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Brainstorm Newsletter

An Interdisciplinary Newsletter about Advances in Health Ethics Theory and Practice - October 2018

Special announcement

Starting this fall, Brainstorm is taking on a new look and a change in focus to reflect the more explicit pragmatic orientations of bioethics research of the Pragmatic Health Ethics Research Unit (formerly the Neuroethics Research Unit, based at the IRCM since 2006).

We will continue our coverage of issues related to foundational issues in health ethics as well as issues related to promising practices. We invite you to follow us in the development of research in health ethics, neuroethics and beyond!



Annonce spéciale

À partir de cet automne, Brainstorm fait peau neuve et se tourne vers de nouveaux thèmes pour refléter l'orientation pragmatique explicite de la recherche en bioéthique à l'Unité de recherche en éthique pragmatique de la santé (auparavant connue sous le nom de l'Unité de recherche en neuroéthique, basée à l'IRCM depuis 2006).

Nous continuerons de couvrir des enjeux liés aux problèmes fondamentaux et

pratiques en éthique de la santé. Nous vous invitons à nous suivre dans le développement de la recherche en éthique de la santé, en neuroéthique et vers de nouveaux horizons!

Discover our new website

Découvrez notre nouveau site

Profile of the month



Cynthia S. Kubu, PhD, ABPP-CN

Dr. Kubu is a Staff Neuropsychologist and Professor at the Cleveland Clinic Lerner College of Medicine of Case Western Reserve University. She was elected a Fellow in the American Psychological Association in recognition of her contributions to the field and is board certified through the American Board of Professional Psychology in Clinical Neuropsychology.

Dr. Kubu is primarily a clinician and has worked extensively on functional neurosurgery teams (i.e., epilepsy and deep brain stimulation [DBS]) throughout her career. She has been a key team member of several innovative DBS clinical trials and has helped establish international guidelines in the field of neuromodulation. She was one of four investigators awarded a RO1 neuroethics grant through the National Institutes of Health BRAIN initiative in 2017. Dr. Kubu's most recent grant focuses on patients' and family members' perceptions of personality change in the context of Parkinson's disease and over the course of DBS.

Short Statement: My research program draws on my clinical work with patients who have brain-based disorders; my patients and their concerns inform the research questions I ask and how I choose to answer those questions. I am committed to conducting empirical neuroethics research that is not only highly pragmatic to clinicians but can also inform as well as complement more conceptual and philosophical neuroethics scholarship. My approach to answering research questions also reflects my 20+year history of working on interdisciplinary clinical teams. My clinical work and research initiatives have been enhanced greatly by the unique perspectives other team members have provided in the context of respectful collaboration. Similarly, neuroethics, as a field, benefits from all perspectives – those of the patients and family members, the public, the frontline clinicians, neuroscientists,

philosophers, lawyers, bioethicists, and many more. I am fortunate to work with such talented collaborators and supportive leadership in the Center for Neurological Restoration, Neurological Institute, Cleveland Clinic.

Selected papers:

- 1. **Kubu CS**, Cooper SE, Machado A, Frazier T, Vitek J, Ford PJ (2017). Insights Gleaned by Measuring Patients' Stated Goals for Deep Brain Stimulation: More than tremor. Neurology; 88(2): 124-130.
- 2. Fins JJ, **Kubu CS**, Merkel R, Mayberg HS, Nuttin B, Schlaepfer TE (2017). Being open minded about neuromodulation trials: Finding success in our "failures". <u>Brain Stimulation</u>; 10(2): 181-6.
- 3. **Kubu CS**, Frazier T, Cooper SE, Machado AG, Vitek J, Ford PJ (2018) Informed consent and patients' shifting goals for deep brain stimulation, <u>Neurology (91) 5</u>: 472-8

MONTREAL HEALTH ETHICS SEMINAR SERIES

Auditorium Jacques-Genest, Institut de recherches cliniques de Montréal, 110 avenue des Pins West Free / No registration necessary.

Non accredited continued education seminar

Join us in person or online via our Youtube channel: Pragmatic Health Ethics Seminar Series YOUTUBE: https://www.youtube.com/channel/UCNSY4aUw4qfLw72EwJSdDDQ

Topic for 2018-2019: Moral awareness

The Montreal Health Ethics Seminar Series is a free, open to the public, interdisciplinary and bilingual seminar series aimed at promoting health ethics. Each year, a general theme guides the interventions of health care professionals, ethicians, patients and other stakeholders.

SEMINAR*	DATE (Thursdays at noon)
Promoting a culture of ethical sensitivity for nursing and related health and human service disciplines Kathryn Weaver (University of New Brunswick)	OCT 18TH 2018
Moral distress: evidence and new horizons. Annie Janvier (CHU Sainte-Justine)	NOV 29TH 2018
What is our responsibility with regard to the care of transgender youth? Annie Pullen-Sansfaçon (Université de Montréal)	JAN 31ST 2019
Moral entanglements and the closure of humanitarian health projects: upholding organizational values Matthew Hunt (McGill University)	FEB 21ST 2019
Bien traités, mal soignés. La relation et l'information au cœur des soins. Josée Blanchette (Le Devoir)	MAR 14TH 2019
La sensibilité éthique et la santé au travail: des liens à explorer	APRIL 18TH 2019
Chantal Caux (Université de Montréal) Disorientation in clinical encounters Ami Harbin (Oakland University)	MAY 23 2019

*Language of title is that of presentation.

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Events and Announcements

Montreal Health Ethics Seminar Series

The Montreal Health Ethics Seminar Series is a bilingual monthly seminar/webinar series aimed at bringing people together to think about and discuss issues in health ethics. Our aim is to promote health ethics through seminars that foster dialogue between groups of participants with different perspectives (e.g., academics, clinicians, patients, community members). These seminars will appeal to audiences both within and outside of academia and healthcare settings with the goal of increasing mutual awareness about health ethics and promote interdisciplinary and community reflections on various cross-cutting health ethics topics.

Our theme for the year 2018-2019 is moral awareness, which will be broached by a wide array of speakers. Questions related to this topic include (but are not limited to): What are the social and psychological mechanisms of moral awareness? How does one cultivate moral sensitivity? How can we respond to moral distress? What is our (personal, institutional, social) responsibility in the face of the awareness or unawareness of moral issues? Seminars/webinars are held on Thursdays over lunch time to facilitate individual and group participation.

Join us for our first seminar/webinar in October:

When: October 18th 2018, 12-1PM

Where: Institut de recherches cliniques de Montréal (110 avenue des Pins Ouest, Auditorium Jacques Genest) OR livestreamed through our YouTube page: Pragmatic Health Ethics (https://www.youtube.com/channel/UCNSY4aUw4qfLw72EwJSdDDQ? view as=subscriber)

What: Dr. Kathryn Weaver, "Promoting a culture of ethical sensitivity for nursing and related health and human service disciplines".

All conferences are free and require no registration!

Visit our website or email us for more information about where seminars will be archived for future viewing or educational use (e.g., journal clubs, classroom, continued education): http://www.pragmatichealthethics.ca/outreach/montreal-health-ethics-seminar-series/

Série de séminaires de Montréal en éthique de la santé

La Série de séminaires de Montréal en éthique de la santé est une série mensuelle qui vise à réunir plusieurs acteurs (citoyen-ne-s, clinicien-ne-s, universitaires et patients) autour de différents sujets en éthique de la santé. Notre objectif est de promouvoir l'éthique de la santé à travers un dialogue vivant entre ces acteurs. Nous voulons promouvoir une réflexion interdisciplinaire et alimenter de nouvelles pistes de réflexion qui pourront rejoindre un public large.

Le thème de notre série pour l'année 2018-2018 est la sensibilité morale (ou "moral awareness"). Certaines des questions qui nous intéressent incluent (sans toutefois s'y

limiter): Quels sont les mécanismes sociaux et psychologiques de sensibilité morale? Comment pouvons-nous cultiver cette forme de sensibilité? Comment pouvons-nous répondre aux signes de détresse morale? Quelles sont nos responsabilités (personnelles, sociales, institutionnelles) face à la sensibilité ou l'insensibilité morale?

Joignez-vous à nous pour un premier séminaire en Octobre :

Quoi: Dr. Kathryn Weaver, "Promoting a culture of ethical sensitivity for nursing and related health and human service disciplines".

Quand : Le 18 octobre prochain, de 12h à 13h.

Où: Institut de recherches cliniques de Montréal (110 avenue des Pins Ouest, Auditorium Jacques Genest) OU en direct sur notre page YouTube: Pragmatic Health Ethics au https://www.youtube.com/channel/UCNSY4aUw4qfLw72EwJSdDDQ?
https://www.youtube.com/channel/UCNSY4aUw4qfLw72EwJSdDDQ?
https://www.youtube.com/channel/UCNSY4aUw4qfLw72EwJSdDDQ?

Toutes les conférences sont gratuites et ne requièrent pas d'inscription!

Visitez notre site internet ou écrivez-vous pour plus d'informations : http://www.pragmatichealthethics.ca/fr/rayonnement/serie-de-seminaires/

Recruitment of Regular and Alternative External Members, Health Canada

Health Canada and the Public Health Agency of Canada are seeking to recruit regular and alternate external members to serve on their Research Ethics Board (REB)

Mandate of the Health Canada (HC) and the Public Health Agency of Canada (PHAC) REB

The REB serves as an independent ethics review Board to help ensure that all proposed or ongoing research involving human participants or communities carried out by, funded by, or otherwise under the auspices of HC or PHAC, meet the highest ethical standards, and that safeguards are implemented to provide the greatest protection to human participants and/or communities. It makes recommendations to HC or PHAC as to whether research projects should be approved, rejected, modified, or terminated. The REB reviews applications in accordance with the considerations set forth in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2 (TCPS 2, 2014) as the minimum standard, and other applicable policies and norms.

Canadian Bioethics Society (CBS) - Call for Abstracts

Canadian Bioethics Society Annual Conference - Embracing the Disruptive Edge of Healthcare

Banff, Alberta - May 22-24, 2019.

This year's conference takes disruptive action as valuable action, and the "disrupters" as crucial voices for change. When our beliefs about health and our structures in health care are challenged, our ethical obligations come most sharply into relief. Patients whose preferences and behaviours are challenging or inconvenient are often labelled as "difficult" or "non-compliant". Yet these individuals hold a mirror up to the system that may highlight its shortcomings and flaws. This can force positive reflection at all levels about the nature and goals of health care and what accommodations and limits are reasonable in healthcare delivery

Deadline for submission is November 23rd, 2018.

Qualitative Methods Conference - Call for Abstracts

Brisbane, Australia - May 1 - 3, 2019. Abstract Submission began October 1, 2018

Keynote Speakers: Drs. Sarah Pink & John Creswell

2019 Petrie- Flom Centre Annual Conference - Call for Abstracts

Consuming Genetics: The Ethical and Legal Considerations of Consumer Genetic

Technologies

Deadline: October 15, 2018

The Petrie- Flom Centre for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School is pleased to announce plans for our 2019 annual conference: "Consuming Genetics: The Ethical and Legal Considerations of Consumer Genetic Technologies." This year's conference is organized in collaboration with Nita A. Farahany, Duke Law School, and Henry T. Greely, Stanford Law School.

<u>Pragmatic Health Ethics Research Unit - Call for Applications - Postdoctoral</u> <u>Fellowships or Graduate Student Scholarship</u>

The Pragmatic Health Ethics Research Unit is seeking TWO (2) postdoctoral fellows or graduate students to work on two main projects.

The first project examines the ethical and social implications of health care transitions for youth with chronic conditions, including rare diseases. The second project examines the ethics of registry-based type-1 diabetes research.

The Johns Hopkins Berman Institute of Bioethics - Call for Applications

The Johns Hopkins Berman Institute of Bioethics is pleased to invite applications for the Hecht-Levi Postdoctoral Fellowship Program in Bioethics. The admissions committee is seeking a few uniquely qualified postdoctoral applicants to begin this two-year fellowship in

September 2019. Applicants with at least some exposure to Bioethics during their education are encouraged to apply, though an extensive background in bioethics is not required. This admissions process is highly competitive, and only a few applicants are accepted into the program each year.

For more information on the Fellowship program or the Johns Hopkins Berman Institute of Bioethics, please visit bioethicsinstitute.org. For inquiries regarding the Hecht-Levi Postdoctoral Fellowship Program, please contact the Director of Education Initiatives, Professor Gail Geller, at ggeller@jhu.edu.

Application review will begin December 15, 2018.

<u>Harvard University - Edmond J. Safra Centre for Ethics - Call for Applications - Fellow in Residence</u>

The Edmond J. Safra Center for Ethics at Harvard University invites applications from a broad range of researchers and practitioners who will work over the course of the year on pressing issues in ethics. Faculty in arts and sciences and professional schools, postdoctoral scholars, practitioners, and researchers from industry, government, and NGOs are eligible to apply.

For the 2019-20 academic year, the theme at the Edmond J. Safra Center for Ethics will be the Ethics of Technological and Biomedical Innovation. Priority will be giventoearly career scholars and practitionerswhose work closely aligns with this theme, but we reserve some "open" slotsforsenior scholars and practitioners, andfor exceptionallycompetitive applicants whose work in ethics falls outside this scope. The goal will be to craft a cohort in which "thematic" fellows and "open" fellows will all find valuable intellectual partnerships to support and spur their work.

<u>University of Washington - Assistant or Associate Professor in Bioethics & Humanities</u>

The University of Washington is recruiting for a full-time (100% FTE, 12 -month service period), tenure-track faculty position in the School of Medicine of the Department of Bioethics & Humanities at Assistant or Associate Professor level, commensurate with experience and qualifications.

Candidates must have a doctoral or terminal degree in a bioethics-related discipline (e.g., PhD, MD, JD, or foreign equivalent) as well as education and demonstrated expertise in bioethics and normative ethics. Candidates must have demonstrated expertise in one or more of the following disciplines: philosophy, history, religious studies, law, literature, anthropology, sociology, health policy, public health, health services research, or related disciplines to complement and/or expand current areas of faculty expertise. For more

information, please see the following link: https://apply.interfolio.com/52706 or contact the Search Committee Chair, Dr. Erika Blacksher, at bhsearch@uw.edu

The position will remain open until filled.

New Mexico Tech - University of Washington - Assistant Professor in Ethical Dimensions of STEM

New Mexico Tech invites applications for Assistant Professor of Ethics The successful candidate will be a specialist in the ethical dimensions of science, technology, and engineering with a promising research program and an innovative pedagogical approach. This faculty member will teach six classes an academic year including an ethics course required by the Biomedical Sciences program among others, and will have funding available to develop a speaker and/or workshop series on STEM ethics. The candidate will also work with the department faculty and chair to establish an interdisciplinary master's degree and contribute to a well-established Bachelor of Science in Technical Communication program.

Literature

Interdisciplinary Foundations of Health Ethics

Solidarity and care as relational practices.

Jennings B. Bioethics. 2018 Sep 28. [Epub ahead of print].

'Bioethical Realism': A Framework for Implementing Universal.

Barugahare J. Dev World Bioeth. 2018 Aug 6. [Epub ahead of print].

Capacity for Preferences: Respecting Patients with Compromised Decision-Making

Wasserman JA, Navin MC. Hastings Cent Rep. 2018 May; 48(3): 31-9.

Patient vs. Community Engagement: Emerging Issues.

Kimminau KS, Jernigan C, LeMaster J, Aaronson LS, Christopher M, Ahmed S, Boivin A,

DeFino M, Greenlee R, Salvalaggio G, Hendricks D, Herbert C, Mabachi NM, Macaulay A,

Westfall JM, Waitman LR. Med Care. 2018 Oct; 56 Suppl 10 Suppl 1: S53-7.

Social value, clinical equipoise, and research in a public health emergency.

London AJ. Bioethics. 2018 Jul 27. [Epub ahead of print]

Methodologies and Practices in Health Ethics

Swiss-CHAT: Citizens Discuss Priorities for Swiss Health Insurance Coverage.

Hurst SA, Schindler M, Goold SD, Danis M. Int J Health Policy Manag. 2018 Mar 6; 7(8): 746-54.

A framework for enhancing ethical genomic research with Indigenous communities.

Claw KG, Anderson MZ, Begay RL, Tsosie KS, Fox K, Garrison NA; Summer internship for INdigenous peoples in Genomics (SING) Consortium. Nat Commun. 2018 Jul 27;9(1): 2957.

The status of ethics in Swedish health care management: a qualitative study.

Höglund AT, Falkenström E. BMC Health Serv Res. 2018 Aug 6; 18(1):608.

The Team Based Biopsychosocial Model: Having a Clinical Ethicist as a Facilitator and a Bridge Between Teams.

Sotomayor CR, Gallagher CM. HEC Forum. 2018 Aug 3. [Epub ahead of print].

An ethical framework for the creation, governance and evaluation of accelerated access programs.

Pace J, Ghinea N, Kerridge I, Lipworth W. Health Policy. 2018 Sep; 122(9): 984-90. Epub 2018 Jul 20.

News and Social Media

Do Clinical Trials Have a Sex Problem?

Elysium Health. Endpoints. May 18, 2018.

Why We Are So Vulnerable to Charlatans Like Trump

Ganz J. New York Times: Opinion. June 12, 2018.

Ethical Concerns Surrounding Psychiatric Treatments: Do Academics Agree with the Public

Cabrera L, McKenzie R, Bluhm R. The Neuroethics Blog. June 12, 2018.

Depression and your sense of self

Malcom L. ABC: Radio National. July 29, 2018

Prisoners Protest at Nova Scotia Jail

The Prisoners of Burnside. Impact Ethics [Reprinted in part from Halifax Examiner]. August 25, 2018.

Why it's hard for blacks to pull themselves up by bootstraps when it comes to health

Assari S. The Conversation. September 04, 2018.

<u>Searching for a diagnosis: how scientists are untangling the mystery of developmental</u> <u>disorders</u>

Geddes L. Mosaic. September 18, 2018.

The Coddling of the American Mind [Lukianoff G, Haidt J] Review: How elite US liberals have turned rightwards

Weigel M. The Guardian: Books. October 02, 2018.

Other Resources

For more resources in health ethics theory and practice, visit our website.







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