



# YOUR BRAIN



## A MOTHER'S STORY OF LOSS AND LEGACY

**Jennifer Stepanek's** tireless campaign against the form of Muscular Dystrophy that took her children.

Autism apps  
How touch technology gives autistic kids a voice.



Helping from within  
What can deep brain stimulation do for neurological issues?



In remembrance  
A granddaughter speaks out about Alzheimer's.

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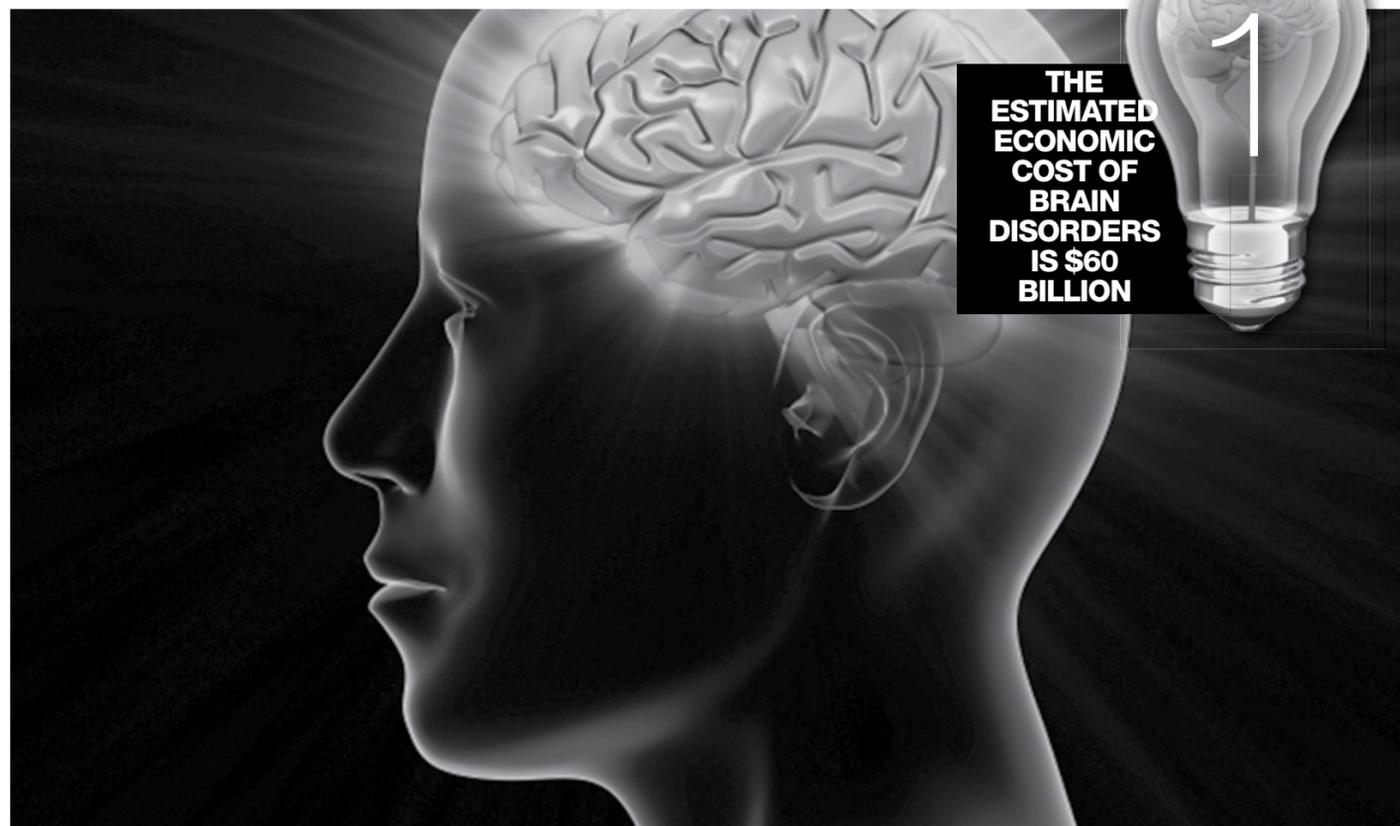
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April is Parkinson's Awareness Month



## CHALLENGES



The toll taken by **brain disorders or injury** is more than cancer and cardiovascular disease combined, affecting over **30 percent** of Canadians.

# A national brain strategy is top of mind for Canadians

**W**alk into any bookstore and you're sure to find tables of books dedicated to the human brain. For some time, we have known about the brain's role as the command centre for the human experience, but only now are we beginning to talk about what's really going on "upstairs".

The brain is a major health, social and economic issue facing individuals, families and communities across Canada—one with complex policy implications for all levels of government. Approximately 11 million Canadians are living with a neurological or psychiatric condition today. That's one in three living with a brain disease, disorder or injury for which there are limited treatments and no cures—a startling statistic for our knowledge-based economy.

## Disorders can strike at any age

Some brain conditions are present at birth, others develop during childhood; some appear suddenly during adulthood and child-rearing years, others progress slowly as we age. Regardless of diagnosis or the age

of the person affected, living with a brain condition presents remarkably similar needs and issues.

Canada needs a national brain strategy, a comprehensive and coordinated approach to tackle the most challenging issues facing more than 30 percent of our population:

- Integrated care and support services
- Caregiver support
- Income security
- Research
- Prevention
- Public awareness

For a person living with a brain condition, access to health care and support services can make the difference between maintaining their independence and requiring costly long-term care. Limited access to specialists, innovative medications and treatments not covered by public programs, and insufficient support in the community, compromise a person's ability to remain healthy, productive and engaged.

## A family burden

Informal caregivers fill these gaps at great risk to their own health and the financial stability of their family. Ensuring that caregivers are properly supported is essential to maintaining this volunteer work force that our



**Joyce Gordon**  
CEO, Parkinson Society Canada  
Chair, Neurological Health Charities Canada

## MY BEST TIPS

### Eat well for brain health

**1** Consume food with high levels of naturally occurring antioxidants (dark-skinned fruits and vegetables) to minimize free radical damage.

### Up the omegas

**2** Omega 3 Fatty Acids support brain function (walnuts, kiwi fruit and cold water fish including halibut, mackerel, salmon, trout and tuna).

### Healthy mind and body

**3** Avoid trans fats and saturated fats—they are linked to cognitive decline.

communities rely upon. This includes income security measures to ensure that families do not experience poverty as an added consequence of living with a brain condition.

Research offers the hope of uncovering more effective treatments and a better understanding of cause and cure. Canadian neuroscientists are the best in the world, but they require increased and sustained investment to find ways to help people live better today and prevent people from facing brain conditions in the future.

## A stifling stigma

With one in three Canadians affected, it's plausible that every family in Canada has been touched by a brain condition. Improving our knowledge about brain health, our recognition of brain conditions and our understanding of how to be helpful to those around us is fundamental to reducing the stigma, discrimination and isolation that many Canadians experience every day.

March 2011 marks Canada's first National Brain Awareness Month, an important first step in raising awareness about brain health and the issues facing millions of Canadians living with brain conditions today.

# Canada: A hub for neuroscience research

## Canada's culture of collaboration has led to advancements in neuroscience including stem cell research and innovative technologies that allow brain surgeons to work throughout the entire country.

"We have a model that is much more collaborative than the models in the United States or even Europe," says Inez Jabalpurwala, president and CEO of NeuroScience Canada. "The research community in Canada is much more collaborative—they want to share."

According to NeuroScience, brain disorders impact one in three Canadians and are the leading cause of disability.

They carry an economic and human burden greater than cancer and cardiovascular disease combined.

When direct costs and costs linked to disability are combined, the economic burden of brain disorders is estimated at \$60 billion.

But Jabalpurwala says an individual approach to each brain disorder won't work.

"There is more in common among brain conditions than there is among cancers," she says. "The idea that we can partition these diseases—that autism may not be linked to Alzheimer's (for example)—is wrong."

## Stemming from community

Jabalpurwala credits this spirit of camaraderie with advancements in the use of stem cells—neutral cells that can be specialized to replace damaged components of the brain.

She says the nineties were devoted to discovering the parts of the brain, whereas the past decade has focused on how those components operate as a system.

"A lot of people in the high tech world say what they think will be the next big breakthrough in technology will be understanding the brain," she says.

Ivar Mendez, head of neurology at Dalhousie University and chairman

of the Brain Repair Centre in Halifax, says modern technology allows doctors to transplant stem cells directly into the brain, which lets the cells move to the damaged sites of the brain and repair it.



But research has a way to go before it can fix the brain as a whole.

"The diseases we're looking at are degenerative diseases," says Mendez. "(Disorders such as) autism are much more difficult—we just don't understand a lot of things about autism."

## Robo-doctor

Mendez notes that in addition to a more comprehensive understanding of stem cells, medical innovation has also developed ways to export medical assistance.

He points to his use of remote-presence robots to service specialist needs in the northern Inuit community of Nain, Labrador.

"The technology is allowing us to provide expert care where expert care is needed in real time," says Mendez.

"The use of RPR will be a part of the way we practice medicine in the future."

ANDREW SEALE

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## WE RECOMMEND



**Dr. V. Wee Yong**  
Harnessing inflammation to promote repair.

PAGE 5

"We've been able to use technology to decipher how a single neuron begins that process."

## Early intervention is key p. 7

Catching autism early can make all the difference in quality of life.

## Apps for autism p. 7

How touch technology gives kids with autism a voice.

# MEDIA PLANET

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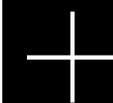
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## YOUR PARKINSON'S IQ

### Which of the following is true about Parkinson's Disease?

- Loss of sense of smell
- Affects both young and old
- Depression
- Shaking or tremors
- Changes in thinking ability
- Slow movement
- Soft speech
- Muscle stiffness and rigidity
- Stopped posture
- Small handwriting
- Difficulty with walking and balance
- Over 100,000 Canadians affected
- Researchers are seeking a cure
- All of the above

If you checked all of the above, you'd be right! Parkinson's is more than a movement disorder. Each person is unique and may experience different symptoms. Find out more at parkinson.ca.

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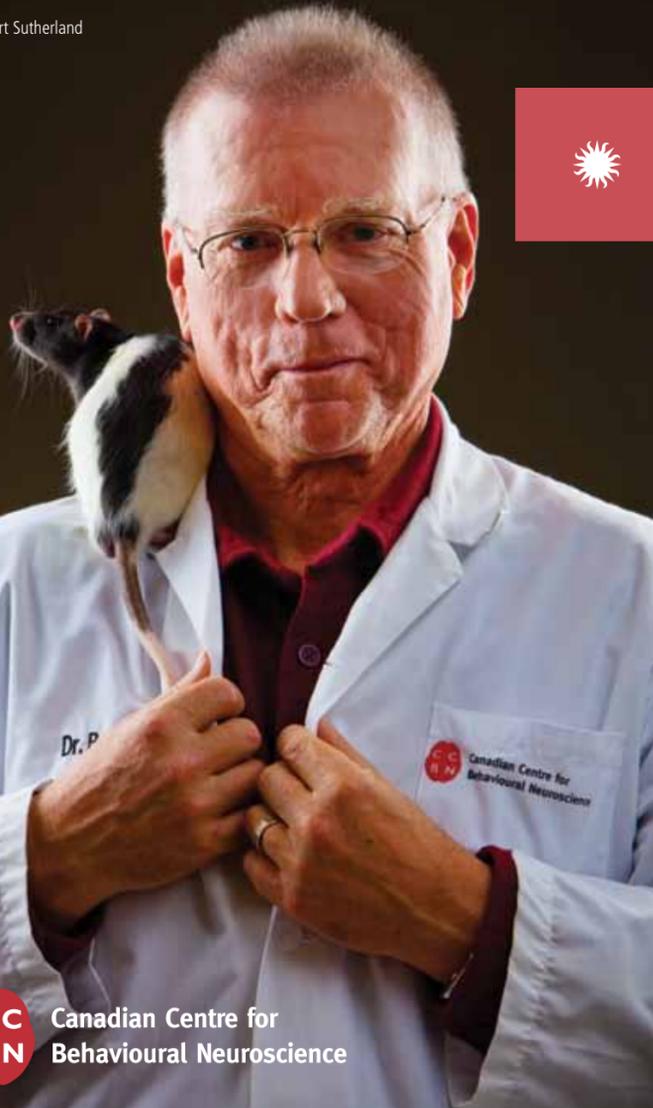
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Dr. Robert Sutherland



## Canadian Centre for Behavioural Neuroscience University of Lethbridge

**In 2010, University of Lethbridge neuroscientist Dr. Robert Sutherland and his research team made a significant advance in repairing damaged brains.**

Building on the work of others showing the brain's capacity to produce new neurons, the team became the first in the world to regenerate cerebral cortex brain cells in adult rats suffering from a neurodegenerative disorder. The implications of this discovery are of particular importance for dementia-related diseases such as Alzheimer's.

Dr. Sutherland is one of the world-renowned scientists at the U of L's Canadian Centre for Behavioural Neuroscience (CCBN), the only research facility of its kind in Canada.

At the CCBN, 16 principal investigators are tackling the complexities of the brain.

Dr. Bruce McNaughton, for example, is one of the world's foremost experts in neurophysiology and the inaugural Alberta Heritage Foundation for Medical Research (AHFMR) Polaris Award recipient. His research focuses on learning and memory disorders resulting from normal and pathological aging, brain trauma, developmental disorders, substance abuse and traumatic experiences.

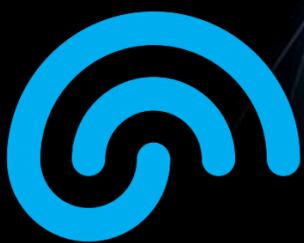
His colleague, pioneering neuroscientist Dr. Bryan Kolb, has devoted his distinguished 30-plus year career to asking questions about the brain and how the brain changes as a result of experience. The answers Dr. Kolb has uncovered have fundamentally changed the field of neuroscience and how we think about the brain.

Drs. Sutherland, McNaughton and Kolb, together with the other researchers, students and staff at the CCBN, are advancing brain-related research. Their discoveries will lead to new knowledge, technologies and treatments.

For more information on the Canadian Centre for Behavioural Neuroscience and the extraordinary research that takes place there, visit: [www.ulethbridge.ca/ccbn](http://www.ulethbridge.ca/ccbn)



**CCBN** Canadian Centre for Behavioural Neuroscience



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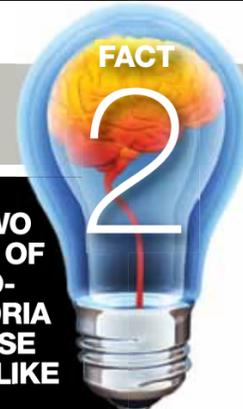
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## INSPIRATION

After losing four children to Dysautonomic Mitochondrial Myopathy, and suffering from the disease herself, **Jennifer Stepanek** campaigns tirelessly for their cause—in the name of her youngest son, Mattie.

**NO TWO CASES OF MITOCHONDRIA DISEASE LOOK ALIKE**



# The lasting legacy of heartsongs

## CHANGE

**Jennifer Stepanek is a fighter. Despite the tragedy and sorrow she has experienced, she forges on as a proponent of selfless love and peace.**

Confined to a wheelchair by muscular dystrophy, Stepanek has no interest in being kept down or debilitated by the disease.

Having lost four children to an extremely rare form of muscular dystrophy, Dysautonomic Mitochondrial Myopathy, Stepanek has turned heartache into action—campaigning tirelessly in the honour of her youngest son Mattie.

“Mattie said ‘it’s not about getting what you want, it’s about getting what you need,’” says Stepanek, who only learned she was a carrier of the disease when she was an adult.

Despite being wheelchair-bound and having to use a respirator for most of his life, Mattie gained world recognition as a published poet, peace advocate and motivational speaker—all before he passed away at 14 in 2004.

While most kids were playing Pokemon, Mattie published poetry, appeared on The Oprah Winfrey Show, Larry King Live and Good Morning America and lobbied Capitol Hill in the name of peace, people with

disabilities, and children with life-threatening conditions.

To this day, Stepanek serves as the executive director of the Mattie J.T. Stepanek Foundation, named in his honour.

“We’re an incredibly small group but we’re trying to do big things,” says Stepanek.

## Mattie’s legacy

There’s no question about it, Mattie’s enduring legacy has touched many lives.

“Seven years after his death it’s still spreading,” says Stepanek. “He had planted so many seeds of hope, I think what we’re seeing now is the effects of that—the gardeners are watching peace grow.”

At the age of three Mattie began writing poetry in an effort to cope with the loss of his siblings. Over his life he published five books of poetry surrounding a concept he developed called Heartsong or, as Mattie put it, “a person’s special gift to be shared with others.” A sixth collection of poems and a book of essays were also published posthumously. All were New York Times bestsellers, selling over two million copies. His writings on peace inspired millions.

“Mattie didn’t believe peace is an endpoint,” says Stepanek. “Peace is a journey.”

## A woman of many hats

Jeni Stepanek is a busy lady. In the seven

## PROFILE

**Jennifer Stepanek**

■ **Jennifer Stepanek, mother of the late poet and childcare and disability advocate Mattie Stepanek, holds a doctorate in early childhood special education. She is currently the executive director of the Mattie J.T. Stepanek Foundation, motivational speaker and peace mentor. She lives in Rockville, Maryland.**

years since Mattie died, she has served on a variety of committees and organizations including a stint as national vice president for the Muscular Dystrophy Association, a governor of the We Are Family Foundation, and—not to mention—her current role as executive director of Mattie’s foundation. She holds a doctorate in early childhood special education. Stepanek also mentors teens as part of the We Are Family Foundation Three Dot Dash initiative.

“The organization partners to collaborate with other organizations that carry similar goals,” says Stepanek. “We are all about international relationships.”

But it is the tireless work with her son’s namesake foundation that drives Stepanek forward.

She points to the accomplishments Mattie achieved in his short life.

“He lobbied for changes in how hospice services are provided to children,” says Stepanek. “That led to elements of reform that have improved the situation—for the first time ever they have enough money to dedicate to mitochondrial diseases.”

Stepanek notes that each case of the disease is different.

“You could have millions of people with mitochondria diseases but no two would look alike,” says Stepanek.



## A world of support

In October of 2008, nearly 1,000 people gathered for the dedication of the Mattie J.T. Stepanek Park, a 26-acre recreation facility in Rockville, Maryland. Oprah Winfrey made a surprise appearance to show her support for Mattie.

Since the park’s dedication, hundreds of bricks from all over the world have already been placed in the Peace Garden area.

“People believe in what we’re doing and support what we’re doing,” says Stepanek.

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

## Brains matter.



## RESEARCH



Millions of Canadians are living with a brain condition today!

We need to learn more about this experience to better serve individuals and families. That’s why the NHCC is collaborating with the Public Health Agency of Canada to lead the first-ever National Population Study of Neurological Conditions.

Research teams across Canada are working to build a better understanding of:

- ✓ the incidence & prevalence of brain conditions in Canada
- ✓ their impact on individuals & families
- ✓ risk factors for onset & progression
- ✓ co-existing conditions
- ✓ best practice health & support services

Register to receive information and regular updates, or to participate in the national study at [www.mybrainmatters.ca](http://www.mybrainmatters.ca) or call the NHCC at (416) 227-9700 x3314.



## EDUCATION



## ADVOCACY



## COLLABORATION



# NHCC

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# INSPIRATION



↓

**DOCTOR PROFILE**

**Dr. V. Wee Yong**  
Professor,  
Clinical Neurosciences and  
Oncology,  
University of  
Calgary

**Dr. V. Wee Yong**

■ Inflammation isn't necessarily a bad thing, according to Dr. V. Wee Yong, a professor of clinical neurosciences and oncology at the University of Calgary and Research Chair of Neuroimmunology.

"We're hoping to harness the beneficial aspects of inflammation to promote repair," says Yong. Yong is referring to inflammation of the central nervous system—a feature common to most neurological disorders.

Yong's research could spell a brighter future for people with multiple sclerosis (MS), spinal cord injuries and malignant gliomas.

Although he's focused on inflammation for 20 years, Yong says recent technology has improved research.

"We've been able to use technology to decipher how a single neuron begins that process," says the neuroscientist.

One of the studies his lab is conducting looks at the role of EMMPRIN, a molecule, in MS.

Mice treated with an EMMPRIN function-blocking antibody had reduced symptoms and lower levels of white blood cell infiltration.

Yong says that down the road he hopes to zero in on utilizing the benefits of inflammation to repair the nervous system while minimizing detrimental effects.

**ANDREW SEALE**  
editorial@mediaplanet.com

1. Jennifer and Mattie.  
2. The bronze statue of Mattie and his dog Micah at the Mattie J.T. Stepanek Park in Rockville, Maryland.  
3. Mattie and Oprah sit down for one of their many heart-to-hearts.  
PHOTOS: PRIVATE

"Mattie looked for the best in everybody, and despite his own painful struggles, he never lost faith. In his almost 14 years on earth, he accomplished what most people only dream of. A day doesn't go by that I don't think of that brave boy, my guy Mattie." —Oprah Winfrey

PHOTO: USED WITH PERMISSION FROM HARPO PRODUCTIONS

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FREEDOM TO MOVE

## PERSONAL INSIGHT

**Sarah Condie** is a 12-year-old, grade seven student in the gifted program at Westwood Middle School in Toronto. She recently submitted a speech to the **Alzheimer Society of Canada** for a writing contest. Sarah was inspired to write about Alzheimer's—a disease that snatched the life of her beloved great-grandfather, **William Butler Gregg**.

**FACT**  
3  
A CANADIAN IS DIAGNOSED WITH ALZHEIMER'S EVERY FIVE MINUTES



# A granddaughter's speech

“It's 7:00 a.m. and the fish need their peanut butter.”  
“How old am I?”  
“Which way is Montreal?”  
“Am I 152?”

These are the type of phrases one might hear in an Alzheimer's ward. They make no sense to us, but these fragmented thoughts are all that remain of the once vibrant seniors who have dementia. The majority of people with Alzheimer's are over 65, but its impact spans all generations. Imagine visiting a loved one who cannot recall who you are or what you have shared in life. For the thousands of memories you treasure, all have been extinguished from the person's mind.

Alzheimer's is an irreversible, progressive disease of the brain that affects one in 11 Canadians 65 and older, and is the most common form of dementia. According to the Alzheimer Society of Canada, by 2038 there'll be over one million diagnosed cases in Canada. This figure doesn't reflect the total number of people who will be directly impacted. Families and caregivers are also on the journey of devastation as this insidious disease slowly steals the minds and the essence of those stricken with the disease.

How to best describe this disease? Think of your brain as a computer. Your whole life is written on the

hard drive. Alzheimer's essentially wipes your hard drive clean, leaving nothing but empty space. Over the 10-year course of the disease, it is as if the backspace and delete button are constantly pressed. Initially you are aware of this technical glitch, but there is no undo button.

In the beginning stages, people may misplace objects, forget the names of new people and experience difficulty with planning and organization. This sounds like a lot of middle school students! But over time people with Alzheimer's become confused about where they are or what day it is. As the disease progresses further, they may experience a disruption in their circadian rhythm. They sleep during the day and become restless at night—often wandering and becoming lost. This phenomenon is referred to as sundowning. Suspicious and paranoid thoughts intrude. The person may begin to believe their caregiver is an imposter. In the final stages, individuals lose the ability to speak and eventually, to control movement. Swallowing becomes impaired. Death is imminent.

#### More than emotionally taxing

Caring for a loved one with dementia is a costly affair. Frequently, families endeavour to care for relatives with Alzheimer's in their own homes.

Primary caregivers are often seniors themselves and may suffer from other age-related conditions. With too few hours of nursing care, families become stressed under the burden of the constant surveillance required by the person with dementia. Coping with agitation, suspicion and paranoia further challenge the caregiver. The financially fortunate can afford caregiving homes dedicated to Alzheimer's. These homes are able to provide compassionate care in a safe environment. Their extensive experience with dementia enables them to preserve the individual's dignity and quality of life despite the ravages of the disease. Families may also find support through the caregiving facility. Unfortunately, far too few families have the financial resources to afford this level of care. As Canada's population ages, the number of people with dementia will grow exponentially. In the year 2038, most of us will be in our mid-thirties. Our parents or grandparents will be of an age where Alzheimer's is a risk. By 2038, we will be the generation responsible for providing care at a cost of \$153 billion dollars each year. Collectively, during this same period, we will spend 756 million hours caring for someone with dementia. Funding for Alzheimer's research needs to increase before this disease becomes an



**Sarah Condie**  
Grade 7 student,  
Westwood Middle School

encumbrance on the entire Canadian economy.

In the time it takes you to read this, one more Canadian will be diagnosed with Alzheimer's disease. Every five minutes, one more family begins

grieving as they watch their loved one being robbed of their unique gifts and precious memories. One more legacy is left in the hands of another generation. What are we waiting for? It's time to act now.

## I'M POSSIBLE

A LESION IN MY BRAIN WAS MAKING NORMAL LIFE IMPOSSIBLE. A LESION NO BIGGER THAN AN APOSTROPHE. SOMETIMES, SOMETHING THAT SMALL CAN MAKE ALL THE DIFFERENCE IN THE WORLD. THE BRAIN REPAIR CENTRE IN HALIFAX KNOWS THAT. THROUGH RESEARCH AND STATE OF THE ART TECHNOLOGY, THEY MADE NORMAL LIFE POSSIBLE. THEY MADE MY LIFE POSSIBLE.



BRAINREPAIR.CA

BRC is a collaboration of Dalhousie University, the Capital District Health Authority, and the IWK Health Centre.



## Alzheimer's disease: it's everybody's business

### Dementia by the numbers

- Number of Canadians with dementia in 2008: 500,000
- Number of new cases every year: 103,700
- Number of Canadians with dementia in 2038: 1.5 million
- Amount of economic burden: \$15 billion
- Number of national brain strategies in Canada: 0

**Is Canada ready? It's time for a National Brain Strategy.**



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

Alzheimer Society

NEWS



**CELEBRATING MILESTONES**  
Malik and his mom, Dorrell, at his graduation.  
PHOTO: PRIVATE

# Early intervention is key for coping with autism

**Question:** What can families do to identify and cope when a child appears to be autistic?

**Answer:** Recognizing early warning signs, which include differences in development, is key to implementing early intervention.

**Dorrell Hall-Chambers' son, Malik Ingleton, was an extremely social child until just before his second birthday. It was then that "he started shutting down."**

Malik stopped responding to his name, developed an intense fascination with water and became largely non-verbal. He was diagnosed with autism a year later.

Now almost 15, Malik has never received early intervention treatment. Bureaucratic frustrations saw him on and off program waiting lists for years. He continues to await treatment, though his verbal and social skills have significantly improved, thanks to his mother's independent research and tireless efforts.

Discoveries in technology over the past five years have given research-



Malik stopped responding to his name, developed an intense fascination with water and became largely non-verbal at an early age.

**Dorrell Hall-Chambers and Malik**  
Living with autism

ers the ability to map key genes implicated in autism. These advances make earlier diagnosis—and intervention—possible.

## Genetic disposition

Dr. Steve Scherer, PhD at the Hospital for Sick Children and University of Toronto, says preliminary work has identified about 100 genes involved in autism, as well as genetic alterations associated with it.

"Typically you have two copies of most genes, but in autism, in some specific genes you merely have one copy, which seems to be a susceptibility factor."

## Early warning signs

Dr. Lonnie Zwaigenbaum, co-director of the Autism Research Centre at the Glenrose Rehabilitation Hospital, is a lead researcher in a study that monitors early warning signs for younger siblings of autistic children.

He points to atypical social development as a key indicator of the disorder.

"By a year of age, the main thing that most parents notice and researchers are able to observe include differences in how the child interacts—less eye contact, less social smiling, less social enjoyment... less use of early gestures like waving and pointing."

## Early intervention

Dr. Zwaigenbaum says genetic testing has allowed intervention programs

used for children diagnosed with autism to be modified to infants and toddlers who are susceptible. The programs emphasize emotional relationships and build communication skills.

"At this point, we don't fully understand why these early interventions work at a brain level...[but] helping those at risk experience social interaction and emotion sharing in a more rewarding way may help get them on track."

## Future of research

Dr. Peter Szatmari, professor at McMaster Children's Hospital and University and Director of the Offord Centre of Child Studies, says the hope is to develop better diagnostic tools to facilitate earlier diagnosis and better understand the biochemical pathways in the brain that lead to the disorder.

"Understanding those pathways could lead to the development of medications that make a profound difference, rather than the very wide-acting drugs we've got now, that are helpful for only certain symptoms."

**JODIE SHUPAC**  
editorial@mediaplanet.com

# How touch gives autism a voice

**When Apple released its iPad in 2010, the target demographic was a generation enthralled with constant connectivity.**

Little did the company know, the device would change the way children with autism interact with the world around them.

Although it wasn't intended for people with learning and communicating disabilities, the iPad has given third party developers a platform to create educational programs geared towards increasing social interaction amongst those students.

Bill Thompson, a school psychologist with the Orange County Department of Education in California, says he noticed most AAC (augmentative and alternative communication) devices were too bulky so he started putting pictures on iPod touch devices to help his special students communicate.

"The parents were thrilled and the children's learning went off the chart," says Thompson.

When the app store opened, Thompson partnered with his brother Steve to create iPad apps geared towards children with speech problems.

Today the device has over 65,000 apps created for it and costs less than traditional AAC devices, says Thompson.

"We're now able to access a device that costs a couple hundred dollars and inspires independence."

## Focus groups

Rhonda McEwen, an assistant professor at the iSchool (Faculty of Information) at University of Toronto, is conducting several studies surrounding the use of touch technology by people with neuro-diverse development issues such as autism.

"We've tied together communication and social interacting very tight now," says McEwen. "For some reason when they use the iPad we can identify that they're understanding what we're saying."

She says one aspect she's noticed in her studies that seems to help with learning is the force feedback feature

on the touch screen.

"It might be that for children with autism that touch helps to pass the information," says McEwen.

## Mum knows best

Shannon Rosa, whose 10-year-old son Leelo has autism, is an unlikely advocate for the product.

"I'm not really the kind of person to line up outside the apple store and wait for a product," says Rosa, who publishes a blog called [www.squidali-cious.com](http://www.squidali-cious.com) about life with Leelo.

Rosa's son won the device after purchasing a five-dollar raffle ticket.

She said it wasn't until watching her son, who, like most children with autism, has challenges when it comes to fine motor skills, manipulate the screen that she realized the potential for the device.

"A lot of the apps just focus on small segments of learning, which is what kids with disabilities need," says Rosa. "You don't have to stick with just one

style of learning, you can come at it from different ways."

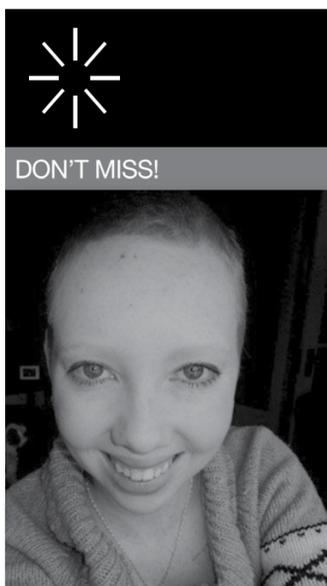
She adds that



has a hard time playing and learning independently.

"With the iPad he's totally self-directed," says Rosa.

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**Kelby Balch**  
Living with Dystonia

## Deep brain stimulation: Kelby's story

**Kelby Balch is a regular 18-year-old who blogs about music, dancing and the contrast between city and small town life.**

"I will be going to see LADY GAGA in concert at the ACC with my good, good friend Tori. I can't wait!" the teen writes of the concert she recently attended, in her Caring-Bridge blog.

Not bad considering she just had a device implanted on her brain as part of a "radical treatment" for dystonia—a neurological movement disorder that causes parts of the body to twist and contort.

"Deep brain stimulation has been in experimental use since the late 90s," says Dr. H. Christopher Hyson, Balch's doctor and Movement Disorder Specialist at London Health Sciences Centre. But the specialist says it's recent that implantable devices have been used to treat dystonia.

For Balch it took about 10 hours and was done in two parts—the first involves implanting an electrode in the brain and the second includes the tunnelling of wires to a battery implanted below the collarbone.

After the surgery, Balch says she was "programmed" to make sure the voltage, pulse and frequency of the "pacemaker" fits the patient's situation.

"Once all said and done, the electrode that was implanted then stimulates the brain to send the correct messages to the muscles, rather than the wrong ones that it was once sending out," says Balch.

## On dystonia

"Dystonia itself is not necessarily a disease—it's a symptom," says Hyson.

Balch, who first noticed the precursors to dystonia in late 2006 while preparing for a dance recital, spent the summer of 2007 waiting for news of her condition.

"That was probably one of the hardest summers," says Balch. "We didn't have a concrete answer as to why my body was contorting into these awkward positions, and we were relying on Google and the 'maybe' diagnosis of dystonia."

For the past four years, Balch has endured relentless physiotherapy, oral medications and even received Botulinum toxin (Botox) injections to loosen up her muscles and help with the symptoms.

"Since DBS and being programmed a few times already, my right wrist can now return to its natural position, allowing me that extra ounce of freedom getting back behind the wheel," says Balch, anxious to drive again.

As for her blog, Balch plans to continue to use it to educate people on the disorder.

"Not only is it a place where I can let my emotions run wild, but it is also a place where individuals struggling with the same issues can go to for support."

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# BrainWave 2011 – the launch of Canada’s first-ever National Brain Awareness Month



## Members:

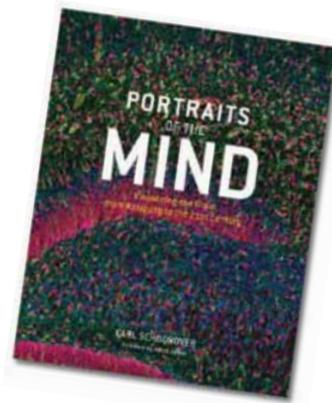
- ALS Society of Canada
- ALS Society of Ontario
- Alzheimer Society of Canada
- Alzheimer Society of Ontario
- Brain Injury Association of Canada
- Canadian Alliance of Brain Tumour Organizations
- Canadian Epilepsy Alliance
- Canadian Neurological Sciences Federation
- Canadian Stroke Network
- Dystonia Medical Research Foundation of Canada
- Heart and Stroke Foundation of Canada
- Headache Network Canada
- Huntington Society of Canada
- March of Dimes Canada
- Multiple Sclerosis Society of Canada
- Muscular Dystrophy Canada
- NeuroScience Canada/ Brain Canada
- Ontario Federation for Cerebral Palsy
- Ontario Neurotrauma Foundation
- Ontario Rett Syndrome Association
- Parkinson Society Canada
- Parkinson Societies in Ontario
- Spina Bifida & Hydrocephalus Association of Ontario
- Tourette Syndrome Foundation of Canada



The Honourable Deb Matthews

More than 300 members of the Canadian brain community came together in Toronto on March 1, 2011 to launch Canada’s first-ever National Brain Awareness Month, an effort to shine the spotlight on issues facing almost 11 million Canadians living with brain conditions (neurological and psychiatric).

The members of Neurological Health Charities Canada hosted people living with brain conditions, caregivers, researchers, clinicians, health charities and policy makers from across Canada. Canadian comedian and advocate for people living with ADHD, Rick Green, was the evening’s emcee introducing keynote speakers including The Honourable Deb Matthews, Ontario Minister of Health and Long-Term Care, and Carl Schoonover, author of the book, *Portraits of the Mind: Visualizing the Brain from Antiquity to the 21st Century*.



“Our goal is to create a platform for dialogue about brain health, and the issues facing so many Canadians and their families,” said Joyce Gordon, CEO of Parkinson Society Canada and Chair of the NHCC coalition. “Individuals and organizations across Canada can leverage National Brain Awareness Month to increase public awareness and education, and to generate important discussions about public policy.”

## 2011 Change-Maker Awards presented to outstanding leaders

As part of National Brain Awareness Month, the members of Neurological Health Charities Canada presented 2011 Change-Maker Awards to three organizations that have demonstrated outstanding leadership in inclusion, innovation and integration for the benefit of Canadians living with brain conditions.

### CONGRATULATIONS TO:

- Baycrest
- Holland Bloorview Kids Rehabilitation Hospital
- The Globe and Mail (special mention to André Picard)



Louise Bradley, Mental Health Commission of Canada CEO; Bev Heim-Myers, Huntington Society Canada CEO; Christina Vardanis, National Deputy Editor, The Globe and Mail; Joyce Gordon, Parkinson Society Canada CEO and NHCC Chair



Scott Dudgeon, NHCC founding member with Dr. William Reichman, Baycrest CEO and Joyce Gordon, NHCC Chair



Marla Spiegel, Muscular Dystrophy Canada with Sheila Jarvis, Holland Bloorview Kids Rehabilitation Hospital CEO and Joyce Gordon, NHCC Chair

## Thank you...

Canada’s Research-Based Pharmaceutical Companies



Les compagnies de recherche pharmaceutique du Canada

The members of the NHCC are grateful to Rx&D, Canada’s Research-Based Pharmaceutical Companies, for their generous support of BrainWave 2011 and Canada’s first-ever National Brain Awareness Month.

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

Neurological Health Charities Canada (NHCC) is a coalition of 24 health charities working together to improve the quality of life for all Canadians living with a brain condition. The NHCC is actively working to develop a National Brain Strategy to address the common issues facing millions and millions of Canadians and their families. To learn more about this work, or to become a member of Canada’s brain community, visit [www.mybrainmatters.ca](http://www.mybrainmatters.ca).



**NHCC**

NEUROLOGICAL HEALTH CHARITIES CANADA

The NHCC does not fundraise or share names of community members with any other organization. Contact information is used for the sole purpose of keeping members informed about the work of the NHCC, including the National Population Health Study of Neurological Conditions and the National Brain Strategy.