Education’s superintendent to inform the board of the situation. The superintendent agreed to bring the matter up at the Board’s next weekly meeting.

In the meantime, the Pervilas asked Liisa’s doctors for letters of support, which they forwarded to the school and the Board of Education.

The following week, the family was informed by the special education co-ordinator of the Board that there had been no change in the decision to pro-



*Henry, Liisa and Laura*

vide an EA for Liisa. However, the co-ordinator was very concerned and asked important questions, specifically about TSC and the side effects of Liisa’s medicine, says Laura.

After their conversation, Laura decided to do some work on raising awareness. She photocopied every piece of literature on TSC that she had, as well as a photo of Liisa, and hand-delivered copies of the package to the superintendent of education, the special education co-ordinator, the principal and the special education resource team at the school.

“Within three days, we were advised that Liisa’s case ‘has been put on high alert’ and that the urgency was now clear,” recalls Laura.

But funds for an EA for Liisa had still not been released.

By this time, the Pervilas were thoroughly frustrated that time allotments and funding in the public school system were keeping Liisa from a healthy education experience. But it only made them more determined.

“Finally, we decided to urge the special education co-ordinator to come to the school to spend some time with Liisa to fully assess the situation for herself,” says Laura.

The co-ordinator did so, and then promised to advocate again for Liisa at the next board meeting.

The following week, the family heard the news they had been waiting for. The Board of Education had granted the Pervilas’ request and released the funds for the school to hire an EA for Liisa.

“I will not forget that moment ever,” says Laura. “The immense feeling of relief and ‘end of battle’ was overwhelming.”

Within a few days, a full-time EA was assigned to Liisa. She has since been formally identified as an exceptional student with physical and intellectual challenges.

Liisa is now a confident, happy Grade 2 student working on her Individual Education Plan with great progress, according to her mother.

## Foster family sends out request for prayer

A family featured in the last issue of *Connections* has recently learned some difficult news.

The Fosters, whose twin daughters, Annie and Audrey, live with the effects of Tuberous Sclerosis Complex (TSC), have been told that the tubers in the girls’ brains are growing.

“This could be the reason for their recent behaviour changes and increase in seizure activity,” says Andrea Foster, mother of the girls, in an e-mail.

One of the twins has also begun to experience a different type of seizure, dropping to her knees and falling backwards, several times a day. The family and their physician are currently watching the situation to determine a possible cause. She may need to begin a different type of anticonvulsant, says Foster, who admits to feeling a little overwhelmed.

“I feel like things were going along relatively well and we have just been derailed into the

waiting game,” she says. “I am sad and feel like even the doctor is baffled.”

The Foster family, of Brampton, Ont., has sent out a request for prayer about their situation.

“We need wisdom more than anything, and so do the doctors,” says Foster. The family is considering the possibility of taking the girls to the Neurogenetics Clinic at Comer Children’s Hospital in Chicago.

They are especially baffled by the fact that the twins’ MRIs, CT scans and EEGs are almost identical, but their behaviours and developmental levels are quite different from each other.

Even as they deal with this situation, however, Foster says her heart’s desire is to help those whose children have just been diagnosed with TSC and to spread awareness about the condition, which she does in whatever small way she can. She talks to the pharmacist



about it and shares information with her neighbours.

Foster, a Christian, says she does nothing in her own strength. The prayers of people around her keep her going.

“I know the Lord will not abandon us and we are so thankful we are not walking this journey alone,” she says.

**Call to Action:**

The Fosters are interested in hearing from others who have visited a Tuberous Sclerosis Complex clinic in the United States. If you would like to share anything about your own experiences, please e-mail [akfosterg8@hotmail.com](mailto:akfosterg8@hotmail.com).

# New autism therapy comes to Canada

Joining the wide range of interventions available to treat autism spectrum disorder is a new parent-based therapy called the Relationship Development Intervention program (RDI). Sue Simmons, a Peterborough resident, will soon be one of three consultants in Ontario to offer the program. There are also consultants in Manitoba and British Columbia.

Simmons, a parent of a child with Asperger's Syndrome, is training to offer the program after seeing its remarkable success with her own child.

"The results astounded us," says Simmons in a telephone interview, noting that her son is much more comfortable in a variety of situations and thoroughly enjoys interacting with people.

The goal of the RDI Program is to address the underlying deficits of autism, which the program creators say lead to a person with autism's preference for a static system versus a dynamic system.

Playing a video game on a computer, Simmons says, is an example of a static system,

where a child with autism tends to feel in control.

On the other hand, a dynamic system, essentially "real life," is very frightening for children on the spectrum, who don't have the cognitive or social skills to make sense of it or to appraise it. "That's when they withdraw or try to control or lash out," says Simmons.

On the official RDI Web site, Dr. Steven Gutstein, developer of the program, writes that true quality of life is to be found in learning how to function well in a dynamic system. He states that this cannot be attained by simply teaching social skills, modifying behaviours, or increasing academic and language ability.

Instead, a child on the autism spectrum must be helped to develop something Gutstein has called dynamic intelligence. Dynamic intelligence refers to a number of relational skills that allow an individual to function well in an ever-changing real-life situation.

Gutstein believes that these skills were blunted in the child's first weeks and months of life, due to the effects of autism

spectrum disorder. Intervention involves assessing at what stage the child lost his relational abilities. Training begins from that point. The program is based on the premise that developing this dynamic intelligence is best achieved through the child's relationship with the parent. So an RDI consultant helps parents develop a program to meet their child's individual needs and then assists them in reaching those goals.

Simmons notes that her own son has discovered that there is a "great deal of joy to be found in dynamic situations. He has developed this confidence through working over time in situations that are at the edge of his competence, with success always being the goal.

"RDI is all about moving children on the spectrum competently through the cognitive developmental processes that they were robbed of when autism strikes. It's about giving them a second chance."

**Call to Action:**  
For more information about the RDI program, see [www.rdicconnect.com](http://www.rdicconnect.com).



## Parents identify top 20 questions to ask following diagnosis

*Connections* conducted an informal poll of parents of children who live with the effects of TSC. The group of eight parents, from British Columbia, Alberta, Ontario and Quebec, were asked to identify the top two or three questions that came to mind when their child was first diagnosed. Below is a list of their most frequently asked questions.

1. What exactly is Tuberous Sclerosis Complex?
2. Is my child going to die?
3. What is the prognosis for my child?
4. Is there a cure?
5. What kinds of tests does my child need to undergo?
6. Where can I learn more about TSC, resources, and support groups?
7. What kinds of challenges will my child face?
8. How will my child be educated?
9. Where will my child be developmentally in five, 10, 15 years?
10. What triggers seizures?
11. Will the seizures ever stop?
12. What damage do the seizures cause to my child?
13. What are the best medications to control the seizures and what are their side effects?
14. What other treatments are out there to control seizures other than medications?
15. Is my child a candidate for surgery?
16. Are there doctors who specialize in TSC?
17. Is TSC hereditary?
18. Should my other children be tested for TSC?
19. What would happen if I had more children?
20. How common is this condition?

Some parents indicated that they did not receive an accurate diagnosis when symptoms first presented themselves; they were, therefore, somewhat relieved to have finally found out what their child is dealing with.

## 'Canada can and must do better' to support people with disabilities: panel

*Reprinted with permission from Community Living Leaders, December 14, 2006*

A recent report to the federal government recommends a series of steps to alleviate the financial burdens faced by many individuals with disabilities and their families.

The panel that delivered the report – entitled "A New Beginning" – was set up by Jim Flaherty, Minister of Finance. It recommends that parents be able to set aside up to \$200,000 tax free in a Disability Savings Plan to provide for their children.

It also stated that parents who have children with severe disabilities should receive annualized cash grants of at least \$1,000 for periods as long as 20 years. The panel asserts that the changes be made on top of existing welfare supports.

"Today, the cold reality for many born with a significant disability is that they will live a life of poverty," said the panel, led by Jim Love, a Toronto tax lawyer, in its report.

"For far too many Canadians with disabilities, social assistance has become their sole possible source of income. This means that many live their entire lives on an income of less than \$10,000 annually," said the report.

"As a nation, Canada can



Jim Flaherty

and must do better."

The panel's recommendations – a three-part plan involving the creation of a Disability Savings Plan, a Disability Savings Grant, and a Disability Bond – would be aimed primarily at people who have "severe" disabilities, a number of roughly 500,000 people nationwide.

The plan would cost the government roughly \$112 million a year, the panel said. It is based on the Registered Education Savings Plan model, hailed for its non-bureaucratic approach.

In its recommendations, the panel underscored that these steps, if taken, would represent a "novel approach" to poverty alleviation and should be merely the start of a broad and more extensive reform of existing financial supports.

The title "A New Beginning," the panel said, "reflects our view that the implementation of our recommendations will certainly be the beginning – that faint sliver of light that is dawn – of brighter and more promising days for Canadians with dis-

abilities and their families."

Love, in an interview with the *Globe and Mail's* Andre Picard, said he hopes the government includes the recommendations in the upcoming budget.

Yet Love also reiterated the panel's report introduction, which declares that "government and government agencies can do better than they are doing today. We urge all levels of government to do more. Over and above the recommendations in this report [...] we encourage all levels of government to seek ways to expand the availability of disability-related supports and alleviate the poverty so disproportionately experienced by Canadians with disabilities. The burdens borne by so many families must be reduced so that individuals with disabilities can become more independent and enjoy family relationships that are not impaired by issues of dependency."

For more information, and to read the report, visit [www.fin.gc.ca/activity/pubs/disability1e.html#chpt1](http://www.fin.gc.ca/activity/pubs/disability1e.html#chpt1).

## Job Board invites members to engage in organization's activities

The Tuberous Sclerosis Canada Job Board works like a job bank. A job is posted on the Job Board, and then members or other interested people who are looking for a way to share their various abilities and interests apply for the job of their choice.

Members may use the Job Board in two ways: advertise a job in their community, or apply for one. All jobs must further the mission of Tuberous Sclerosis Canada: to raise awareness, to support families affected by TSC, and to support TS research.

*Connections* is currently seeking copy writers, both English and French (bilingual). People interested in writing for TS Canada's print publication should possess a degree in journalism or equivalent experience. Ideal candidates will also have an awareness of issues of diversity. Experience with disability issues will also be an asset. Send your résumé and samples of your work to Linda Viscardis at [linda.viscardis@sympatico.ca](mailto:linda.viscardis@sympatico.ca).

**Call to Action:**

To get help with the activities you are undertaking on behalf of TS Canada, place an ad on the web site's Job Board. Send your request to Karen Shulist at [kshulist@sympatico.ca](mailto:kshulist@sympatico.ca).

## Did you know ...

On March 19, 2007, Federal Finance Minister Jim Flaherty tabled a budget that contained several measures of interest to the readers of *Connections*. The Budget proposes to introduce the Registered Disability Savings Plan (RDSP) to help parents and others save for the long-term financial security of a person with a severe disability. The RDSP is meant to benefit persons eligible for the Disability Tax Credit and will be similar in concept to Registered Education Savings Plans. For more information, visit [www.budget.gc.ca/2007/index\\_e.html#2](http://www.budget.gc.ca/2007/index_e.html#2).

## HANDLE's Neurodevelopmental approach melts obstacles, unlocks treasures within

*continued from page 3*

Africa, Australia, India, United Arab Emirates, Belgium, and now Canada." MacLean is consulting with professionals across Canada, and is providing the HANDLE ® service to people in Ontario, Quebec and Florida.

When families or individual clients come to MacLean, they are usually in crisis. MacLean works to identify and target the root cause of learning, social and behavioural disorders. People of all ages, from babies to seniors, may present to a HANDLE ® Provider with such labels as ADD/ADHD, Autism Spectrum Disorders, Tourettes Syndrome, Dyslexia, Learning Disabilities, Brain Injuries, Seizure Disorders, Oppositional Defiance Disorder, Down Syndrome, Bipolar Disorder, Global Developmental Delays—or undiagnosed, perplexing behaviours.

MacLean says that the HANDLE ® program is like "finally being able to open a locked safe." HANDLE seeks to unveil what has been preventing individuals from achieving their goals, and helps to take down the barriers. Many parents and educators have known these children (or adults) are capable. HANDLE ® provides the key to help unlock and embrace the treasure within.

One parent whose child attends Phoenix drew a comparison: "It's like thinking of your child as a computer. A computer can have lots of viruses. You come along and keep plugging new programs into it. That's like tutoring. The new information, like a new computer program, just doesn't seem to work to its full potential due to the virus using up valuable resources. In the type of learning provided by MacLean at Phoenix, you go back, strip the viruses and start from scratch. It's almost like you go in and access what they didn't get in their first years of life."

"Regardless of the calibre of either an academic or cognitive program, if an underlying neurodevelopmentally-based challenge or a hyper- or hypo-sensitivity is present, the person will be unable to intake or process information as efficiently as they otherwise would. This often results in challenges behaviourally, academically or socially. More often than not, more than one of these challenges is present. We need to figure out where their energy is being spent, and support those systems. We must address their attentional priorities. If all of your energy and attention is being used to address your foundational systems, you have less energy to do things like math, reading and spelling [for example] with ease and efficiency," explains MacLean.

Fundamental to HANDLE is the knowledge that stressed systems cannot strengthen. "When we examine how the Sympathetic and Parasympathetic Nervous Systems operate, we can appreciate the foundational HANDLE ® Paradigm of Gentle Enhancement®. We can speak about the signs and symptoms and labels that are out there, but we really want to find out the root reason," says MacLean. "We want to find out which systems are weakened or challenged or working overtime to compensate for other things. Then we develop an individually designed program to address these particular systems."

Based in neuroscience and neurodevelopmental science, the HANDLE ® program has already made a dramatic impact on clients, students and parents working with MacLean. One parent told her that it was very comforting being in the presence of someone who could finally explain their son to them. Another said how comforting it was to "actually discuss [our son's] condition to someone who actually gets it."

Dramatic differences are being realized with both MacLean's students and clients as well. "For example, I had a student who came to me last summer who was barely speaking and within weeks was able to speak in sentences," says MacLean. "There is no way that I taught him that. It was inside of him and I addressed his obstacles. As the obstacles melted away, he was able to express what was always inside him."

**Call to Action:**

Find out more about The Phoenix Alternative Centre at [www.phoenixalternative.com](http://www.phoenixalternative.com). Contact Valerie MacLean at [valerie@phoenixalternative.com](mailto:valerie@phoenixalternative.com).

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## Connecting with other fathers remains challenging

*continued from front*

much of an issue for Aldoria.

Zachary, now a teenager, attends school daily. "The school has been a big help," says Aldoria. "They understand our situation." Zachary has epilepsy and experiences about 35 seizures a month. His supporters at the school have learned what to do when he has a seizure and don't call on Aldoria, as they did at one time.

Paul, whose son Ben is now three years old, has much fewer hours to call his own, since his son does not attend school full-time – although he does go to nursery school. Paul works very hard to ensure he and his family are well-supported, but admits the situation is still far from what he would like it to be.

"It just seems like everybody is so busy these days," he says, noting that he has made various efforts to connect with other fathers, but for the most part has had little success.



Paul and Ben

Both fathers agree that while the role they've taken on is no bed of roses, the payoff is certainly there.

For Paul, the benefit has been seeing his son blossom under his focused support.

"Ben has progressed in a huge way because of the love and support of his parents," he says. "The time we put into his eating, reading and physio at home are reflected in his progress. His happy nature and his new expressions of independence and, at times, disgust with us are what make it so that

we want to be around him."

Aldoria believes that having one parent home for his children – the Caissies also have a 12-year-old son Matthew – contributes to their sense of security.

"The routine is always the same. They know what's coming. They know mom or dad will be there. I think they feel way more secure," he says.

There are benefits for the parent, too, he adds. Aldoria's years as a stay-at-home father have taught him the importance of slowing down and taking time to enjoy his children, and his life.

## Microboard provides network of support for all involved



Developing a microboard for a British Columbia woman has benefited all those involved, says Linda Perry, a member of the woman's microboard.

Perry tells the story of her good friend Shanti Miller, who lived in a group home and was to be moved to an institution because she had been labelled "difficult to serve."

Perry knows Shanti as a "wonderful woman with a variety of complex needs."

"Those who know Shanti know that she also loves people and is a great social convener. She has a gift for getting a room of strangers connected and laughing," says Perry.

Shanti uses a wheelchair for mobility, has a developmental disability and has mental health challenges. It is for the latter reason that she had been labelled difficult.

Shanti's mother, upset by the plan to remove her daughter from community life, called the Vela Microboard Association in Surrey, B.C. for help.

Subsequent discussions between the family and Perry, executive director of the association, focused on "what Shanti did want instead of what people were prepared to offer," says Perry. "The fact that the philosophy of microboards is based on person-centred thinking was very appealing to Shanti and her family."

Once the decision to form the microboard had been made, the first step was to gather together people who knew Shanti and held her in high regard, including family,

friends and acquaintances.

"These folks first got together to just connect and update one another," says Perry in an e-mail interview. "Over time they began to discuss with Shanti what she wanted to enrich her life and ways to help her realize her dreams."

The Vela Microboard Association supported these discussions, and then assisted the group as it incorporated under provincial requirements for non-profit societies. The group developed a plan with Shanti to work out what supports and services she would need. They negotiated for funds to provide those supports and hired staff to assist Shanti.

Perry notes that since Shanti's microboard was the first in B.C., there were many challenges along the way. "But with lots of determination and support, obstacles were overcome," says Perry. The process took about a year.

Perry says that now that microboards are recognized in B.C. – there are about 450 in the province – one can be formed in a matter of weeks "if folks are clear on the goals and have worked in a person-centred manner."

Shanti has gone from living in a group home, where she felt isolated and had limited contact with family and virtually none with friends, to living in her own home in a community she chose and with staff she has helped to hire. She spends time with family and friends in activities she has chosen. She hangs out with

the locals and is known and respected in her community.

"My microboard is about love," says Shanti. "We all care for each other, help each other. My microboard helps me live my life the places I want, the way I want."

Currently, Shanti's microboard includes Shanti, her mom, her sister, brother, sister-in-law, and two long-term friends. Recently Shanti and her two friends from her microboard, one of them Perry, took a holiday to visit her sister in Regina. Her mom also joined them.

"We had a wonderful time shopping, dining out and taking in the sites," says Perry. "This was not volunteer work. We are not 'staff.' We were a group of friends taking a holiday."

Perry says that the two main advantages of a microboard are that it allows the person supported to "truly have a say over how your life is unfolding," and it provides a "wonderful" network of support for the person.

"But the hidden surprise is the network it provides for everyone else as well," says Perry. "I can honestly say I would never have had the friendships I have with Shanti's family if not for Shanti and sitting on her microboard. My network has also expanded and they are all like family. This is a gift that is priceless."

**Call to Action:**

Visit [www.microboard.org](http://www.microboard.org) to learn more about microboards.



## Toronto Argonauts support TS community with hockey game

A personal connection made an impact on the decisions of both Bruce Good, president of IMS Pharmaceutical, and Adrion Smith, community relations ambassador for the Toronto Argonauts football team, to become involved in an event to support Tuberous Sclerosis Canada recently.

Last month, Good and Smith took part in a hockey game played by the Frozen Boatmen, the Toronto Argonauts' charity hockey team, against the TS Thunderbolts of Tuberous Sclerosis Canada. Smith was the Master of Ceremonies, and Good's company sponsored the event and donated hockey jerseys for the TS team. Good also played in the game.

Both Good and Smith say they became aware of Tuberous Sclerosis Complex after the daughter of James Neal, who plays for the Plymouth Whalers of the Ontario Hockey League, was diagnosed with the condition.

"I still remember the day he rushed out of the office to go to the hospital. Something had happened with his child—he didn't know what... So I saw the effects [of TSC] on his life," says Smith in a telephone interview.

"When I was told we were having a charity event to support TSC, I had to be involved in any way I could."

Smith adds that the Argos have a mandate to be the "most community-recognized" team in Toronto. As a result, they have supported a number of organizations in the community over the years.

"The players aren't getting paid for this," he points out. "They just do it to have fun and make connections with the community."

Good says it was Neal who asked him to consider sponsoring the hockey event. He chose to do so because Neal is a friend and Good knows he has experienced some "tough times" as a result of his

daughter's condition. Good also chose to support the event because he knows that there is some important TSC research taking place. "The funds will hopefully lead to finding a cure," he says, adding that IMS Pharmaceutical is a major supporter of research.

The hockey event, held Sunday, February 18, raised a good deal of both funds and awareness, according to Karen Shulist, TS Canada Board member. Over \$6000 was brought in and the event was covered by a number of media outlets, including the *Toronto Star*, Global TV, and CP24.

There are discussions about making the charity hockey game an annual event.

"This is a cause that's dear to me," says Smith. "Hopefully we can be involved for years to come."

Good says he anticipates future involvement, as well. "Whenever Jamie [Neal] calls, if I can help, I will."

## Consider training when choosing a holistic doctor

*continued from page 4*

When researching which homeopathic doctor to visit, consider their training. "There is a minimal standard of training," Han says. "We have a license. You can call the Naturopathic Association to verify their credentials. Not all naturopathic doctors have homeopathic training. I have seven years of homeopathic training on top of naturopathic training. It's really an art, so it's never-ending training. Ask about how many years of training they have, and where they got it. And word of mouth [recommendation] is good."

Her best advice comes last. "Pay attention to your kids," she says. "They will give you the information we need to treat them. Pay attention to things like cravings, dreams, temperament, things that ameliorate or aggravate, etc. These are things that a medical doctor would not care about, and that parents might think are irrelevant, but they are relevant to us."

Find a qualified Naturopathic Doctor in your province by visiting the Canadian Association of Naturopathic Doctors' Web site at [www.cand.ca](http://www.cand.ca). Click on "Professional Affiliations."

### Wei-Wei Han, B.Sc. (Hons), N.D.



As a young child, Dr. Han dreamt of healing and nurturing the sick. Being naturally drawn to the healing arts, Dr. Han fulfilled her passion through nine years of education that began with an Honours degree in science from The University of Toronto, and culminated with graduate studies at the Canadian College of Naturopathic Medicine.

In addition to training at the Naturopathic College, Dr. Han's passion for healing has led her to explore and seek out knowl-

edge from various sources. She traveled to China and spent over 1,000 hours apprenticing with three famous traditional Chinese medical doctors. Furthermore each year she spends hundreds of hours attending seminars on various healing modalities. She has advanced training in Bowen Therapy, and an additional seven years of advanced training in classical homeopathy.

As a Naturopathic Doctor, Dr. Han's approach to treatment is individualized and eclectic. She draws from all aspects of the individual's life in order to understand the cause of their suffering. She believes health is not the absence of disease, but the freedom to manifest potential. She understands that healing is a process - medicine is not just a science, an art and a philosophy, it is a way of living. She believes the ultimate goal of good medicine is to educate and empower people to make knowledgeable choices about their own health.

## Reach for the Rainbow facilitates successful camp experience

Everyone knows Paul Tiller at Camp Wanakita. From camp administrators, to the counsellors, to his fellow campers – they all recognize the young man who enjoys new experiences and facing difficult challenges.

It is thanks to Reach for the Rainbow, and the one-to-one support the program provides, that Paul has had a very successful "career" at Camp Wanakita, located in Haliburton, ON.

Reach for the Rainbow is a non-profit organization that makes it possible for children who live with disabilities to go to summer camp with peers who do not have disabilities. Rather than creating a whole new system of camps, Reach for the Rainbow supports and modifies the structure of established camps to provide integrated opportunities for children with disabilities.

Reach for the Rainbow facilitated very successful March break, day and residential camp experiences for Paul, who has attended Camp Wanakita for the past 11 years.

Paul, who lives with the effects of Tuberous Sclerosis Complex, started as a camper at age 10. His involvement in camp activities happened naturally, as he shared a cabin with his fellow campers and joined in with what the other campers were doing throughout the day. His camping experience



culminated three summers ago, when Paul reached the age of 19. No longer eligible to be a camper, he was able to continue at Wanakita as a volunteer worker, with the support of Reach for the Rainbow.

Such a success story did not just happen. Each summer, Paul's mother, Lucinda Hage, noticed that camp encouraged him to build new skills and try new activities that are unique to summer camp. Being away from home gave Paul a new sense of independence, according to Lucinda. As camp staff encouraged him to try new activities, like swinging on a rope swing or sleeping in a tent on an island, he rose to their expectations, resulting in renewed self-confidence and self-esteem.

"I would like to encourage parents to let their children go," she adds. Reach for the Rainbow makes "letting go" possible. Lucinda visited a few camps the summer before applying to the Reach for the Rainbow program to find the right fit for Paul and then applied for the support provided by Reach for the Rainbow in plenty of time the following year.

"I am convinced that he is able

to do many challenging things today because of his experience as a camper," says Lucinda.

Reach for the Rainbow was created by Donna Trella in 1983 when she noticed that her daughter, who has a disability, was treated "differently" at summer camp. Donna was determined to bring about integration and awareness, and to promote and expand inclusive programs in Ontario, according to the Reach for the Rainbow Web site.

The intent of Reach for the Rainbow is to provide a one-to-one support counsellor to a very small number of children with disabilities per camp session, making it possible for these campers to fully participate with the other campers, counsellors and staff. The camps partner with Reach for the Rainbow to put all the necessary pieces together to make the camping experience work, which includes, among other preparations, an extensive interview to create a detailed personal profile that allows the camp to become familiar with each child.

Find out more about Reach for the Rainbow by visiting their Web site at [www.reachfortherainbow.ca](http://www.reachfortherainbow.ca).

The screenshot shows the TSC Canada website with a navigation menu on the left including Home, Information on TS, Resources, FAQs, Fact sheets, Organ & Tissue Donations, News & Events, Newsletter, Events Calendar, Events Photos, Media Room, TSC in the News, Get Involved (Make a Donation, Become a Member, Become a Volunteer, Corporate Sponsorship, Organize an Event, Store, Discount Tickets, Online Discussion), and How Can TS. The main content area features a 'Raising awareness, providing support and finding a cure for Tuberous Sclerosis' banner, a 'Blue Jays Game' section, and a 'May Awareness Month' section.

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

Newly designed site includes

- Resources•
- FAQs•
- News and Events•
- TS Store•
- Online Discussion Groups•



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## TS Canada acknowledges supporters

Tuberous Sclerosis Canada receives no government funding. The organization operates entirely through the proceeds of fund raisers and the generosity and commitment of its constituents. All proceeds are used to fulfill the organization's mandate to provide encouragement and support to individuals diagnosed with Tuberous Sclerosis Complex (TSC) and their families, to raise public awareness and educate our communities about TSC, and to promote and support research aimed at controlling Tuberous Sclerosis symptoms and finding a cure for TSC.

Tuberous Sclerosis Canada wishes to acknowledge the many people who have so generously supported this organization with their generous donations and their membership fees over the past few months. With this issue of *Connections*, the organization's board of directors is making a commitment to recognizing its dedicated supporters at least once a year in the organization's newsletter.

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Richard Robins  
Brenda Roud  
Maki and Michael Rose  
Jerome Shulist  
Betty Taylor  
Mrs. Tibbenham  
Ms. Marie Cecile Unis  
John Wiggins  
*In Memory of Leo Winnicki:*  
Joan Coons  
Chairman, Members of Council of the Regional Municipality of Niagara.  
Brad & Janice Dickerson  
Don Evans  
Fonthill Fossils  
Scott & Heather Furtney  
Mr. & Mrs. Gasiosek  
Eugene Golec  
Stefania Lazowska  
Frances & Bill Lyle  
Alec & Ann Mardarowicz  
Glenna Miller  
Richard Robbins  
L.V. Tibbenham *In Memory of Peggy Renshaw*  
Michael & Debra Wood  
Mr. & Ms. Tony Fargo  
*In Memory of Sharon Gifford:*  
Molly Aderson  
Evelyn Morrison

Thank You to all our very special volunteers who continue to go above and beyond and truly are making a difference.

Also a very special Thank you to the Toronto Argonauts for their participation in our charity hockey game to benefit TS Canada.

## Mission Statement

TS Canada is a voluntary non-profit charitable organization dedicated to the principles of raising public awareness of Tuberous Sclerosis Complex, encouraging mutual support between families with affected members and promoting research and education.

**Check [www.tscanada.ca](http://www.tscanada.ca) for upcoming events in your area**

**Now you've read it, pass it on**

**YES! I would like to help TS Canada raise awareness and help even more families.**

Amount of cheque .....  Membership only  Donation only  Membership + Donation

Name: .....

Address: .....

City/Prov/PC: ..... Phone: .....

Email Address: .....

In Memory of: .....

I'm unable to financially support TS Canada at this time, but would like to receive the newsletter

Please detach and return to **TS Canada, 28 McGregor Dr., Ajax ON L1T 3W8**

TS Canada Charitable Registration #892417643 RR0001.  
Receipts for income tax purposes will be issued. English 1-800-347-0252 Français 1-866-558-7278.

\*TS Canada does not sell, rent or distribute mailing list information



*Thank you for your support*