If you or someone you know has Parkinson’s, we’re here for you.

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

A MOTHER’S STORY OF LOSS AND LEGACY

PHOTO: USED WITH PERMISSION FROM HARPO PRODUCTIONS
PHOTO: PRIVATE

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.

If you or someone you know has Parkinson's, we’re here for you.

Parkinson Society Canada
Société Parkinson Canada

10 regional partners, 240 Chapters and Support Groups
We’re in your community
parkinson.ca 1-800-565-3000

April is Parkinson’s Awareness Month
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 model in the United States or even Europe,” says Louise Jolliet, 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 leading the brain’s rate of disability.

“They vary from economic and financial 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.

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

Fact: The estimated economic cost of brain disorders is $60 billion

Challenges

A stiffing 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.

Your brain's IQ

Your Parkinson’s IQ

The diseases we’re looking at are degenerative diseases,” says Mendez. “Disorders such as autism are much more difficult—we just don’t understand them as well.”

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 cases of remote-presence robots to service specialist needs in the northern Inuit community of Nain, Labrador.

“Researchers are seeking a cure—the use of RPR will be a part of it for sure,” says Mendez.

Diseases can strike at any age

Some conditions are present at birth, others develop during childhood, some appear suddenly during prime earning and child-rearing years, others develop slowly as we age. Regardless of diagnosis or age, the person affected, living with a brain condition presents remarkable similar needs and issues. Canada’s national brain strategy, a comprehensive and coordinated approach to the most challenging issues facing the most 10 percent of our population: integrated care and support services, income security, research, public awareness.

For a person living with a brain condition, access to health care and support services can make the difference between maintaining independence and requiring costly long-term care. Limited access to specialty care, innovative medications and treatments not covered by public programs, and insufficient support in the community, compromised 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. Featuring that caregivers are properly supported is essential to maintaining the volunteer workforce that our communities rely upon. This includes revenue as an added consequence of living with a brain condition.

Research offers the hope of uncovering new cures—a startling statistic for our time. But we’re beginning to talk about what’s really going on “upstairs”. For some time, we have been able to discover the parts of the brain, to discovering the parts of the brain, to understanding how a single neuron begins that process. “We’ve been able to use technology to decipher how a single neuron begins that process.”

Inez Jabalpurwala, president and CEO of Neuroscience Canada. “The diseases we’re looking at are degenerative diseases,” says Mendez. “Disorders such as autism are much more difficult—we just don’t understand them as well.”

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MY BEST TIPS

Eat well for brain health

If naturally occurring antioxidants (dark-skinned fruits and vegetables) to minimize free radical damage.

Up the omegas

Omega-3 fatty acids support brain function (walnuts, kiwi fruits, and cold water fish including tuna).

Healthy mind and body

Avoid trans fats and saturated fats (fried foods, sausages, bacon, meat, and dairy products).

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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/Neurosciences and the extraordinary research that takes place there, visit: www.ulethbridge.ca/ccbn

THE SHAPE OF HEALTHY LIVING

Why is DHA so important? DHA, an omega-3 fatty acid, supports the normal development of the brain, eyes and nerves. So it’s smart to get it more often. And even smarter to find ways that you and your family enjoy — like our nutritious eggs. For a serving of Naturegg™ Omega 3 eggs, you get 75 mg of DHA omega-3 and 70 mg in one of our Omega 3 Hard Boiled eggs. With Omega Pro™ shell and liquid eggs you get 125 mg of DHA omega-3 plus 1 mg of lutein per serving.

Our eggs are a healthy habit to get into.

P R O U D L Y   C A N A D I A N

FOR MORE INFORMATION AND GREAT RECIPE IDEAS VISIT US AT WWW.NATUREGG.COM
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.

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

Despite being wheelchair-bound and confined to a wheelchair by muscular dystrophy, Mattie gained world recognition as a motivational speaker and peace mentor. As a child, his writings on peace inspired millions. His words and actions—campaigning tirelessly in the name of her youngest son Mattie—kept down or debilitated by the disease.

While most kids were playing Pokémon, Jennifer Stepanek was busy. In the seven years after his death, his enduring legacy has touched many lives.

“We're an incredibly small group but we're trying to do big things,” says Stepanek. “We're trying to do big things,” says Stepanek. “Peace is a journey.”

Despite the tragedy and sorrow we're trying to do big things,” says Stepanek. “We're trying to do big things,” says Stepanek. “Peace is a journey.”

“ stroll, up a slope, or call the NHCC at (416) 227-9700 x3314.

www.mybrainmatters.ca

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 in 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 or call the NHCC at (416) 227-9700 x3314

A world of support

In October of 2006, 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.
Dystonia is an often painful neurological disorder that causes involuntary muscle spasms. Dystonia affects men, women and children of all ages and backgrounds. Dystonia affects over 50,000 Canadians.

**Fact 1.** Jennifer and Mattie.

**Fact 2.** The bronze statue of Mattie and his dog Micah at the Mattie J.T. Stepanek Park in Rockville, Maryland.

**Fact 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

One in six Canadians are providing support to a loved one at home. We have a variety of resources to help you.

Our book “Caring For Loved Ones At Home” is an easy-to-follow guide for caregivers. To receive your FREE copy, or talk about your caregiving needs call: 1.877.625.5567 or email info@saaintellabeth.com

**Caring for a loved one? You’re not alone. Saint Elizabeth is here to help.**

Saint Elizabeth is an award-winning provider of home and community care with over one hundred years of experience. We have a full range of services to fit your needs, from helping with household tasks and personal care, to expert nursing and therapy services.

**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.

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
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


www.alzheimer.ca

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.
Early intervention is key for coping with autism

**Question:** What can families look for to identify early warning signs?

**Answer:** Recognizing early warning signs, which include difficulties in learning, self-stimulatory or self-injurious behavior, and delays in social development, is key to identifying early intervention opportunities.

**FACT**

“Recognizing early warning signs, which include differences in development, is key to identifying early intervention opportunities,” says Thompson.

**EXAMPLE**

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

Little did the company know, the device would change the very 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 special needs families a platform to develop educational apps geared toward increasing social interaction amongst these students.

Bill Thompson, a school psychologist with the Orange County Department of Education in California, says the technology’s arrival has opened the door to a world of opportunities for children with autism.

“Children with autism are able to observe differences in how the child interacts—less eye contact, less social smiling, less social eye contact... less use of gestures like waving and pointing.”

Early warning signs

Early intervention is key for detecting the differences in development, which is what the iPad is designed to help with.

When Leelo’s younger brother went to line up outside the apple store and wait for a product, the mum knew best.

She says it wasn’t until watching her son that she realized the potential for the device.

“Not only is it a place where I go to for support,” says Balch, “the children are a constant reminder of why we have to show how to be a human being... it’s hard to not see the impact... it’s hard to not see the progress.”

Don’t miss!

**AN INDEPENDENT SUPPLEMENT BY MEDIAPLANET TO THE NATIONAL POST**

**MARCH 2011**

** kelley balch is a regular 18-year-old who blogs about managing dystonia—a neurological movement disorder that causes parts of my body to tighten and contract.**

“i will be going to see the lzn gaga in concert this summer. i normally attend concerts, but the special event was recently attended, in her caring bridge blog.”

Not bad considering she just had a device implanted on her brain as a form of deep brain stimulation—a neurological movement disorder that causes parts of my body to tighten and contract.

“Deep brain stimulation has been in experimental use since the late 90s,” says Dr. Christopher Hyson, director and chair of the movement disorders service at SickKids.

Part of the surgery, Balch says she was “programmed” to make sure that the wrong areas were stimulated and that the wrong neurotransmitters were released.

“One isn’t cured and the other is electively stimulated with the wrong neurotransmitters,” says Hyson.

On dystonia

“Dystonia is not necessarily a disease—it’s a symptom,” says Hyson.

For the past four years, Balch has endured relentless physical therapy, occupational therapy and medication. She has even received humanitarian teams injections to loosen up her muscles and help with the symptoms.

“Since DBS and being programmed are not a ‘radical’ approach, my right wrist can now return to its natural position, allowing me to write sentences without my extra summer... freedom of being able to move behind the wheel,” says Balch, adding, “it’s a great day.”

As for her future, Balch plans to continue to educate and advocate people on the disorder.

“i believe that there is a place where i can let my emotions run wild, but i believe it is a place where individuals struggle with the same emotions,” says Balch.
BrainWave 2011 – the launch of Canada’s first-ever National Brain Awareness Month

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)

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

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

Louise Bradley, Mental Health Commission of Canada CEO, Bro Hean-Moyer, Huntington Society Canada CEO, Christina Vardares, National Deputy Editor, The Globe and Mail, Joyce Gordon, Parkinson Society Canada CEO and NHCC Chair

Thank you...

Canada’s Research-Based Pharmaceutical Companies

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.