

~ REQUEST TO ESTABLISH THE ~

BRITISH COLUMBIA BRAIN INJURY LEGACY FUND

The collective well-being of all British Columbians is reflected in the well-being of each of us. Our collective well-being is diminished because of physical or mental impairment that can affect any of us.

- Government of British Columbia 2002 -



Submitted by the



~ TABLE OF CONTENTS ~

Introduction	1
Acceptability	8
Access	9
Accountability	9
Administration And Distribution Of The Fund	3
Advancement	9
Appropriateness	9
Benefit To The Public	7
Brain Injury Funding Comparisons	5
Brain Injury Funding Mechanisms	5
Brain Injury Legacy Fund Capital	3
Brain Injury Service Providers Need Special Training	4
Conflict and Resolution	8
Consumer Focused	8
Continuity	9
Current Population Of Brain Injured Persons In British Columbia	4
Current Rate Of Brain Injury In BC	4
Effectiveness	9
Efficiency	9
Eligibility	8
Equity	8
Formula For Fair And Unbiased Fund Disbursement	3
Functions	10
Highest Risk Groups	4
How BC Associations/Societies Are Funded	6
How Much Money Will Be Required To Establish And Maintain The Fund?	3
How Other Jurisdictions Fund Brain Injury	6
Need For A Brain Injury Legacy Fund	3
Number Of BC Associations/Societies	5
Participation	8
Planning	8
Positive Outcomes Anticipated	11
Prevention Awareness	8
Rate Of Brain Injury Versus Other Life-altering Issues	4
Recommendation	2
Respect and Dignity	8
Shared Responsibility	9
The British Columbia Brain Injury Fund	2
Who And What Is The Brain Injury Alliance?	2
Conclusion	12

BRITISH COLUMBIA BRAIN INJURY FUNDING



Today and Tomorrow

The Brain Injury Alliance is grateful for the opportunity to address the Committee, and to set forth its request for the establishment of the British Columbia Brain Injury Legacy Fund to facilitate the efficient, professional and competent delivery of services to the BC brain injury community (survivors, families, friends and support organizations), which exceeds 350,000 persons.

Acquired brain injury devastates lives. When untreated, the cost to taxpayers in health care, lost wages, increased reliance on social welfare, justice costs and the devastating impact on families, is nearly incalculable. People living with brain injury are often the most complex and difficult to serve. Traditional service strategies, based on motivational or behavioural management, are ineffective for people living with cognitive disabilities from an acquired brain injury. Their needs cannot be adequately met by the limited resources and abilities offered by generic programs and case management services.

The government has already demonstrated remarkable leadership through many initiatives that have positively influenced the health of the population; now there is an exciting opportunity to further advance that leadership by reducing use of emergency medical and correction services, improving long-term care and community support services, properly managing chronic conditions, and preventing injury.

The Brain Injury Alliance (the Alliance) applauds government for its fiscal vision, and strongly believes there is an opportunity for the brain injury community to play a significant role in helping government advance its current, and future objectives. In this submission, the Alliance outlines critical areas of service which require attention as the government evaluates its investments in the future of British Columbia.

By necessity, the focus of health care resources and service emphasis must shift from primarily institutional-based illness care, to more comprehensive, community-based services. These services must not only encompass the full range of health (from preventative to supportive, and throughout the lifespan), but must also address other social determinants of health, such as mental health, substance abuse and addiction. Providing services within an integrated and participatory structure will provide more effective access to services for the population of people affected by acquired brain injury.



Experience has proven that integrated planning must occur at the local level, and requires established and sustainable broader partnerships across all social policy ministries, as well as with community partners. In order to effectively serve the brain injury community, there needs to be a greater emphasis on creating collaborative partnerships and networking with all partners to build capacity, reduce costs and increase effective regional services.

Research shows that health care is best understood, and most effectively managed, at the community level.*¹ Adequate and secure funding of community initiatives make a significant difference, and saves money, by addressing concerns before they require emergency medical, and/or justice interventions. The Alliance is committed to quality services for survivors of brain injury, ensuring efficiencies, improving population health, and helping government achieve its goals.

For decades formal requests for government to adequately fund the complex needs of the BC brain injury community have been denied. Denial was due to a lack of cohesiveness within the brain injury community, and the lack of a cooperative body to receive and distribute funding. However, the lack of adequate stable funding for community brain injury organizations and societies, and the ever increasing unmet needs of the community have only served to compound government costs, reduce quality of life for British Columbians, and place increased demands on social and justice resources.

Recommendation:

In order to provide brain injury survivors and their families in British Columbia with the highest quality of services, the 2014 Brain Injury Alliance (Alliance) requests government to establish the Brain Injury Legacy Fund (BILF). The Alliance's request requires no 'new' funding, but rather redirects existing funding to maximize return on investment.



Who And What Is The Brain Injury Alliance?

The Brain Injury Alliance is a legal entity created to address the resource needs of British Columbia's community brain injury service providers. The organization is member based, and is governed by a board of directors comprised of brain injury stakeholders and representatives from brain injury organizations/societies from throughout the province. The Alliance's mandate encompasses cooperation, fiscal accountability, self-regulation, professionalism, quality professional practice environments, and healthy public policy.

What Is The British Columbia Brain Injury Fund?

The Brain Injury Legacy Fund is a provincial mechanism to ensure that brain injury community services and supports in British Columbia are funded in an adequate, sustainable, comprehensive, cohesive and coordinated manner. The Fund is intended to build on the strengths of the current health service delivery structure, and to ensure that continuous progress is made in providing quality services and supports to persons with brain injury and their families.

Where Will The Money For The Brain Injury Legacy Fund Come From?

Following Saskatchewan's successful model of ensuring that the major causes of brain injury are financially liable for funding community services for survivors. The Brain Injury Legacy Fund will combine monies from the Ministry of Justice via the Victim Surcharge Special Account (BC Neurotrauma Fund), with RoadSafetyBC funds collected from driver penalty point premium tax, seatbelt violations, motorcycle helmet/passenger violations and fines, and, annual contributions from ICBC (motor vehicle crashes are the number one cause of brain injury). This allows each contributor to only make a minimal investment, but achieve maximum benefits to the health and safety of British Columbians.



By sharing costs and reducing service duplication, government expense will go down as community service capacity improves. Currently, health authorities are struggling to maintain adequate service levels for brain injury, as issues such as mental health and addiction take priority. Local brain injury associations/societies offer outstanding services at minimal cost, making their utilization to provide 'gap' services an excellent investment.

How Much Money Will Be Required To Establish And Maintain The Fund?

Given that BC's population is considerably higher than that of Saskatchewan, the Alliance recommends a minimum of a \$5 million initial investment (slightly above the amount Saskatchewan currently provides). The Alliance also recommends annual increases as provincial brain injury associations/societies service levels return to those in 2002. As government begins to see increasing multi-disciplinary benefits and cost savings, funding can be further increased to best serve BC's brain injury needs.



Is There A Formula For Fair And Unbiased Fund Disbursement?

Yes, Brain Injury Alliance members have worked together to develop a formula that all feel is fair and adequate for the present. However, as community services increase to address the current unmet needs of the BC brain injury community, the funding formula will need to be adjusted accordingly to ensure that fair and equitable disbursement is maintained.

Who Will Administrate And Distribute The Fund?

The 2014 Brain Injury Alliance.

Why Is There A Need For A Brain Injury Legacy Fund?

Brain injury devastates lives, and when it remains untreated, the actual cost to taxpayers in health care, lost wages, increased reliance on social welfare, justice costs and the devastating impact on families, is nearly incalculable. Estimates of acute, rehabilitative, and long term care costs are conservatively put at \$686 million annually.^{*3} But, those dollars only deal with health issues. They do not include all of the other related costs.





Brain injury also has a huge impact on industry and businesses. Statistics verify that nearly 20% of people hospitalized for traumatic brain injury will never return to work.^{*3} Many more will have serious life-long employment challenges. Community brain injury services help people to cope with their challenges, and in many cases secure employment better suited to their needs and abilities.

What Is The Current Rate Of Brain Injury In British Columbia?

There are approximately 22,000 new brain injury cases per year in British Columbia.^{*7}

What Is The Current Population Of Brain Injured Persons In British Columbia?

Currently, approximately 180,000 survivors of brain injury live in British Columbia.^{*4}

Do Brain Injury Service Providers Need Special Training?

Yes. People living with brain injury are often the most complex and difficult to serve. Traditional service strategies, based on motivational or behavioural management, are ineffective for people living with cognitive disabilities from an acquired brain injury. Moreover, the specific and complex needs of brain injury survivors simply cannot adequately be met by the limited resources and abilities offered by generic programs and case management services.

What Are The Highest Risk Groups?

The highest risk groups are males aged 16-24; First Nations of all ages; and seniors. Males experience brain injury twice as often as females. Brain injury holds the highest fatality rate of those under the age of 45; is the greatest disabler of those under the age 44, and more children die from brain injury every year than from all other causes combined.^{*5}

Data demonstrates that brain injury is a permanent chronic condition that plays a significant "gateway" role in the development of other costly health and social issues.^{*6} Here are a few examples:

- 53% of homeless individuals live with brain injury. The vast majority (77%) were injured prior to becoming homeless.^{*3}
- 82% of the prison population in British Columbia live with an untreated disability due to traumatic brain injury.^{*4}
- Up to 10% of children have an undiagnosed brain injury that, without help, will affect their learning abilities life long.^{*8}
- 20% of children diagnosed with emotional disabilities, and 30% classified as Learning Disabled, have brain injuries.^{*5}
- After brain injury, people are up to 7 times more likely to develop mental illness.^{*3}



What Is The Incidence Rate Of Brain Injury Versus Other Life-altering Issues?

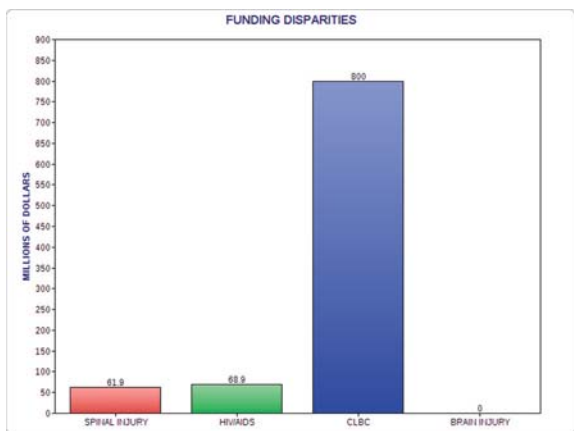
Brain injury occurs at a rate of 100 times that of spinal cord injury;^{*5} 30 times that of breast cancer, and 400 times that of HIV / AIDS.^{*4} In fact, brain injury occurs at a rate greater than that of all known new cases of Multiple Sclerosis, Spinal Cord Injury, HIV / AIDS and Breast Cancer per year combined.^{*4}

How Does Brain Injury Funding Compare To Other Life-altering Issues Funding?



Every dollar spent by government is now under extreme scrutiny, so budgetary considerations must factor where need is greatest in all fiscal decisions. There are currently some major funding priority disparities in the health and family service sectors. The Alliance asks the committee to consider the following opportunities, and then to adjust its recommendations accordingly:

It is well documented that from the year 1997 to the year 2014, despite the reality that brain injury occurs at a rate of 100 times that of spinal cord injury^{*5}, the government of British Columbia has invested over \$61.9 million in spinal cord injury research and services. Over the same period (1997 to 2014), it invested less than \$1.5 million into community based brain injury services and projects.



There are approximately 14,000 persons with HIV/AIDS in BC. Exclusive of medical costs, and despite that brain injury occurs at a rate of 400 times that of HIV / AIDS.^{*4}, the government has spent \$68.9 million just on HIV/AIDS prevention since 2009. The amount of dollars provided to community brain injury service organizations in secure funding over the same period? Zero.

Community Living BC (CLBC) has an annual budget that exceeds \$800 million^{*9}, and serves approximately 20,000 persons. BC brain injury organizations serve a population of 180,000, with many persons served coping with challenges and deficits similar to those served by CLBC. However, brain injury service providers receive zero dollars in secure funding.

Is There A Current Provincial Brain Injury Funding Mechanism In Place?

Yes, Bill 8 - British Columbia Neurotrauma Contribution Fund Act of 1997. The fund was established for the purpose of funding services and projects respecting neurotraumatic injury, and victims of neurotraumatic injury. The Fund receives \$2 million per year from the Solicitor General.

Why Is A New Funding Mechanism Necessary?

The Neurotrauma Fund has received over \$36 million to date. Brain injury services and projects have received less than \$1.5 million since 1997. Management of the Neurotrauma Fund has been proven not to be beneficial to the brain injury community of BC.

How Many Local Brain Injury Associations/Societies Are There In BC?

In the year 2002, there were 45 community brain injury associations/societies providing quality services to 150,000 survivors of brain injury.^{*1} They delivered services to survivors, performed community education and were heavily engaged in prevention programs. In 2014, a thorough survey of provincial services and organizations by the Northern Brain Injury Association found that there are only 21 local brain injury associations/societies remaining. These few organizations must operate without secure funding, and as a result, are forced to provide diminished services to an increasing population of brain injury survivors, currently estimated to exceed 180,000.



How Are Local Brain Injury Associations/Societies Currently Funded?

Brain injury associations/societies in British Columbia are currently funded through a fragile patchwork of donations, grants, services for fee, small allocations from health authorities and local fundraising efforts.



However, fundraising, applying for grants and securing service contracts are demanding, very time consuming, do not allow for future financial planning, and are not conducive to staffing stability. Nor do they allow for long term (multi-year) planning to meet the growth and increasing needs of the BC brain injury community. Community based service providers in British Columbia are among the best in the world, and they deserve the same financial security and respect that their counterparts enjoy virtually everywhere else in North America.

How Do Other Jurisdictions Fund Brain Injury?

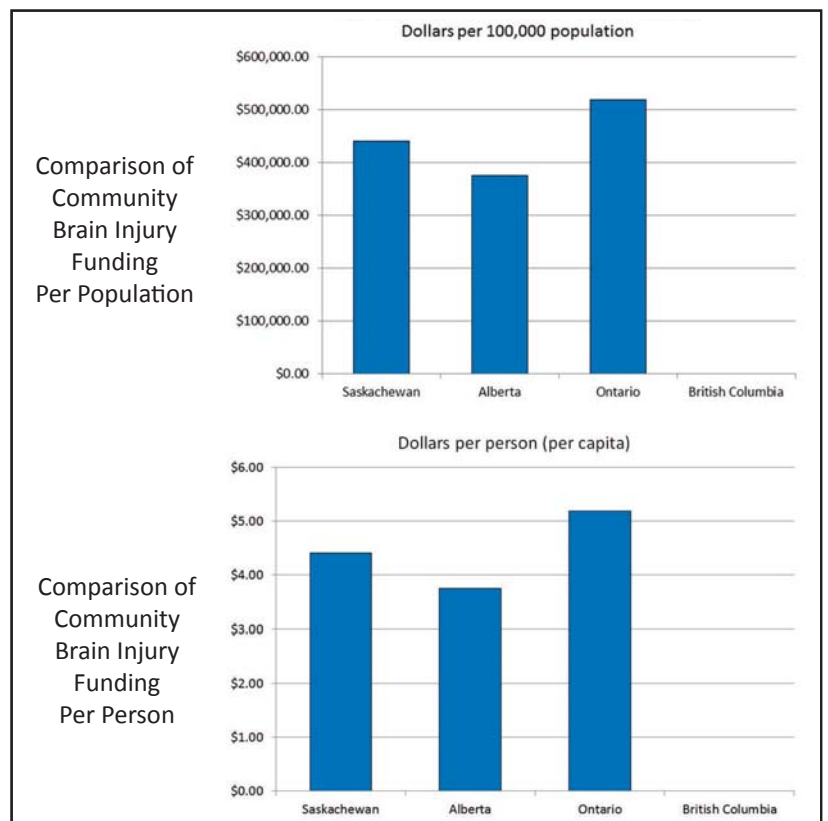
The primary model that is used to establish and maintain brain injury funding in North America, is that of Saskatchewan. It created the Acquired Brain Injury Partnership Project with participation by BC brain injury service pioneer, John Simpson. The project is an innovative partnership between Saskatchewan Government Insurance (SGI), the Saskatchewan Ministry of Health, and community based programs. Its success is recognized around the world. The Partnership develops and implements services and supports for persons with acquired brain injuries and their families. The 36 community based programs that receive funding under the project are responsible for providing service to the whole province.^{*11}

With a population of about 1.1 million people, Saskatchewan's Acquired Brain Injury (SABI) Partnership Project receives \$4.85 million per year.^{*11}

The province of Ontario created a similar fund; and with a population of approximately 13.8 million people, provides \$71.6 million per year to community brain injury organizations.^{*12}

The province of Alberta, with a population of 4.082 million people, provides an estimated \$15 million per year to community brain injury service providers.^{*14}

The province of British Columbia has a population of 4.6 million people, but provides no dedicated brain injury funding; and has no secure direct annual funding for its community brain injury organizations.^{*15}



THE FUTURE IS OURS TO CREATE



How Will Adequately Funding Brain Injury Services Benefit The Public?



The complex needs of persons with brain injury, the regional disparity in resources, lack of a comprehensive database to reflect the actual incidence of brain injury in the regions; absence of community awareness of the varying and usually life-long needs of this population, and geographic moves by persons with brain injury between regions, present many challenges.

Properly funding brain injury services, education and prevention will result in an enormous reduction of government expense, and will improve the quality of life for thousands of British Columbians. For example, in 1998, preventable injuries cost the people of British Columbia \$2.1 billion, or \$513 for every citizen.*¹³ The amount has since increased by a minimum of 20%. By reducing preventable injuries by just 1%, hundreds of families will avoid tumultuous tragedy, and \$20 million per year will be saved; an outstanding return on investment – each and every year!

It is estimated that 60-80% of all inmates have suffered at least one brain injury, and most have never received help to rehabilitate and cope with their injury(ies). The current estimated cost of provincial incarceration in BC is around \$1.19 billion per year. If treatment and assistance were available, a conservative 5% reduction of inmates would result, saving just under \$25 million per year; not including the resulting significant reduction in the number of victims of crime. Again, another outstanding return on the province's investment!

A 2013 Health and Housing in Transition study found 69% of the homeless surveyed in Vancouver had suffered a traumatic brain injury. Research also found homeless brain injury survivors are more likely to visit emergency rooms, be arrested or jailed, or be victims of physical assault. Given the high costs of emergency department visits, and the burden of crime on society, these findings indicate that adequate investment in brain injury services at the community level will dramatically reduce demand for government resources, providing an outstanding return from the province's participation.



Will There Be Eligibility Requirements For Funding From The Fund?

Yes. The following principles will guide the evaluation of services funded at the provincial, regional and local levels:

Respect and Dignity

Persons with brain injury and their families will be treated with respect and dignity regarding life choices, access to services, and programming. Every person with brain injury is unique, and the recovery path will be different for each person. Services and supports will be needs based, and targeted to take into account culture and beliefs, developmental stage, special needs, and gender-specific concerns.

Prevention Awareness

Brain injury is forever, so prevention and public education are paramount, and must occur within communities across the province to reduce help the incidence of brain injuries. A small reduction in brain injury incidence will result in large cost savings, and reduced pain and suffering.

Consumer Focused

Services will be developed, delivered, and evaluated in collaboration with persons with brain injury, and their families, and will respect the cost and impact to all British Columbians. Services will focus on the rebuilding of skills, cognitive enhancements, family education and enhancing quality of life.

Participation

Persons with brain injury and their families will participate in the evaluation of services and supports. Families of persons with brain injury will receive support and education in order to remain actively, and positively, involved in the care and support of their loved ones.

Planning

Coordination with agencies and government ministries is required. Collaborative planning at all levels supports the seamless flow of information between government, health authorities, support agencies, brain injury associations, survivors, families and other stakeholders.

Acceptability

Long-term care institutions and extended care units are often inappropriate for the needs of younger persons with brain injury. Wherever possible, community integration and inclusion must be the goal.

Conflict and Resolution

Each funded organization will have a conflict resolution process and procedure so service recipients will be informed of, and assisted with, the complaint resolution process in order to ensure quick, effective and respectful resolution of issues.

Equity

Funding for services and supports will be delivered in a manner that respects diverse geographical and cultural needs, with a focus on decreasing disparity in service levels among all population groups.

Shared Responsibility

The Brain Injury Alliance, with equitable provincial representation and participation by brain injury survivors, stakeholders, and community service organizations and societies, will ensure shared responsibility in managing and distributing the Fund

Access

Services and supports will be accessible within a reasonable travelling distance of place of residence. Persons with brain injury may require post-acute resources several years post-injury, or at transition points in recovery. Acute care and hospital-based rehabilitation services for persons who have brain injuries are reasonably accessible in British Columbia. However, persons with brain injuries often experience difficulties in obtaining community services.

Effectiveness

Services and supports will be managed and delivered to provide the best possible outcomes for all British Columbians. Survivors of brain injury deserve the opportunity to recover and develop intellectually, physically, emotionally and socially. Services and supports need to provide opportunities to maximize the recovery of independence and functional potential.

Continuity

The Fund will provide the necessary security for agencies to ensure future planning and continued coordination of long term objectives, and effective data collection. Secured funding allows community organizations to achieve adequate and stable staffing levels, which directly translates to improved services for persons living with a brain injury.

Efficiency

Timely and responsive services and supports will be available, managed and delivered in a cost-effective manner, consistent with quality, evidence-based services. Service provided is based on brain injury best practices and relevant research; Standardized data collection and reports will be mandatory.

Appropriateness

Services and supports will remain flexible, needs based, and will take into account culture, beliefs, developmental stage, special needs, and gender-specific concerns, and be provided in the least restrictive manner possible.

Advancement

The Fund will support the British Columbia Brain Injury Association (BC BIA) as the brain injury community's provincial resource providing information, resources and education to brain injury survivors, their families, and the public at large.

Accountability

Standard reports will be designed to monitor services, and to evaluate outcomes. Standard reports provide methodical ways to determine service and support effectiveness.

Functions

All funded services and supports will be required to include the following elements, to varying degrees:

Coordination – community development, linking to resources, risk management, case management, regular reports, reviews, and a seamless flow of information.

Collaborative Planning – inclusion of survivors, their families and other stakeholders in the planning of individual programs and resource use.

Inclusion - Appropriate and anticipatory planning to ensure that individuals in crisis are given priority without jeopardizing the access of others not in crisis.

Transition Management – persons with brain injury and their families will be supported so they can manage transitions effectively. Once a person has been identified as having an acquired brain injury, specific mechanisms will facilitate the person receives coordinated and appropriate care, at all stages of recovery and life.

Crisis Response – services and supports, including risk management, immediate crisis intervention, and follow-up will form part of crisis response.

Complaint Resolution – written processes and procedures to resolve complaints, as well as easily accessible information about use of the processes.

THE BRITISH COLUMBIA BRAIN INJURY LEGACY FUND

A Win-Win For All British Columbians!





Positive Outcomes Anticipated From The British Columbia Brain Injury Legacy Fund:

- Increased public awareness about brain injury prevention;
- A reduction in the incident rate of brain injury;
- Province wide instant access to user-friendly information about brain injury, how to support a family member with brain injury, and how to live with a family member who has a brain injury;
- Meaningful inclusion of Aboriginal peoples and other ethnic/cultural groups' values, beliefs and healing practices, and specific supports to address diversity and other special needs of persons with brain injury, and their families;
- Evidence-based services and supports designed for positive health outcomes, delivered in a cost-effective manner;
- Services providers will be knowledgeable about the complexities of brain injury, and trained to support persons with brain injury and their families;
- Services will maximize the recovery of independence, and functional potential capacities and skills, of persons with brain injury in the community;
- Persons with brain injury will have access to appropriate needs-based services and supports within the community where possible, and specialized services as close to home as possible;
- Community brain injury awareness and involvement, with evidence of direct and in-kind community support for prevention activities;
- Brain injury services and supports delivered in a timely manner in order to prevent further complications;
- A reduction in the duplication of services and supports at several levels;
- Increased quality and quantity of services to survivors of brain injury and their families resulting in decreased costs to Government;
- Brain injury survivors and their families will be supported in decision-making through the provision of accurate and timely information to enable informed choices;
- Families will be supported in their choice of role as care givers;
- Persons with brain injury and their families will be supported in managing transitions effectively;
- Collaborative planning will be enhanced at all levels; processes will support a seamless flow of information among all partners; and,
- Persons with brain injury and their families will experience satisfaction with services and supports received. However, these shall be provision of a complaint resolution process at the local level, to ensure quick, effective and satisfactory resolution of issues.

~ IN CONCLUSION ~

WHEREAS of all types of injury around the world, injuries to the brain are among the most likely to result in death, or, permanent disability;

WHEREAS brain injury is the number one cause of seizures in the world;

WHEREAS brain injury in British Columbia occurs at a rate greater than that of all known cases of Multiple Sclerosis, Spinal Cord Injury, HIV/AIDS and Breast Cancer per year combined;

WHEREAS brain injury is the leading cause of death and disability among children, with 50 per cent of all fatalities the result of injury to the brain;

WHEREAS motor vehicle crashes are the number one cause of brain injury in British Columbia;

WHEREAS violence against persons is a major cause of brain injury in British Columbia;

WHEREAS sport accidents, strokes, surgery, disease and tumors are a major cause of brain injury in British Columbia;

WHEREAS addressing the complex needs of brain injury survivors and their families is fundamental to the future of British Columbia;

WHEREAS a fair, non-partisan and equitable provincial brain injury funding and distribution mechanism needs to be established to meet the complex needs of brain injury survivors and their families;

WHEREAS there is great need for comprehensive, coordinated, post-medical rehabilitative and case management services for brain injury survivors and their families;

WHEREAS the development of innovative research, brain injury educational materials and rehabilitative programs will restore British Columbia as a world leader in brain injury research, treatment and services;

WHEREAS the British Columbia Neurotrauma Contribution Funding Act is non-specific and poorly worded;

WHEREAS community brain injury associations and societies receive no money from the British Columbia Neurotrauma Contribution Funding Act;

The 2014 Brain Injury Alliance respectfully requests the establishment of the British Columbia Brain Injury Legacy Fund to provide a fair, efficient, and sufficient financial resource to meet the needs of brain injury survivors and their families, currently, and into the future.

The Brain Injury Alliance is member based, and is governed by a board of directors comprised of brain injury stakeholders and representatives from brain injury organizations/societies from throughout the province. The Alliance's mandate encompasses cooperation, fiscal accountability, self-regulation, professionalism, quality professional practice environments, and healthy public policy.



~ SOURCES ~

- *1 - https://www.health.gov.bc.ca/library/publications/year/2002/MHA_Brain_Injury_Guidelines.pdf
- *2 - Center For Disease Control
- *3 - http://www.vistacentre.ca/_files/statistics.pdf
- *4 - Brain Injury Association of Canada
- *5 - <http://www.biaww.com/stats.html>
- *6 - http://www.vistacentre.ca/_files/statistics.pdf
- *7 - BC Brain Injury Association
- *8 - figures extrapolated from CDC rates of Canadian brain injury
- *9 - http://www.bcbudget.gov.bc.ca/Annual_Reports/2012_2013/pdf/agency/clbc.pdf
- *10 - Public Health Agency of Canada
- *11 - <http://www.abipartnership.sk.ca/index.cfm>
- *12 - Government of Ontario
- *13 - Smartrisk 1998, The Economic Burden of Unintentional Injury in Canada, p.9
- *14 - Government of Alberta
- *15 - Government of British Columbia

~ NOTES ~