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# BRAINSTORM

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

PRAGMATIC  
HEALTH ETHICS  
RESEARCH UNIT 

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IRCM INSTITUT DE RECHERCHES  
CLINIQUES DE MONTRÉAL

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## Monthly profile

### Kathleen Bogart, Ph.D.

Dr. Bogart is Associate Professor of Psychology at [Oregon State University](#). She is a social/health psychologist specializing in ableism and rare disorders such as facial paralysis. She has received grants from the National Institutes of Health, Good Samaritan Hospital (Erkkila Endowment), and the Moebius Syndrome Foundation. An advocate for people with rare disorders and disabilities, she has served on several boards, including the American Psychological Association Committee on Disability Issues in Psychology, the Rehabilitation Psychology editorial board, and the Moebius Syndrome Foundation Scientific Advisory Board.



A person with a rare disorder herself, her research focuses on the psychosocial implications of living with rare disorders or disabilities, such as Moebius syndrome. Rare disorders can be stigmatizing because people with them are frequently misunderstood, isolated, and blamed. Her lab is working to build social support and resist stigma in the rare disorder community.

## **Applying the social model of disability to rare disease research**

There are approximately 7,000 different rare diseases, each affecting fewer than 1 in 200,000. Although they are medically rare, the social experiences of people with rare diseases are collectively common, with approximately 8-10 in 100 people having any rare disease. Consider the medical model of disability, which conceptualizes difference as an individual abnormality or pathology, compared to the social model of disability, which views difference as a social construction. Most rare disease research has been limited by following a medical model approach. This research focuses on individual disease processes and is limited by a restricted view of factors contributing to quality of life and extremely small sample sizes. Most people with rare diseases will not receive a biomedical treatment or cure within their lifetime.

I advocate for a social model approach, which focuses on structural, environmental, and social factors like stigma, social support, and accessibility. This approach offers a more complete understanding of quality of life. A social model approach can be disease-agnostic, focusing on common psychosocial challenges across many disorders. In one study, we examined rare disorders collectively in a large sample size of 1,218 adults and found they experience lower quality of life and greater stigma compared to the general population and people with prevalent chronic diseases. Social model research is most likely to benefit people with rare diseases directly, empowering them to share narratives and producing actionable psychosocial interventions that could be efficiently applied to many different rare disease populations simultaneously. Rare disease advocacy and health research funding agencies should prioritize this approach.

### **Selected publications**

Bogart, K. R., & Dermody, S. S. (2020). [Relationship of rare disorder latent clusters to anxiety and depression symptoms](#). *Health Psychology*, 39(4), 307-315.

Bogart, K. R., & Irvin, V.L. (2017). [Health-related quality of life among adults with diverse rare disorders](#). *Orphanet Journal of Rare Diseases*, 12(177).

Bogart, K. R., Tickle-Degnen, L., & Joffe, M. (2012). [Social interaction experiences of adults with Moebius syndrome: A focus group](#). *Journal of Health Psychology*, 17(8), 1212-1222.

### **Websites**

[Research website](#)

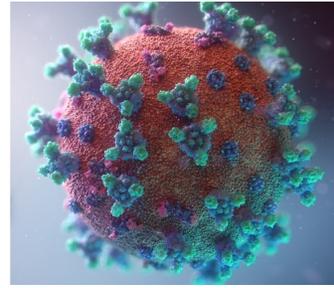
[Psychology Today Blog](#)

[Twitter: @Kathleen\\_Bogart](#)

## **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 [our website](#).



## Events and announcements

### [The Montreal Health Ethics Conference Series](#)

The Montreal Health Ethics Conference Series is a monthly 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.

#### ***Conference schedule for 2021:***

**For more information and to register, [click here!](#)**

## FÉVRIER - FEBRUARY

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**24**

**Rose-Marie Charest**  
Psychologue et conférencière

## MARS - MARCH

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**4**

**Carol Ryff, PhD**  
Hilldale Professor of psychology, University of Wisconsin-Madison; Director, Institute on Aging

**25**

**Claudia Barned, PhD**  
Bioethicist, University Health Network's (UHN)

**Kevin Rodrigues, PhD**  
Clinical Ethicist, Toronto Rehabilitation Institute, UHN

## AVRIL - APRIL

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**22**

**Ghislain Picard**  
Chef de l'Assemblée des Premières Nations Québec-Labrador

## MAI - MAY

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**6**

**Alain Ehrenberg, PhD**  
Sociologue; Directeur de recherche, Centre national de la recherche scientifique-CNRS (France)

**27**

**Erik Parens, PhD**  
Senior Research Scholar, The Hastings Center

## JUIN - JUNE

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**16**

**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

## SEPTEMBRE - SEPTEMBER

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**9**

**Vincent Dumez**  
Co-directeur, Centre d'excellence sur le partenariat avec les patients et le public (CEPPP), Faculté de médecine, Centre de recherche du CHUM, Université de Montréal

**30**

**Joanne Castonguay**  
Commissaire à la santé et au bien-être, Gouvernement du Québec

## OCTOBRE - OCTOBER

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**14**

**Gregory Aiguier, PhD**  
Enseignant-chercheur, Centre d'éthique médicale, Faculté de Médecine et de Maieutique (France)

## NOVEMBRE - NOVEMBER

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**4**

**Teresa Blankmeyer Burke, PhD**  
Bioethicist; Professor of Philosophy, Gallaudet University, Editor, Journal of Philosophy of Disability

## DÉCEMBRE - DECEMBER

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**Panel de clôture/closing panel**

## Conference

**Indianapolis, IN, US**

**October 13-16, 2021**

ASBH's 23rd Annual Conference, "Bioethics and Humanities at the Crossroads", takes its inspiration from its scheduled meeting place at the "Crossroads of America": Indianapolis, Indiana. Whether you plan to attend in person, virtually, or both ways, they invite your submissions that explore critically the many intersections of bioethics, health humanities, and the worlds with which we engage. The responses to COVID-19—both national and global—have awakened deep concerns about our healthcare systems, systemic inequity, and divergent worldviews, as well as awareness of the potential for new alliances and creative solutions.

Recognizing that we have different values, beliefs, identities, perspectives, experiences, knowledge, and skills, our diverse community has the strengths to address these challenges, envision these possibilities, and chart new paths forward. But how can the essential contributions made at the intersection of bioethics and health humanities be recognized and amplified? What relationship to activism and advocacy may or should these fields have? With increased attention being given to critical and intersectional methodologies in bioethics and health humanities discourse that engage with age, class, disability, immigration status, race and ethnicity, religion, sexuality, and gender identity, and other essential perspectives—how might we think about the scope and access of our fields? What expanded public roles or new contributions might lie ahead for these fields?

ASBH invites submissions responsive to questions like these, as well as those on perennial topics in bioethics and health humanities. Interprofessional, interdisciplinary, and intersectional approaches are especially welcomed. Different submission formats are welcomed: preconference workshops, workshops, panel presentations, debates, performances and exhibitions, paper presentations, as well as flash presentations. For more information, please check out the link above. If you have any questions, please contact the ASBH office at [info@asbh.org](mailto:info@asbh.org) or 847.375.4745.

**Deadline:** The call for proposals is open until 11:59 pm PST, **Monday, March 1, 2021**.

### **Call for applications: Reviewer for the ASBH 2021 Annual Conference**

**American Society for Bioethics and Humanities Program Committee, Indianapolis, IN, US**

The ASBH 2021 Annual Conference Program Committee invites new and returning reviewers to help select proposals for presentation at the conference. Emerging scholars and those who are new to ASBH are especially encouraged to apply as the committee is building a review process that reflects the diversity of ASBH's members. Those interested in serving as a reviewer are invited to review the expectations and eligibility requirements below. Then, using the link below, to submit the online volunteer form detailing their willingness to serve and areas of interest. If you have any questions, please contact the ASBH office at [info@asbh.org](mailto:info@asbh.org) or 847.375.4745.

**Expectations and Eligibility Requirements for 2021 Reviewers:**

1. Each reviewer is expected to rate up to 20 proposals and provide comments on them between March 9 and March 23;
2. Reviewers must be ASBH members;
3. Reviewers must have attended a previous ASBH conference;
4. Reviewers must have been either a presenter or co-author of a presentation given at a previous ASBH conference.

**To apply:** [Click here.](#)

**Deadline:** Before Monday, February 8, 2021. Volunteers will be notified of their status by early March 2021.

**[Call for abstracts: Behind the mask - Ethical issues revealed by COVID-19 in Canada and beyond](#)**

**2021 Canadian Bioethics Society Annual Conference**

**May 25 to May 28, 2021 (virtual event)**

The theme is intended to capture issues and concerns both created by and exacerbated by the pandemic. These may include the roots of social and health inequity that perpetuate racism and oppression, the governmental responses to the pandemic, and those issues that may be endemic to the field of bioethics itself. We welcome submissions addressing a broad range of topics, ranging from local to global, individuals to populations, theoretical to practical, and from practice to policy. We also welcome discussions focusing on the next best steps for bioethics as a field of study, inquiry and practice. Presentations can be given as standard concurrent sessions, bioethics M&M rounds, rapid rounds or preconference workshops. Detailed guidelines for drafting of abstracts are available [here](#).

**To submit an abstract:** [Click here.](#)

**Deadline for abstract submission:** February 28, 2021.

**[Call for applications: Clinical medical ethics fellowship \(Academic year 2021-2022\)](#)**

**The MacLean Center for Clinical medical ethics, University of Chicago, Chicago, IL, US**

This Clinical medical ethics fellowship program is the oldest and largest such program in the world. Since 1984, they have trained more than 525 clinical ethics fellows including 400 physicians of whom 90 are surgeons. Please feel free to share this message to any colleagues who may be interested in applying for this unique, year long, part-time (about 30%) clinically-oriented fellowship. You can access the fellowship application form [here](#). Please submit your application and any questions to Kimberly Conner, the MacLean Center Manager, at [kconner1@medicine.bsd.uchicago.edu](mailto:kconner1@medicine.bsd.uchicago.edu).

**Deadline :** The application deadline is **March 1, 2021**.

**[Call for applications: Clinical operations associate – Clinical ethics](#)**

**Center for Medical Ethics and Health Policy, Baylor College of Medicine, Houston TX US**

The Center is seeking an experienced Clinical operations associate to manage the daily administrative and operational aspects of the Center's robust clinical ethics services at their affiliate partners at Baylor St. Luke's Medical Center and Houston Methodist Hospital. The Center's mission in clinical ethics is to serve as national leaders in exemplary ethics

consultation and education driven by innovative research and the development of transformative policies and practices, with the goal of enhancing the quality of healthcare within diverse institutions. The successful candidate will work closely with Center leadership, faculty program directors, and affiliate partners of our clinical ethics service lines to advance and accomplish the overall mission and goals of the programs.

Qualifications notably include: a Bachelor's degree in business, healthcare, or related field; interest or experience with bioethics and/or clinical ethics preferred; demonstrated experience in project management and 2 years of relevant experience, process improvement, planning, and execution; and professional, positive attitude with strong interpersonal skills and communication skills.

**To apply:** Submit a resume and cover letter indicating their desire to be considered [here](#).

**Deadline:** Open until filled

**[Webinaire: 2e Café de bioéthique à l'international pour la francophonie](#)**

**9 février 2021 à 12h30 p.m. (heure normale de l'Est)**

**Comité étudiant de bioéthique, Université de Montréal, Montréal, QC, CA**

Le Comité étudiant de bioéthique de l'Université de Montréal est ravi de vous annoncer son deuxième Café de Bioéthique 2020-2021, qui portera sur « Les enjeux socio-éthiques des diagnostics anténataux ». Ce nouveau café vous réserve des intervenants de qualité : Vardit Ravitsky Ph.D, Anne-Marie Laberge M.D. Ph.D, et Julie Cousineau LLM DLC M.Sc. (c).

Pour vous inscrire, [cliquez ici](#).

**[Appel aux publications: Les Cahiers de droit, « La pandémie et le droit »](#)**

**[Call for publications: Les Cahiers de droit, "The pandemic and the law"](#)**

**Cahiers de droits, Université Laval, Québec, QC, CA**

La pandémie liée au virus de la COVID-19 justifie l'introduction de mesures exceptionnelles sur tous les plans. Certaines transformations sont temporaires, tandis que d'autres modifient durablement les comportements des individus et le fonctionnement des institutions. Face aux bouleversements sociaux et politiques qui font émerger la nécessité de comprendre les effets de la pandémie dans l'univers du droit, la revue [Les Cahiers de droit](#) invite les juristes, de même que les chercheuses et les chercheurs d'autres disciplines qui s'intéressent au droit, à publier leurs réflexions dans un numéro spécial sur le thème suivant : « **La pandémie et le droit** ». La direction scientifique de ce numéro thématique des Cahiers de droit est assurée par les professeures Louise Langevin et Michelle Cumyn de la Faculté de droit de l'Université Laval. Tous les textes soumis à la revue font l'objet d'une évaluation anonyme par deux experts externes. Les Cahiers de droit publient des textes originaux en langue française et anglaise. Pour plus d'informations, veuillez consulter [le site internet de la revue](#) ou communiquer avec [cahiers.de.droit@fd.ulaval.ca](mailto:cahiers.de.droit@fd.ulaval.ca).

**Date limite :** Les textes, de 20 à 30 pages sont attendus d'ici le **1er juillet 2021**, par courriel ([cahiers.de.droit@fd.ulaval.ca](mailto:cahiers.de.droit@fd.ulaval.ca)).

**[Call for papers: Special issue on ethics and complaints commissioner offices \(ombudsperson\) for the Canadian journal of bioethics](#)**

**Office of the Commissioner of Complaints and Quality of Services, Centre intégré universitaire de santé et de services sociaux du Centre-ouest-de-l'Île-de-Montréal, Montréal, QC**

This special issue aims to document the experience of complaints commissioner's offices **worldwide** and across **various sectors of activity**. There are complaints commissioner offices (ombudsperson) in various public, para-public and private organizations. Complaints commissioner offices examine processes and situations related to dissatisfaction, experiences and respect for rights of users (e.g., students, patients). These examinations aim primarily at improving the quality of services, but also at easing social tensions and thus diverting conflicts from the courts. The complaints commissioner office is intended to be a neutral and independent trusted actor. Following a complaint or intervention by the complaints commissioner, a review may lead to recommendations to the organization with the aim of improving the organization's practices. Complaints commissioner's offices have received limited attention in the ethics literature. Nevertheless, many important ethical issues arise in the context of complaints commissioners' offices that are distinctive and that warrant careful analysis.

**Instructions:** Contributions are welcome in different formats: articles, critical commentaries, "response" to commentaries, perspective and testimonies, reviews, case studies, art, culture and creative works, etc. For additional information on Complaints Commissioner Offices, for topic examples or for instructions regarding manuscript preparation, and types of manuscripts, see: <https://cjb-rcb.ca/index.php/cjb-rcb/about/submissions>. If you have any questions about a possible submission, please contact: [ombudsman.ccomtl@ssss.gouv.qc.ca](mailto:ombudsman.ccomtl@ssss.gouv.qc.ca)

**Deadline:** The deadline to submit manuscripts is **April 30th, 2021**. Contributions may be written in **English** or **French**.

## **Literature**

### **Interdisciplinary foundations of health ethics**

**[In defense of dignity: Reflections on the moral function of human dignity.](#)**

Árnason V. *Bioethics*. 2021 Jan;35(1):31-9.

**[Vulnerability: An integrative bioethics review and a proposed taxonomy.](#)**

Mergen M, Akpinar A. *Nursing Ethics*. 2021 Jan 12. Online ahead of print.

**[Bioethicists should be helping scientists think about race.](#)**

Russell C. *Journal of Bioethical Inquiry*. 2021 Jan 7:1-3.

**[Reasons to redefine moral distress: A feminist empirical bioethics analysis.](#)**

Morley G, Bradbury-Jones C, Ives J. *Bioethics*. 2021 Jan;35(1):61-71.

[Nothing to be ashamed of: sex robots for older adults with disabilities.](#)

Jecker NS. *Journal of Medical Ethics*. 2020 Nov 12;47(1):26-32.

## Methodologies and practices in health ethics

[An electronic tool to support patient-centered broad consent: A multi-arm randomized clinical trial in family medicine.](#)

Golembiewski EH, Mainous AG 3rd, Rahmanian KP, Brumback B, Rooks BJ, Krieger JL, Goodman KW, Moseley RE, Harle CA. *Annals of Family Medicine*. 2021 Jan-Feb;19(1):16-23.

[Mitigating ethical conflict and moral distress in the care of patients on ECMO: impact of an automatic ethics consultation protocol.](#)

Wirpsa MJ, Carabini LM, Neely KJ, Kroll C, Wocial LD. *Journal of Medical Ethics*. 2021 Jan 13. Online ahead of print.

[Twelve years of the Italian program to enhance relational and communication skills \(PERCS\).](#)

Borghini L, Meyer EC, Vegni E, Oteri R, Almagioni P, Lamiani G. *International Journal of Environmental Research and Public Health*. 2021 Jan 8;18(2):E439.

[Identifying and classifying tools for health policy ethics review: A systematic search and review.](#)

Henein M, Ellis C. *Health Care Analysis*. 2021 Jan 1. Online ahead of print.

[Public reasoning about voluntary assisted dying: An analysis of submissions to the Queensland Parliament, Australia.](#)

Kirchhoffer DG, Lui CW. *Bioethics*. 2021 Jan;35(1):105-116.

## News and social media

[The government-control virus, unlike the coronavirus, is nearly impossible to fully recover from](#)

Lau M. *The Financial Post*. January 21, 2021.

[Opinion: As pressure increases on Quebec healthcare system, a public debate is needed on who gets care](#)

Brabant B & Johnson N. *CTV News*. January 17, 2021.

[Canadian expert's research finds lockdown harms are 10 times greater than benefits](#)

Furey A. *The Toronto Sun*. January 9, 2021.

[Il faut combattre les idées qui parasitent nos esprits, selon le professeur Gad Saad](#)

Bureau S. *Bien entendu - Ici Première*. 29 décembre 2020.

[Medscape article reviews the fatal flaws of the DSM](#)

Simons P. *Mad in America*. December 28, 2020.

[China's artificial intelligence surveillance state goes global.](#)

Andersen R. *The Atlantic*. September 2020.

## Other resources

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



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