

The National Core for Neuroethics is an interdisciplinary group dedicated to the ethical, legal, and social implications of neuroscience discovery.

For more information:

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HIGHLIGHTS

NATIONAL CORE FOR NEUROETHICS
LA NEUROÉTHIQUE

Aligning innovations in the brain sciences with societal, cultural and individual human values through high impact research, education and outreach.



BRAIN INJURY, DISORDERS OF CONSCIOUSNESS, AND HUMAN RIGHTS

Neuroimaging techniques such as functional magnetic resonance imaging enable scientists to detect brain responses in some severely brain injured patients even though they are behaviorally unresponsive during clinical examination. These patients, with a disorder of consciousness (DoC), are considered to be covertly aware. Their surprising brain signals raise questions about how families, physicians, and society ought to interact with and relate to them. Recently, our team presented its findings from two years of qualitative research on covertly aware DoC patients in a workshop with leading ethicists, neurologists, lawyers, health economists, and health care policy analysts. Results from this international, interdisciplinary group broke new ground by advancing a disability rights framework to address ongoing challenges on the continuum of research to translation for severe brain injury.

FROM THE LABORATORY TO THE LOCKER ROOM

Mild brain injuries such as those characterized as sports-related concussions represent 1.6 to 3.8 million injuries overall per year in North America. Increased awareness of the seriousness of this injury for long-term brain health and increased susceptibility to a second injury within a critical period has led to the creation and availability of a remarkable number of uncoordinated concussion guidance documents authored by experts and non-experts alike. With the protection of athletes' health as our principal driving value, we are examining how relevant policies are created, who is creating them, what scientific evidence is grounding them, and how they are maintained and enforced. Beyond these issues, we are characterizing the specific ethics discourse in the literature about concussion from the perspectives of a wide range of authors – from those trained in medicine through scholars in philosophy. We are especially focused on publications as they relate to pressures on athletes and their surrounding networks of teammates, coaches and physicians, and where, given scientific evidence for increasing danger, game-changing rules and oversight may be needed.

BIOTECHNOLOGIES IN THE WORLD OF SOCIAL MEDIA

In recent surveys, 90% of respondents aged 18 to 24 said they trust medical information shared on their social media networks, and 40% of online users of all ages reported that information found on social media affects the way they deal with their health. There is no shortage of conversations on social media about health and biomedical advances, and especially about emerging and cutting edge technologies with a focus on brain and spinal cord. A question remains, however: how are popular platforms such as Twitter used to disseminate information and generate discussions about related health issues? From studies of tweets about stem cells and optogenetics, the Robillard lab has revealed an important focus on the research process, and that research is generally viewed favorably with high expectations for the treatment of a large variety of conditions of the brain and spinal cord. Social media platforms such as Twitter are rapidly becoming a connecting forum for the many voices in the discussion about health and healthcare, and are likely to become a dominant influence in health decision-making. We continue to study and monitor this dynamic online environment to ensure that our connected health world benefits us all.

ONLINE RESOURCES ABOUT DEMENTIA: IS DR. GOOGLE REALLY IN?

Within a generation, over one million Canadians will suffer from Alzheimer disease or a related dementia, and the costs for dementia care will reach \$153 billion. Faced with this epidemic, older adults and their families are increasingly turning to the Internet for health resources: over half of adults aged 65 or over use the Internet, and 80% of these Internet users specifically seek information about health. Websites hosting dementia-related information receive up to several million visitors per month. Despite the popularity of these resources, little is known about their scientific validity or usefulness. The Robillard lab is studying the quality and ethics of online self-assessments for dementia and of online articles about the prevention of Alzheimer disease. We have discovered that the quality of these resources is highly variable. We also found that a significant portion of online resources about Alzheimer disease have ethical lapses, such as conflicts of interest. Much research is still needed to identify critical gaps in online resources and to improve these tools in a way that maximizes their benefit for the growing cohort of computer-savvy older adults.

NEUROETHICS FOR NEURODEVNET

The Neuroethics Core has been an integral component of NeuroDevNet Inc., a Canadian Network of Centres of Excellence (NCE) dedicated to helping children and their families overcome the challenges of neurodevelopmental disorders (NDDs). Recent highlights include the publication of *The Science and Ethics of Antipsychotic Use in Children* (Di Pietro & Illes [Eds.], 2015, Elsevier Press), an international workshop in 2015 that identified how predominantly rural, low-resource, and historically marginalized communities affected by fetal alcohol syndrome can be better served through early diagnosis, and a CIHR award for our video on stem cells and cerebral palsy, produced as part of our series on Conversations in Ethics and Neurodevelopmental Disorders.

THE NEUROSCIENCE OF AUTONOMY

Autonomy – the notion that individuals have the right to decide for themselves – is one of the cardinal values of Western thought. It is autonomy that allows patients to decide the course of their treatment and citizens to vote for political candidate of their choice. But freedom of choice is not always ideal as our brains sometimes make decisions that are suboptimal, such as when we find ourselves eating an entire container of ice cream instead of a small square of chocolate. Well-meaning government programs – sometimes called ‘nudges’ – have been developed to help people make better decisions, but these run the risk of infringing upon autonomy. Our insights into the fundamental neurobiology of decision-making, as well as surveys of public attitudes about being nudged, have been providing policymakers with a roadmap to evaluate the types of nudges that are and are not acceptable.

CHALLENGES AND CHOICES: THE STEM CELL DISCUSSION

Our stem cell research team is devoted to the collaborative science of stem cell research and to the smooth and effective translation of its products into the clinic. For example, in the context of spinal cord injury, we demonstrated that open communication between physicians and affected individuals about stem cell interventions should be privileged over silence, as avoiding discussions may cause harm to trusted communication between the two. In the area of stem cell research policy, we demonstrated that the rigour of the research environment, mentoring, and quality of life are driving forces for career decisions, far more than policies and regulations that past research had predicted. Also in a departure from prior research, we showed unprecedented social responsibility in how media talk about advances in biotechnology on both ends of the lifespan – for children with neurodevelopmental disabilities, and for older people suffering from diseases such as Parkinson disease and multiple sclerosis. When scientists and science reporters engage in discussion, it's not all hype: People get the results of solid, balanced reporting. Neuroethics continues to provide the frameworks for this kind of engagement that is urgently needed.

ENVIRONMENTAL NEUROETHICS

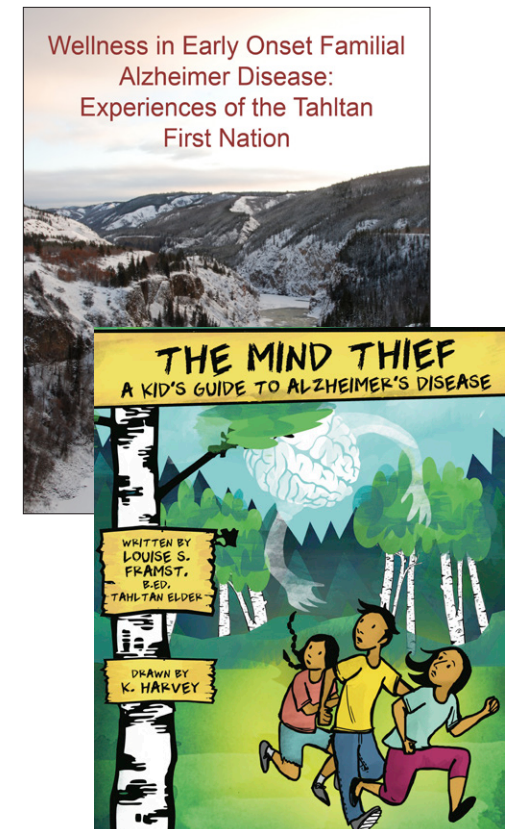
As we move deeper into the 21st century, issues such as pollution and global climate change pose challenges to society's ability to accommodate the needs of expanding populations while mitigating the negative impacts of resource development and new technologies on human health and well-being. Research on environmental change has largely focused on cancer and respiratory illnesses, and gaps persist in understandings of how environmental change affects brain and mental health. For example, in our review of unconventional gas production, we found that brain and mental health are rarely considered in studies of the industry, and ethical implications are almost entirely unexplored. We seek to close these gaps in traditional knowledge and experiences with western systems of ethical thought and scientific study. Our work encompasses the creation of new knowledge related to how multicultural societies perceive the relationships and divisions among brain, body, and environment.

COGNITIVE ENHANCEMENT: PAST, PRESENT, FUTURE

Should we use modern technology to enhance the brains of normal people? This question lies at the heart of the debate over cognitive enhancement, a debate that began with worries over the misuse of drugs for attention hyperactivity disorder, and continues with concerns over direct-to-consumer devices that purport to make people smarter by sending small amounts of current into our brains. We predict that the debate will grow in new directions in coming years as people begin to resemble cyborgs and acquire expanded cognitive abilities by relying upon ever-present computers. As the cognitive enhancement terrain shifts, the Reiner Lab's program of probing the hopes and fears of the public towards these developments is increasingly informing needed regulations to advances in modern neurotechnology.

TWO-EYED SEEING AND EARLY ONSET ALZHEIMER DISEASE

In 2007, UBC researchers and collaborators identified a novel pathogenic genetic mutation associated with early onset familial Alzheimer disease (EOFAD) in the Tahltan Nation living in communities across British Columbia. Over the past seven years, working closely with members of this large First Nations family, we have explored approaches to wellness in relation to the disease. We found that while biomedical explanations of disease permeate the knowledge and understanding of EOFAD, traditional concepts about wellness are upheld simultaneously. Our findings bring together the theoretical framework of “two-eyed seeing” to the case of EOFAD for which the contributions of different ways of knowing are embraced, and in which traditional and western ways complement each other on the path of maintaining wellness in the face of progressive neurological disease. Among the many products of this collaborative research, we published a resource for adults, *The Mind Thief* for children, and in a recent trip up to the communities, the team and members of the Nation distributed copies of these books to individuals and families at their homes and in community gatherings.



The Core's major projects are focused on high impact, high visibility research on neurodevelopment, aging and dementia, neuroimaging, cognitive enhancement, stem cells, addiction, cross cultural challenges in brain research, science communication and neuroliteracy, and the ethics of personalized medicine.