

Prepared by the  
Neuroethics research unit  
at the IRCM

Préparé par l'unité de  
recherche en neuroéthique  
de l'IRCM

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# BRAINSTORM

A newsletter about ethics, neuroscience, and society  
Un bulletin sur l'éthique, les neurosciences et la société



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## Profile | Profil



**Hervé Chneiweiss** est docteur en médecine et docteur en science, directeur de recherches au CNRS, neurobiologiste et neurologue. Il anime l'équipe « Plasticité Gliale » et est directeur du laboratoire Neurosciences Paris Seine-IBPS (Inserm/CNRS/UPMC) à Paris-Jussieu.

Ses travaux portent sur la biologie d'une population de cellules gliales du système nerveux, les astrocytes. Les astrocytes constituent la moitié des cellules cérébrales et remplissent de nombreuses fonctions depuis la mise en place de l'architecture du cerveau jusqu'au fonctionnement à chaque instant des communications entre neurones. De plus certains astrocytes forment les cellules souches cérébrales adultes et la plupart des maladies dites neurologiques sont en fait liées à une altération de la fonction astrocytaire. Son équipe étudie plus particulièrement les mécanismes liant l'astrocyte à la genèse et au développement des tumeurs cérébrales.

La caractérisation au sein de tumeurs cérébrales de cellules tumorales aux caractères « souches » pourrait permettre de développer de nouvelles stratégies thérapeutiques anticancéreuses ce qu'il cherche en liant protéomique, métabolisme et épigénétique.

Hervé Chneiweiss est rédacteur en chef depuis 2006 de la revue *Médecine/Sciences*. Il étudie également les questions éthiques de la recherche biomédicale. Il est président du comité d'éthique de l'Inserm, membre du comité national d'éthique (CCNE) français et du CIB de l'UNESCO. Il a contribué à des articles publiés dans des revues scientifiques internationales et/ou livre de bioéthique, dont *Bioéthique : Avis de tempêtes* (avec Jean-Yves Nau, Alvik, 2003), *Neuroscience et Neuroéthique : des cerveaux libres et heureux* (Alvik 2006) et *l'homme réparé* (Plon 2012).

Selon Dr. Chneiweiss, « nous entrons dans l'ère des neurosciences et l'éthique y est partout interpellée: quel magnifique défi! »

If you would like to post any events, announcements, or news of interest please contact us at [neuroethics@ircm.qc.ca](mailto:neuroethics@ircm.qc.ca) (subject line: Brainstorm Events and Announcements)



## Announcements | Annonces

**Call for Applications:** Interdisciplinary Research Week “Pediatric Neuro-Enhancement—Ethical, social and legal questions in comparison between North America and Germany”, March 7-11, 2016, University of Osnabrück, Germany

**Submission Deadline:** December 13, 2015, [click here for more info.](#)

**Call for Abstracts:** The 6th Cambridge Consortium for Bioethics Education: Practical Problems and Shared Solutions, July 11-13, 2016, Paris, France

**Submission Deadline:** December 15, 2015, [click here for more info.](#)

**Call for Abstracts:** The Science of Consciousness, April 25-30, 2016, Tucson, AZ

**Submission Deadline:** December 15, 2015, [click here for more info.](#)

**Call for Papers:** International Network on Feminist Approaches to Bioethics World Congress, 13-15 June, 2016, Edinburgh, Scotland

**Submission Deadline:** January 12, 2016, [click here for more info.](#)

**Call for Abstracts:** 13th World Congress of the International Association of Bioethics, June 14-17, 2016, Edinburgh, Scotland

**Submission Deadline:** January 15, 2016, [click here for more info.](#)

**Call for Abstracts:** Rudolf-Carnap-Lectures 2016, Prof. Patricia S Churchland “Neurophilosophy 30 years on”, March 7-10, 2016, Ruhr-Universität Bochum, Germany

**Submission Deadline:** January 15, 2016, [click here for more info.](#)

**Call for Papers:** Designing Moral Technologies—Theoretical, Practical and Ethical Issues, July 10-15, 2016, Ascona, Switzerland

**Submission Deadline:** January 31, 2016, [click here for more info.](#)

## Events | Événements

**Montreal Neuroethics Network Seminar:** “Consciousness Unbound: The Ethics of Neuroimaging After Severe Brain Injury” — Charles Weijer, Ph.D., Western University, Canada

**Date:** December 3, 2015, 12:00pm-1:00pm

**Location:** 110, avenue des Pins Ouest, Room André-Barbeau, Institut de recherches cliniques de Montréal (IRCM)

**Summit on Animals, Public Health, and Ethics**

**Date:** December 9-10, 2015

**Location:** Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

[Click here for information and registration.](#)

# Announcements | Annonces



## Postdoctoral fellowship or graduate student scholarship\*

Area of research: Vulnerability and mental health research ethics

Neuroethics research unit – Institut de recherches cliniques de Montréal (IRCM)  
Supported by the Canadian Institutes of Health Research (CIHR)

\*This offer could be transformed into a scholarship for a graduate student supervised at the IRCM

We are seeking a postdoctoral fellow or graduate student to join the Neuroethics research unit ([www.ircm.qc.ca/neuroethics/](http://www.ircm.qc.ca/neuroethics/)) to lead research examining ethical and social issues in mental health research. Our project will investigate the theoretical assumptions and practical implications of the concept of "vulnerability" in research with psychiatric patients. Outcomes of this project would include novel and original work examining how the concept of vulnerability affects research ethics policies and practices. This position is funded by a grant from the Canadian Institutes of Health Research. This is a 12-month position with possible renewal.

### REQUIREMENTS

- PhD training in bioethics or social science or philosophy or health sciences/mental health (undergraduate degree for candidates to the graduate student scholarship)
- Interest in pursuing theoretical and empirical research in neuroethics
- Very good communication and interpersonal skills
- Publication and scientific communication experience
- Organization skills and proficient time management
- Interdisciplinary teamwork experience an asset
- Ideally, experience in action research or stakeholder research

### DEADLINES

Position remains open until filled.  
Start date: as soon as November 15, 2015

### APPLICATIONS

Submit a resume (CV), cover letter and two reference letters to **Eric Racine**, PhD, Director of the Neuroethics research unit, by email at [neuroethics@ircm.qc.ca](mailto:neuroethics@ircm.qc.ca). Please specify whether you are applying for postdoctoral fellowship or graduate scholarship. Only those selected for an interview will be contacted.

[Click here  
for more  
info!](#)

# Announcements | Annonces



## Postdoctoral fellowship or graduate student scholarship\*

### Areas of research:

- **Interventional ethics research in transitional care**
- **Autism and person-centered research ethics**

### Neuroethics research unit – Institut de recherches cliniques de Montréal (IRCM)

Supported by NeuroDevNet

\*This offer could be transformed into a scholarship for a graduate student supervised at the IRCM

We are seeking a postdoctoral fellow or graduate student to join the Neuroethics research unit ([www.ircm.qc.ca/neuroethics/](http://www.ircm.qc.ca/neuroethics/)) to contribute to research examining ethical and social issues in neurodevelopmental disabilities. The selected candidate will be involved in two projects: (1) an interventional ethics project in transitional care and (2) research on person-centered research ethics in autism. The first project will aim to characterize current best transition practices from an ethics standpoint and the subsequent piloting of an ethics intervention for youth with neurodevelopmental disorders. The second project will involve the design of an innovative ethics framework for autism spectrum disorder research (including alternative informed consent strategies). This position is funded by a grant from NeuroDevNet, a national centre of excellence. This is a 12-month position with possible renewal. Candidates with expertise in implementation science of action-research are invited to submit their application.

#### REQUIREMENTS

- PhD training in bioethics or social science or health sciences or outcomes research (undergraduate degree for candidates to the graduate student scholarship)
- Interest in pursuing empirical research in bioethics
- Ability to work in collaboration with stakeholders
- Very good communication and interpersonal skills
- Publication and scientific communication experience
- Organization skills and proficient time management
- Interdisciplinary teamwork experience
- Ideally, experience in health outcomes research or implementation research

#### DEADLINES

Position remains open until filled.  
Start date: as soon as November 15, 2015

#### APPLICATIONS

Submit a resume (CV), cover letter and two reference letters to **Eric Racine, PhD**, Director of the Neuroethics research unit, by email at [neuroethics@ircm.qc.ca](mailto:neuroethics@ircm.qc.ca). Please specify whether you are applying for a postdoctoral fellowship or graduate scholarship. Only those selected for an interview will be contacted.

[Click here for more info!](#)



## Announcements | Annonces



International Neuroethics Society

[www.neuroethicssociety.org](http://www.neuroethicssociety.org)

December 1, 2015

Dear Colleague,

We would like to invite you to become a member of the [International Neuroethics Society \(INS\)](http://www.neuroethicssociety.org).

Since the [Society](http://www.neuroethicssociety.org) was founded in 2006 with the goal of promoting the development and responsible application of neuroscience, membership has grown to 330 today from 26 countries. The annual meetings each year are held with distinguished speakers on a range of topics from psychopharmacology and global mental health to neuroscience in the courts. In the last two years, the INS presented over \$15,000 in awards and travel stipends to deserving students while developing exciting new opportunities for trainee leadership.

We hope that you will join us as we continue to provide a better understanding of the ethical uses of neuroscience and foster its most beneficial practices. Benefits of membership are:

- meeting and working with colleagues in neuroethics
- leadership and committee opportunities
- opportunities to shape the field and provide input to ethical matters in neuroscience discovery
- participation in society elections
- discounts to International Neuroethics Society events
- discounted subscription to AJOB-Neuroscience, the official journal of the Society
- listing in the INS online directory for networking
- the opportunity to list events, jobs and place announcements in the newsletter
- access to the Society's LinkedIn Group.

You may also want to explore "[About Us](#)" where you will find the leadership, mission, governance and committees. As a member, you will have access to many networking activities including the [latest newsletter](#) and the [annual meeting](#).

The easiest way to join is to go to the INS [website](#) and, under the Membership tab, click [Membership Application](#). If you have any questions, please feel free to contact Karen Graham, executive director, [kgraham@neuroethicssociety.org](mailto:kgraham@neuroethicssociety.org)

The next annual meeting of the INS is in San Diego, on November 10 and 11, again as a satellite of the Society for Neuroscience. We look forward to seeing you there.

Best wishes,

**Barbara J. Sahakian**  
*President*

**Judy Illes**  
*President-Elect*

**Steven E. Hyman**  
*Past President*

If you would like to post any events, announcements, or news of interest please contact us at [neuroethics@ircm.qc.ca](mailto:neuroethics@ircm.qc.ca) (subject line: Brainstorm Events and Announcements)

# International Neuroethics Forum

## In pursuit of a child's potential: a parent's reflections on hope and futility

Jennifer Johannesen

*From the author: Parents with young children with severe neurodevelopmental disabilities are extraordinarily committed to helping them achieve as much as they can, despite the significant odds against them. I was one of those parents until I started to question why we were working so hard, to achieve so little, at such tremendous cost. I have met many families who share this experience. Hopefully this story sparks a discussion about the role clinicians can play in helping families like mine establish realistic goals and priorities.*

Owen's brain scans didn't give us many clues. Although his basal ganglia were underdeveloped (this news caused a flurry of inquiry but produced no leads), there was little else to hint at why Owen was the way he was. He was about as disabled as you could imagine: he could not crawl, sit, stand, walk, chew, swallow or hear. He was a tiny boy – just 58 pounds when he died, at 12 years old. The list of medical issues and complications was alarmingly long. In a way, it was remarkable he lived as long as he did. He died sometime overnight while the surrounding household slept, unaware of his struggle to turn himself back over. (The diagnosis was SUDEP – [Sudden Unexpected Death in Epilepsy](#) – which was given despite the fact that Owen didn't have epilepsy, and despite his post-death position. His autopsy revealed that he did not suffocate.)



I mention Owen's scans because for a while, in the early days, I thought they would reveal his secrets. Owen's doctors and therapists would explain to me that his brain was misfiring; it was sending wrong or mixed signals to his body, causing his dystonia and spasticity. So I made the logical assumption that his problems were located in his brain, and I became especially focused on brain scan results. Unfortunately more scans didn't reveal more information – especially as there was nothing to see. (By the way: I could say the same about bloodwork, genetic testing and muscle biopsies. He endured a lot of tests, none of which revealed the clues I was seeking.)

All of this to explain that none of us, including his doctors, knew what was wrong with him. We only knew what we could see, which is that he was developing in unusual ways, never meeting developmental milestones, not gaining any skills. But this wasn't too discouraging: our unfruitful quest to answer 'why' left plenty of room for hopes and dreams. No diagnosis meant there were no limits—which suggested that anything was possible.

# International Neuroethics Forum

Our therapists were creative and energetic. Together we heroically embarked on a years-long journey to help Owen ‘reach his full potential’. We tried to figure out communication, gross and fine motor function, and literacy. We charted out goals and plans, noting with each failed benchmark that there was always next time. To aid development (and handling) Owen was implanted with an intrathecal baclofen pump (a small programmable pump that administers anti-spasticity medication directly into the cerebrospinal fluid), and we began to explore deep brain stimulation. For a while, I felt purposeful and fulfilled – I performed well and was praised as ‘such a great mom’. It almost didn’t matter that Owen seemed to simply be along for the ride, not concerned in the least that he wasn’t achieving the goals we’d set out for him. And it almost didn’t matter that somewhere in the back of my mind was a small but rapidly growing sense of futility.

I don’t know if I would have changed course if Owen’s baclofen pump hadn’t malfunctioned. But it did—he endured a long and difficult few weeks in intensive care as the neurosurgeon and his team tried to figure out why Owen appeared to be experiencing intermittent symptoms of overdose and withdrawal. It was a dark time of difficult decisions and terrible waiting. At one point I lay beside him in his hospital bed, contemplating uncomfortable thoughts. What sort of childhood was he experiencing? What sort of mother had I become? If he dies now, will I find comfort in all that work? How will I remember our time together?

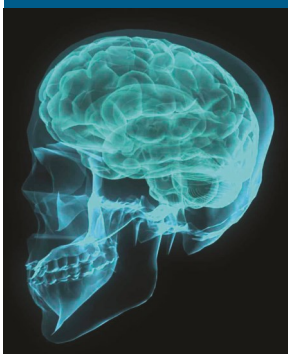
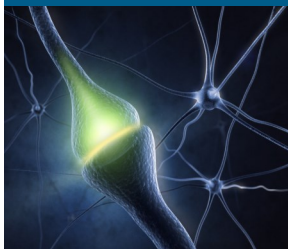


Shortly after discharge from the hospital, I rearranged our lives. I withdrew him from school and any therapy that had come to feel pointless—which, frankly, was all of them. We focused instead on meaningful experiences and enjoyable excursions. (These decisions were not made lightly or recklessly – please read [this post](#) for more context, or my book, [No Ordinary Boy](#), for a fuller account.)

His last few years of life were spent with people who loved him, doing things that were enjoyable for all. The physical work of caring for Owen became no easier, but we were relieved of the tyranny of chasing Owen’s ‘potential’, which had cost us so much already.

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*Jennifer Johannesen ([@jenjohannesen](#)) writes and speaks about healthcare and disability. She is completing a Master of Science in Bioethics and Policy at The Bioethics Program of Union Graduate College and the Icahn School of Medicine at Mount Sinai. Her book, [No Ordinary Boy](#), is available on [Amazon](#).*



# Literature | Littérature

## BOOKS AND BOOK REVIEWS

[Review of "Neuroethics in Practice," by Anjan Chatterjee and Martha J. Farah.](#)

Shattuck J. Dev Neuropsychol. 2015 Nov 18: 1-2. [Epub ahead of print].

## ARTICLES

[Informed consent instead of assent is appropriate in children from the age of twelve: Policy implications of new findings on children's competence to consent to clinical research.](#)

Hein IM, De Vries MC, Troost PW, Meynen G, Van Goudoever JB, Lindauer RJ. BMC Med Ethics. 2015 Nov 9; 16(1): 76.

[Abandoning the dead donor rule? A national survey of public views on death and organ donation.](#)

Nair-Collins M, Green SR, Sutin AR. J Med Ethics. 2015 Apr; 41(4): 297-302. Epub 2014 Sep 26.

[Talking about death is not the same as communicating about death.](#)

Youngner SJ. J Med Ethics. 2015 Apr; 41(4): 303. Epub 2015 Jan 9.

[Triage practices in stroke units: Physicians' perceptions and ethical issues](#)

Yger M, Crozier S, Dubourdieu S, Vivien B, Dolveck F, Samson Y. Rev Neurol (Paris). 2015 Nov 9. [Epub ahead of print].

[The Return of Lombroso? Ethical Aspects of \(Visions of\) Preventive Forensic Screening.](#)

Munthe C, Radovic S. Public Health Ethics. 2015 Nov; 8(3): 270-83. Epub 2015 Jan 28.

[Neural Technologies: The Ethics of Intimate Access to the Mind.](#)

Green RM. Hastings Cent Rep. 2015 Nov; 45(6): 36-7.

[Analyzing 7000 texts on deep brain stimulation: what do they tell us?](#)

Ineichen C, Christen M. Front Integr Neurosci. 2015 Oct 26; 9: 52.

[Brain-dead and pregnant in Texas.](#)

Mayo TW. Am J Bioeth. 2014; 14(8): 15-8.

[The social construction of death, biological plausibility, and the brain death criterion.](#)

Gervais KG. Am J Bioeth. 2014; 14(8): 33-4.

[Young Persons in Research: A Call for the Engagement of Youth in Mental Health Research.](#)

Bell E. Am J Bioeth. 2015 Nov; 15(11): 28-30.

## NEWS AND SOCIAL MEDIA

['Smart drugs' are here – should college students be allowed to use them?](#)

Ojiaku P. The Washington Post. November 03, 2015.

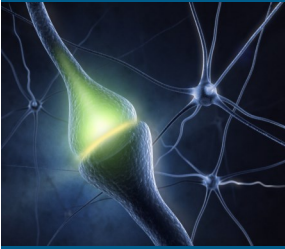
[Canada creates science-minister post: New prime minister Justin Trudeau gives research a higher profile.](#)

Jones N. Nature News. November 04, 2015.

[To Study the Brain, a Doctor Puts Himself Under the Knife](#)

Piore A. MIT Technology Review. November 09, 2015.





## Literature | Littérature

[Does psychotherapy research with trauma survivors underestimate the patient-therapist relationship?](#)

Cook J. The Conversation. November 11, 2015.

[When Men Take Risks, They Are Perceived as More Creative. Women, Not So Much.](#)

Baggaley K. Brain Decoder. November 11, 2015.

[The Weak Science Behind the Wrongly Named Moral Molecule](#)

Yong E. The Atlantic. November 13, 2015.

[The Return of Electroshock Therapy](#)

Hurley D. The Atlantic. November 16, 2015.

[Points Unknown](#)

Paradis J, van der Kolk N, Baker B. Love + Radio. November 16, 2015.

[Research project studies benefits of therapy dogs on mental health](#)

CTV News. November 17, 2015.

[Can you think yourself into a different person?](#)

Storr W. Mosaic. November 17, 2015.

[McGill student sued for destruction of Master's thesis](#)

Hanrahan L. The McGill Tribune. November 17, 2015.

[Chipping Away at the Physical / Psychological Harm Distinction: 8th Amendment Edition](#)

Nadler R. Law and Biosciences Blog. November 18, 2015.

[Would you wear a chip in your brain?](#)

Dixon P. Wired. November 18, 2015.

[The Feminist Asylum That Redefined Women's Mental-Health Treatment](#)

Wolfe A. The Atlantic. November 23, 2015.

[Widening the use of deep brain stimulation: Ethical considerations in research on DBS to treat Anorexia Nervosa](#)

Plunkett C. The Neuroethics Blog. November 24, 2015.

[#SfN15 recap: Neuroethics and the Minimally Conscious State](#)

McKay C. PLOS Neuro. November 24, 2015.

[User behaviour: Websites and apps are designed for compulsion, even addiction. Should the net be regulated like drugs or casinos?](#)

Schulson M. Aeon. November 24, 2015.

[Rowan's Law: Ontario proposes concussion rules for youth sports](#)

CBC News. November 25, 2015.

[Do We Need A Neuroscience of Terrorism?](#)

Neuroskeptic. November 25, 2015.

[Why Torture Doesn't Work: The Neuroscience of Interrogation, by Shane O'Mara - Review](#)

Rose S. Times Higher Education. November 26, 2015.



## Resources | Ressources

[University of British Columbia, National Core for Neuroethics](#)

[Neuroethics at the University of Pennsylvania](#)

[International Neuroethics Society](#)

[Neuroethics Research Unit / L'Unité de recherche en neuroéthique](#)

[Journal of Ethics in Mental Health](#)

[Novel Techethics](#)

[Neuroethics at the Stanford Center for Biomedical Ethics](#)

[Berman Institute of Bioethics' Program in Ethics and Brain Sciences](#)

[Centre interfacultaire en bioéthique et sciences humaines en médecine](#)

[The Neuroethics Blog](#)

[Emory Program in Neuroethics](#)

[American Journal of Bioethics Neuroscience](#)

[Neuroethics Women \(NEW\) Leaders](#)



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