

The Case for Canada's Increased Investment in Neuroscience Research

Les arguments en faveur d'un investissement accru
du Canada pour la recherche en neuroscience



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Executive summary

One in three (10 million) Canadians will be affected by a neurological or psychiatric disease, disorder or injury at some point in their lives. This figure will increase as the population ages due to degenerative brain diseases associated with agingⁱ. Diseases, disorders and injuries of the brain, spinal cord and nervous system, such as Alzheimer's disease, stroke, schizophrenia, multiple sclerosis, spinal cord injury, depression, sense organ diseasesⁱⁱ and traumatic brain injury afflict Canadians of all ages and backgrounds, and can strike anyone at anytime. These conditions are often chronic, leading to a profound deterioration of a person's quality of life. Brain disordersⁱⁱⁱ are a result of a complex interplay of genetic and environmental factors. Research is the key to unraveling the intricacies of the brain and nervous system. It is the only hope for finding therapies and cures.

The brain is the most critical and mysterious organ, and is what makes us human. It is the "last frontier" of human biology. Ninety per cent of what we have learned about the brain has been in the past fifteen years, but researchers still have far to go toward fully understanding brain function. There is a currently an explosion in brain research with unlimited potential for growth in knowledge based societies, with benefits for both Canada and the world.

The following report prepared by NeuroScience Canada presents the case for Canada's increased investment in neuroscience research. The first part of this report establishes the need: the enormous burden that neurological and psychiatric diseases, disorders and injuries place on the Canadian healthcare system. The second part of the case establishes the excellence and capacity of Canadian neuroscience research, and calls for governments to increase funding available for neuroscience research, so that our world-class researchers can fully utilize the investments already made in infrastructure and salaries.

When looking at Health Canada data, there is no single class of disease associated with the range of neurological, psychiatric and sense organ diseases, disorders and injuries that encompass the range of the conditions included in the neurosciences. The absence of a single recognized category for all brain and nervous system disorders exacerbates the difficulty to obtain precise figures for the burden of this disease group, as existing information and surveys have been compiled using different parameters. Therefore, in an effort to determine an accurate burden of brain, spinal cord and nervous system disorders for the creation of this report, data had to be culled from several sources. A number of stakeholder groups who share NeuroScience Canada's concern about the absence of reliable data on the incidence, prevalence, and economic and social impact of brain, spinal cord and nerve-related conditions in Canada, supported and aided the process^{iv}.

Health Canada estimated the total economic burden of illness in 1998 to be \$159.4 billion^v. Of this, neurological and psychiatric conditions accounted for \$22.7 billion or 14% of the total burden of illness. In comparison, cardiovascular diseases accounted for \$18.5 billion or

12% of the total burden of illness; cancer accounted for \$14.2 billion or 9% of the total burden of illness. However, Health Canada used mortality data as the basis for calculating burden of illness statistics in that study, and this is not considered adequate as this practice fails to consider disability, which results in a reduction of quality of life. The leading causes of disability are substantially different from the leading causes of death. There should be a relation between investment and burden of disease, and therefore, there is a need to reframe health care investment in services and research to morbidity data.

The Global Burden of Disease (GBD) 1990 study conducted by The Harvard School of Public Health, the World Health Organization, and the World Bank, created a new metric using a disability component for determining burden of disease that is becoming universally accepted. The Disability Adjusted Life year (DALY) is a measure that expresses years of life lost to premature death and years lived with a disability of specified severity and duration. The DALY combines years of life lost (YLLs) with years lived with disabilities (YLDs) into a single indicator and allows for a comparison of the burden of illness. Based on the GBD 2002 study, neurological and psychiatric conditions account for 38.3% of DALYs, compared with 12.7% for cancer and 11.8% for cardiovascular disease. In addition, six of the top 10 leading causes of burden in established market economies can be attributed to neurological and psychiatric conditions, with unipolar depressive disorders second only to ischemic heart disease.

Health Canada's *Economic Burden of Illness in Canada (EBIC)* report and the GBD study aims to examine the economic impact of long-term disability costs attributed to neurological and psychiatric diseases, disorders and injuries, most significantly for mental disorders. Independent reports by stakeholders in Canada and the US recognize the shift in the global burden of disease from infectious to non-communicable disorders, and are unanimous in their message that neuropsychiatric disorders, specifically those pertaining to mental health, have been seriously underestimated and impose a far greater burden in terms of lost productivity and costs to society than was originally believed. In addition to this enormous burden, there is considerable stigma surrounding neuropsychiatric^{vi} diseases and only recently has there been public recognition that these conditions have a physiological basis.

Canada has a critical role in addressing the enormous burden of neuropsychiatric conditions. Canada is a leader in neuroscience research and is home to a number of important discoveries in the neurosciences. This country has leading laboratories in the areas of neurodegenerative disease, neurotrauma, neuroimaging, tissue engineering and biomaterials, regeneration, protection and functional recovery and genetics.

The Canadian government has recognized the need to invest in research and has created successful programs such as the Canada Research Chairs program to recruit top talent, Canadian Foundation for Innovation to fund infrastructure, and Genome Canada, which

provides funding for large-scale genomics and proteomics research. Private donors have also aided in providing infrastructure, including establishing a number of neuroscience research centres across Canada. However, physical infrastructure and salaries are not sufficient; there must be increased investment in operating funding to enable researchers to run their labs and provide training environments for doctoral students and postdoctoral fellows.

The Canadian Institutes of Health Research is currently the major source of public funding for health research, but at \$662 million in 2004 (the budget will be almost \$700 million by 2006), it is still short of the \$1-billion target it had established to provide adequate funding to Canadian researchers, including those involved in neuroscience research. Even when private funding is included, the current allocation of funding to the neurosciences is disproportionate to the burden of disease, and is disproportionate in comparison to the funding other disease groups are receiving. Through the CIHR's open competition, an estimated \$81 million was allocated to neuroscience research in 2003/2004, compared with \$94 million for cancer and \$109 million for cardiovascular. However, cancer receives an additional \$64 million^{vii} per year from the Canadian Cancer Society and the National Cancer Institute of Canada, and cardiovascular receives an additional \$51 million^{viii} per year from the Heart and Stroke Foundation of Canada. There is no similar source of major funding from private donors or foundations for neuroscience research, and the combined research funding from neuroscience-focused Voluntary Health Organizations is estimated at only \$15 million (Please see Appendix 4 for a Table depicting research and public awareness expenditures for Canadian Voluntary Health Organizations).

Canadian researchers are increasingly having to turn to American institutes such as the National Institutes of Health and the Howard Hughes Medical Institute for funding. Although there are a number of Voluntary Health Organizations that raise money for public awareness and research into specific conditions, NeuroScience Canada is the only Canadian, national non-profit, non-governmental organization devoted to raising funds for research into the full range of diseases, disorders and injuries that encompass the neurosciences. However, the current funding capacity of NeuroScience Canada is modest in comparison to the umbrella organizations for the other disease groups. Increases in neuroscience operating research funds, in tandem with the government programs already established, will help Canada remain a leader in neuroscience research, but more importantly, will help in the global effort to alleviate the tremendous burden of neurological and psychiatric diseases, disorders and injuries.

NeuroScience Canada recommends the following steps be taken:

- The neuroscience community should develop a public awareness campaign about the true burden of brain disorders to help stimulate increased private and public investment. NeuroScience Canada intends to take the leadership in organizing such a campaign, but this would require an initial investment and the appropriate support from other stakeholders in this area.
- The federal government should immediately invest \$5 million per year for five years, for a total of \$25 million to support large-scale neuroscience research projects. These funds would be leveraged by NeuroScience Canada to attract and stimulate additional private funding, at a ratio of \$1 from private sources for every \$2 in government funding.
- Finally, the neuroscience community should seek an increase in the Canadian Institutes of Health Research's (CIHR) allocation to the Institute of Neuroscience, Mental Health and Addiction (INMHA), to support both individual investigators and team grants. In order not to divert funds from other areas, this would mean increasing the CIHR budget to its \$1 billion target.

Résumé

Un Canadien sur trois (10 millions) sera atteint d'une maladie, d'un trouble ou d'une lésion neurologique ou psychiatrique à un moment donné de sa vie. Ce nombre augmentera avec le vieillissement de la population à cause des maladies dégénératives du cerveau associées au vieillissementⁱ. Les maladies, troubles et lésions du cerveau, de la moelle épinière et du système nerveux tels que la maladie d'Alzheimer, les accidents cérébrovasculaires, la schizophrénie, la sclérose en plaques, les lésions de la moelle épinière, la dépression, les maladies des organes sensorielsⁱⁱ et les traumatismes cérébraux se déclarent chez les Canadiens de tout âge et de tout horizon et peuvent frapper n'importe qui, n'importe quand. Ces maladies sont souvent chroniques et entraînent une forte détérioration de la qualité de la vie. Les troubles du cerveauⁱⁱⁱ sont le résultat de l'interaction de multiples facteurs génétiques et environnementaux. La recherche détient la clé qui permettra de comprendre la complexité du cerveau et du système nerveux. Elle seule nourrit l'espoir de découvrir des thérapies et des cures.

Le cerveau est le plus critique et le plus mystérieux des organes, l'essence même de l'humain. Il représente la « dernière frontière » de la biologie humaine. 90 % de nos connaissances sur le cerveau ont été acquises au cours des 15 dernières années, mais les chercheurs ont une longue route à parcourir avant de pleinement comprendre son fonctionnement. Nous connaissons actuellement une explosion en recherche sur le cerveau qui offre des possibilités illimitées de croissance chez les sociétés axées sur le savoir, bénéficiant le Canada et le monde entier.

Le présent rapport préparé par NeuroScience Canada présente les arguments en faveur d'un investissement accru du Canada pour la recherche en neuroscience. La première partie du rapport définit la nécessité : l'écrasant fardeau économique que sont les maladies, troubles et lésions neurologiques et psychiatriques pour le système de santé canadien. La deuxième partie définit l'excellence et la compétence de la recherche canadienne en neuroscience, et lance l'appel aux gouvernements pour augmenter les fonds disponibles à la recherche en neuroscience afin de permettre aux chercheurs de classe mondiale de profiter pleinement des investissements déjà faits en infrastructure et en salaires.

Les données de Santé Canada démontrent qu'il n'y a pas une seule et unique catégorie de maladie associée à la gamme des maladies, troubles et lésions neurologiques, psychiatriques et des organes sensoriels regroupant toutes les maladies comprises dans les neurosciences. L'absence d'une seule catégorie reconnue pour toutes les troubles du cerveau et du système nerveux exacerbe la difficulté à obtenir des chiffres précis pour le fardeau de ces maladies car l'information existante et les sondages ont été compilés à partir de paramètres différents. Donc, afin de déterminer le fardeau des troubles du cerveau, de la moelle épinière et du système nerveux de façon précise pour ce rapport, nous avons dû recueillir l'information de sources variées. Quelques groupes d'intervenants qui partagent les inquiétudes de NeuroScience Canada face à l'absence de données fiables sur l'incidence, la prévalence, et les répercussions sociales et économiques des troubles du cerveau, de la moelle épinière et du système nerveux au Canada, se sont engagés dans le processus^{iv}.

Selon Santé Canada, le coût total de la maladie en 1998 était estimé à 159,4 milliards \$^v. De ce montant, 22,7 milliards \$ étaient attribués aux maladies neurologiques et psychiatriques, soit 14 % du coût total de la maladie. En comparaison, les maladies cardio-vasculaires représentaient 18,5 milliards \$ ou 12 % du coût total, et le cancer 14,2 milliards \$ ou 9 % du coût total. Par contre, Santé Canada a utilisé les données de la mortalité pour calculer les statistiques du coût total de la maladie dans cette étude et cette méthode n'est pas considérée comme étant adéquate car elle ne tient pas compte de l'invalidité qui cause une diminution de la qualité de la vie. Les principales causes d'invalidité sont très différentes des principales causes de décès. Il devrait y avoir une relation entre l'investissement et le fardeau de la maladie, il faudrait donc ajuster les investissements faits en services des soins de la santé selon les données de la morbidité.

L'étude de la « charge mondiale de morbidité » (dite GBD pour *Global Burden of Disease*) effectuée en 1990 par la *Harvard School of Public Health*, l'Organisation mondiale de la Santé et la Banque mondiale, a mis au point un nouveau système pour estimer le fardeau de la maladie en utilisant des données sur l'invalidité qui est de plus en plus accepté unanimement. L'année de vie corrigée de l'incapacité (AVCI) est une mesure d'écart de santé qui tient compte des années de vie perdues à la mortalité prématurée et des années vécues avec une incapacité d'une gravité et durée spécifiées. Les AVCI combinent les années de vie perdues (AVP) avec les années de vie vécues avec une incapacité (AVI) afin d'obtenir un indicateur unique qui permet une comparaison du fardeau de la maladie. D'après une étude GBD de 2002, les maladies neurologiques et psychiatriques comptent pour 38,3 % des AVCI, comparé à 12,7 % pour le cancer et 11,8 % pour les maladies cardio-vasculaires. De plus, six des dix principales causes du fardeau dans les pays à économie de marché sont attribuables aux maladies neurologiques et psychiatriques, le trouble unipolaire n'étant surpassé que par la cardiopathie ischémique. Le rapport de Santé Canada, « Le fardeau économique de la maladie au Canada (FEMC) », et l'étude GBD visent à examiner l'impact économique des coûts d'une incapacité de longue durée attribués aux maladies, troubles et lésions neurologiques et psychiatriques, et aux troubles mentaux en particulier. Des rapports indépendants réalisés par des intervenants du Canada et des États-Unis reconnaissent que le fardeau mondial de la maladie est passé des maladies infectieuses aux maladies non transmissibles, et ils sont unanimes dans leur message : les troubles neuropsychiatriques, plus particulièrement ceux reliés à la santé mentale, ont été sérieusement sous-estimés et imposent un fardeau bien plus lourd que l'on croyait en termes de perte de productivité et de coûts sociaux. En plus de l'énorme fardeau, une stigmatisation bien réelle accompagne les maladies neuropsychiatriques^{vi} et la reconnaissance publique que ces troubles sont d'origine physiologique n'est que très récente.

Le Canada doit jouer un rôle crucial en réaction au lourd fardeau des troubles neuropsychiatriques. Le Canada est un chef de file de la recherche en neuroscience et bon nombre de grandes découvertes en neuroscience y ont été réalisées. De grands laboratoires oeuvrant dans les domaines des maladies neurodégénératives, de la neurotraumatologie,

de la neuroimagerie, du génie tissulaire et des biomatériaux, de la régénération, protection et du rétablissement fonctionnel, et de la génétique sont établis au Canada.

Le gouvernement canadien a reconnu le besoin d'investir en recherche et a créé d'excellents programmes comme le Programme des chaires de recherche afin de recruter les meilleurs scientifiques; la Fondation canadienne pour l'innovation (FCI) qui finance les infrastructures; et Génome Canada qui finance des projets de recherche à grande échelle en génomique et en protéomique. Des donateurs privés ont aussi aidé avec les infrastructures, notamment en établissant des centres de recherche en neuroscience partout au Canada. Mais les infrastructures et les salaires ne suffisent pas, un investissement accru en fonds d'exploitation est nécessaire afin de permettre aux chercheurs de faire fonctionner leurs laboratoires et afin d'offrir des environnements formatifs aux étudiants de doctorat et aux boursiers postdoctoraux.

Les Instituts de recherche en santé du Canada sont actuellement la principale source de fonds publics pour la recherche en santé, mais le budget de 662 millions \$ en 2004 (il sera de près de 700 millions \$ en 2006) est loin d'atteindre la cible d'un milliard de dollars que les IRSC ont fixée comme étant adéquate au financement des chercheurs canadiens, incluant ceux qui travaillent en neuroscience. Même lorsqu'on tient compte du financement privé, la répartition des fonds pour les neurosciences n'est proportionnelle ni au fardeau de la maladie ni au financement que reçoivent d'autres catégories de maladies. Dans le cadre des concours ouverts des IRSC, un montant estimé à 81 millions \$ a été alloué à la recherche en neuroscience en 2003-2004, comparé avec 94 millions \$ pour le cancer et 109 millions \$ pour les maladies cardio-vasculaires. De plus, le cancer reçoit un montant additionnel de 64 millions \$^{vii} par année de la Société canadienne du cancer et de l'Institut national du cancer du Canada, et les maladies cardio-vasculaires reçoivent un montant additionnel de 51 millions \$^{viii} par année de la Fondation des maladies du cœur du Canada. Il n'existe aucune source de financement équivalent provenant de donateurs privés ou de fondations pour la recherche en neuroscience, et en combinant tout le financement de la recherche alloué par les organisations bénévoles de la santé concentrées en neuroscience, le montant est estimé à seulement 15 millions \$ (veuillez consulter l'appendice 4 pour un tableau illustrant les dépenses en recherche et en sensibilisation du public encourues par les organisations bénévoles canadiennes de la santé).

Les chercheurs canadiens doivent de plus en plus se tourner vers les institutions américaines, telles que la *National Institutes of Health* et la *Howard Hughes Medical Institute*, afin de recevoir du financement. Bien qu'il existe des organisations bénévoles de la santé qui recueillent des fonds pour la sensibilisation du public et pour la recherche sur des maladies spécifiques, NeuroScience Canada est la seule organisation canadienne sans but lucratif, non gouvernementale, vouée à recueillir des fonds pour la recherche sur toute la gamme des maladies, troubles et lésions qui relèvent des neurosciences. Cependant, la présente capacité de financement de NeuroScience Canada est modeste lorsque comparée avec les organisations qui chapeautent les autres catégories de maladies. Une augmentation des fonds

de fonctionnement pour la recherche, combinée aux programmes gouvernementaux déjà en place, permettra au Canada de demeurer chef de file en recherche en neurosciences, mais aidera surtout à l'effort mondial pour alléger le lourd fardeau des maladies, troubles et lésions neurologiques.

NeuroScience Canada fait les recommandations suivantes :

- La communauté des neurosciences devrait élaborer une campagne de sensibilisation du public décrivant le véritable fardeau des troubles du cerveau afin de stimuler une augmentation de l'investissement privé et public. NeuroScience Canada prévoit prendre l'initiative dans l'organisation d'une telle campagne, mais des frais d'établissement seront nécessaires ainsi qu'un appui adéquat de la part des autres intervenants dans ce domaine.
- Le gouvernement fédéral devrait investir immédiatement cinq millions de dollars par année, pendant cinq ans, soit au total 25 millions de dollars afin d'appuyer des projets de recherche à grande échelle en neurosciences. NeuroScience Canada se servirait de ces fonds pour attirer un financement privé additionnel, selon un ratio de 1 \$ de financement privé pour chaque 2 \$ de financement gouvernemental.
- Finalement, la communauté des neurosciences devrait demander une augmentation des fonds attribués par les Instituts de recherche en santé du Canada (IRSC) à l'Institut des neurosciences, de la santé mentale et des toxicomanies (INSMT), afin de mieux appuyer à la fois les chercheurs individuels et les équipes de recherche. Pour ne pas réaffecter des fonds d'autres secteurs, il faudrait porter le budget des IRSC à son objectif de un milliard de dollars.

Introduction

The brain is an extremely complex organ, made up of 100 billion neurons that communicate with each other primarily through biochemical signals (neurotransmitters) traveling at speeds up to 220 mph [360 km/hour] along a network that involves trillions of synaptic connections. Neuroscience is the study of the brain and the nervous system and covers more than 1,000 illnesses and injuries including major ones such as Alzheimer's disease, Parkinson's disease, multiple sclerosis, brain tumours, chronic pain, depression, stroke, sense organ diseases, addiction and brain and spinal cord injuries. These diseases, disorders and injuries involve a complex interplay of genetic and environmental factors, afflict Canadians of all ages and backgrounds, and can strike anyone at anytime. For example, diseases such as autism, Cerebral Palsy and epilepsy appear in childhood; multiple sclerosis is most often diagnosed in late teens; depression mostly occurs between the ages of 15 and 25; and Alzheimer's and Parkinson's disease strike in late adulthood. Other conditions such as chronic pain and brain tumours can occur at any point in a person's lifetime. Neuroscience focuses on much more than diseases and disorders. It really reaches into who we are as human beings – our emotions, our behaviour and our capacity to think and reason.

The promise of research

Neuroscience researchers have already made enormous progress in understanding the complexity of the nervous system, protecting the brain against insult, repairing the brain when injury or disease occurs, and promoting recovery of function. Recent innovations in imaging, molecular biology and genomics have led to many advances in the past few years; however the brain still represents one of the last frontiers of science. It is the most critical organ and yet still the least understood.

Ninety per cent of what we have learned about the brain has been in the past fifteen years, but researchers still have far to go toward fully understanding brain function.

The United States has deemed research into the brain so important that the 1990's were declared "The Decade of the Brain". It had long been accepted that the central nervous system does not regenerate itself after a traumatic injury, as seen in people with brain or spinal cord trauma who are generally not able to recover their pre-injury level of function. However, recent discoveries – including the revelation that adult brains can form new nerve cells and that immature neural stem cells can migrate to injured areas of animals' brains – have forced a reconsideration of this accepted principle (Dana 2002).

As we move through the 21st century, neuroscientists are aiming to:

- Provide new insights into aging, memory and mental illness;
- Deliver more effective treatment for acute injury – stroke, brain and spinal cord injuries;
- Develop therapies for chronic neurodegenerative diseases such as Alzheimer's disease and Parkinson's Disease;
- Sharpen diagnostic techniques - neuroimaging, bioinformatics and cognitive neuropsychological testing;
- Develop more effective and targeted medications and treatments for depression, schizophrenia, bipolar disorder, chronic pain, macular degeneration, glaucoma/blindness, addiction, and other neurological and psychiatric conditions;
- Understand the causes of psychiatric disorders and substance abuse.

Section 1: The burden of neurological and psychiatric diseases, disorders and injuries

One in three (10 million) Canadians will be affected by a neurological or psychiatric disease, disorder or injury at some point in their life. These conditions are the leading cause of health disability. We estimate that fifty per cent of all Canadians – about 15 million people have had a neuroscience-related disorder impact their family during their lifetime.

Until recently, many governments lacked the most basic data they needed to assess priorities for public health (GDB 1990). Mortality and hospitalization rates were used to determine health priorities, although it was widely realized that such statistics had many inadequacies in the way they were presented and that these rates did not properly account for the huge impact of non-fatal diseases. In particular, mortality and hospitalization rates fail to take into consideration suffering and disability that do not result in death or hospitalization, nor lost productivity and psychosocial costs to patients and their caregivers. New studies were needed that combined fatal and non-fatal diseases – incorporating disability and mortality. Health economists have begun to develop burden of disease studies to look at the incidence of diseases and injuries and their economic impact on nations' healthcare systems. There is a need to reframe health care investment in services and research according to morbidity data and not mortality data. There should be a relation between investment and burden of disease.

There is no comprehensive study on the burden of brain disease in Canada that encompasses all of the categories of illness that fall under the umbrella of neuroscience. This highlights the need for increased epidemiological research on the burden of brain disease in Canada in order to truly understand the magnitude of the economic costs and prevalence of brain disease within Canada and world-wide. In an attempt to compile the most thorough example of the burden of neurological and psychiatric diseases and provide a clearer understanding of the scope of brain disease, NeuroScience Canada has analyzed the data from a Health Canada study on the *Economic Burden of Illness in Canada 1998* (known as EBIC), in conjunction with the World Health Organization (WHO) *Global Burden of Disease study* (known as GBD 2000), as well as studies conducted by key stakeholder groups in Canada and the US.

The 1998 Health Canada Study on Economic Illness in Canada

The primary goal of Health Canada's 1998 study was to supply objective and comparable information on the magnitude of the economic burden or cost of illness and injury in Canada based on standard reporting units and methods. These estimates, along with other health

indicators, provided an important piece of the evidence required for health policy and planning. In analyzing this data, NeuroScience Canada had to define the “brain disease” category, as it was not identified in the 1998 Health Canada Study. To reconstitute the category, NeuroScience Canada had to group in a single category, diseases, disorders and injuries of the brain and nervous system. This category includes brain and spinal cord injuries, chronic pain and sense organ disorders. Cerebrovascular accidents (strokes), which occur when blood flow to the brain is cut off causing death or brain damage, were also categorized as a neurological disorder although they are often included in the cardiovascular disease group. We did not include brain and neurological injuries (either intentional or unintentional), as the data did not identify brain injury specifically. There were other neuropsychiatric diseases that had to be excluded from the data as overlap between disease categories made it impossible to allot them proportionately.

According to the EBIC study, the total cost of illness in Canada in 1998 was estimated to be \$159.4 billion. NeuroScience Canada estimates that \$16.17 billion of this total or 10% was represented by the category of neurological and sense organ diseases (Please see Appendix 1). The 1998 EBIC study did not identify such a category and used more traditional classifications. The four major categories used by the EBIC were cardiovascular disease, cancer, musculoskeletal diseases and injuries and represented 35% of the total burden of disease. But the cardiovascular disease category included stroke, which as mentioned above, should be assigned to the neuropsychiatric category. In addition, suicide and self-inflicted injury were defined as injuries, and diseases of the back and spine have been grouped with musculoskeletal diseases. As a result of these methodological choices, the EBIC study did not estimate the true incidence of neuropsychiatric diseases, disorders and injuries. The definition of neuropsychiatric diseases and disorders should include mental disorders and nervous system/sense organ diseases. A second limitation was the narrow view of the costs associated with disease. EBIC took into account the major direct costs such as the expenditures for Hospital Care, Drugs, Physician Care, Care in other institutions and the indirect costs consisting of mortality and morbidity due to both short-term and long-term disability. But it did not include costs associated with areas such as lost work as well as psychosocial costs to patients or caregivers. (These costs will only be incorporated into subsequent EBIC studies)

Economic burden of mental health problems in Canada 2001

In an effort to address the above limitations and provide a comprehensive estimate of the economic burden of mental health problems in Canada, the *Economic Burden of Mental Health Problems in Canada 2001* (EBMH) study funded by the Mental Health Promotion Unit of Health Canada was conducted. In compiling data for the study, the limitations of EBIC were somewhat corrected. A large number of Canadians with mental health problems that were treated outside the medical system were included in medically based calculations of the direct cost of illness.

The costs of non-medical services and the value of short-term disability associated with mental health problems were added. (For instance, costs for consultations with psychologists and social workers not covered by public health insurance or “direct costs” was \$278 million.) Finally, the value of reduced productivity associated with depression and distress over the short term or “indirect costs”, which totaled \$6 billion, was also taken into account. This led to a new estimate for the total burden of mental health problems of approximately \$14.4 billion, which places mental health problems among the costliest conditions in Canada. When combining this estimate with that of nervous system/sense organ diseases, the total cost of illness of neurological and psychiatric illnesses (neuroscience) is \$22.7 billion. This represents 14% of the overall cost of illness, compared to 12% for cardiovascular disease and 9% of overall costs for cancer. (Please see Appendix 2 for a Table of the Burden of Disease in Canada 2001) The 2001 study also reveals that within the disease diagnostic categories, indirect costs are significantly higher than direct costs. This highlights the enormity of mortality and morbidity costs due to both short-term and long-term disability on society. (EBIC, 2002, p. 5)

World Health Organization Global Burden of Disease reports – 1990 and 2000

Researchers at the Harvard School of Public Health and the World Health Organization have compiled a comprehensive, internally consistent and comparable set of estimates of current patterns of mortality and disability from disease and injury for all regions of the world. This study is called the *Global Burden of Disease and Injury* (GDB). It was first done in 1990 and was updated in 2000.

This study was the first major study to use a new metric for the disability component in burden of disease. The Disability Adjusted Life Year (DALY) is a measure that expresses years of life lost to premature death and years lived with a disability of specified severity and duration. Though this metric is not without controversy, the DALY is currently the only measurement that combines years of life lost (YLLs) with years lived with disabilities (YLDs) into a single indicator, to better compare the burden of various illnesses. Essentially, one DALY can be viewed as “one lost year of ‘healthy’ life”. It positions the burden of diseases as a measurement of the gap between current health status and an ideal situation where every one lives into old age free of disease and disability (Mathers et al. p3).

Neuropsychiatric conditions account for 38.3% of DALYs, (Disability Adjusted Life Year) compared with 12.7% for cancer and 11.8% for cardiovascular disease.

Using figures from the 2000 study, the incidence by disease categories for cancer, cardiovascular and neuropsychiatric diseases (neurological and psychiatric diseases) are compared^x.

Neuropsychiatric conditions are also the most important causes of non-fatal disability, accounting for over 37% of YLDs (Years Lived with Disability) among adults (age 15+). Seven of the 10 leading causes of disability are related to neuropsychiatric conditions, with unipolar depressive disorders the leading cause (Please see Appendix 3). The surprisingly high percentage of YLDs and indirect costs attributed to long-term disability clearly indicates their significant effect in terms of lost productivity.

Another study, the 2001 WHO report on mental health titled, *Mental Health: New Understanding, New Hope*, reiterates that the burden of mental illnesses, such as depression, alcohol dependence and schizophrenia, were seriously underestimated by traditional approaches that take into account only death and not disability. While psychiatric conditions are responsible for slightly more than one per cent of deaths, globally they account for almost 11 per cent of the burden of disease. The leading causes of disability are shown to be substantially different from the leading causes of death, which stresses the limitation of mortality data to assess population health.

Most significantly, this 2001 study shows that the burden of psychiatric conditions has been significantly underestimated. Of the 10 leading causes of disability worldwide in 1990, five were psychiatric conditions: unipolar depression, alcohol use, bipolar affective disorder (manic depression) schizophrenia and obsessive-compulsive disorder. Unipolar depression alone was responsible for more than one in every 10 years of life lived with a disability worldwide. In total, neurological and psychiatric diseases and disorders accounted for 28 per cent of all Years Lived with a Disability (YLDs), compared with 1.4 per cent of all deaths and 1.1 per cent of years of life lost.

Additional research in Canada

Several reports from various stakeholder groups have recognized the shift in perception of the global burden of disease from infectious to non-communicable disorders and disabilities as public health concerns and the serious underestimation of the cost of burden attributed to neuropsychiatric diseases, in particular those in the area of mental health.

The Global Business and Economic Roundtable on Addiction and Mental Health's *Vision 2020 Report* profiled the challenge of addiction and mental health to be faced by NAFTA and the European Community. This report stresses the key role of chronic and brain-based health problems and the fact that disabilities have surpassed life expectancy concerns as a global public health priority. As a result, the issue of lost productivity has become a major factor on the economic burden of illness with depression and other mental health disorders having a profound effect on the productive capacity of the labour force. The report has outlined several factors to consider, some of which are as follows:

1. The cost of mental illness is about \$33 billion a year in Canada. This is more or less equivalent to three per cent of GDP;
2. About 30 per cent of the total disability insurance and self-insurance claims experience in Canada relate to “mental and nervous” conditions. The Canada Pension Plan estimates its payout for these conditions is nearing one-in-four;
3. That said, the impact of mental and stress-related disabilities are characterized more by their duration and dollar cost than volume. This is characteristic of mental disability;
4. The longer employees are off the job for any reason, the more likely there is a mental health component to their disability.

Another study, Health Canada's Report on *Mental Illnesses in Canada*, prepared in collaboration with the Mood Disorders Society of Canada, provides a comprehensive examination of the incidence and prevalence, causation, impact, stigma, prevention and treatment of the major mental illnesses. The report discusses the economic impact of mental illness on the Canadian economy in terms of lost productivity and health care costs. It discusses both the EBIC and EBMH studies mentioned previously, recognizes the lack of complete data on lost productivity and costs and use of services, and concludes that the economic burden of mental illness is far greater than previously reported. Mental illnesses are also a major contributor to hospital costs. According to the Canadian Institute for Health Information (CIHI), Canadian hospitals reported nearly 200,000 mental-illness-related separations defined as “the discharge or death of an inpatient”. General hospitals accounted for 86% and provincial psychiatric hospitals for 14% (*Health Canada Report 2002*, p. 21). This report notes “mental illnesses touch the lives of all Canadians, exerting a major effect on relationships, education, productivity and overall quality of life. In fact, approximately 20% of individuals will experience a mental illness during their lifetime, and the remaining 80% will be affected by an illness in family members, friends or colleagues. With sufficient attention and resources, much can be done to improve the lives of people living with mental illness” (*Health Canada Report 2002*, p. 3).

American Research

In the United States, the *President's New Freedom Commission on Mental Health* (April 2002) identified six goals as the foundation for transforming mental health care in America. Of important note was the Commission's recommendation for “the reviewing of existing scientific literature and initiating new studies to examine the impact of mental health and mental illnesses on physical illnesses and health.”

The *Surgeon General's Report on Mental Health* (1999), the first report ever issued by the Surgeon General on the topic of mental health and mental illness, acknowledged that the

burden of mental illness on health and productivity has long been profoundly underestimated. Two key messages emerging from the report were that mental health is fundamental to health and that mental disorders are real health conditions that have an immense impact on individuals and families not only in the US but also globally. The report provides statistics that describe the extent of the impact of mental illness in the US .

The National Institute for Mental Health (NIMH) has reported in 1999 that the highest cause of disability in the US is mental illness. Four of the 10 leading causes of disability in the US and other developed countries are mental disorders—major depression, bipolar disorder, schizophrenia, and obsessive-compulsive disorder. Suicide, the third leading cause of death in adolescence, accounts for 30,000 deaths each year in the US. Total costs in fiscal year 2003 for mental health care were \$71 billion for treatment and \$79 billion in indirect, social costs for a total of \$150 billion. The NIMH has acknowledged that the burden of mental illness on health and productivity in the US and throughout the world has long been underestimated. In referring to the WHO GBD study, it reports that mental illness, including suicide, accounts for over 15 percent of the burden of disease in established market economies, such as the US^x.

Conclusion

Neurological and psychiatric diseases, disorders and injuries represent the leading costs to the healthcare system and to society, ahead of the more publicized categories of cancer and cardiovascular. Estimates of the annual costs to the Canadian economy vary between \$22 billion and \$30 billion or nearly 3% of GDP. Neuropsychiatric conditions are associated with high DALY (Disability Adjusted Life Year) and high YLD (Years Lived with Disability) as people with such diseases tend to go on living with their disabilities, imposing significant costs to their family. But more importantly, the incidence of neuropsychiatric conditions is much higher than commonly assumed, touching every family.

Section 2: Neuroscience research in Canada and the world

With 0.5 percent of the world's population, Canada generates about four percent of the world's scientific knowledge^{xi}. A significant proportion of that new knowledge is related to health. The Canadian government has long recognized the need to invest in health research and has taken many steps to ensure that the best talent comes to Canada and stays in Canada. Three recent examples are the Innovation Fund of the Canadian Foundation for Innovation, the Canada Research Chairs Program, and Genome Canada. However, while these investments have built capacity in infrastructure and salaries, they have provided limited funding for operations. Currently, the Canadian Institutes of Health Research (CIHR) is the primary source of public funding for health research, and in 2004 provided \$662 million for health research.

It is estimated that Canada annually spends \$3.5 billion on health research. This total includes the clinical studies done in Canada by pharmaceutical companies, whose spending is estimated to be a third of the total. (Secor, *"Canada's Innovation Policy and the Biopharmaceutical Industry"*, 2003, pgs 14, 16 and 20) Most of the research is carried out in universities and hospital-related health centres.

The Canada Foundation for Innovation (CFI) has an endowment of \$3.65 billion and is an independent corporation created by the Government of Canada to fund research infrastructure. The CFI's mandate is to strengthen the capacity of Canadian universities, colleges, research hospitals, and non-profit research institutions to carry out world-class research and technology development that benefits Canadians (CFI website). The CFI has made great strides in improving infrastructure; however, the Innovation Fund does not cover the costs of the people required to perform the research, develop new projects or manage the resources to drive projects forward. In 2004 the CFI gave \$585.9 million to health research projects.

Established in 2000, the Canada Research Chairs Program (CRC) is a \$900 million program geared towards providing a competitive edge in attracting and retaining top researchers. This program is investing in research excellence by establishing 2,000 Canada Research Chairs in Canadian universities in the areas of health, natural sciences and engineering, and social sciences and humanities. In 2004, the CRC program disbursed just over \$146 million.

An additional initiative of the federal government is Genome Canada. Created in 2001, the mandate of Genome Canada is to provide operating funds for large-scale genomics and proteomics projects with the goal of improving Canada's position in this area. The organization's mission is to "develop and implement a national strategy in genomics and proteomics research for the benefit of Canadians". There are five regional genomic centres across Canada and each of these centres leverages the federal funding they receive with partner and provincial funds. Genome Canada has already invested more than \$379 million across Canada. It should be

noted that the scientific community has criticized the co-funding model of Genome Canada whereby researchers must match the Genome Canada funds they receive by raising an equal amount from private sources. (Science Magazine June 24, 2005 - *Problems with Co-Funding in Canada*)

While these three programs have had significant positive outcomes on the research climate in Canada, this government commitment to research needs to be sustained by providing operating grants in order to have a long-standing impact, so that Canada can keep its place as one of the top countries in health research.

Canada's leadership is particularly significant in the area of neuroscience research. (Please see Appendix 4 for examples of Canadian achievements in neuroscience). There is huge capacity and activity in the neurosciences, as seen from the quantity and quality of neuroscience-related journal articles by Canadians and the high number of university programs in neuroscience. Unfortunately, current funding does not match the capacity and additional operating dollars are required to maintain what has been created and to accelerate the pace of discovery.

Neuroscience is well represented in the Canada Research Chairs Program with an estimated 89 chairs out of 487 chairs in the area of health^{xii}. The Canada Foundation for Innovation has also invested significant funds into improving infrastructure in neuroscience, funding a number of projects across the country. Since 1998, there have been 49 projects in neuroscience-related areas with an investment totaling over \$29 million. (This is a conservative figure excluding many projects that do not have a focus directly on neuroscience but that are relevant to this area.) An additional boost to infrastructure is seen through major gifts from private donors that have resulted in the creation of institutes devoted to the study of neuroscience, such as the Hotchkiss Brain Institute in Calgary, the Krembil Neuroscience Centre in Toronto and The Rotman Research Institute. As well, in February of 2005, the University of British Columbia received a \$10 million anonymous gift towards mental health research, Canada's largest gift ever to this area.

Medical Research and Medical Services Studies

Numerous studies are being undertaken to illustrate the benefits of medical research for society. There are a number of ways to estimate the economic return on medical research investments, such as healthcare costs saved, jobs created, the value of increased longevity, the value of reduced morbidity and disability, and the benefits of newer medicines^{xiii}.

The National Institute of Health spends, on an annual basis, more than \$28 billion on health research (94.68\$ per capita based on 2005 US population figures of 295,734,134).

This compares with an annual budget of \$662 million for the CIHR, its Canadian counterpart (20.18\$ per capita, based on 2005 Canadian population figures of 32,805,847).

In 2004/2005, National Institutes of Health (NIH) health research spending was \$94.68 per capita.

In 2004/2005, Canadian Institutes of Health Research (CIHR) health research spending was \$20.18 per capita.

The value of large investments in health research is well understood in the US. Between 1999 and 2003, the budget of the National Institutes of Health (NIH) was doubled. This increase was justified by the burgeoning scientific opportunities that are now available, particularly as a result of the scientific achievement of sequencing the human genome, and the large economic benefits that accrue as progress is made against diseases (Ad Hoc Group for Medical Research Funding 2002).

The NIH compiled a document titled, *Investments, Progress, and Plans - Selected Examples from FY 1999 – 2003*, highlighting some of the many uses of its increased funding. They acknowledge that benefits from research often take many years to produce major discoveries, but they have several examples of where the money has already yielded positive results.

Completing the circle: increasing operating funds for Canadian researchers

Canadian neuroscience research is underfunded by international standards despite its world-class quality. An average grant from the NIH (US) in 2003 was US\$338,600 whereas the average grant from the Canadian Institutes of Health Research (CIHR) was only Cdn\$103,500^{xiv}. Indeed, Canadian researchers have often turned to US institutes such as the NIH and Howard Hughes Medical Institute for additional operating funding.

The Canadian government has succeeded in improving research infrastructure and attracting the top talent to the country. However, there is still a lack of sufficient funds for research operating grants. According to David Hill, chair of the Council for Health Research in Canada, and Scientific Director at the Lawson Health Research Centre in London, "*The substantial funding put into new infrastructure and retention of the best scientists will not yield the research*

knowledge output to fully justify those programs without sufficient operating funds to do the work. It is a matter of balance, leverage, and maximization of outcome between a variety of investments."

The 2004 CIHR operating grants competition had success rates of 28%. This resulted in scientists, whose projects ranked in the fundable rangexv , not being successful in receiving grants needed to continue to operate their labs to capacity. This will slow their ability to get to advances^{xvi}.

The CIHR realizes that sustained financial support is necessary to ensure that Canada stays competitive on the international health research front, and in their "Blueprint for Health Research and Innovation," has asked the federal government to increase the CIHR budget from \$662 million per annum to \$1 billion, in order to support research initiatives.

In 2003/4, neuroscience research (including mental health and addiction) received an estimated \$85 million^{xvii} or 14.9% of the CIHR budget, through the open grants competition. This compares with the NIH directing \$4.9 billion or 18% of its total budget to neuroscience research. Such support for neuroscience in Canada, \$85 million, is disproportionate to the cost of neurological and psychiatric disorders, conservatively estimated at \$22.7 billion.

One must consider that in addition to the CIHR, the private sector is potentially a major source of research funding. A discrepancy in funding between neuroscience and cancer and cardiovascular becomes apparent when funding from umbrella non-governmental organizations is considered. In addition to the CIHR funding, cancer research receives \$64 million from the National Cancer Institute of Canada and cardiovascular receives \$51 million from the Heart and Stroke Foundation of Canada (2004 figures). In comparison, it is estimated that all neuroscience-related Voluntary Health Organizations combined disburse approximately \$15 million per year (please see Appendix 5). (In the neuroscience area, foundations allocate most of their funds to public education and patient support, where the need is significantly stronger, the latter because of the high disability component of neurological and psychiatric disorders). Moreover, the funding is fragmented and used to support research in a number of different areas, with limited coordination among the various Voluntary Health Organizations. One obstacle to fundraising has been the stigma associated with mental illness that is not seen in other disease categories.

In Canada, The Kirby Report, tabled in November of 2003 (officially known as the *Interim Report of The Standing Senate Committee On Social Affairs, Science And Technology on the*

subject of Mental Health, Mental Illness and Addiction), examined the state of mental health services and addiction treatment in Canada, and the role of the federal government in this area. The goal is to develop a national agenda on mental health, mental illness and addiction. The report acknowledges the profound effects of mental health on society, and witnesses to the report indicate that the current funding for research in this area is far from adequate. Further consultations on the results of the report took place across the country, in February through June of 2005, and the recommendations will be published in the near future.

It has been discovered that while the many diseases, disorders and injuries of the brain and nervous system have different manifestations and symptoms, there are often root causes and mechanisms that are common among them. Cell loss, abnormal functioning of nerve cells, and chemical and molecular imbalances are three such underlying causes that are shared among a range of conditions.

Cell loss, for instance, is implicated in multiple conditions such as stroke, multiple sclerosis, Parkinson's disease, schizophrenia and spinal cord injuries. The best approach to neuroscience research is to bring together scientists from different disciplines and institutions to study these common mechanisms. In this way, a single breakthrough has the potential for therapies and cures for a number of illnesses.

Recognizing the strong need for a collaborative approach to address the burden of neurological and psychiatric disorders, the NIH has created the *Blueprint for Neuroscience Research*, whereby 14 NIH centres have pledged a percentage of their funds to a common pool for neuroscience initiatives. The aim of the Blueprint is to "better coordinate existing efforts to spur discovery and create resources and a toolkit for all neuroscientists to use". The Institute of Neurosciences, Mental Health and Addiction (INMHA) of the Canadian Institutes of Health Research has been assigned the responsibility on behalf of the federal government for funding research on the functioning and disorders of the brain, the spinal cord, the sensory and motor systems, and the mind, but it does not currently have the funding scale to alleviate the huge burden of neuropsychiatric disorders in Canada. There is an urgent need to increase the allocation of federal government spending for neurosciences research by increasing the CIHR budget. This will allow more funds to be directed to the INMHA.

There is a parallel urgent need for a consolidated approach in Canada to raising funds from private sources exclusively for neuroscience research. NeuroScience Canada is currently the only national non-profit organization that is devoted to supporting all of neuroscience

research (not restricted to one disease, disorder, injury, or a disease grouping). NeuroScience Canada has a particular focus on collaborative, multidisciplinary, multi-institutional research that has the potential to benefit a range of disorders. In November 2003, the organization launched the Brain Repair Program™, an \$8-million program focused on brain repair, a new field of scientific endeavour that is exploring the brain's ability to be repaired or to repair itself. Though a relatively modest addition to neuroscience research funding, this is currently the largest fund available for brain repair research, and will provide five teams of researchers with \$1.5 million each over three years, plus additional funds for networking. The program announcement generated a significant level of interest from the scientific community, and resulted in 21 team applications from across the country. All of these teams had potential to lead to excellent research projects, however, only three could be funded in the first competition. Funding for three teams does not come close to filling the need, but it is clear from the positive response to this new program that there is an enormous capacity for and interest in collaborative, multidisciplinary, multi-institutional, large-scale science in the area of the neurosciences. (See Appendix 6 for more detail about the program)

NeuroScience Canada estimates that about \$100 million^{xviii} at most is invested in operating costs for neuroscience research in Canada annually. This compares to a burden of disease in the order of \$20 billion to \$30 billion, a ratio of 200 to 1! The large discrepancy points to a significant inequality. Despite a strong infrastructure, Canada's neuroscience research is considerably underfunded. The investment in neuroscience research from the government and private donors must be increased – by raising awareness of the true impact of neurological and psychiatric conditions. NeuroScience Canada is taking a lead in this area.

Recommendations

Neuroscience research is an area where Canada has excelled and continues to be a leader, and this expertise must be fostered and encouraged. Canada must remain competitive in the area of neuroscience research because this holds the greatest promise for developing new diagnostics and therapeutics to deal effectively with brain disorders that afflict Canadians of all ages. This will require a significant increase in the funding that is directed to neuroscience research, to support both individual investigators and teams of investigators involved in large-scale projects. Canada's commitment to financing neuroscience research should be consistent with the burden of this disease group, and the capacity in Canada to conduct research into this area. Furthermore, the government's commitment to fund neuroscience research should take into consideration the current lack of private funds raised in Canada to support neuroscience research.

NeuroScience Canada recommends the following steps be taken:

- The neuroscience community should develop a public awareness campaign about the true burden of brain disorders to help stimulate increased private and public investment. NeuroScience Canada intends to take the leadership in organizing such a campaign, but this would require an initial investment and the appropriate support from other stakeholders in this area.
- The federal government should immediately invest \$5 million per year for five years, for a total of \$25 million to support large-scale neuroscience research projects. These funds would be leveraged by NeuroScience Canada to attract and stimulate additional private funding, at a ratio of \$1 from private sources for every \$2 in government funding.
- Finally, the neuroscience community should seek an increase in the Canadian Institutes of Health Research's (CIHR) allocation to the Institute of Neuroscience, Mental Health and Addiction (INMHA), to support both individual investigators and team grants. In order not to divert funds from other areas, this would mean increasing the CIHR budget to its \$1 billion target^{xix}.

Conclusion

The brain, spinal cord and nervous system are complex organs and systems that allows us to think, learn, feel and move. Research into the brain is progressing rapidly though scientists are still far away from fully understanding brain function and are continuing to work on finding treatments and cures for the range of neurological and psychiatric diseases, disorders and injuries that fall under the umbrella of the neurosciences. The burden of these disorders is enormous, an estimated \$20 to \$30 billion or 14% of the total cost of illness in Canada. Increasing funding to neuroscience research can help to alleviate these costs, translating into benefits for individuals, families, workplace productivity and the Canadian economy. Canada is a leader in the area of the neuroscience research and many important discoveries have taken place in this country. The government has acknowledged our research strengths and has initiated programs such as the Canada Research Chairs program for recruiting talent, the Canada Foundation for Innovation for funding infrastructure, and Genome Canada. However, one aspect that is lacking is sufficient operating funds to ensure that our researchers are able to collaborate and work to their fullest in order to achieve breakthroughs. It is our responsibility as Canadians to ensure that research is being conducted to capacity in order to lessen the burden of neurological and psychiatric diseases, disorders and injuries which impact one in three Canadians at some point in their lives.

Endnotes

- ⁱ In 2001, one in eight Canadians was 65 years of age or older. By 2026, this will have risen to one in five.
En 2001, un Canadien sur huit était âgé de 65 ans ou plus. D'ici 2026, un Canadien sur cinq aura atteint l'âge de 65 ans.
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- ⁱⁱ Sense organ diseases are made up of diseases, disorders and injuries affecting vision, hearing and other sense organs.
Les maladies des organes sensoriels regroupent les maladies, troubles et lésions de la vision, de l'ouïe et des autres organes des sens.
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- ⁱⁱⁱ The term "brain disorders" used throughout this Case refers to diseases, disorders and injuries of the brain, spinal cord and nervous system.
Le terme « troubles du cerveau » utilisé dans ce document s'applique aux maladies, troubles et lésions du cerveau, de la moelle épinière et du système nerveux.
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- ^{iv} In the near future, this lack of documentation about the impact of these conditions will be partially rectified by a comprehensive surveillance study commissioned by the Canadian Brain and Nerve Health Coalition (CBANHC) and being conducted by the Canadian Institute for Health Information assisted by Health Canada. CBANHC is an umbrella group of neurological practitioners, neuroscientists and voluntary health organizations that relate to the neurosciences. The results of this surveillance study will be available in June, 2006.
Le manque de documentation sur l'impact de ces maladies sera bientôt partiellement comblé grâce à une étude commandée par la Canadian Brain and Nerve Health Coalition (CBANHC), menée par l'Institut canadien d'information sur la santé, et aidée par Santé Canada. CBANHC est un regroupement de neurologues praticiens, de neuroscientifiques et d'organisations bénévoles de la santé oeuvrant en neuroscience. Les résultats de l'étude de surveillance seront disponibles en juin 2006.
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- ^v Major direct and indirect costs—expenditures in hospital care, drugs, physician care, care in other institutions and additional direct health, mortality costs, and morbidity costs due to both long-term and short-term disability
Importants coûts directs et indirects – coût des soins hospitaliers, coût des médicaments, coût des soins médicaux, coût des soins dispensés dans d'autres établissements et autres coûts directs relatifs à la santé, coût de la mortalité, et coût de la morbidité attribuable à l'invalidité de longue durée et de courte durée.
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- ^{vi} This disease group may hereafter be referred to as "brain diseases" or "neuropsychiatric conditions". Neuropsychiatric disorders refers to the category encompassing both neurological and psychiatric disorders and not the subset of disorders that contain both a neurological and psychiatric component such as Alzheimer's disease.
Cette catégorie de maladie sera ci-après appelée « maladies du cerveau » ou « troubles neuropsychiatriques ». Les troubles neuropsychiatriques englobent les troubles neurologiques et psychiatriques et non le sous-ensemble des troubles qui comprennent une composante neurologique et une composante psychiatrique tels que la maladie d'Alzheimer.
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- ^{vii} Funded by the Canadian Cancer Society and The Terry Fox Foundation, the National Cancer Institute of Canada (NCIC) is a research organization devoted to advancing cancer control. In 2004, the NCIC provided \$64 million to support excellent cancer research and related programs across Canada.
Financé par la Société canadienne du cancer et par la Fondation Terry Fox, l'Institut national du cancer du Canada (INCC) est un organisme de recherche canadienne voué à l'avancement de la lutte contre le cancer. En 2004, l'Institut a versé plus de 64 millions \$ pour soutenir d'excellents programmes apparentés à la grandeur du pays.
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- ^{viii} Figures from Heart and Stroke Foundation of Canada 2004 Annual Report
Les chiffres proviennent du rapport annuel 2004 de la Fondation des maladies du cœur du Canada.
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- ^{ix} The structure used for classification of disease and injury causes is broadly similar to the GBD 1990, but rely on more detailed codes than Health Canada's study. This allows a finer classification of diseases, as smaller mutually exclusive diseases, identified as falling under the umbrellas of one of the three main disease groups can be to each category. Cerebrovascular disease (stroke) was included in the neuropsychiatric category. Furthermore, consistent with Health Canada's classifications, sense organ diseases were included in the neuropsychiatric category.
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^x - An estimated 22.1 percent of Americans ages 18 and older—about 1 in 5 adults—suffer from a diagnosable mental disorder in a given year. This figure translates to 44.3 million people when applied to the 1998 U.S. Census residential population estimate;- Approximately 15 percent of all adults who have a mental disorder in one year also experience a co-occurring substance (alcohol or other drug) use disorder, which complicates treatment;- In the mental health field, progress in developing preventive interventions has been slow because, for most major mental disorders, there is insufficient understanding about etiology (or causes of illness) and/or there is an inability to alter the known etiology of a particular disorder;- About 10 percent of the U.S. adult population use mental health services in the health sector in any year, with another 5 percent seeking such services from social service agencies, schools, or religious or self-help groups. Yet critical gaps exist between those who need service and those who receive service; - Mental illness and less severe mental health problems must be understood in a social and cultural context, and mental health services must be designed and delivered in a manner that is sensitive to the perspectives and needs of racial and ethnic minorities.

^{xi} Advisory Council on Science and Technology - The Expert Panel on Canada's Role in International Science and Technology, 2000

^{xii} These 89 chairs represent chairs that have a direct link to neuroscience. There are other chairs that are indirectly related to neuroscience but were not included in this figure.

^{xiii} The Mary Lasker Charitable Trust in the United States has sponsored research into quantifying the benefits of health research in the US. Most remarkable are the benefits from solving some specific diseases. For instance, the development of a lithium treatment for manic-depressive illness results in health cost savings of more than \$9 billion annually. Preventing hip fractures in postmenopausal women at risk for osteoporosis saves \$333 million annually. A 17-year program which invested only \$56 million in research on testicular cancer has led to a 91% cure rate and an annual savings of \$166 million (Lasker Foundation 2000).A seminal study in the benefits of health-related research is the 1995 study by S. C. Silverstein entitled "A few basic economic facts about research in the medical and related life sciences". It indicated that for every dollar invested throughout the public and private sectors, there was a return of at least three to one from cost savings alone. The study also emphasized that an important area of savings were those in the field of psychiatry, where the development of medications for schizophrenia and manic-depressive illness alone, saved nearly US\$34 billion a year in avoided hospitalization costs (Silverson 1995).

^{xiv} In some cases, there are expenses allowed in NIH grants that are not allowed in CIHR grants.

^{xv} CIHR grants are rated on a scale from 0 - 4.9, within descriptive categories ranging from unacceptable to outstanding. Committees are instructed that anything rated 3.0 and above, i.e., solid significant research, should be FUNDABLE in its present form. (Fundable should be distinguished from what is actually approved for funding in a given competition, which is limited by the amount of money available.) Any proposal not considered fundable (e.g., where there are questions of feasibility, errors of logic etc.) is rated below 3.0. (CIHR website)

^{xvi} This past year, more than 600 grants that ranked over 3.5 in the CIHR scale were not funded and included 78 that ranked 4.0 and over. Applications rated 4.0 and above are considered to fall in the 'must be funded' category. The fact that 78 applications in this range did not receive funding not only demoralizes and frustrates the applicants but also those individuals who have been involved in the review process and consistently see excellent research proposals that could make significant advances in science go unfunded. The federal budget released in February 2005 announced a \$32 million increase in the CIHR's base budget beginning in 2005/2006. The revised success rate for the CIHR grants competition has been increased to 28% but there are still some projects that ranked over 4 on the CIHR scale that could not be funded.

^{xvii} 2003/2004 CIHR figures provided by the CIHR Institute for Neuroscience, Mental Health and Addiction.

^{xviii} \$81 million from CIHR added to \$15 million from neuroscience-related VHO's

^{xix} Each of the 13 CIHR institutes receives exactly the same annual budget of \$7.2 million regardless of the size of the research community they are serving. INMHA affiliated researchers account for 14.9% of the operating grants funded by CIHR (2004 CIHR Annual Report), however given the limited budget given to INMHA for strategic grants, they receive proportionally less from this pool of money.

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Appendices

Appendix 1: Economic burden of illness in Canada by diagnostic category and cost component EBIC1998

Illness	Direct Cost	Indirect Cost	Total	% of overall
Cancer	2.46 \$	11.76 \$	14.22 \$	9%
Cardiovascular (with stroke)	6.82 \$	11.65 \$	18.47 \$	12%
Nervous System/ Sense Organs Diseases + Mental Disorders	7.50 \$	8.69 \$	16.17 \$	10%

All figures are in billions

Total cost of illness in Canada in 1998 is estimated to be \$159,4 billion.

Figures from Health Canada's *Economic Burden of Illness in Canada, 1998* Table 2, *Summary of Results*

Direct Costs: Expenditures in Hospital Care, Drugs, Physician Care, Care in other institutions and additional Direct Health

Indirect Costs: Mortality Costs, and Morbidity Costs due to both Long-term and Short-Term disability

Appendix 2: The burden of disease in Canada 2001 Three major categories

Illness	Direct Cost	Indirect Cost	Total	% of overall
Mental Disorders*	6.26 \$	8.13 \$	14.39 \$	9%
Nervous System/ Sense Organ Diseases	2.82 \$	5.48 \$	8.30 \$	5%
Subtotal Mental Disorders + Nervous System/ Sense Organ Diseases	9.08\$	13.61\$	22.69\$	14%
Cancer	2.46 \$	11.76 \$	14.22 \$	9%
Cardiovascular	6.82 \$	11.65 \$	18.47 \$	12%
Sub Total – three major disease areas	18.36\$	37.02\$	55.38\$	35%
Total			159.00\$	100%

All figures are in billions

Figures from Health Canada's *Economic Burden of Illness in Canada, 1998* Table 2, *Summary of Results*

*Figures extrapolated from *The Economic Burden of Mental Health Problems in Canada, 2001*

Appendix 3: Ten leading causes of YLD, global estimates for 2002

% of total YLD		% of total YLD	
1 Unipolar depressive disorders	11.8%	6 Schizophrenia	2.8%
2 Hearing loss, adult onset	4.6%	7 Perinatal conditions	2.7%
3 Cataracts	4.5%	8 Osteoarthritis	2.6%
4 Alcohol use disorders	3.3%	9 Vision loss, age-related and other	2.5%
5 Maternal conditions	3.3%	10 Bipolar affective disorder	2.5%

Global Burden of Disease in 2002: data sources, methods and results. Mathers et al.

Appendix 4 : Canadian Achievements in Neuroscience

- 1949 - Dr. Donald O. Hebb published “The Organization of Behavior: A Neuropsychological Theory”, a keystone of modern neuroscience.
- 1954 - Dr. Herbert Jasper, co-authored, along with Dr. Wilder Penfield, the influential monograph “Epilepsy and the Functional Anatomy of the Human Brain”. Dr. Jasper was noted for studies on electrical activity in human and animal brains.
- 1957 - Dr. Wilder Penfield, a pioneering brain surgeon, and Dr. Theodore Rasmussen, mapped out the functional areas of the brain.
- 1957 - Dr. Heinz E. Lehmann, a gifted psychiatrist, was awarded the prestigious Lasker award for being the first to introduce anti-psychotic medication to North America for the treatment of schizophrenia.
- 1965 - Dr. Ronald Melzack and Dr. Patrick D. Wall published the “Gate Control Theory of Pain”, which had an enormous impact on the field of pain research and therapy. The basis of the theory is that psychological as well as physical factors guide the brain’s interpretation of painful sensations and subsequent response.
- 1974 - Dr. Donald Calne was the neurologist who first used synthetic dopamine to treat patients with Parkinson’s disease.
- 1980 - Dr. Albert Aguayo and his co-workers at McGill University made the revolutionary discovery that damaged central nervous system cells in animals can regenerate and form new connections, a phenomenon previously regarded to be impossible.
- 1981 - Dr. David H. Hubel was the co-winner of the Nobel Prize in Physiology or Medicine for mapping the visual cortex and studying how the brain processes visual information so that a person is able to see.
- 1990 - Dr. Philip Seeman and his research group cloned three dopamine receptors, which are now being tested for their possible role in abnormalities seen in patients with psychotic disorders.
- 1992 - Dr. Samuel Weiss found natural stem cells in the brains of adult mammals, proving for the first time, that stem cells exist in all stages of development.
- 2000 - Dr. Peter St. George-Hyslop and his research group identified a key protein involved in the degeneration of nerve cells in Alzheimer’s Disease.
- 2001 - Dr. Freda Miller and her colleagues isolated stem cells from the dermis of adult rodents, a finding that underlines the potential for the use of stem cells from a non-controversial source.
- 2003 - Michael Salter from Toronto Sick Kids and researchers from the National Institute of Health Sciences in Japan identified a molecule that causes neuropathic pain, a sharp and chronic pain associated with nerve injury and diseases affecting the nervous system.

Appendix 5 : Canadian Voluntary Health Organizations - Research and Public Awareness Expenditures

Organization	Total Revenue	Total Expenditures	Total \$ towards research	Research/expense (%)	Total \$ towards public awareness	Public awareness/expense	%Other expenditures (note 1)
ALS Society of Canada	\$3,273,459.00	\$2,545,755.00	\$500,000.00	19.64%	\$423,626.00	16.64%	63.72%
Alzheimer Society of Canada	\$11,204,962.00	\$11,021,518.00	\$3,717,117.00	33.73%	\$504,418.00	4.58%	61.69%
Canadian Psychiatric Research Foundation	\$799,773.00	\$1,163,094.00	\$802,534.00	69.00%	\$220,988.00	19.00%	12.00%
Epilepsy Canada	\$689,432.00	\$1,137,062.00	\$178,154.00	15.67%	n/a	n/a	n/a
Huntington Society of Canada	\$2,137,901.00	\$2,136,977.00	\$373,806.00	17.49%	\$212,569.00	9.95%	72.56%
Multiple Sclerosis Society of Canada	\$26,522,000.00	\$25,852,000.00	\$7,035,000.00	27.21%	\$2,068,000.00	8.00%	64.79%
Muscular Dystrophy Association of Canada	\$6,814,039.00	\$7,006,765.00	\$732,659.00	10.46%	\$1,279,734.00	18.26%	71.28%
NeuroScience Canada	\$876,412.00	\$871,850.00	\$524,640.00	60.18%	n/a	n/a	n/a
Parkinson Society of Canada	\$4,896,108.00	\$3,633,517.00	\$1,059,354.00	29.16%	\$431,906.00	11.89%	58.95%
Schizophrenia Society of Canada Foundation	\$104,853.00	\$117,379.00	\$86,400.00	73.61%	n/a	na/	n/a
Total	\$57,318,939.00	\$55,485,917.00	\$15,009,664.00		\$5,141,241.00		

Note 1: other expenditures include: fundraising, administration, governance, caregiver support, volunteer development etc.

Appendix 6: The Brain Repair Program™

In November 2003, NeuroScience Canada launched the Brain Repair Program™ with the goal of fast-tracking “transformative” research to discovery and treatment. Brain Repair is a new field of multidisciplinary, collaborative research aimed at exploring the brain’s ability to be repaired, or to repair itself. This field of research is relevant not only to neurological conditions such as stroke, Alzheimer’s and Parkinson’s disease, but also to mental illness and addiction, the latter increasingly recognized as resulting from chemical and molecular imbalances in the brain that may be amenable to repair strategies.

The Brain Repair Program™ has several distinctive features:

- **First and foremost**, it is a national program that aims to support the best researchers doing the best research in Canada, and to provide the optimal conditions for collaboration across the country and across institutions. The emphasis is on excellence and innovation and research that addresses common mechanisms across brain diseases and disorders.
- **Second**, the program encourages multidisciplinary approaches to brain repair: traditional neurosciences along with biomedical disciplines such as genetics, molecular biology, physiology and pharmacology, as well as physics, chemistry, imaging and nanotechnology.
- **Third**, the program encourages teams that link basic research with clinical research including the disciplines of neurology, neurosurgery, psychiatry and rehabilitation medicine—so that there is a clear and direct interface between research and patient care, the translation of basic research into new and better treatments and cures.
- **And fourth**, the program aims to develop and retain world-class researchers in the neurosciences by encouraging the formation of teams that include young scientists and provide them with a training milieu to ensure there are opportunities to develop their skills and knowledge in Canada.

NeuroScience Canada will allocate \$8 million of our \$10-million campaign objective to fund the top five *Brain Repair Program™* teams in Canada. \$1.5 million will be provided to each team over three years, plus \$60,000 over the same period for networking. The three years of funding will allow for meaningful and sustained collaborations among the researchers. The networking funds are separate from the grant and intended to enable the teams to meet face-to-face, as well as to attend relevant conferences/meetings that will expand their knowledge and contacts and contribute to the success of their project.

The Brain Repair Program™ review process and results

The peer review process for the first *Brain Repair Program™* competition was rigorous and highly competitive. Following a call for applications, NeuroScience Canada received 21 Letters of Intent (LOIs), and our Science Advisory Council reviewed the LOIs and selected eight to advance to the Full Application stage. In May of 2004, the Full Applications were sent to a committee of seven internationally recognized experts from the US and Europe. Each application was assigned one primary and one secondary reviewer, who provided written reviews in advance of a committee meeting held in Montreal in July 2004.

The reviewers were provided with guidelines adapted from the Canadian Institutes of Health Research (CIHR), and the full review committee discussed each application, in accordance with the CIHR review process. The reviewers were told that only teams ranked in the “excellent” to “outstanding” range along the CIHR scale would qualify for funding. At the time, NeuroScience Canada had full funding for two teams.

Following the review process, three projects were unanimously recommended for funding. The three projects are complementary, covering the range of neurological and psychiatric diseases and disorders, chronic pain and spinal cord injuries, and were judged to have a high potential for breakthroughs in the neurosciences. NeuroScience Canada committed to raising additional funds in order to be able to fund all three projects; by the public announcement in November 2004, NeuroScience Canada had reached this goal. NeuroScience Canada must raise \$3 million in order to be able to launch a second competition and fund the final two *Brain Repair Program™* projects of our five-project objective.

The *Brain Repair Program™* teams we are funding will be closely monitored throughout the three years of the program. The teams are required to provide regular updates with regard to their progress, including a full report at the end of each year, that measures their results against the milestones established at the beginning of the program. Funding is provided on a yearly basis, and only if the team has successfully reached the milestones for the previous year. One of the international reviewers will be assigned to each project/team to evaluate the annual reports. Following the close of this first round of the program, based on the feedback we receive from the recipients, the science community and our partners and funders, we will evaluate the best way to continue the *Brain Repair Program™*.

The first three *Brain Repair Program™* grants have been awarded to teams led by the following researchers:

1. Dr. Freda Miller, *Hospital for Sick Children*, Toronto for their work on **Novel approaches to central nervous system white matter repair**
2. Dr. Michael W. Salter, *Hospital for Sick Children*, Toronto for their work on **Transforming research on chronic pain in Canada**
3. Dr. Yu Tian Wang, *University of British Columbia/Vancouver Coastal Health Research Institute, Brain Research Centre at UBC Hospital*, for their work on **Novel therapeutic strategies to repair brain abnormalities in psychiatric disorders**

If you are interested in joining our efforts to raise awareness about the need for increased funding for neuroscience research, please contact NeuroScience Canada at **info@neurosciencecanada.ca**

Si vous êtes intéressés à participer à nos efforts de sensibilisation face aux besoins pour un financement accru de la recherche en neuroscience, veuillez contacter NeuroScience Canada à **info@neurosciencecanada.ca**



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