

ALZHEIMER'S DISEASE
This online test can determine if your memory is normal or if you should see a doctor. **p03**

ANCESTRAL STRESS
Psychological trauma experienced by ancestors can be passed onto future generations. **p07**

TECHNOLOGY
Humanoid robots that assist older Canadians with dementia. **p08**

NEUROLOGICAL CONDITIONS

PERSONALHEALTHNEWS.CA

Former WWE Wrestler Christopher Nowinski Leads Charge in Treating and Preventing Brain Injury in Athletes



Five weeks after taking a hit to the head in the ring, professional wrestler Chris Nowinski had an experience so disturbing he remembers it vividly 14 years later. While sleeping one night, he dreamt that he jumped up to catch a falling object. Moments later, he woke up on the floor. He had leapt off the bed and crashed into a nightstand. This incidence of REM Sleep Behaviour Disorder, a condition in which people act out their dreams, along with pounding headaches and nausea, convinced Nowinski that something was *really* wrong. He had post-concussion syndrome.

That was the beginning of the end of his WWE career, and the start of a life of advocacy. Perhaps more than any other individual, Nowinski is responsible for sparking the public conversation about concussions and Chronic Traumatic Encephalopathy (CTE), a degenerative disease of the brain found in athletes with a history of repetitive brain trauma.

Those with CTE, including many former football and hockey players as well as boxers, suffer from

worsening mental, emotional and physical symptoms, including dramatic mood swings, personality changes, and loss of memory. In some cases, CTE leads to severe depression and even violence.

Nowinski, who played on the Harvard University football team while doing his undergraduate degree there, wrote *Head Games: Football's Concussion Crisis* in 2006. The book examines the long-term effects of head trauma among athletes and has since been made into a documentary.

A year later, Nowinski and Dr. Robert Cantu, a neurosurgeon who had treated him, founded what is now known as the Concussion Legacy Foundation, a nonprofit organization dedicated to advancing the study and treatment of brain trauma in athletes and other at-risk groups. The organization now has a Canadian affiliate.

In 2008, the foundation partnered with the Boston University School of Medicine to form the BU CTE Centre. The centre operates the largest brain bank in the world. More than 400 brains have been do-



"REM Sleep Behaviour Disorder... convinced Nowinski that **something was really wrong**. He had post-concussion syndrome."

minated to date, helping the bank create a compelling body of evidence that illustrates the connection between brain trauma and CTE. Nowinski serves as Outreach, Recruitment, Education, and Public Policy Leader for the organization.

In 2011, researchers studied the brain of NHL enforcer Derek Boogaard, who died of an overdose of alcohol and painkillers, and determined he had been suffering from CTE.

Nowinski says the end goal is for researchers to learn how to treat

CTE, including preventing it from starting or stopping the progression of CTE. "The other challenge is prevention," he adds. "We can reduce the rate of CTE by changing the way we play sports — by banning tackling in kids' football games, for example, and by restricting hitting in practice in professional football leagues. It's the same logic that applies to smoking," he explains. "Cutting back on the number of cigarettes you smoke in a day helps reduce the risk of lung cancer."

Despite the challenges ahead, Nowinski is optimistic. "This is a fight we can win but we need everybody who cares about concussions and CTE to step up and play a role — fans and athletes along with their parents and friends. We're building a movement," he says. "But it's still early."

Randi Druzin

A New Approach to the Treatment of Cerebral Concussion

Meditech Rehabilitation has developed specific protocols to mitigate the symptom complex associated with traumatic brain injuries, resulting in the restoration of the patient's quality of life.

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**Multiple Sclerosis**

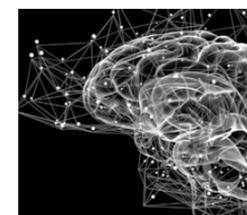
The importance of finding the right therapy to manage symptoms and uphold quality of life.

p04-05

**Brain Injury**

Canada's silent epidemic and the challenges faced by victims and caregivers.

p06

**Brain Tumours**

A current lack of Canadian data and how building a registry will help save lives.

p08

Photo: Yeganeh Ghasemi

Discoveries on the Path to Cures Have the Potential to Improve Lives

Every nine minutes, a Canadian has a stroke — it is the leading cause of severe disability.

Strokes often permanently alter the life of affected individuals and their families, as they can result in memory loss, paralysis, or diminished vision, among other consequences. Finding a cure for stroke would be transformative.

However, equally transformative are the improved patient outcomes being achieved through research that increases understanding of brain function and leads to advances in prevention, diagnosis, and treatment options. Canada is a world leader in brain research, and our scientists and clinicians are making contributions across the full spectrum from basic discovery through the pathway to cures. Brain Canada, with the financial support of Health Canada (through the Canada Brain Research Fund) and many partners and donors, is funding research in this space.

One example is the emergency stroke drug NA-1, currently being tested in a clinical trial, which has shown the potential to prevent the death of neurons when administered within three to four and half hours of the stroke.

When a person has a stroke, time is of the essence — 1.9 million neurons are lost every minute. This loss means that with every half hour that passes, the likelihood of the patient making a positive recovery decreases from anywhere between 10-20 percent. While not a cure, the impact of stroke could be reversed and the damage mitigated by as much as 50 percent if NA-1 proves effective,

**Inez Jabalpurwala**

President and CEO, Brain Canada

reducing the impact on the affected individual's quality of life after the stroke.

Research can reduce stigma. In the case of mental illness and addiction, improvements in brain imaging have allowed us to see their biological basis — that these are diseases of the brain with targets to develop treatments and, one day, cures.

Research leads to new technologies that can help reduce the burden of disease. For example, it can give someone living with amyotrophic lateral sclerosis (ALS — also known as Lou Gehrig's disease) a means to regain communication.

Prevention and diagnosis are also important targets; the latter because the earlier a disease is detected, the earlier treatment can begin. Projects supported by Brain Canada include a patient trial testing a combination of electrical stimulation and brain exercises to delay the onset and slow the progres-

sion of Alzheimer's; the development of an inexpensive retina exam to detect early signs of Alzheimer's; the implementation of a sustainable early childhood mental health intervention that engages families and communities; and the testing of a system that monitors mobility, balance, and gait to predict and prevent falls in dementia patients, which can also be used to monitor rehabilitation after a stroke.

Other studies are focused on developing or testing new treatments, including the study of techniques to deliver drugs across the blood-brain barrier, which would dramatically improve treatment options for many neurological conditions; the development of therapies to treat the millions of people worldwide who suffer from irreversible vision loss, caused by the loss of the neurons in the retina that sense light; and the implementation of a physical exercise regimen for individuals with spinal cord injury to prevent secondary complications.

The above examples, which are by no means exhaustive, are an indication of the kind of impact that research investment is having on people today, and could have in the near future.

We call on all those who are part of the community supporting and advancing brain research to help promote an understanding and vision of brain research as a process, where every discovery carries the potential to improve lives. **Q**

Inez Jabalpurwala



INSIGHT

Science Proves Program Helps Cognitive Function

**Dr. Frank Knoefel**

Physician and Clinical Scientist, Bruyère Memory Program in Ottawa and the Bruyère Research Institute

**Dr. Nouha Ben Gaied**

Director of Research and Development, the Federation of Quebec Alzheimer Societies

With at least half a million Canadians suffering from dementia, and that total expected to jump by 66 percent in 14 years, scientists are looking for new ways to treat the condition.

In a recent 10-year study, the Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE), determined that speed training — computer exercises that get users to visually process information more quickly — dramatically reduces the risk of developing dementia and prevents cognitive decline.

Posit Science Corporation, whose Canadian partner is DynamicBrain, made a modern version of that speed training as part of the cognitive training program BrainHQ.

Frank Knoefel, a physician at the Bruyère Memory Program in Ottawa and Clinical Scientist at the Bruyère Research Institute, says it's the only brain training program he recommends to patients and his own family. "One of the benefits," he says, "is that the algorithm adapts to the individual's abilities and gently pushes them to improve."

BrainHQ exercises are designed to improve memory, speed, and attention. With more than a hundred peer-reviewed studies substantiating its claims, and *TIME* magazine listing the ACTIVE study as a top scientific discovery of 2016, BrainHQ is used to help people at risk of developing dementia and to slow the progression of the condition in those who have it.

Dr. Nouha Ben Gaied, Director of Research and Development at the Federation of Quebec Alzheimer Societies, says her organization is working with DynamicBrain to incorporate BrainHQ into its program and services. "There are several brain training programs out there," she says, "but what matters to us is the scientific data behind BrainHQ." **Q**

Randi Druzin

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Dementia: A Global Health Crisis That Needs to Be Tackled

**Dr. Yves Joannette**

Scientific Director, CIHR Institute of Aging Professor, Faculty of Medicine, University of Montreal Chair, World Dementia Council

Mediaplanet How much of a public health challenge is dementia for Canada? Is the challenge the same for all countries, even developing ones?

Dr. Yves Joannette Dementia is a devastating health condition that is characterized by a progressive loss of autonomy due to the impairment of memory and other brain functions. Nearly 600,000 Canadians are currently living with dementia and this number will double over the next 20 years. In other parts of the world, the

numbers of people living with dementia will more than triple by 2050. The global economic impact of dementia is estimated to be 1 trillion dollars by next year.

MP What kind of research is needed to face the challenge of dementia?

YJ There is currently no cure for the different diseases causing dementia; therefore, extensive research is needed in three areas: (a) how to identify the initial mechanisms responsible for dementia, (b) how to slow down or stop the process once it has started, and (c) how to help those living with dementia to have the best possible quality of life. Since no single researcher, university or country can alone come up with the answers and solutions, the research needs to be collaborative and inclusive of all disciplines and sectors, such as the research supported by the CIHR Dementia Research Strategy.

MP Is there a global response to the challenges of dementia? Where does Canada fit in?

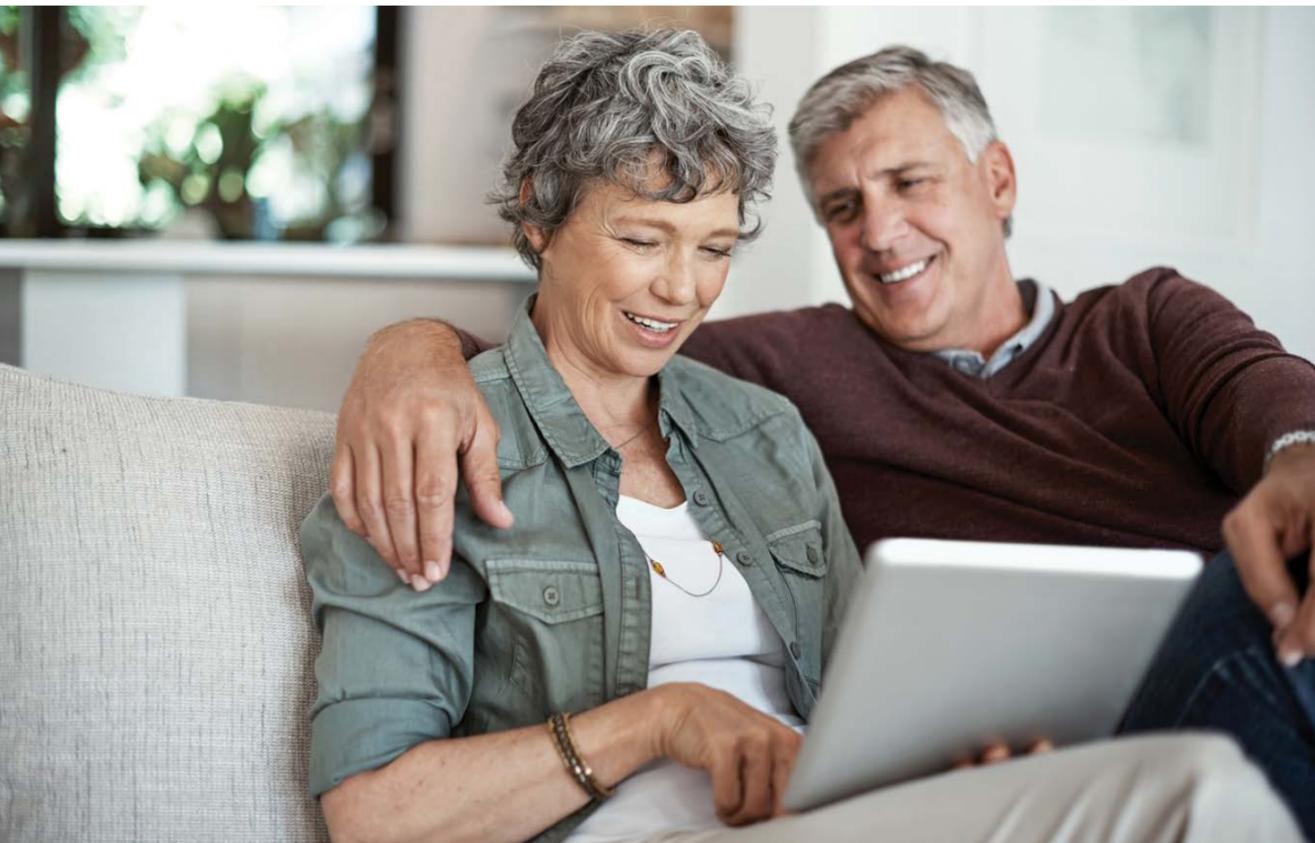
YJ The World Health Organization considers dementia to be one of the most important public health challenges.

In May of this year, all member countries of the WHO will be invited to adopt a Global Action Plan for dementia. Another prominent global organization is the World Dementia Council, which was created in 2013 by the former Prime Minister of the United Kingdom, David Cameron, as an investment in the cause for dementia. As I, a Canadian, currently chair the Council, Canada is truly at the forefront of the global response to the challenge of dementia.

MP How can we help people living with dementia?

YJ People living with dementia can be helped by a number of strategies. First, a healthy diet and physical exercise are good for both the heart and the brain. Second, keeping the brain active, maintaining a rich social network, and living with an optimistic attitude can also have positive effects. Third, supporting the caregivers is important, as their role is critical to the health and well being of the person living with dementia. Finally, enhancing the awareness of dementia in society, and understanding the needs of those living with dementia, will help them to enjoy an active presence in society as long as possible. **Q**

Check out the extended version of this article at personalhealthnews.ca **+**



ARE YOU WORRIED ABOUT YOUR MEMORY?



Take the free online assessment created by leading brain health scientists.

Most adults find it more difficult to remember names, faces, and dates as they age. But many struggle to get an answer to the question, are those changes due to normal aging or are they an early sign of something more serious such as Alzheimer's Disease?

That is why Baycrest Health Sciences, a world leader in the research on memory and aging, created the Cogniciti Brain Health Assessment. This online tool has been designed to meet the needs of concerned boomers and seniors. It is free, private, online, takes just 20 minutes to complete, and has been research-validated to provide adults ages 50-79 with an immediate brain health score and an answer to the question — is my memory normal or should I see my doctor?

More than 50,000 Cogniciti assessments have been completed by adults across Canada and beyond. If you have a desktop or laptop computer with internet access you can too. Simply go to Cogniciti's website: www.cogniciti.com.

Managing your brain health made easy

In addition to helping adults proactively manage their brain health, Cogniciti's assessment is playing an important role in developing the next generation of dementia therapies. Historically, researchers have focused on finding solutions for people suffering from Alzheimer's Disease. While this important work continues, new research is concentrating on prevention: helping adults at risk of dementia stay healthy longer.

"Once Alzheimer's disease starts interfering with day-to-day living doctors can't do anything to stop its progression. But medical science does know how to maximize healthy living in cognitively healthy adults and those with dementia through smart lifestyle choices such as exercise and diet," says Michael Meagher, President and CEO of Cogniciti (a subsidiary of Baycrest). "In addition, there are now numerous drugs in clinical trials that developers hope will become 'statins for the brain'

— drug therapies that lower the risk of Alzheimer's in adults with risk factors. The challenge for scientists is to speed the best of these solutions from the lab to those in need."

A big hurdle in getting new brain health drug and non-drug therapies to market is recruiting enough volunteers into clinical trials. The traditional process of finding volunteers through doctors' offices isn't effective, because adults who see their doctor for a memory issue are often too far into the disease process to qualify for at-risk studies. And print and TV ads have been attracting too many healthy adults. Cogniciti's assessment addresses this issue by inviting adults who have completed the test to join a free Research Registry for brain health studies. Cogniciti's team uses the data from the assessment to match Registry volunteers to clinical research studies that fit their brain health scores and health history. The result: a much smoother and effective process for all concerned.

The importance of being proactive

Shirley Whitfield knows all too well how dementia can shatter lives. Both of her parents and all four of her grandparents suffered from the disease.

"I remember as a young child being quite frightened by the behaviours of my grandparents due to the impact of their cognitive disorders," says the Windsor, ON resident.

Dementia also figured prominently in Whitfield's work life. A retired geriatrics nurse, she regularly witnessed how memory problems frustrated patients and diminished their quality of life. This aging-related disease is more top-of-mind for Whitfield now that she's approaching 70, and because dementia is often genetic.

"My personal history combined with my work experience have left me hungry for better ways to proactively manage my brain health," she says.

Proactively managing your brain health is easy. All it takes is 20 minutes and a visit to www.cogniciti.com.

Gavin Davidson

Is my memory normal or should I see a doctor?

Take the free online brain health assessment validated by scientists from Baycrest, a world leader in the research of memory and aging.

Many adults over the age of 50 have a little more difficulty than they used to remembering names, faces, and dates. They wonder if this is simply normal aging or something to discuss with their family doctor. There is now an online tool to help with that decision that has been research-validated to help you to answer this question.

The Cogniciti Brain Health Assessment is:

-  Free
-  Quick 20 minute online test
-  Private
-  Science-validated for ages 50 – 79



Start your free assessment today!
Go to www.cogniciti.com

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Available MS Treatments Have Nearly Tripled Since 2005



You may know that Canada has the highest rate of multiple sclerosis (MS) in the world, with an estimated 100,000 Canadians living with the disease. But did you know that approximately 85 percent of Canadians with MS are initially diagnosed with treatable relapsing-remitting multiple sclerosis (RRMS)?



Dr. Jiwon Oh
Staff Neurologist, St. Michael's Hospital,
Scientist, Keenan Research Centre of the
Li Ka Shing Knowledge Institute,
Assistant Professor, Division of
Neurology, University of Toronto

Effective therapies exist for RRMS
The three main types of multiple sclerosis are PPMS (primary-progressive multiple sclerosis), SPMS (secondary-progressive multiple sclerosis), and RRMS, which is by far the most common. The two main presenting types of MS are RRMS and PPMS, which unfortunately does not yet have any approved treatments. The number of women and men affected by PPMS are approximately equal, and the onset tends to be in one's 40s or 50s. In RRMS, for which numerous effective therapies are available, women are affected two to three times as often as men and most people are diagnosed in their 20s and 30s. Over time, people living with RRMS can transition to SPMS.

parent progression of the disease during periods of remission. Although not all people with MS will experience all symptoms, the most common include vision problems, spasticity or stiffness, bowel and bladder problems, fatigue, episodic bouts of numbness, and problems with cognition (learning and memory or information processing).

Early diagnosis is key
MS attacks the protective covering — myelin — of the brain and spinal cord, as well as the axons underlying myelin, causing inflammation and damage. When this happens, the usual flow of nerve impulses is interrupted or distorted. Because the relapsing phase of the disease is characterized by ongoing inflammation, it is essential to diagnose the disease and begin treatment as early as possible.

Medical history and a neurological exam are fundamental to diagnosing MS, but such a diagnosis is only made once other potential causes for symptoms have been ruled out. As there is no one test that can be used to diagnose MS, doctors leverage a variety of available tools in diagnosing patients as quickly and accurately as possible.

"Although diagnosis can sometimes be challenging in the initial stages, the increased availability and use of magnetic resonance imaging (MRI) has greatly facilitated the diagnosis of MS, and we are now able to identify MS

earlier," says Dr. Oh. "Another huge benefit of using new technologies such as MRI is that they help us to personalize treatment for individual patients, which is currently a huge unmet need in clinical practice."

Having multiple treatment options for MS is beneficial for patients
As MS is a variable disease, and no single pathway, diagnostic test or reliable biomarker has yet been identified to predict how patients will fare on specific treatments, it is essential MS patients have multiple treatment options, as well as the flexibility to transition to another treatment when needed. Moreover, there are genetic variants within the disease that have been shown to vary significantly across different populations and individuals, heightening the need for individualized therapies.

There are a growing variety of ways to manage MS symptoms, ranging from pharmacological treatments to non-medicinal strategies such as physiotherapy, occupational therapy, and diet and exercise programs. Given that MS is a lifelong and, as yet, incurable disease, the long-term safety and tolerability of treatments are important considerations in selecting therapies for individual patients, both in terms of efficacy and compliance.

"One of the greatest difficulties we have is that MS is an extremely variable disease, so when you're diagnosing someone it can be tricky to decide on the right course of treatment," says Dr. Oh. "That's why we need technology not just for diagnosis, but for helping us to tailor treatment appropriately."

An exciting time in MS research
Twenty years ago, tailoring MS treatments to individual patients was unheard of, but the treatment scenario of multiple sclerosis has radically changed. Dr. Oh points to the fact that there were no disease-modifying treatments available until the early 1990s, and it was not until 2005 that a shift truly occurred. Now, the increasing availability of effective disease-modifying therapies has shifted the aim of therapeutic interventions from a reduction in relapses to the absence of any signs of MS.

"Since 2005, we have nearly tripled the agents available to treat people with RRMS," says Dr. Oh. "In part because of the increased treatment options, but also because our understanding of MS is very quickly changing, doctors have become much more aggressive in terms of identifying MS early and quickly changing treatments as required by a patient's needs."

Researchers such as Dr. Oh continue to work toward finding the cause of MS, developing better treatments with fewer side effects, and ultimately hope to cure the disease. But in the meantime, it is heartening and important to know that through a variety of currently available treatment options, health and wellness, including emotional well-being, can be achieved even in the presence of a chronic illness or disability such as MS. ●

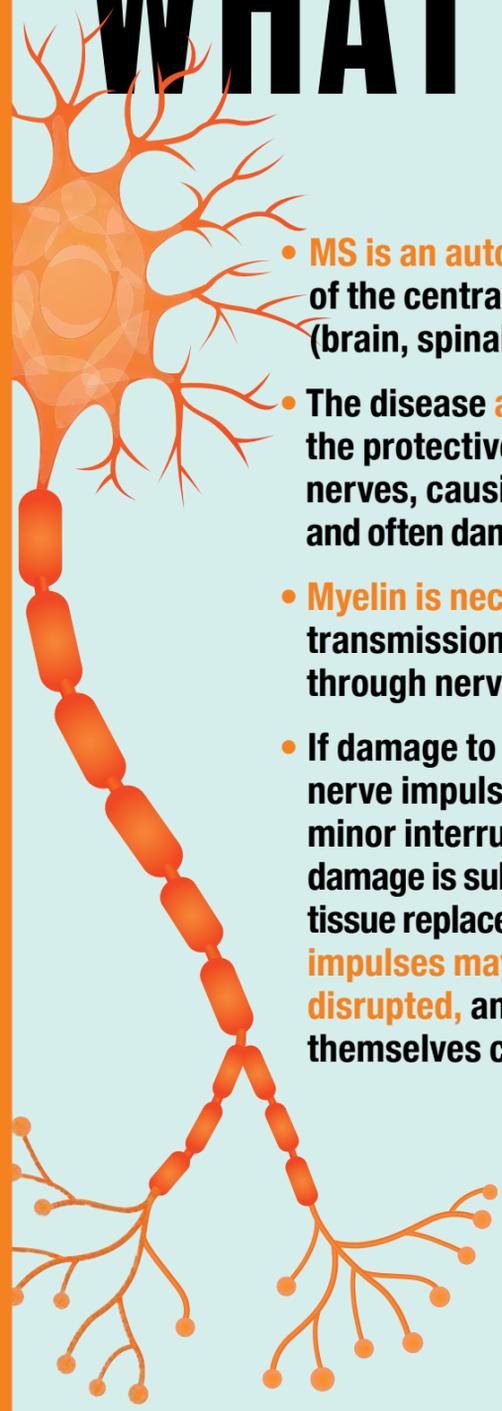
Gravin Davidson

"It is essential MS patients have multiple treatment options."

"MS is distinct from many other common chronic neurological diseases because the median of onset is in one's late 20s and early 30s," explains Dr. Jiwon Oh, a physician at St. Michael's Hospital and a leader in MS research and treatment. "So as you can imagine, this is a disease with the potential to significantly impact people's lives."

RRMS is characterized by clearly defined attacks of new or increasing neurologic symptoms, which are followed by periods of remission, during which symptoms may improve or disappear. While some symptoms may continue and become permanent, there is no ap-

WHAT IS MS?



- MS is an autoimmune disease of the central nervous system (brain, spinal cord).
- The disease attacks myelin, the protective covering of the nerves, causing inflammation and often damaging the myelin.
- Myelin is necessary for the transmission of nerve impulses through nerve fibers.
- If damage to myelin is slight, nerve impulses travel with minor interruptions; however, if damage is substantial and if scar tissue replaces the myelin, nerve impulses may be completely disrupted, and the nerve fibres themselves can be damaged.

POTENTIAL RISK FACTORS

- Lifestyle habits
- Age
- Gender
- Family history

COMMON SYMPTOMS

- Extreme fatigue
- Lack of coordination
- Weakness
- Tingling
- Impaired sensation
- Vision problems
- Bladder problems
- Cognitive impairment
- Mood changes

IMPACTS

- Physical
- Mental
- Social
- Financial

People aged 20-30 are the **MOST DIAGNOSED**



Finding the Right Therapy Combination for MS Patients

Rona McGugan is a beacon of positivity. Although she suffers from multiple sclerosis (MS), a lifelong disease that requires multiple types of treatment, she has a good quality of life and hope for the future due to finding the right combination of therapies.

Facing the diagnosis

MS is currently classified as an autoimmune disease of the central nervous system, which comprises the brain and spinal cord. While it is most often diagnosed in young adults aged late 20s and early 30s, younger children and older adults are also diagnosed with the disease. Despite decades of research, the cause of MS remains a mystery. There are theories that environmental, genetic, and biological factors all play a role in MS.

MS is unpredictable and can cause symptoms such as extreme fatigue, lack of coordination, weakness, tingling, impaired sensation, vision problems, bladder problems, cognitive impairment, and mood changes. Its effects can be physical, emotional, and financial.

"When I was diagnosed, my condition was pretty awful," recalls McGugan, who suffers from relapsing-remitting multiple sclerosis (RRMS). "After suffering through dizziness, memory loss and loss of concentration, I had a serious episode which led me to visit my doctor."

"After suffering through dizziness, memory loss and loss of concentration, I had a serious episode which led me to visit my doctor."

Finding the right therapy

RRMS is characterized by clearly defined attacks of neurologic symptoms, much like the one experienced by Rona, and it is treatable. But the recent explosion in available therapies for RRMS has brought new complexities to treatment decisions faced by physicians. More and more, doctors need to anticipate the impact of a particular therapy on a specific patient before deciding on treatment sequencing.

McGugan worked closely with her physician, Dr. Jiwon Oh of St. Michael's Hospital, to develop a multi-pronged approach to treatment that includes a disease modifying therapy and daily oral medications to manage symptoms,

along with yoga every morning, which was suggested by McGugan's physiotherapist.

"Dr. Oh recommended this therapy combination right after my first episode, and I've been on the same treatment for the past four-and-a-half years," says McGugan. "It's been a huge help to be on the right therapy, as I have not had any more episodes since I started treatment."

Focusing on the positive

While there is currently no cure, every day researchers are learning more about what causes MS and are zeroing in on ways to prevent it. Studies funded by the MS Society are looking at whether certain risk factors, such as lifestyle habits, age, gender, or family history impact a person's susceptibility to MS. Progress is being made every day and more new treatments are on the horizon.

"It is a huge motivating force and extremely rewarding to be able to see things that were just a concept at one point being applied every day in practice," says Dr. Oh. "I continue to balance research responsibilities with my

clinical duties because it directly benefits the patients in front of me."

This particular patient, Rona McGugan, has always been one to look on the bright side. She is certainly very thankful to have a leader in MS research and treatment such as Dr. Oh based right here in Canada. And she is optimistic that the tremendous progress made in MS treatment over the past 20 years is just the beginning.

"You can never lose hope," she says. "I'm thankful I'm in this treatment program because it's been a great help to me and I have hope that things will get even better in the future." 

Gavin Davidson



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Brain Injury: Canada's Silent Epidemic

Brain injuries can be caused by many factors including motor vehicle accidents, falls, sports injuries, physical abuse, and alcohol-related incidents. Generally, the public doesn't realize how widespread brain injuries are or the extensive and potentially devastating effects they can have on physical, cognitive, emotional, and behavioural levels. A traumatic blow to the head can lead to the disruption of brain functioning, resulting in confusion, forgetfulness, headaches with associated symptoms, and behavioural issues including depression. Although some head injuries may not immediately appear to be serious, many have long-lasting and very detrimental effects.

Complex challenges for victims and caregivers alike

According to Brain Injury Canada, 160,000 Canadians suffer a brain injury annually. The World Health Organization estimates 10 million people per year are affected by a traumatic brain injury (TBI); however, this number is likely underestimated due to common misconceptions as to what constitutes a brain injury. In Canada, income lost (indirect costs) from disabilities related to brain injuries are predicted to rise from \$7.3

to \$8.2 billion between 2011 and 2031, which exceeds the indirect cost of the sum of six other neurological conditions, including epilepsy and multiple sclerosis, combined.

The stress on caregivers can be huge. As one caregiver noted, "Brain injury doesn't just change the life of the individual. It changes the lives of everyone around them." When brain injury is accompanied by cognitive impairment and/or behavioural issues, it can cause caregivers (most often the family members of those afflicted) potentially overwhelming distress. These indirect and human costs are added to financial costs that often include out-of-pocket expenses for care and medication. Compounding this situation is the lack of regulatory blood/body fluid tests for victims of brain injury, which are key to accurate diagnoses and effective treatment. The Canadian Traumatic Brain Injury Research Consortium is currently addressing this difficult situation.

Navigating the health care system can be difficult and is made even more challenging by the lack of uniformity of care. Some treatment centres, for example, are designed to offer acute care and may not accept referrals for patients who need ongoing care. To further complicate things, the needs of patients

and their families are often complex and multifaceted, as several factors — namely, the interaction between genes, the environment, and lifestyle — play a role when it comes to chronic conditions. Treatment often includes modifiable personal lifestyle factors such as sleep/relaxation, exercise/movement, nutrition, stress/self-management, and social relationships.

Making progress to offer better care

Affecting all age groups and areas of the country, the epidemic of traumatic brain injuries requires a proactive

and comprehensive approach, including a robust applied research agenda. The federal government is currently polling Canadians about its proposed inclusive Disabilities Act. In tandem, Employment and Social Development Canada has crafted a Social Development Partnership Program involving community-based disability groups. This program is informed by Australia's existing inclusive National Disability Insurance Scheme.

The good news is that significant progress is being made both in terms of bio-medical research and clinical care for patients with brain injuries. But much more needs to

be done, from public education to active government leadership. The tens of thousands of brain injury patients and their families and caregivers deserve no less. **Q**

*Daniel C. Andraea
Suzanne McKenna
Richard J. Riopelle*

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Steps Toward a Canadian Action Plan for Brain Health

Kayleigh has Rett syndrome. Seemingly healthy until she was 23 months old, she then lost the ability to speak, to use her hands, and eventually to walk.

Caring for a child with a neurodevelopmental disorder — like Rett syndrome — can consume the life of an entire family. When Kayleigh reached 18, she was discharged from five specialists at the local children's hospital and her care switched to the family doctor. He became responsible for the management of her seizures, cardiac and urological issues, gastrostomy tube, osteoporosis, pain, and so much more. Leaving the coordinated care at the children's hospital for decentralized medical care has been overwhelming for Kayleigh and her family. Kayleigh's story is one amongst millions of individuals and fam-

ilies affected by brain conditions. Brain conditions affect an individual's mobility and damage dexterity; they impair memory and the ability to think; they make it hard to see, speak, and communicate. Caring for someone with a brain condition leaves many Canadian families and caregivers feeling isolated and struggling to maintain their own emotional and mental health.

Neurological Health Charities Canada (NHCC) know, there are solutions — solutions that build directly on the findings of the ground-breaking National Population Health Study of Neurological Conditions.

The first step is for the Government of Canada to work with NHCC on the first-ever Canadian Action Plan for Brain Health. The Action Plan would spur research into desperately needed treatments and cures and would, by bringing people

with brain conditions together with experts, finally develop health and non-health services to truly support those living with brain conditions, their families, and caregivers.

NHCC is a coalition of organizations representing individuals and families affected by brain diseases, disorders, and injuries. **Q**

Go to www.mybrainmatters.ca to learn more about the Canadian Action Plan for Brain Health.

Deanna Groetzinger

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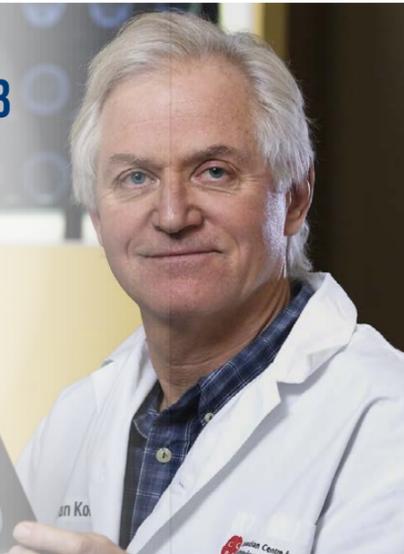
NHCC volunteers Cynthia Milburn (Canadian Epilepsy Alliance) and Terry Boyd (Ontario Rett Syndrome Association) meet with MP Don Davies to discuss the Canadian Action Plan for Brain Health.

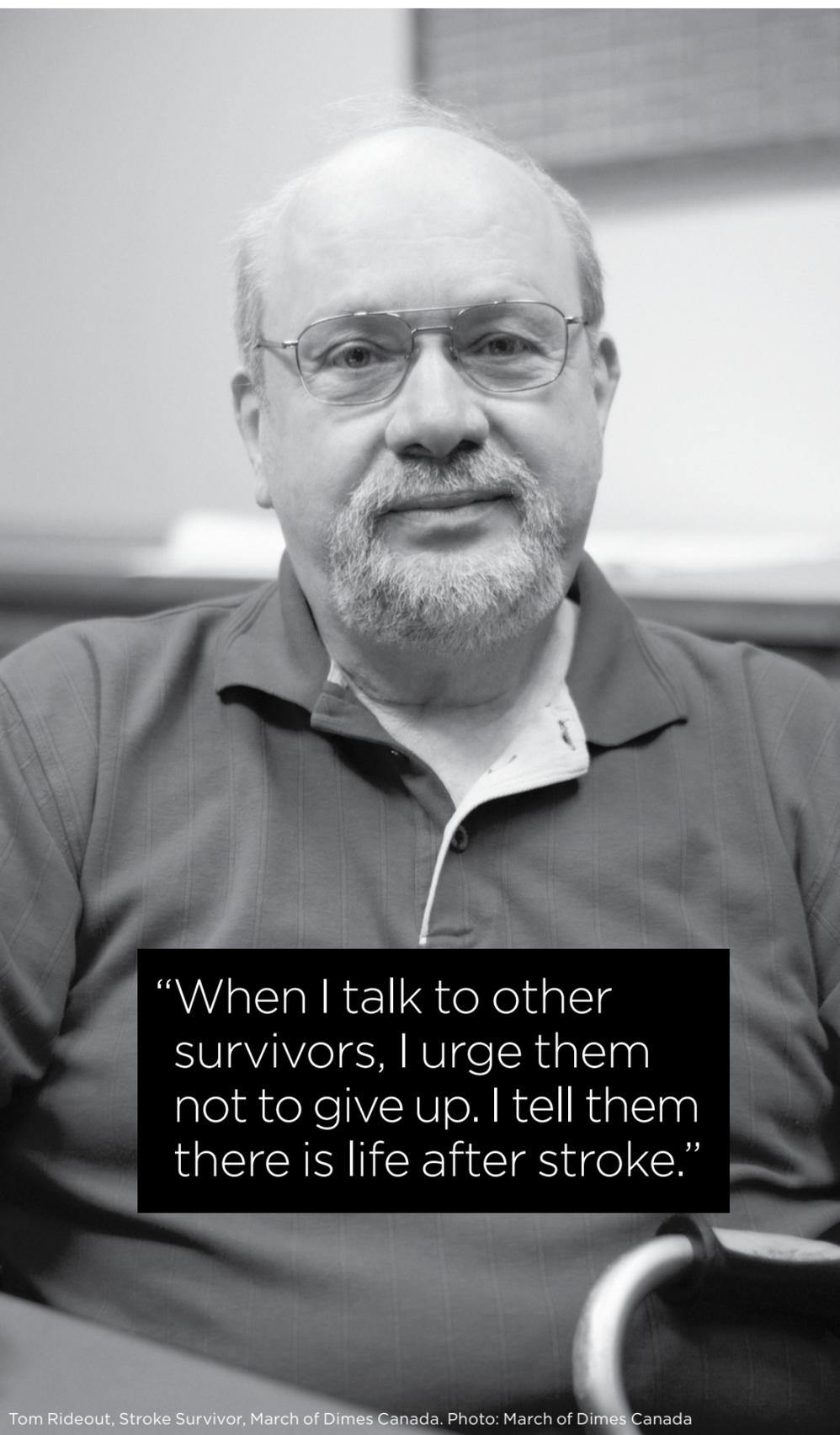


THE UNIVERSITY OF LETHBRIDGE CONGRATULATES DR. BRYAN KOLB ON HIS APPOINTMENT AS AN OFFICER OF THE ORDER OF CANADA.

Dr. Kolb is an internationally renowned behavioural neuroscience expert and academic, and his explorations have revolutionized brain science. A University of Lethbridge faculty member since 1976, co-founder of the University's Canadian Centre for Behavioural Neuroscience, and honorary degree recipient, Kolb has been instrumental in establishing the U of L as a world leader in neuroscience research.

We thank Dr. Kolb for his pioneering research, inspiring a passion for discovery in countless students, and his dedication to advancing the health of Canadians for generations to come.





“When I talk to other survivors, I urge them not to give up. I tell them there is life after stroke.”

Tom Rideout, Stroke Survivor, March of Dimes Canada. Photo: March of Dimes Canada

March of Dimes Canada Helps Stroke Survivors Rediscover Joy in Life

Tom Rideout was mid-conversation when he felt an intense pain in his head. The next thing he remembers experiencing was waking up in a Toronto hospital four weeks later and learning he had suffered a stroke. At the age of 46, he was unable to speak or move the right side of his body.

In the months that followed, Rideout found life to be unbearable. “I didn’t want to live because I felt useless,” he says, looking back 13 years. After suffering another stroke, he attempted suicide for a second time — this time saved by bystanders in the subway. “They asked me what was wrong and I just broke down in tears.”

Rideout turned a corner when he was put in touch with Stroke Recovery Canada, a national service run through March of Dimes Canada offering support, education, and community programs for stroke survivors, along with their family members and caregivers.

“I attended support group meetings, and as I got more involved I started spending more time laughing and less time crying.”

Rideout is just one of many stroke survivors who has found a new lease on life through March of Dimes Canada, one of the largest community-based service providers for people with physical disabilities in the country.

Since the 1980s, the organization has devoted growing amounts of resources to helping stroke survivors, a population that includes people of both genders and all ages. In fact, survivors of stroke comprise the highest percentage of people affiliated with March of Dimes Canada. With at least one Canadian suffering a stroke every 10 minutes — the incidence is higher in black and South Asian communities — there are about 400,000 survivors and that number is expected to grow due to Canada’s aging population.

“Our organization is not focused on finding a cure for stroke,” says president and CEO Andria Spindel. “We’re focused on providing support, care, and education for survivors and the people close to them. We’re focused on improving the survivors’ quality of life. We would like to see them lead independent lives full of activity, engagement, and meaning.”

To that end, the March of Dimes Canada runs the Aphasia and Communications Disabilities Program, which is funded by the Central Local Health Integration Network. Its mandate is to improve the quality of life for survivors with aphasia — the loss of the ability to articulate ideas or understand language, resulting from brain damage caused by injury, stroke, or disease — through services and mutual aid groups. Speech-language pathologists play a key role in assessing and treating survivors’ communication and cognitive skills.

Among the many other services the organization provides is the Stroke Recovery Warmline. It connects survivors and their caregivers with various services and peer support groups, which organize local meetings, activities, and seminars providing practical and emotional support.

Fourteen years after contemplating suicide, Rideout is dedicated to helping other stroke survivors rediscover the joy in life through Peers Fostering Hope, a program in which survivors visit hospitals and support groups. “When I talk to other survivors, I urge them not to give up. I tell them there is life after stroke,” he says. “No one knows that better than me.”

Stroke Recovery Canada Warmline:
1.888.540.6666

Stroke Recovery Website:
www.marchofdimes.ca/EN/programs/src/Pages/src.aspx

Randi Druzin

Research Raises Hope for **Reversing** Neurological Effects of Early Adversity



Dr. Bryan Kolb
Canadian Centre for
Behavioural Neuroscience,
University of Lethbridge

Dr. Bryan Kolb played a founding role in the study of neuroscience. As a neuroscientist at the Canadian Centre for Behavioural Neuroscience (CCBN), Kolb’s primary interests are in brain development, brain plasticity, and brain changes over time, including after injury. A recipient of the Order of Canada, Kolb has published five books and more than 400 articles and chapters. In the process, and with the help of a pioneering faculty and research team, Kolb has turned the University of Lethbridge, a relatively young institution currently celebrating its 50th anniversary, into a hotbed for neuroscience research.

Reducing the effects of early adversity on the brain

Over the past two decades, Kolb’s re-

search has focused on understanding how early experiences alter brain and behavioural development, in both positive and negative ways, including whether it is possible to intervene after negative events and reverse, or at least reduce, the effects of early adversity.

“Our brains actually form using what I call the Michelangelo Technique,” explains Kolb. “Much like he did when chiselling David from a solid block, we start out with a brain that has two-fold more cells than an adult brain before environmental chisels start shedding cells once we are born.”

Animal research by Kolb, his colleague Dr. Robbin Gibb, and their students has even shown that a father’s experiences before conception and a mother’s experiences while pregnant can change the brains of their offspring and those of subsequent generations. Realizing the value of this

knowledge not just to neuroscience, but also to society in general, Kolb is now dedicating much of his time to talking about the implications of this important discovery.

“Given my age, I see my role changing,” says the 70-year-old Kolb. “I give a lot of public talks to try to bring this knowledge to the communities not only in southern Alberta, but beyond, to try to explain some of these things in words that people can understand.”

Using neuroscience to help native communities heal

One of Kolb’s most memorable talks was a public lecture in Lac La Biche, AB, attended by many First Nations elders. He spoke about how stress and abuse during childhood can cause certain genes in the brain to be turned on or off, and how these changes can be passed

from one generation to another — altering the behaviour of the offspring. Through this explanation, the elders began to see the problem of residential schools in an entirely new light.

“It gives us an explanation for how severe stress, for example in residential schools, could cross generations and cause all kinds of problems later,” says Kolb. “So how can we change this? I think the place to start is recognizing why it’s happening.”

Thanks to institutions like the CCBN, recognition is certainly beginning to spread. But the wide-ranging societal implications of the ongoing research, being conducted by Kolb at the University of Lethbridge, suggests the most important work — actually reversing the neurological effects of early adversity — is still to come.

Gavin Davidson

Photo: Bryan Kolb
Canadian Centre for Behavioural
Neuroscience, University of Lethbridge

New Technologies for Healthy Aging and Better Brain Health

Sponsored by



As Canada's population ages, finding ways to support older Canadians in living full and independent lives is crucial.

AGE-WELL is a pan-Canadian network of researchers, non-profits, industry, government, older adults, and caregivers that is harnessing the power of new technologies to provide useful solutions for healthy aging.

"When I was fresh out of engineering school, I met a man who was caring for his wife who had early onset dementia," says AGE-WELL Scientific Co-Director Dr. Alex Mihailidis. "He was telling me about all the difficulties they had and he said, 'Wouldn't it be great if technology could help us solve these problems?' That idea really stuck with me."

Solutions for aging's varied issues

Today, AGE-WELL research teams are developing humanoid robots that can assist older Canadians with dementia in their homes by reminding people of tasks and routines, playing brain-strengthening games with them, and even acting as a remote avatar for medical professionals.

Another team is testing a smart glove which takes the same vibration-damping technology that stabilizes buildings against earthquakes, and uses it to reduce hand tremors from Parkinson's disease and other movement disorders.

There's a new tablet software that analyzes a person's speech to detect and monitor Alzheimer's. And an add-on system that turns a regular powered wheelchair into one that automatically alerts the user to obstacles. The list goes on.

Not just better technology, but better access to it

"We have over 40 research projects underway that will benefit older people, including those with neurological conditions, and their caregivers — while also producing economic and social benefits for Canadians and the global community," say AGE-WELL Scientific Co-Director Dr. Andrew Sixsmith.

"One common challenge that people have is identifying the services, supports and technologies that are available to them, and finding the right ones for their needs," he says. AGE-WELL teams are developing powerful online platforms that match people with the right solutions.

Interwoven with all these initiatives are questions of privacy, ethics, and access. What are the consent issues surrounding assistive technology for people with dementia? When does Internet connectivity of smart home systems become a privacy concern? What can be done to enhance access to technologies across the country? AGE-WELL sees these questions not as afterthoughts but as fundamental to the mission.

It's this big picture approach that is positioning Canada to become a world leader in the development of technologies for healthy aging. "Canada has great talent in this area," says Dr. Mihailidis. "And a key mandate of AGE-WELL is to bring everyone together and make Canada a global leader in this field."

Launched in 2015, AGE-WELL is a federally funded Network of Centres of Excellence.

D.F. McCourt



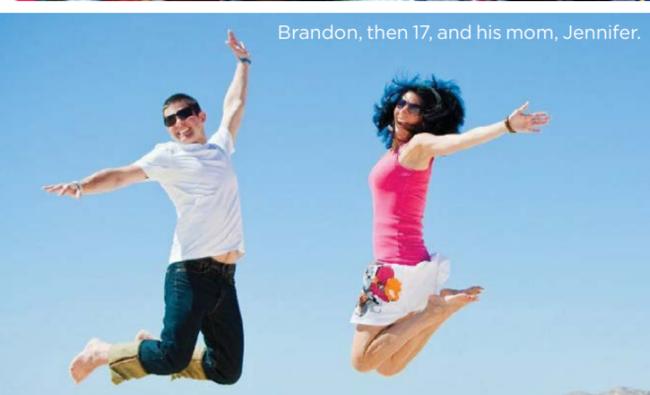
AGE-WELL research. Photos: AGE-WELL



(Left) Dr. Pooja Viswanathan and the innovative add-on feature that can transform a regular powered wheelchair into a "smart" wheelchair. (Right) Dr. Goldie Nejat and Casper the robot.



Brandon battled against brain cancer for 14 years. Photos: Jennifer Gouchie-Terris



Brandon, then 17, and his mom, Jennifer.

BUILDING A BRAIN TUMOUR REGISTRY WILL SAVE CANADIAN LIVES

An estimated 55,000 Canadians live with brain tumours, with 27 new diagnoses made every day, according to the Brain Tumour Foundation of Canada. While those are important figures, a complete picture of brain tumour health issues amongst Canadians is not available due to a lack of crucial data.

Dr. Faith Davis, Vice-Dean of the University of Alberta's School of Public Health, is determined to change that. Backed by 20 years of experience with brain tumours, she has become one of the leaders in creating a Canadian Brain Tumour Registry. "There's an urgent need for data to be recorded completely and accurately," she says.

The Brain Tumour Registry could produce its first report in 2019 — one that could save lives by providing health care professionals with more comprehensive data. "Right now, we just don't know how widespread brain tumours are in this country," Dr. Davis explains. "The figures we have are based on statistics from the United States that may not apply here. Canada may have some of the highest rates of brain cancer in the world, according to one report."

A mother's quest to assist others

As a mother who lost her son to a brain tumour, Jennifer Gouchie-Terris, a journalist from Riverview, NB, is equally committed to making a national registry a reality. Her son,

Brandon, was just 18 years old when he passed away, ending his battle with a non-malignant low-grade glioma, which began at age four.

Brandon's initial symptoms — vomiting, headaches, and a loss of balance — had doctors stumped. "There was a long time before diagnosis because brain tumours just aren't on the radar for many physicians," Gouchie-Terris says.

Unfortunately, over the last 50 years, very little progress has been made in the treatment and long-term survival rates of brain tumour patients. A lack of good statistics plays a big role in this stagnation.

Things are changing, however. Gouchie-Terris was successful in collaborating with her local member of parliament, Bill Casey, to introduce the Private Members Bill M-235 to establish the Canadian Brain Tumour Registry on Valentine's Day, 2007. She and Brandon met with former Prime Minister Stephen Harper in Ottawa just before the bill was passed in the House of Commons. It was a victory, but there was no money attached to the bill, and the need for funding is critical.

Brandon worked to boost awareness, visiting schools, hosting and funding fundraising events, and sharing his story far and wide. "He was very unselfish," his mom says. Even after his death in October of 2012, he fought for the cause by donating his organs and brain to research.

Gouchie-Terris and her husband Darren are continuing the work they started. Last fall, the couple embarked on a 500-km trek as part of the Riding for the Registry fundraiser and cycled from Cambodia to Bangkok, Thailand, raising a total of \$60,000 for the cause. "I find comfort in moving forward with what we started, establishing the registry and helping other families affected by brain tumours," Gouchie-Terris says. "It's Brandon's legacy. I can still hear him saying, 'Good for you, mom! I'm so proud!'"

Getting involved

With much important groundwork completed, the next step for moving the registry forward is getting the necessary funds. The provinces and the medical community are on board. Now, it's up to Canadians to build on the efforts of people like Dr. Davis and Jennifer Gouchie-Terris by donating to the Brain Tumour Foundation of Canada (braintumour.ca), the non-profit organization currently celebrating 35 years of providing hope and support.

"This registry is within reach if we can get the funds needed," Gouchie-Terris says. "We hope to build a tool that will help us understand brain tumours better and to spare Canadian families the heartache we experienced."

Visit www.BrainTumour.ca for more information.

Michele Sponagle

PEOPLE AFFECTED BY BRAIN TUMOURS SHOULD NEVER WALK ALONE

Brain tumours are unpredictable and complex. They can affect vision, hearing, memory, balance and mobility. Their effects are physical, emotional, financial, and last a lifetime. There is no cure.

Brain Tumour Walk events help Brain Tumour Foundation of Canada support thousands of Canadians affected by a brain tumour through information, education, support and research.



JOIN THE MOVEMENT TO END BRAIN TUMOURS

Walk Locations:

- | | | |
|------------------|--------------------|-------------|
| Belleville | Kitchener-Waterloo | Sudbury |
| Brampton | London | Toronto |
| Calgary | Montréal | Vancouver |
| Edmonton | Newfoundland | Victoria |
| Fredericton | North Bay | Windsor |
| Guelph | Ottawa | Winnipeg |
| Hamilton-Niagara | Saskatoon | Yellowknife |

Register Now:

www.BrainTumourWalk.ca

