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THE UNIVERSITY OF BRITISH COLUMBIA

NATIONAL CORE FOR NEUROETHICS
LA NEUROÉTHIQUE

ANNUAL REPORT
2012-2013

MESSAGE FROM THE DIRECTOR

It has been another strong year for Neuroethics at UBC: publications and featured articles in wide-reaching journals such as Nature, Science and Cell, as well as specialty journals such as AJOB-Neuroscience and Neuroethics. We moved the dial on incidental findings of potential medical significance in brain imaging and genetics; we drew widespread attention to the growth of do-it-yourself brain stimulation; and we reported on critical differences in the way that individuals with spinal cord injury and their physicians perceive risk and what that means for communication and consent. Coincident with the increasing number of clinical trials in developing countries where regulatory protections for human subjects are less strict than in North America and the EU, we called for ethical reproducibility in the publication of all research.

We received new grants for our empirical work in neuroethics and stem cells, neuroscience communication, aging and dementia, and mental illness. We also were awarded support to explore uncharted themes through consultative working groups, such as the ethics and policy of prescribing antipsychotic medication to young children, many with neurodevelopmental disorders, as well as to support public outreach in association with Brain Matters! Vancouver – a major international conference that we are hosting next spring.

Our trainees have been finishing their degrees and competing successfully for their next professional positions – extraordinary accomplishments in today's tough job market – and they continue to be recognized with awards for travel to present their work at national and international meetings. Our faculty members have also been recognized significantly this year, and we call out Dr. Lynn Beattie in particular whose lifelong, tireless commitment to patients with Alzheimer's disease was rewarded with the Queen Elizabeth II Diamond Jubilee Medal by the Canadian Geriatrics Society. Luckily for us, her retirement from clinical practice has not deterred her unfailing commitment to research, and in particular to the imperative of considering diversity, culture and values in everything we do in neuroscience and ethics.

In this year's annual report, we highlight six major projects in some detail, but they are only examples of the continued breadth and depth of the work in which we engage, the impact we are having and further developing in the policy arena, and the exciting directions we are taking.

We are grateful to our colleagues and collaborators within and outside the university, locally and worldwide, and to all who support our work and share our vision.

Judy Illes, Director

FACULTY

Dr. Judy Illes, Ph.D., F.R.S.C., F.C.A.H.S.
Dr. Judy Illes, Professor of Neurology and Canada Research Chair in Neuroethics at UBC, is Director of the National Core for Neuroethics at UBC, and faculty in the Brain Research Centre at UBC and the Vancouver Coastal Health Research Institute. She also holds affiliate appointments in the School of Population and Public Health and the School of Journalism at UBC, and in the Department of Computer Science and Engineering at the University of Washington in Seattle, WA, USA. She is an elected fellow of the Royal Society of Canada, of the Canadian Academy of Health Sciences, and of the American Association for the Advancement of Science. As a pioneer and eminent scholar in the field of neuroethics, she has made groundbreaking contributions to ethical, social, and policy challenges at the intersection of biomedical ethics and neuroscience, with specific interests in aging and dementia, addiction and mental health, neuroimaging, stem cells, cross-cultural values, and the commercialization of health care.

Peter B. Reiner, V.M.D., Ph.D.
Dr. Peter Reiner, Professor of Psychiatry and faculty in the Brain Research Centre, co-founded the Core with Dr. Illes in 2007. He is an expert in cellular and molecular neuroscience and former President and CEO of Active Pass Pharmaceuticals. Today, Dr. Reiner investigates the ways in which advances in the neurosciences impact everyday lives and personal well-being, including how we seek to improve our cognitive selves and the effects of modern neuroscience on society at large.

B. Lynn Beattie, M.D., F.R.C.P.C.
Dr. Lynn Beattie, Professor Emerita, Division of Geriatric Medicine and Director of the Clinic for Alzheimer's Disease and Related Disorders at UBC, co-leads the Core with Drs. Illes and Reiner. She is a world-renowned force in clinical care and research related to brain diseases like Alzheimer's disease that progressively strips people of their cognitive and motor abilities.

RESEARCHERS, VISITING SCHOLARS AND ADMINISTRATIVE STAFF (2012-2013)

James A. Anderson, Ph.D., Research Associate
Marianne Claire Bacani, B.A., Events Coordinator
Elena Brief, Ph.D., Consulting Research Fellow
Lindsey Bruce, M.Sc., Ph.D. Student/Research Assistant
Daniel Buchman, M.S.W., R.S.W., Ph.D. Candidate
Kevin Budiman, Research Intern
Adrian Byram, M.Sc., Honorary Research Fellow
Laura Cabrera, Ph.D., Postdoctoral Fellow
Noah Castelo, H.B.Sc., Research Intern
Rob Carlson, M.D., Senior Research Fellow
Hervé Chneiweiss, M.D., Ph.D., Visiting Scholar
Nina Di Pietro, Ph.D., Senior Research Fellow
Marleen Eijkholt, Ph.D., LL.M. Postdoctoral Fellow
Nicholas Fitz, B.A., Research Assistant
Vera Khramova, B.A. & Sc., Research Technician
Grace Lee, Ph.D., Postdoctoral Fellow
Holly Longstaff, Ph.D., Senior Research Consultant
Lesley McBain, Ph.D., Visiting Scholar
Jennifer Mackie, M.Sc., Research Assistant
Selina Mak, B.Com., Interim Administrator
Praveena Manogaran, B.Sc., Research Intern
Danny Mendelsohn, M.D., M.Sc., Neurosurgery Resident
Ania Mizgalewicz, B.A., Research Assistant
Roland Nadler, B.A., M.A. Student
Julie Robillard, Ph.D., Postdoctoral Fellow
Dylan Roskams-Edris, B.Sc., Research Consultant
Keith Rozendahl, Ph.D., Journalism Intern
Osamu Sakura, Ph.D., Visiting Scholar
Christine Stables, M.D., Neurology Resident
Shaun Stevenson, M.A., Research Coordinator
Christopher Thomas Scott, M.L.A., Ph.D. Student
Katelyn Verstraten, B.A., Journalism Intern

CORE SCIENTIFIC ADVISORY BOARD

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Howard Feldman, M.D., F.R.C.P., Professor of Neurology and Executive Associate Dean, Research, Faculty of Medicine, University of British Columbia.

Joseph J. Fins, M.D., F.A.C.P., E. William Davis Professor of Medical Ethics & Chief, Division of Medical Ethics, Weill Cornell Medical College.

Anthony Phillips, Ph.D., F.R.S.C., Director, Institute of Neuroscience and Mental Health, Canadian Institutes of Health Research.

Art Caplan, Ph.D., Emanuel and Robert Hart Professor of Bioethics & Director, Center for Bioethics, University of Pennsylvania.

Gladys Maestre, M.D., Ph.D., Professor, Department of Neurosciences, School of Medicine, University of Zulia, Maracaibo, Venezuela.

Michael Burgess, Ph.D., Principal, College for Interdisciplinary Studies and Professor, Center for Applied Ethics, University of British Columbia.

SCIENTIFIC ADVISORS, ADVANCES IN NEUROIMAGING (NIH/NIMH)

Mildred Cho, Ph.D., Professor and Associate Director Stanford Center for Biomedical Ethics, Stanford University.

Gary H. Glover, Ph.D., Professor of Radiology and Director, Radiological Sciences Laboratory, Stanford University.

Hank Greely, J.D., Professor, School of Law, Stanford University.

Joachim Hallmayer, M.D., Associate Professor, Department of Psychiatry and Behavioral Sciences, Stanford University.

David Magnus, Ph.D., Professor, Department of Pediatrics and Director, Stanford Center for Biomedical Ethics, Stanford University.

Barbara J. Sahakian, Ph.D., Professor, Department of Psychiatry, University of Cambridge.

FACULTY AFFILIATES

Jehannine C. Austin, Ph.D., Associate Professor, Department of Psychiatry, University of British Columbia.

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Eric H. Chudler, Ph.D., Executive Director, Center for Sensorimotor Neural Engineering, University of Washington.

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Dan Goldowitz, Ph.D., Canada Research Chair in Developmental Neurogenetics, Senior Scientist at the Center for Molecular Medicine and Therapeutics.

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Michael Krausz, M.D., Ph.D., F.R.C.P., Professor of Psychiatry, Epidemiology and Public Health, University of British Columbia.

Brian K. Kwon, M.D., Ph.D., F.R.C.S.C., Associate Professor, Department of Orthopaedics, Faculty of Medicine, University of British Columbia; Attending Spine Surgeon, Vancouver Spine Program, Vancouver General Hospital.

Michelle LeBaron, LL.B., Professor, Faculty of Law, University of British Columbia.

David Li, M.D., Professor, Department of Radiology, University of British Columbia.

Eric Racine, Ph.D., Director, Neuroethics Research Unit, Institut de Recherches Clinique de Montréal.

Urs Ribary, Dr.sc.nat., Professor and LEEF Leadership Chair in Cognitive Neuroscience in Childhood Health and Development, Department of Psychology, Simon Fraser University.

Edie Rasmussen, Ph.D., Professor and Chair of the School of Library, Archival and Information Studies, University of British Columbia.

Elizabeth M. Simpson, Ph.D., Professor, Departments of Medical Genetics and Psychiatry, University of British Columbia.

David Silver, Ph.D., Chair in Business and Professional Ethics, W. Maurice Young Centre in Applied Ethics, University of British Columbia.

Lawrence Ward, Ph.D., Professor, Department of Psychology, University of British Columbia.

Hendrik F. M. Van der Loos, Ph.D., Associate Professor, Division of Mechanical Engineering, University of British Columbia.

Neuroimaging for the Minimally Conscious State: Exploring Ethics Challenges in the Clinical Landscape

Neuroscientists have developed novel brain imaging techniques to probe and elucidate levels of consciousness in brain trauma patients that may improve diagnosis of these patients and may, one day, allow them to communicate with the outside world for the first time after injury. The goal of this project is to explore the ethical issues related to this research, implications for the health care system, and to produce evidence-informed guidance toward the translation of results and capabilities into further discovery and possible clinical practice.

To achieve these goals, we are elucidating the perspectives of key stakeholders (practitioners, ethicists, neuroimaging researchers, lawyers, and family members) in interviews, focus groups and through wiki-based online discussion.

To date, our results reveal optimism for the actionability of neuroimaging for untangling the complexities of consciousness, and highlight scientific validity and the reliability of the technology as the areas for continued and immediate attention.

Recent Publication:

Garnett, A., Lee, G., Illes, J., Publication trends in neuroimaging of minimally conscious states. *PeerJ*, 1: e155

Aging 2.0: Sharing and Learning About Dementia Online

Over 80% of adult Internet users report seeking health information online and through social media applications. As the population gets older and the prevalence of dementia increases, online health information holds the potential to significantly impact public health. However, little is known about how information pertaining to age-associated diseases is disseminated and shared online, and about the quality and value of this information.

To fill these knowledge gaps, we are using data mining, content analysis and expert panel reviews to empirically examine online information-seeking and information-sharing relating to dementia as well as the validity and ethics-related factors of online health information about age-associated diseases.

We found that on Twitter, a majority of tweets contained a link to a third party site rather than personal information, and these links redirected mainly to news sites and health information sites. As well, a large number of tweets discussed recent research findings related to the prediction and risk management of Alzheimer's disease. In a separate study looking at freely accessible online tests for Alzheimer's disease, we found that the majority of these tests are not suitable for the diagnosis of the disease and that they conform poorly to ethical norms.

Overall, our results highlight the need for the dementia research community to harness the reach of online content and its potential as a tool for multidirectional engagement, and to promote the benefits of online health information while mitigating the risks.

Recent Publications:

Robillard, J.M., Johnson, T.W., Hennessey, C., Beattie, B.L., Illes, J., Aging 2.0: Health information about dementia on Twitter. *PLoS One*, 2013, 8(7): e69861.

Robillard, J.M., Federico, C.A., Tairyan, K., Ivinson, A.J., Illes, J., Untapped ethical resources for neurodegeneration. *BMC Med Ethics*, 2011, 12: 9.

Do-It-Yourself Brain Stimulation

Transcranial direct current stimulation (tDCS), a simple means of brain stimulation, possesses a trifecta of appealing features: it is relatively safe, relatively inexpensive and relatively effective.

In the clinical realm, investigators are evaluating its use as a treatment for stroke, pain, depression, addiction, and more. However, the real excitement lies in its use as a tool to modify the brains of healthy humans: it seems that many normal functions—memory, numerical ability, risk-taking behaviour, and more—can be either enhanced or enfeebled by tDCS.

Much as functional MRI has fuelled a revolution in measuring brain activity, tDCS seems poised to radically change our ability to manipulate brain activity in living humans. Together, these are the Swiss Army knives of human neuroscience.

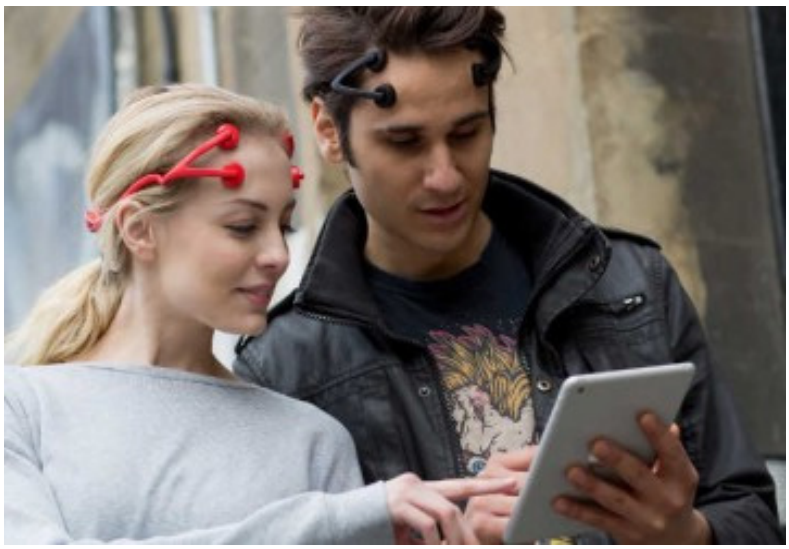
The same qualities that constitute the egalitarian promise of tDCS—efficacy and access—simultaneously give rise to its peril. It is relatively easy to obtain a device and the do-it-yourself (DIY) community has become galvanized by reports of tDCS as a cognitive enhancer.

Our work in this field closely monitors developments in the field of DIY tDCS, and we provide practical recommendations for researchers, practitioners, and regulators to generate best practices and propagate norms of safe use as tDCS rapidly evolves from an arcane but exciting experimental tool to the next new thing.

Recent Publications:

Fitz, N.S., Reiner, P.B., The challenge of crafting policy for do-it-yourself brain stimulation. *Journal of Medical Ethics*, 2013, doi: 10.1136/medethics-2013-101458.

See also editorial in *Nature* entitled “Brain blast”. *Nature*, 2013, 498: 271–2.



Stem Cell Researchers: Brain Drain or Brain Gain?

It has been suggested that funding and regulatory environments have a significant impact on the ability of a jurisdiction to attract and retain scientific talent, and contribute to the "brain drain" of talent from one geographic region to another.

However, the movement of researchers, whether across institutions within countries or across borders, may also reflect a "brain circulation" that serves to fuel fresh thinking and healthy competitiveness. The purpose of these stem cell-related studies is to identify the actual push and pull mechanisms that underlie movement among senior researchers and trainees.

The methods for this study revolve around three important aims:

Aim (1): The creation of a database of researchers involved in human stem cell research sourced from peer-reviewed literature, government grants databases, and institutional websites.

Aim (2): Interviews with researchers about forces that motivate movement between research institutions.

Aim (3): Maps of movement patterns on to major milestones in stem cell research by jurisdiction. The findings from this work will provide evidence-informed guidance for institutions and policy-makers in the further development of stem cell research and clinical translation.

Recent Publication:

Longstaff, H., Khramova, V., Eijkholt, M., Mizgalewicz, A., Illes, J., Hopes and fears for professional movement in the stem cell community. *Cell Stem Cell*, 2013, 12(5): 497-630.

Risk and Returns for Stem Cells and Spinal Cord Injury

Risks have been a central concern in stem cell research overall, and in clinical trials of individuals with spinal cord injury in particular. We have been working to elucidate how two important stakeholder groups – health care professionals (HCPs) and individuals with a spinal cord injury (ISCIs) – view and value both the physical and non-physical risks of stem cell interventions.

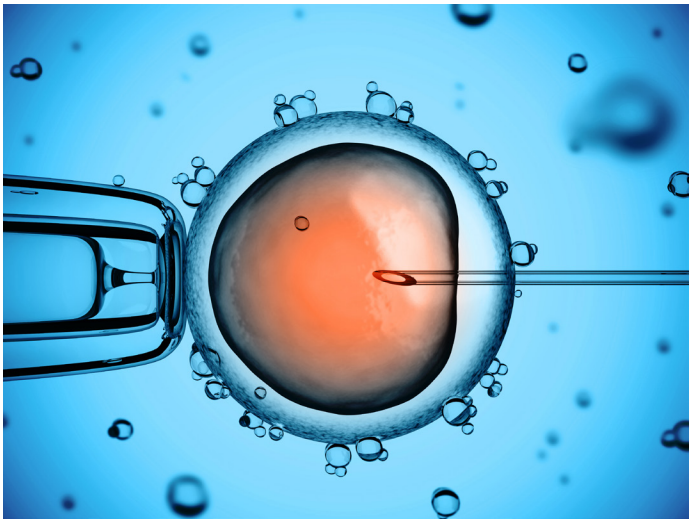
Using semi-structured interviews, a constant comparative analytic strategy to derive themes from the discourse, we have found that HCPs focus on the physical causes of risks, and the ISCIs on their downstream consequences as well as on non-physical risks; HCPs are concerned about evidence, and ISCIs about experience; and, HCPs approach risk narrowly while the approach of ISCIs is more broad and contextualized.

While the major themes were common to the two stakeholder groups, the components of the themes were dissociable and illustrate differences in what HCPs and ISCIs worry about, why they worry, and how they approach their worries. We draw upon these findings to make recommendations for improving risk communication and informed consent for stem cell research for SCI.

Recent Publications:

Eijkholt, M., Kwon, B.K., Illes, J. Dissociations in the meaning of risk between health care professionals and individuals with spinal cord injury. *Nature, Spinal Cord Injury*, 2013, doi: 10.1038/sc.2013.103.

Illes, J., Reimer, J., Kwon, B.K. Stem cell clinical trials for spinal cord injury: Readiness, reluctance, redefinition. *Stem Cell Reviews and Reports*, 2011, 7(4): 997-1005.



Ethics, Gene Therapy for the Brain, and Online Social Media

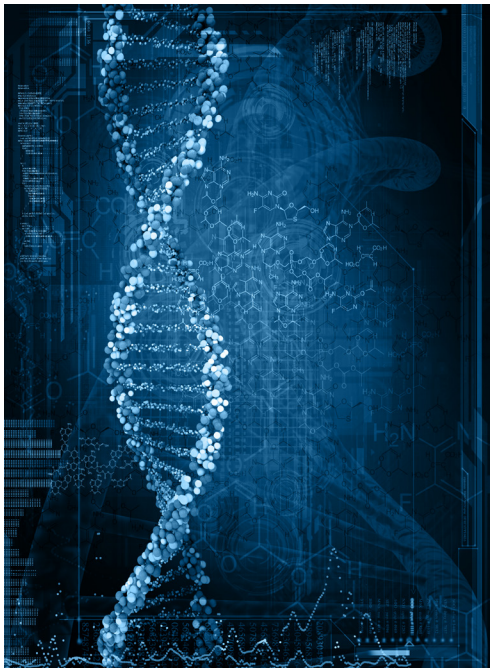
The field of gene therapy is rapidly evolving, and while hopes of treating disorders of the central nervous system and ethical concerns have been articulated within the academic community, little is known about views and opinions of different stakeholder groups. As part of the CanEuCre research team based at the Center for Molecular Medicine and Therapeutics, we conducted a content analysis for questions and answers about gene therapy from the social media Q&A platform, Yahoo! Answers. Our results reveal high expectations for gene therapy that range from cures for genetic and non-genetic diseases to pre- and postnatal enhancement of physiological attributes.

Ethics questions are commonly expressed as fears about the impact of gene therapy on self and society. To gain a more in-depth understanding of public perceptions of the ethics of gene therapy, we followed up our analysis with an online survey. Results show that the acceptance of gene therapy varies with its applications, and that a main concern with the idea of undergoing gene therapy is not receiving adequate information about the procedure.

Overall, the findings highlight the powerful role of social media and online platforms as a rich resource for research into attitudes toward biomedicine, and as a venue for knowledge exchange and public engagement for topics relating to health and disease.

Recent Publications:

Robillard, J.M., Whiteley, L., Johnson, T.M., Lim, J., Wasserman, W.W., Illes, J., Gene therapy: Capturing hopes and fears through an online Q&A platform. *Journal of Medical Internet Research*, 2012, 15(3): e44.



PUBLICATIONS (August 2012-September 2013)

Anderson J., Garnett, A., Mizgalewicz A., Illes J., Reviews of functional MRI: the ethical dimensions of methodological critique. *PLoS One*, 2012, 7(8): e42836.

Anderson, J., Eijkholt, M., Illes, J., Ethical reproducibility: Towards transparent reporting in biomedical research. *Nature Methods*. In press.

Anderson, J., Mizgalewicz, A., Illes, J., Triangulating the evidence: Perspectives on functional neuroimaging in disorders of mental health. *BMC Psychiatry*. In press.

Anderson, J.A., Illes, J., Drowning in a sea of acrimony. *American Journal of Bioethics – Neuroscience*, 2012, 3(4): 42-43.

Borgelt E.B., Buchman D.Z., Illes J., Neuroimaging in mental health care: Voices in translation. *Frontiers in Human Neuroscience*, 2012, 6: 293.

Borgelt, E., Buchman D.Z., Weiss M., Illes J., In search of "Anything that would help": Parent perspectives on neuroimaging for attention disorders. *Journal of Attention Disorders*, 2013, 43: 122-133.

Brief, E., Mackie, J., Illes, J., Incidental findings in genetic research: A vexing challenge for community consent, Minnesota. *Journal of Law, Science and Technology*, 2012, 13(2): 435-736.

Cabrera, L., Reiner, P.B., The emotional impact of 'study drugs': unsurprising and unconvincing. *AJOB Neuroscience,* 2013, 4: 20-21.

Di Pietro, N., Illes, J., Disparities in Canadian health research. *Journal of Developmental & Behavioral Pediatrics*. In press.

Di Pietro, N., Mizgaelwicz, A., Johnson, T.W., Illes, J., Disclosing incidental findings in brain research: The rights of minors in decision-making. *Journal of Magnetic Resonance Imaging*, 2013, doi: 10.1002/jmri.24230.

Di Pietro, N., Whiteley, L., Illes, J., Broken links: Rhetorical citations to online treatments for neurodevelopmental disorders. *Journal of Autism and Developmental Disorders*, 2013, 43(1): 122-33.

Eijkholt, M., Kwon, B.K., Illes, J. Dissociations in the meaning of risk between health care professionals and individuals with spinal cord injury. *Nature, Spinal Cord Injury*, 2013, doi: 10.1038/sc.2013.103.

Eijkholt, M., Kwon, B.K., Mizgalewicz, A., Illes, J., Decision-making in stem cell trials for spinal cord injuries. *Regenerative Medicine*, 2012, 7(4): 513-522.

Felsen, G., Castelo, N., Reiner, P.B., Decisional enhancement and autonomy: Public attitudes towards overt and covert nudges. *Judgement and Decision Making*, 2013, 8: 202-213.

Fitz N.S., Nadler, R., Manogaran, P., Chong, E.W.J., Reiner, P.B., Public Attitudes Toward Cognitive Enhancement. *Neuroethics*, 2013, doi: 10.1007/s12152-013-9190-z.

Fitz, N.S., Reiner, P.B., The challenge of crafting policy for DIY brain stimulation. *Journal of Medical Ethics*, 2013, doi:10.1136/medethics-2013-101458.

Fitz, N.S., Reiner, P.B., The Perils of DIY Cognitive Enhancement: Taking Minimally-Invasive Transcranial Direct Current Stimulation Seriously, in: The Stimulated Brain (R. Cohen-Kadosh, ed.). *Elsevier*. In press.

Forlini, C., Hal,l W., Maxwell, B., Outram, S.M., Reiner, P.B., Repantis, D., Schermer, M., Racine, E., Ethical issues in research on cognitive enhancers for healthy individuals. *EMBO Journal*, 2013, 14: 123-128.

Garnett, A., Lee, G., Illes, J., Publication trends in neuroimaging of minimally conscious states. *PeerJ*, 1: e155

Illes, J., Reiner, P.B., Why is neuroethics important to neuroscientists (and what did it take for us to find out it is)? In: Neurobiology of Brain Dysfunction. *Biological Basis of Neurological and Psychiatric Disorders* (ed.: M. Zigmond). In press.

PUBLICATIONS **(cont'd)**

Kwon, B.K., Ghag, A., Dvorak, M., Tetzlaff, W., Illes, J., Expectations of benefit and tolerance to risk of individuals with spinal cord injury regarding potential participation in clinical trials. *Journal of Neurotrauma*, 2012, 29(18): 2727-37.

Kwon, B.K., Ghag, A., Reichl, L., Dvorak, M.F., Illes, J., Tetzlaff, W., Opinions on the preclinical evaluation of novel therapies for spinal cord injury - A comparison between researchers and spinal cord injured individuals. *Journal of Neurotrauma*, 2012, 29(14): 2367-2374.

Lee, G., Illes, J., Never say never: Limitations of neuroimaging for communicating decisions after brain injury. *AJOB Neuroscience*, 2013, 4(1): 58.

Longstaff, H., Eijkholt, M., Mizgalwicz, A., Illes, J., Hopes and fears for professional movement in the stem cell community. *Cell Stem Cell*, 2013, 12(5): 517-519.

Nagel, S., Reiner, P.B., Autonomy support to foster individual's flourishing. *American Journal of Bioethics*, 2013, 13(6): 36-7.

Peters, K., Beattie, L.B., Feldman, H., Illes, J., A conceptual framework and ethics analysis for prevention trials of Alzheimer Disease. *Progress in Neurobiology*. In press.

Reiner, P.B., Comment on "Can transcranial electrical stimulation improve learning difficulties in atypical brain development? A future possibility for cognitive training" by Krause and Cohen Kadosh. *Developmental Cognitive Neuroscience*, 2013, doi: 10.1016/j.dcn.2013.05.002.

Reiner, P.B., Biopolitics of cognitive enhancement, in: Cognitive Enhancement- An Interdisciplinary Perspective, (E. Hildt & A. Franke, eds.). *Springer*, 2013, 189-200.

Reiner, P.B., How reliable are intuitions of fairness? in: Explorations of Fairness (J. Sarra, ed.). *UBC Press*, 2013.

Reiner, P.B., The modern debate over cognitive enhancement. *INK*, 2012, 1: 18-20.

Robillard, J.M., Johnson, T.W, Beattie, B.L., Illes, J. Aging 2.0: Health information about dementia on Twitter. *PLoS One,* 2013, 8(7): e69861.

Robillard, J.M., Whiteley, L., Johnson, T.W., Lim, J., Wasserman, W., Illes, J., Gene therapy: Information-seeking and ethics debate in online Q&A. *Journal of Medical Internet Research*, 2013, 15(3): e44.

Scott, C.S., Kwon, B.K., Illes, J., Eaton, M., Money and morals: Ending clinical trials for commercial reason. *American Journal of Bioethics*. In press.

Scott, N., Murphy, T., Illes, J., Incidental findings in neuroimaging research: A framework for anticipating the next frontier. *Journal of Empirical Research on Human Research Ethics*, 2012, 7(1): 53-7.

MAJOR NEW AWARDS AND HONOURS

Dr. Lynn Beattie, awarded Queen Elizabeth II Diamond Jubilee Medal, Canadian Geriatrics Society.

Dr. Judy Illes, elected Fellow, American Association for the Advancement of Science, Division of Neuroscience.

Dr. Judy Illes, appointed to the Editorial Board, Journal of Law and Biosciences, and to the International Advisory Committee, Cambridge-ICM Neuroethics Network.

Dr. Peter B. Reiner, appointed to the Editorial Board of AJOB-Neuroscience.

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