



CTRC

Canadian Traumatic Brain Injury
Research Consortium

TBI as a chronic condition

Alexis Turgeon, MD, MSc

Co-Chair, CTRC

Professor, Department of Anesthesiology & Critical Care
Medicine

Faculty of Medicine, Université Laval, Québec City, Québec,
Canada

Canada Research Chair in Critical Care Neurology and Trauma



Vision

- A **collaborative, integrated and impactful Consortium structure** for the Canadian TBI research community, and to elevate Canadian research in the field to a new level

What is the CTRC?

- Facilitate linkages, communication and knowledge translation across the Canadian TBI research community
- Help support research that will help integrate national TBI research efforts and align them with global research efforts
- Help develop and support investigator-led multicenter TBI research in Canada

CTRC Structure



DR. JAMIE HUTCHISON
Co- Chair
Canadian Traumatic Brain
Research Consortium



DR. ALEXIS TURGEON
Co-Chair
Canadian Traumatic Brain
Research Consortium

CTRC Structure

- **Co-chairs:** Jamie Hutchison, Alexis Turgeon
- **Members:** Carolyn Emery, Isabelle Gagnon, Michelle McDonald (Brain Injury Canada), William Panenka, Keith Yeates, Cheryl Wellington, Anne Wheeler, Olivier Costerousse (coordinator),
- Meetings organization
- Operationalization of the CTRC
- Strategic planning

CTRC Structure

- Executive Committee
- Training and career development Committee
- Knowledge Synthesis Platform
- Grants and Manuscript Review Committee

Scientific Meetings

- Open and inclusive process
 - Presentation request by members
 - Submission of a structured abstract
 - Questions to the group planned in advance
 - Presentation of projects/programs
 - Discussion by the group
 - Endorsement of the project/program as a CTRC project/program
 - Document collaborators interested in participating
 - Presentations and discussions minuted

The CTRC in brief

- >400 Members
 - > 150 Researchers
 - > 200 Trainees/Students
 - > 35 Research Coordinators/Research Associates
- 75 Different institutions
- >150 Independent researcher Projects/Programs of research

Patients and patient representative involvement

- Patient-partners involvement
- Patient-partner organisations
 - Brain Injury Canada
- Involved in the prioritization of research, development of research programs and



Traumatic Brain Injury: A Lifelong Condition

Moderate to Severe Brain Injury as a
Chronic Condition

Calling to action to Designate Moderate to Severe TBI as a Chronic Condition

- Traumatic Brain Injury: A Lifelong Condition
 - Moderate to Severe Brain Injury as a Chronic Condition
- A moderate or severe TBI is a devastating event—not only in the instance it occurs, but for most individuals, in the years that follow. This single event triggers a chronic condition, a process that results in varied and complex care needs.

Calling to action to Designate Moderate to Severe TBI as a Chronic Condition

My severe brain injury just didn't happen to me. It happened to my whole family. My husband suddenly didn't have his wife, and our children didn't have their mother. The injury never goes away, and you are never the same person you once were.

-- Barb Butler, Regina, Saskatchewan; Injured in a motor vehicle accident in 1993

Hugh and Rosemary (Finlay) use his favourite songs to get Scott (their adult son with a severe TBI) in the mood to stand to get into bed, which he does with the aid of a specialized wheelchair every morning, afternoon and night. There's a floor-to-ceiling steel pole, like a fireman's pole, beside his bed. It's covered in strips of white tape to help Scott get a grip.

His parents usually feed him. Sometimes, he feeds himself. But Hugh and Rosemary have to watch closely because he tends to eat too fast.

-- Excerpt from "When love runs out of time: Parents fear for injured son" by Randy Starkman, Toronto Star, March 3, 2011

Calling to action to Designate Moderate to Severe TBI as a Chronic Condition

In Canada, the most common causes of moderate to severe TBI are:



Falls: Falls are the leading cause of TBI in Canada, accounting for more than **50%** of all cases. They are most common among children and seniors, but they can happen to anyone. Falls from significant heights, such as from ladders or roofs, are particularly likely to result in severe TBI.



Motor vehicle accidents: Motor vehicle accidents are the second leading cause of TBI in Canada. They are most common among young adults aged 15-24 and are often the result of high-speed collisions or accidents involving motorcycles and cars.



Sports: Sports-related TBI is also a significant cause of moderate and severe TBI in Canada, particularly among children and adolescents who play contact sports like football or hockey. Sports-related activities were the leading cause of TBI hospitalizations among children and youth aged 5 to 19 years, accounting for **45%** of all TBI hospitalizations in this age group.



Assaults: Assaults—including intimate partner violence and criminal assaults—are another cause of TBI in Canada, accounting for a considerable number of moderate to severe TBI cases.

Calling to action to Designate Moderate to Severe TBI as a Chronic Condition

The range of impairments and other associated medical effects affect daily functioning, independence, and integration back into pre-injury like work, school, sport and parenting:



Cognitive impairment: Problems with attention, learning and memory, ability to process information quickly, communication, processing of visual and spatial information, problem-solving, judgement, planning and follow-through, self-awareness



Physical and sensory impairments: Problems with physical strength (including paralysis), coordination, pain (e.g., headaches), sensory disturbances, hearing and/or vision loss



Behavioural changes: Impulsivity, uncontrolled anger and aggression, and disinhibition



Emotional changes: Emotional lability (e.g., crying unexpectedly), mood disorders (depression) and anxiety



Sleep disorders: TBI disrupts normal sleep patterns, leading to difficulties falling asleep or staying asleep and resulting sometimes in debilitating fatigue

Calling to action to Designate Moderate to Severe TBI as a Chronic Condition



Social and financial impacts:



Reduced quality of life: TBI leads to a significant reduction in an individual's quality of life due to physical, cognitive, and emotional impairments.



Loss of employment and income: TBI makes it difficult or impossible for individuals to work, resulting in loss of income and financial strain. One in three adults living with moderate/severe brain injury identify challenges with managing money and/or paying bills. Financial struggles and unemployment are cited as the most significant unmet rehabilitation needs and barrier to community participation.



Increased health care costs: TBI requires ongoing medical care, rehabilitation, and medication, which can be cost-prohibitive over the course of a lifetime.



Caregiver burden: TBI places a major burden on family members and caregivers, who are needed for ongoing support and care.



Social isolation: TBI can lead to social isolation and difficulty maintaining relationships, which further impacts an individual's quality of life.

Calling to action to Designate Moderate to Severe TBI as a Chronic Condition

GAPS IN CANADIAN SURVEILLANCE DATA

It is a challenge to provide real-time or up-to-date information on moderate to severe TBI in Canada due to the significant gaps in data surveillance, including:



Inconsistent data collection methods: Varying data collection methods across provinces and territories can lead to inconsistencies and challenges in aggregating data at the national level. This makes it difficult to accurately assess the full prevalence and impact of TBI in Canada.



Lack of standardized reporting: The absence of a standardized reporting system for TBI cases makes it more challenging to compare and combine data from different health care providers and institutions.



Limited access to rural and remote communities: Data collection in rural and remote areas is less comprehensive due to limited resources and infrastructure, leading to under-reporting of TBI cases.



Under-reporting of moderate to severe TBI occurrences: Many moderate to severe TBI cases are not reported or recorded, leading to an incomplete understanding of how extensive the problem really is.



Incomplete data on long-term outcomes: There is limited data on the long-term outcomes of TBI patients that are patient oriented, such as the overall neurological function. More so for more specific cognitive, emotional, behavioural, and social functioning. Although important, mortality is not the gold standard outcome measure in moderate and severe TBI. This hinders the development of targeted interventions and support programs.



Limited data on vulnerable populations: Certain populations, such as Indigenous communities, homeless or individuals suffering from IPV, are underrepresented in TBI data. This makes it difficult to accurately assess the impact of TBI on these groups and to develop targeted prevention and intervention strategies.



Challenges in data sharing and collaboration: Data privacy and confidentiality concerns limit the sharing of TBI data among health care providers, researchers, and other stakeholders, leading to gaps in knowledge and understanding.

Calling to action to Designate Moderate to Severe TBI as a Chronic Condition

CALL TO ACTION

Moderate to severe TBI should be classified as a chronic health condition under the **Canadian Chronic Disease Surveillance System**, as it is a progressive and long-term condition that has ongoing impacts on cognitive, physical, and emotional health, as well as the quality of life for the injured and his or her family, and community.

This classification will help address the lack of recognition and understanding of TBI as a chronic health condition and ensure health systems have the data to allocate appropriate supports and resources over the life span.

Bill-C277

First Session, Forty-fourth Parliament,
70-71 Elizabeth II, 2021-2022

HOUSE OF COMMONS OF CANADA

BILL C-277

An Act to establish a national strategy on brain injuries

The Canadian Traumatic Brain Injury Consortium: a collaborative initiative

The Canadian Traumatic Brain Injury Research Consortium: Epitomizing Collaborative Research in Canada

James S. Hutchison,^{1-4,*} Carolyn Emery,^{5,6} Isabelle Gagnon,^{7,8} Caroline Léger,⁹ Richard Riopelle,^{10,11}
Cheryl Wellington,¹² Elisa Wilson,² and Alexis F. Turgeon^{9,13,*}
on behalf of the Canadian Traumatic Brain Injury Research Consortium

J Neurotrauma 2018

www.ctrcc-cprt.ca