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An interdisciplinary and bilingual newsletter about advances in health ethics theory and practice



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Profil du mois

Amaryllis Ferrand, M.D.

Amaryllis is a neonatologist and PhD student in clinical ethics at the University of Montreal. She is a recipient of the Vanier Canada Graduate Scholarship. She is a staff physician at the Montreal Jewish General Hospital and holds a position of Assistant professor of Medicine at McGill University. Prior to this, Amaryllis studied biomedical sciences and psychology at the University of Ottawa. After attending medical school at the University of Ottawa, she completed a residency in pediatrics at the University of Western Ontario, followed by a fellowship in neonatology and a fellowship as a clinical investigator at the Sainte-Justine University Hospital in Montreal. During her fellowships, Amaryllis pursued a master's



degree in the clinical ethics option of the biomedical sciences program at the University of Montreal under the supervision of Dr. Antoine Payot where she worked on parental projection of the future quality of life of newborns hospitalized in the NICU. She aims to further her doctoral research on factors influencing physicians' prognostication of pregnancies presenting with congenital malformations of the fetus or at risk of extreme preterm delivery under the co-supervision of Dr. Eric Racine of the Pragmatic Health Ethics Research Unit located at the Montreal Clinical Research Institute.

Prognostication biases in neonatal-perinatal medicine

Findings of severe congenital malformation of the foetus or threatened premature labor at the limit of viability can direct obstetrical care towards critical decisions These include whether or not to continue a pregnancy, as well as the level of care that should be offered to the newborn after birth. These choices fall within a grey zone, where decisions are complex, outcomes uncertain and can justify each level of care. In a shared decision-making model, physicians counsel and guide families towards a decision that reflects their values. Prognosis of survival, morbidity and quality of life are essential elements of this decision-making process for families, where physicians' framing of information has a strong impact on parental choices. However, there are many discrepancies in physician's prognosis, either variable from one physician to another or more pessimistic or optimistic than actual outcomes. Furthermore, physicians often directly associate risk of disability with poor quality of life, which is different from the experience of patients. In neonatal-perinatal medicine, physicians likewise tend to lean towards more pessimist prognoses, especially when it comes to predictions of quality of life. There are many hypotheses to explain these negative predictions, including viewing premature newborns as having a different moral status, a lack of exposure to long-term positive outcomes of patients, physicians' personal tolerance towards disability, and the influence of their own values and attitudes.

Our research aims to identify which factors lead physicians to make biased prognoses for premature newborns at the limit of viability and newborns born with significant congenital malformations, alongside strategies to reduce the impact of these factors on prognostication.

Selected publications

- 1. **Ferrand A**, Gorgos A, Ali N, Payot A. Resilience rather than medical factors: how parents predict quality of life of their sick newborn. *J Pediatr*. 2018;200(September 2018):64-70.
- 2. **Ferrand A**, Racine E. Can clinicians be objective? Inherent challenges in using decision-making tools in cases of entrenched disagreements. *Am J Bioeth*. 2018;18(8):80-82.
- 3. Rasmussen LA, Cascio MA, **Ferrand A**, Shevell M, Racine E. The complexity of physicians' understanding and management of prognostic uncertainty in neonatal hypoxic-ischemic encephalopathy. *J Perinatol.* 2019;39(2):278-285.

Websites and social media

Profile on the Pragmatic Health Ethics Research Unit's website
ResearchGate
LinkedIn

Events and announcements

The Montreal Health Ethics Conference Series

The Montreal Health Ethics Conference Series is a monthly bilingual livestreamed conference aiming to bring clinicians, academics, patients, politicians, public figures, students and community members together to think about and discuss issues in health ethics.

2021 theme: Wellness, health and human flourishing

More than ever, the question of well-being is at the heart of our lives and our concerns, but what role do we really give it in our personal and professional lives and more broadly in our society? Is this ideal accessible to all? How does our health care system respond to different visions of health and wellness? This series of lectures will highlight the perspectives of leading international experts reflecting on ethical issues related to wellness. The series will also focus on a number of critical interventions that will lead us to reflect on an inclusive vision of wellness and health. Click here for the conference series calendar.



Upcoming conferences in June:

Politiques publiques et inégalités sociales de santé

Marie-France Raynault, MD, PhD

Directrice, Centre de recherche Léa-Roback sur les inégalités sociales de santé de Montréal; Professeure émérite, École de santé publique, Département de médecine sociale et préventive, Université de Montréal 16 juin 2021 – 12h à 13h PM

Pour vous inscrire: Cliquez ici.

Online event: The ethics of medical cannabis for children in an unregulated world

Collaboration between Neuroethics Canada and the Canadian Childhood Cannabinoid Clinical Trials

Wednesday, June 23, 2021, 4:00PM - 5:30PM PDT

Moderated by:

Hal Siden, MD, MHSc, Medical Director, Division Head and Investigator,

BC Children's Hospital, Canuck Place Children's Hospice &

Clinical Professor, University of British Columbia

Judy Illes, CM, PhD

Director, Neuroethics Canada & Professor of Neurology, University of British Columbia

To register: Click here.

Call for abstracts: 2021 INS Annual Meeting

Social Justice at the Center: Shaping the Future of Neuroethics

International Neuroethics Society

Online Conference: November 4-5, 2021

See call for abstracts here

Abstracts should be related to the field of neuroethics from any disciplinary background, using any methodological approach. Abstracts will be peer reviewed, and acceptance will be based on content and overall program fit. Outstanding abstracts may be selected for oral presentations and special recognition.

Submission deadline: July 2, 2021 at 11:30pm EDT.

Call for essays: Neuroethics essay contest

International Neuroethics Society

Authors from all countries and regions are encouraged to participate, and we welcome applicants from underrepresented or marginalized groups. Essay submissions can cover any topic in neuroethics and should address a focused problem at the intersection of the mind and brain sciences, ethics, and law.

Submission deadline: July 2, 2021 at 11:30pm EDT.

Call for registration: ASBH's 23rd Annual Conference

Online conference: October 11-16, 2021

The Conference takes its inspiration from its previously scheduled meeting place at the "Crossroads of America", Indianapolis, Indiana. Attendees are invited to explore the many intersections of bioethics, health humanities, and the worlds with which we engage.

NEW: Student Sponsorship:

Institutions can now sponsor student registrations at \$60 each. Lock in your sponsorship now by submitting a **completed form**, student registration payment, and the \$500 sponsorship fee. **Submit forms** and any questions on Student Sponsorships or additional sponsorship and advertising opportunities to Josh Karney at **jkarney@asbh.org**.

<u>Call for abstracts and registration: Colloquium series on African philosophy, genetics and genomics</u>

Virtual colloquium: June 23, 2021 – 2PM to 5PM (GMT+2)

Three to five presenters will each present a 15-minute paper, followed by discussion involving all attendees.

To register – free of charge – click here: https://bit.ly/3ujl5sn. The Zoom link will be emailed to all registered attendees.

To submit a 300-word abstract, contact: healthlaw@ukzn.ac.za

Deadline for submissions: May 25, 2021. Are welcomed: abstracts that address human heritable genome editing from the perspective of African philosophy.

Announcement: UBC's 2021 Distinguished University Scholars

<u>Dr. Judy Illes</u>, Medicine (Neurology), Faculty of Medicine is one of the recipients of the Distinguished University Scholar awards. This award recognizes exceptional members of faculty who have distinguished themselves as scholars in research and/or teaching and learning. Visit the <u>Distinguished University</u>

Scholar award page to learn more about the program.

Call for applications: Ethicist - clinical ethics & policy

Sunnybrook Health Science Center, Toronto, Canada

There is a temporary full-time opportunity available for an ethicist in the Department of Clinical Ethics & Policy at North York General Hospital and Markham Stouffvile Hospital.

For more information: Click here.

Call for abstracts and registration:

Congress of the Feminist Approaches to Bioethics

Reimagining Feminist Bioethics (July 18th – 19th, 2022)

• 16th World Congress of Bioethics

Bioethics post Covid-19: Responsibility and transparency in a globalized and interconnected world (July 20th-22nd, 2022)

Institute for Biomedical Ethics, University of Basel, Switzerland

Abstract submission (both events): Click here. The deadline is July 30th, 2021.

Registration (both events): Click here. The deadline is January 31st, 2022.

For more information: Click here.

<u>Call for abstracts: Interdisciplinary conference – The ethical, legal, and social aspects of cognitive</u> enhancement strategies

August 24th - 26th, 2021 (2pm-7pm CET), Cologne

Fritz Thyssen Foundation (Germany) & online

Organizers:

- Dr. Sebastian Sattler (University of Cologne, Germany)
- Prof. Dr. Guido Mehlkop and Floris van Veen (University of Erfurt, Germany)

Deadline for abstract submission: May 12th, 2021.

<u>Call for contributions: Framework: Responsible Conduct of Research (2016) – Proposed revisions</u> for public consultation

Panel on Responsible Conduct of Research, Government of Canada

The set of proposed revisions to the responsible conduct of research framework is now available online.

Deadline for submitting written comments on the proposed revisions: June 23rd, 2021

Call for abstracts and registration: The 24th IUHPE World conference on health promotion

Theme: Promoting policies for health, well-being and equity

Global scientific committee

May 15th to 19th, in Montreal - Hybrid event

Abstract submission: Click here.

Deadline for abstract submission: September 17th, 2021

For any queries: Please contact the Conference Secretariat – iuhpe2022@jpdl.com.

Literature

Interdisciplinary foundations of health ethics

Statement in support of revising the uniform determination of death act and in opposition to a proposed revision.

Shewmon DA. J Med Philos. 2021 May 14:jhab014. Online ahead of print.

Taking stock of the availability and functions of National Ethics Committees worldwide.

Hummel P, Adam T, Reis A, Littler K. BMC Med Ethics. 2021 May 10;22(1):56.

Managing drug shortages during a pandemic: tocilizumab and COVID-19.

Verma AA, Pai M, Saha S, Bean S, Fralick M, Gibson JL, Greenberg RA, Kwan JL, Lapointe-Shaw L, Tang T, Morris AM, Razak F. *CMAJ*. 2021 May 5:cmaj.210531. Online ahead of print.

Ethics review of big data research: What should stay and what should be reformed?

Ferretti A, Ienca M, Sheehan M, Blasimme A, Dove ES, Farsides B, Friesen P, Kahn J, Karlen W, Kleist P, Liao SM, Nebeker C, Samuel G, Shabani M, Rivas Velarde M, Vayena E. *BMC Med Ethics*. 2021 Apr 30;22(1):51.

Ricoeur's hermeneutic arc and the "narrative turn" in the ethics of care.

Russo MT. Med Health Care Philos. 2021 Apr 29. Online ahead of print.

Methodologies and practices in health ethics

<u>Development of a scale to measure trust in public health authorities: prevalence of trust and association with vaccination.</u>

Holroyd TA, Limaye RJ, Gerber JE, Rimal RN, Musci RJ, Brewer J, Sutherland A, Blunt M, Geller G, Salmon DA. *J Health Commun*. 2021 May 16:1-9.

50 Years of advance care planning: What do we call success?

Knight K. *Monash Bioeth Rev.* 2021 May 8. Online ahead of print.

Application of a framework to guide genetic testing communication across clinical indications.

Hallquist MLG, Tricou EP, Ormond KE, Savatt JM, Coughlin CR 2nd, Faucett WA, Hercher L, Levy HP, O'Daniel JM, Peay HL, Stosic M, Smith M, Uhlmann WR, Wand H, Wain KE, Buchanan AH. *Genome Med.* 2021 Apr 29;13(1):71.

<u>Patient perspectives on how to demonstrate respect: Implications for clinicians and healthcare organizations.</u>

Bridges C, Duenas DM, Lewis H, Anderson K, Opel DJ, Wilfond BS, Kraft SA. *PLoS One.* 2021 Apr 29;16(4):e0250999.

Impact of an educational comic to enhance patient-physician-electronic health record engagement: prospective observational study.

Alkureishi MA, Johnson T, Nichols J, Dhodapkar M, Czerwiec MK, Wroblewski K, Arora VM, Lee WW. *JMIR Hum Factors*. 2021 Apr 28;8(2):e25054.

Debates arising in news and social media

When scientific orthodoxy resembles religious dogma

Loeb A. Scientific American. May 17, 2021

Release of genetically altered mosquitoes in the Keys needs better public vetting than it's had Kaebnick GE. *Miami Herald*. May 11, 2021.

<u>Un « pouvoir presque divin » : ces avocats qui décident qui vivra et qui mourra dans les zones de guerre</u>

Jones C. The Conversation, 11 mai 2021.

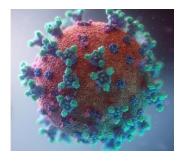
Apprendre à débattre

Moreau P. Le Devoir. 6 mai 2021.

<u>L'IA gagne du terrain en santé. Comment les ordres professionnels peuvent-ils l'encadrer?</u> Régis C & Laverdière M. *The Conversation*. 5 mai 2021.

Health ethics and the COVID-19 pandemic Recent and relevant literature

A list of the most recent and relevant health ethics scholarly publications relating to the COVID-19 response is available on <u>our website</u>.



Other resources

For more resources on pragmatic health ethics theory and practice, visit our website at http://www.pragmatichealthethics.ca.