# **Josephine Johnston**

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EDUCATION  Masters of Bioethics and Health Law with Distinction (MBHL)	University of Otago, Dunedin, New Zealand	2002	
Admitted as a Barrister and Solicitor	High Court of New Zealand Wellington, New Zealand	1997	
Bachelor of Laws with Honors (LLB (Hons))	University of Otago	1996	
Bachelor of Arts (BA) in Theatre Studies	University of Otago	1996	
EMPLOYMENT Director of Research The Hastings Center, Garrison, New York, USA		2012 –present	
Lecturer "Law and Bioethics"  Masters of Science in Bioethics program, Columbi	a University, New York, USA	2012 -2014	
Director of Research Operations The Hastings Center, Garrison, New York, USA		2006 -2012	
Research Scholar (former title: Associate for Law The Hastings Center, Garrison, New York, USA	and Bioethics)	2003 –present	
Research Associate  Department of Bioethics, Dalhousie University, Halifax, Canada			
Research Assistant to Prof. Carl Elliott, NIH Grant "Ethnicity, Citizenship, Family: Identity after the Human Genome Project" Center for Bioethics, University of Minnesota, USA			
Lawyer in Banking and Securities team Clifford Chance, Frankfurt, Germany		1999	
Barrister and Solicitor in Commercial Litigation Management teams Chapman Tripp, Wellington, New Zealand	on, Employment and Resource	1997 –1999	

## **FUNDING AWARDS**

Award Title	Funder	Role	Year
Gene Editing and Human Flourishing	John Templeton Foundation	Co-Investigator	2015 -2018
Goals and Practices for Next Generation Prenatal Testing	NHGRI/NIH	Principal Investigator	2015 -2018
Sequencing of Newborn Blood Spot DNA to Improve and Expand Newborn Screening (Nussbaum at UCSF is PI)	NIH	Co- Investigator	2013 -2018
The Bioethics Project	Kent Place School	Principal Investigator	2013 2017
Bioethics Units for i2 Summer Camps	i2 Camps	Principal Investigator	2013 -2014
Center for Research on the Ethical, Legal and Social Implications of Psychiatric, Neurological and Behavioral Genetics (Appelbaum at Columbia is PI)	NHGRI/NIH	Co- Investigator	2013 -2018
Fertility Treatment and Multiple Births: Ethical and Policy Issues on the Path to a Healthy Singleton	March of Dimes	Principal Investigator	2011 -2012
Civil Bioethics In Action: An Interactive Educational Platform for Students, Teachers, Schools and Communities	Private donor	Principal Investigator	2011 -2013
Interpreting Neuroimages: Interdisciplinary Engagement with the Complexities	Dana Foundation	Co-Investigator	2008 -2010
Ethical Issues in Synthetic Biology	Woodrow Wilson International Center	Principal Investigator	2007 -2008
ELSI in Biomedical Nanotechnology	NIH (Director's Office)	Co-Investigator	2007
Pharmacological Treatment of Behavioral Disturbances in Children: Engaging the Controversies	NIMH/NIH	Co-Investigator	2006 -2009
Intellectual Property Rights in Pharmaceuticals and Biological Materials: Ensuring Innovation or Barring Access?	Sasakawa Peace Foundation	Principal Investigator	2004 -2006
Frozen Embryos for Research: A Survey of Canadian IVF Clinics	Associated Medical Services, Inc.	Co-Investigator	2003 -2004
Our Cells/Ourselves: The Ethics of Embryonic Stem Cell Research	The Stem Cell Network	Co-Investigator	2003 -2005
Postdoctoral Fellowship Award	The Stem Cell Network	Principal Investigator	2002 -2003

Capacity Development Program – Research Skills	Nova Scotia Health Research Foundation	Principal Investigator	2002
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#### PROFESSIONAL ACTIVITIES

#### **Awards**

Prestigious Speaker, Royal Society of New Zealand's Prestigious Speakers Series, September 21-29, 2017.

Recipient, 2014 Hope Award for Advocacy from RESOLVE: The National Infertility Association (for research on fertility treatments and multiple births)

Highly commended, British Medical Association Medical Book Awards 2011 for Thomas H Murray and Josephine Johnston (ed.s), *Trust and Integrity in Biomedical Research: The Case of Financial Conflicts of Interest*, Baltimore (MD); Johns Hopkins University Press: 2010.

## **Committee Memberships**

Tri-Institutional Embryonic Stem Cell Research Oversight Committee, 2006-present Weill Medical College of Cornell University, Memorial Sloan-Kettering Cancer Center, and The Rockefeller University

Social and Ethical Issues in Research (SEIR) Review Panel (ad hoc)

National Institute of Health

October 2016

Editorial Committee, Hastings Center Report

2006-2014

#### **PUBLICATIONS**

#### **Books**

Erik Parens and Josephine Johnston (ed.s), *Human Flourishing in an Age of Gene Editing* (under consideration at Oxford University Press).

Thomas H Murray and Josephine Johnston (ed.s), *Trust and Integrity in Biomedical Research: The Case of Financial Conflicts of Interest*, Baltimore (MD); Johns Hopkins University Press: 2010. Highly commended, British Medical Association Medical Book Awards 2011.

#### **Journal Articles**

Josephine Johnston and Rachel Zacharias, "The Future of Reproductive Autonomy" *Hastings Center Report 2017*; 47(): forthcoming.

Louise P. King, Rachel L. Zacharias, and Josephine Johnston, "Autonomy in Tension: Reproduction, Technology, and Justice," *Hastings Center Report 2017*; 47(6): forthcoming.

Josephine Johnston, Ruth M Farrell, and Erik Parens, "Supporting Women's Autonomy in Prenatal Testing, *New England Journal of Medicine* 2017; 377(6):505-7.

Insoo Hyun, Amy Wilkerson and Josephine Johnston, "Revisit the 14-day Rule," *Nature* 2016; 533: 169-171.

Josephine Johnston, "Little People, Big Problems" *Hastings Center Report* 2016; 46(1): inside front cover.

Josephine Johnston, Mohini P. Banerjee and Gail Geller, "Trustworthy Research Institutions: The Challenging Case of Studying the Genetics of Intelligence," *Hastings Center Report* 2015; 45(5): S59-S65.

Josephine Johnston, Michael K. Gusmano, and Pasquale Patrizio, "Reducing Rate of Fertility Multiples Requires Policy Changes," *JAMA Pediatrics* 2015; 169(3): 287.

Josephine Johnston, "Is There Room for Not Knowing 'Everything'?" *Hastings Center Report* 2015; 45(1): inside back cover.

Josephine Johnston, Michael K. Gusmano, and Pasquale Patrizio, "In Search of Real Autonomy for Fertility Patients," *Health Economics, Policy and Law* 2014; 10(3): 243-50.

Josephine Johnston, Michael K. Gusmano, and Pasquale Patrizio, "Preterm Births, Multiples, and Fertility Treatment," *Fertility and Sterility* 2014; 102(1): 36-40.

Josephine Johnston, "The Ghost of the Schizophrenogenic Mother," *AMA Journal of Ethics* 2013; 15:801-805, <a href="http://virtualmentor.ama-assn.org/2013/09/oped1-1309.html">http://virtualmentor.ama-assn.org/2013/09/oped1-1309.html</a>.

Josephine Johnston and Michael K. Gusmano, "Why We Should All Pay for Fertility Treatment," *Hastings Center Report* 2013; 43(2): 18-21.

Amy Wilkerson, Kathaliya Wongsatittham and Josephine Johnston, "The NIH Stem Cell Registry: An Absence of Gamete Donor Consent," *Cell Stem Cell* 2013; 12(2):147-8.

Josephine Johnston, "Normalizing Atypical Genitalia: How a Heated Debate Went Astray," *Hastings Center Report* 2012; 42(6): 32-44.

Erik Parens and Josephine Johnston, "Troubled children: Diagnosing, Treating, and Attending to Context," *Hastings Center Report* 2011; 41(2): S1-S31, http://childpsychiatry.thehastingscenter.org.

Josephine Johnston, "Unify guidelines for reviewing embryonic stem-cell research" (Correspondence), *Nature* 2010; 466 (7303):179.

Erik Parens, Josephine Johnston and Gabrielle A. Carlson, "Pediatric Mental Health Care Dysfunction Disorder?" *New England Journal of Medicine* 2010; 362(20): 1853-1855. Erik Parens, Josephine Johnston and Gabrielle A. Carlson, response to Pies; Hoffman, Rahtz and Wein; Biederman, Wozniak and Faraone (Correspondence), *New England Journal of Medicine* 2010; 363 (12):1188-9.

Erik Parens and Josephine Johnston, "Controversies Concerning the Diagnosis and Treatment of Bipolar Disorder in Children," *Child and Adolescent Psychiatry and Mental Health* 2010; 4:9-23; <a href="www.capmh.com/qc/content/4/1/9">www.capmh.com/qc/content/4/1/9</a>.

Josephine Johnston, "Judging Octomom," *Hastings Center Report* 2009; 39(3): 23-25. Reprinted in David DeGrazia, Thomas A Mappes and Jeffrey Brand-Ballard (ed.s), *Biomedical Ethics*, 7<sup>th</sup> Edition, New York; McGraw-Hill, 2010: 176-8.

Erik Parens and Josephine Johnston, "Facts, Values, and Attention-Deficit Hyperactivity Disorder," *Child and Adolescent Psychiatry and Mental Health* 2009; 3:1; www.capmh.com/content/3/1/1.

Erik Parens, Josephine Johnston, and Jacob Moses, "Do We Need Synthetic Bioethics," *Science* 2008; 321(5895): 1449. Erik Parens, Josephine Johnston and Jacob Moses, response to Boldt and Müller (Letters), *Science* 2009: 323(5912): 339.

Josephine Johnston, "Talking Points," Hastings Center Report 2008; 28(3): i.

Josephine Johnston, "The Ethics of Outsourcing Surrogate Motherhood to India," *The Medscape Journal of Medicine* 2008; 10(3): 52; <a href="http://medgenmed.medscape.com/viewarticle/5698299">http://medgenmed.medscape.com/viewarticle/5698299</a>.

Erik Parens and Josephine Johnston, "Understanding the Agreements and Controversies surrounding Childhood Psychopharmacology," *Child and Adolescent Psychiatry and Mental Health* 2008; 2:5; <a href="www.capmh.com/content/2/1/5">www.capmh.com/content/2/1/5</a>, reprinted in *Focus: The Journal of Lifelong Learning in Psychiatry* 2008; 6(3): 322-330.

Josephine Johnston, "Tied up in Nots Over Genetic Parentage," *Hastings Center Report* 2007; 37(4):28-31.

Erik Parens and Josephine Johnston, "Does it make sense to speak of neuroethics? *EMBO Reports* 2007; 8(Special Issue):S61-S64. Erik Parens and Josephine Johnston, response to Racine (Correspondence), *EMBO Reports* 2008: 9(1): 3–4.

Josephine Johnston, "Health-Related Academic Technology Transfer: Rethinking Patenting and Licensing Practices," *International Journal of Biotechnology* 2007; 9(2):156-171.

Josephine Johnston and Angela Wasunna, "Patents, Biomedical Research, and Treatments: Examining Concerns, Canvassing Solutions," *Hastings Center Report* 2007; 37(1) (Special Report): S1-S36.

Josephine Johnston, "Is research in Canada Limited to "Surplus" Embryos?" *Health Law Review* 2006; 14(3):3-13.

Josephine Johnston, "Paying Egg Donors: Exploring the Arguments," *Hastings Center Report* 2006; 36(1):28-31.

Josephine Johnston, "Stem Cell Protocols: The NAS Guidelines Are a Useful Start," *Hastings Center Report* 2005; 35(5):16-17.

Josephine Johnston, "It's not about the money," Hastings Center Report 2005; 35(2):i.

Josephine Johnston, "ES Cell Research: In the Shadow of the Ban," *Hastings Center Report* 2004; 34(2):48.

Josephine Johnston, "Outing the Conflicted: Et tu NIH?" (Letters), *Science* 2004; 303(5664):1610.

Josephine Johnston and Françoise Baylis, "Two Steps Forward, One Step Back: Inching Towards Gene Therapy," *Canadian Medical Association Journal* 2004; 179(12): 1785-86.

Josephine Johnston and Françoise Baylis, "What Happened to Gene Therapy? A Review of Recent Events," *Clinical Researcher* 2004; 4(1):11-15.

Françoise Baylis, Brenda Beagan, Josephine Johnston, and Natalie Ram, "Cryopreserved Human Embryos in Canada and Their Availability for Research," *Journal of Obstetrics and Gynaecology Canada* 2003; 25(12):1026-31.

Josephine Johnston and Mark Thomas, "Summary: The Science of Genealogy by Genetics, *Developing World Bioethics* 2003; 3(2):103-108.

Josephine Johnston, "Case Study: The Lemba," Developing World Bioethics 2003; 3(2):109-111.

Josephine Johnston, "Resisting a Genetic Identity: The Black Seminoles and Genetics Tests of Ancestry," *Journal of Law, Medicine and Ethics* 2003; 31(2):262-71.

Josephine Johnston and Christopher Eliot, "Chimeras and 'Human Dignity'," *American Journal of Bioethics* 2003; 3(3):6a-8a.

Josephine Johnston, "Just your roots are showing," The Hastings Center Report 2002; 32(6):6.

Josephine Johnston, "Mum's the Word: Donor Anonymity in Assisted Reproduction," *Health Law Review* 2002; 11(1): 51-55.

Josephine Johnston, "New Rules for Embryo Research: The Assisted Human Reproduction Bill and CIHR's Stem Cell Research Guidelines," *Journal of Obstetrics and Gynaecology Canada* 2002; 24(9):722-6.

Josephine Johnston and Carl Elliott, "Ethical and legal aspects of healthy tissue removal: the case of voluntary limb amputations," *Clinical Medicine* 2002; 2(5):431-35.

J M Johnston, "Are Sex Selective Abortions Wrong?" New Zealand Bioethics Journal 2001; 2(1):9-16.

### **Special Issues of Journals**

Louise King, Rachel Zacharias and Josephine Johnston (ed.s), "Just Reproduction: Reimagining Autonomy in Reproductive Medicine," *Hastings Center Report 2017*; 47(6): forthcoming.

Josephine Johnston and Erik Parens (ed.s), "Interpreting Neuroimages: An Introduction to the Technology and Its Limits," *Hastings Center Report* 2014; 44(2): S1-S50.

Erik Parens and Josephine Johnston (ed.s), "Troubled children: Diagnosing, Treating, and Attending to Context," *Hastings Center Report* 2011; 41(2): S1-S31, http://childpsychiatry.thehastingscenter.org.

Josephine Johnston, Angela Wasunna (Guest Editors), "Special Issue: Biomedicine, Patents, and Access," *International Journal of Biotechnology* 2007; 9(2).

Lynette Reid, Josephine Johnston, and Françoise Baylis (Guest Editors), "Special Issue: Stem Cell Research," *Journal of Bioethical Inquiry* 2006; 3(1-2).

Josephine Johnston and Carl Elliott (Guest Editors), "Special Issue: Identity and Genetic Ancestry Tracing," *Developing World Bioethics* 2003; 3(2).

## **Book Chapters**

Josephine Johnston, "'Good Parents'" Can Promote Their Own and Their Children's Flourishing," In Erik Parens and Josephine Johnston (ed.s), *Human Flourishing in an Age of Gene Editing* (under consideration at Oxford University Press).

Josephine Johnston, "Traumatic Responsibility: Victor Frankenstein as Creator and Casualty," In David H. Guston, Ed Finn and Jason Scott Robert (ed.s), *Frankenstein: Annotated for Scientists*, *Engineers, and Creators of All Kinds* (Cambridge MA: MIT Press, 2017) at pp 201-208.

Josephine Johnston, "If Thy Leg Offend Thee, Cut It Off: Surgery, Consent and the Criminal Law," In Mark Henaghan and Jesse Wall (ed.s), *Law, Ethics, and Medicine: Essays in Honor of Peter Skegg* (Wellington (New Zealand): Thomson Reuters New Zealand, 2016) at pp147-169.

Josephine Johnston and Naomi Scheinerman, "Protecting Research, Preserving Trust: The Importance of Managing Industry Relationships in Psychiatric Research," in John Z. Sadler, *Oxford Handbook of Psychiatric Ethics* (London: Oxford University Press, 2015).

Josephine Johnston and Erik Parens, "Neuroethical Issues in the Diagnosis and Treatment of Children with Mood and Behavioral Disturbances" in Jens Clausen and Neil Levy (eds.), *Handbook of Neuroethics* (Heidelberg: Springer, 2014) at pp. 1673-1688.

Josephine Johnston, "Financial Conflicts of Interest in Biomedical Research: Background to the Debate," in Thomas H Murray and Josephine Johnston (ed.s), *Trust and Integrity in Biomedical Research: The Case of Financial Conflicts of Interest* (Baltimore (MD); Johns Hopkins University Press, 2010) at pp. 3-32

Matthew Herder and Josephine Johnston, "Access Concerns and Business Models in Public-Sector Technology Transfer of Genetic Inventions," in E. Richard Gold and Bartha Maria Knoppers (ed.s), *Biotechnology IP & Ethics* (Vancouver: LexisNexis Canada, 2009) at pp. 165-198.

Michael Davis and Josephine Johnston, "Understanding and Managing Conflict of Interest: A Comparative Analysis," Appendix C in Bernard Lo and Marilyn Field (Ed.s) *Conflict of Interest in Medical Research, Education, and Practice* (Washington DC: National Academies Press, 2009) at pp C1-C43.

Paul B Miller and Josephine Johnston, "Consent and Private Liability in Clinical Research," In Oonagh Corrigan, Kathleen Liddell, John McMillan, Martin Richards and Charles Weijer, *The Limits of Consent – A Socio-Legal Approach to Human Subject Research in Medicine* (London: Oxford University Press, 2009) at pp. 39-56.

Josephine Johnston, "U.S. Stem Cell Research Policy: An Introduction," In Anthony Atala, Robert Lanza, James A Thompson, and Robert M Nerem (ed.s), *Principles of Regenerative Medicine* (Burlington (MA): Elsevier, 2008) at pp. 1354-1365; republished in Anthony Atala, Robert Lanza, James A Thompson, and Robert M Nerem (ed.s), *Foundations of Regenerative Medicine* 2009 and revised for second edition of Principles of Regenerative Medicine, 2011: 1131-1143.

Carl Elliott and Josephine Johnston, "The Practice of Bioethics," In Cooper DN (ed.) *Nature Encyclopaedia of the Human Genome* (London: Nature Publishing Group Reference, 2003) at pp. 285-288. [Revised and reprinted September 2009 <a href="http://www.els.net/">http://www.els.net/</a> [Doi: 10.1002/9780470015902.a0005892.pub2]

## Reports

Erik Parens, Josephine Johnston, and Jacob Moses, "Ethical Issues in Synthetic Biology: An Overview of the Debates," a report for the *Foresight and Governance Project at the Woodrow Wilson International Center for Scholars*, Washington DC (2009); www.synbioproject.org/library/publications/archive/synbio3/.

Josephine Johnston, "Reproductive Health: Control and Use of Gametes and Embryos" and "Reproductive Health: Storage and Disposal of Gametes and Embryos," Royal College of

Physicians and Surgeons Bioethics Education Project (2009) at <a href="http://rcpsc.medical.org/bioethics/cases/case\_4\_3\_2\_e.php">http://rcpsc.medical.org/bioethics/cases/case\_4\_3\_2\_e.php</a> and <a href="http://rcpsc.medical.org/bioethics/cases/case\_4\_3\_2\_e.php">http://rcpsc.medical.org/bioethics/cases/case\_4\_3\_2\_e.php</a>.

The Hastings Center [Josephine Johnston, Erik Parens, and Thomas Murray], "ELSI in Bioethical Nanotechnology," a report for the *Office of the Director, National Institutes of Health*, Washington DC July 2007).

Matthew Herder and Josephine Johnston, "Licensing for Knowledge Transfer in Human Genetics Research: A Study of Business Models for Licensing and Technology Transfer in Human Genetics Patents," a report for *Health Canada*, Ottawa, Canada (May 2007).

Josephine Johnston, "National and International Legislation and Declarations Concerning Human Stem Cell Research," a report for *Independent Biotechnology Advisory Council, Ministry of Research, Science and Technology*, Wellington, New Zealand (November 2000).

## Media Articles/Blog Posts

Josephine Johnston, "The Nebulous Ethics of Human Germline Gene Editing," cross-posted January 23, 2017 in *Hastings Bioethics Forum*, <a href="http://www.thehastingscenter.org/nebulous-ethics-human-germline-gene-editing/">http://www.thehastingscenter.org/nebulous-ethics-human-germline-gene-editing/</a> and <a href="https://impactethics.ca/2017/01/23/the-nebulous-ethics-of-human-germline-gene-editing">https://impactethics.ca/2017/01/23/the-nebulous-ethics-of-human-germline-gene-editing</a>.

Josephine Johnston and Eric Trump, "Uterus Transplants Are No Match For The Safety Of Surrogacy," *STAT*, March 7, 2016: <a href="https://www.statnews.com/2016/03/07/uterus-transplants-surrogacy">www.statnews.com/2016/03/07/uterus-transplants-surrogacy</a>.

Josephine Johnston, "Embrace Uncertainty" in "Experts debate: Are we playing with fire when we edit human genes"? *STAT*, November 15, 2015: <a href="https://www.statnews.com/2015/11/17/gene-editing-embryo-crispr">www.statnews.com/2015/11/17/gene-editing-embryo-crispr</a>.

Josephine Johnston, "New Zealand Case and New York Times Magazine Article Draw Attention to Physician Aid in Dying," *Bioethics Forum*, May 26, 2015: www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=7444&blogid=140#ixzz3bppisnhp.

Josephine Johnston and Miriam Zoll, "Is Freezing Your Eggs Dangerous? A Primer," *The New Republic*, November 1, 2014: <a href="http://www.newrepublic.com/article/120077/dangers-and-realities-egg-freezing">http://www.newrepublic.com/article/120077/dangers-and-realities-egg-freezing</a>.

Josephine Johnston, "Prenatal Identification of Increased Risk for Schizophrenia," *Braingenethics*, January 9, 2014: <a href="http://braingenethics.cumc.columbia.edu/prenatal-identification-of-increased-risk-for-schizophrenia/">http://braingenethics.cumc.columbia.edu/prenatal-identification-of-increased-risk-for-schizophrenia/</a>.

Josephine Johnston, "The FDA and 23andMe: Overreaching and overreacting?" *Braingenethics*, December 2, 2014: <a href="http://braingenethics.cumc.columbia.edu/the-fda-and-23andme-overreaching-and-overreacting/">http://braingenethics.cumc.columbia.edu/the-fda-and-23andme-overreaching-and-overreacting/</a>.

Josephine Johnston, "Pitch Perfect," *The Scientist* 2012; 26(1): 24-25: <a href="http://thescientist.com/2012/01/01/pitch-perfect/">http://thescientist.com/2012/01/01/pitch-perfect/</a>.

Erik Parens and Josephine Johnston, "As Tests to Predict Alzheimer's Emerge, So May Debates Over the Right to Die," *TIME*, June 8, 2011: <a href="http://healthland.time.com/2011/06/08/as-tests-better-predict-alzheimers-patients-may-contemplate-their-right-to-die/">http://healthland.time.com/2011/06/08/as-tests-better-predict-alzheimers-patients-may-contemplate-their-right-to-die/</a>.

Josephine Johnston and Erik Parens, "What State Budget Cuts Mean for the Most Troubled Children," *Medicine, Mind and Morals* (a *Psychology Today* blog), March 30, 2011; <a href="http://www.psychologytoday.com/blog/medicine-mind-and-morals/201103/what-state-budget-cuts-mean-the-most-troubled-children">http://www.psychologytoday.com/blog/medicine-mind-and-morals/201103/what-state-budget-cuts-mean-the-most-troubled-children</a>.

Josephine Johnston, "Why I Mostly Love ASB Bank's IVF Ad," *Bioethics Forum*, December 20, 2010; <a href="www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=5032&blogid=140">www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=5032&blogid=140</a>.; republished on *Medicine*, *Mind and Morals* (a *Psychology Today* blog), December 21, 2010: <a href="http://www.psychologytoday.com/blog/medicine-mind-and-morals/201012/why-i-mostly-love-asb-bank-s-ivf-ad">http://www.psychologytoday.com/blog/medicine-mind-and-morals/201012/why-i-mostly-love-asb-bank-s-ivf-ad</a>.

Josephine Johnston, "America's Stem Cell Mess," The Scientist 2010; 24(10): 33.

Josephine Johnston, "The Trouble with Twin Births: Government Limits and Price Controls," *New York Times* Room for Debate, October 11, 2009;

http://roomfordebate.blogs.nytimes.com/2009/10/11/the-trouble-with-twin-births/#josephine.

Josephine Johnston, "At Issue: Should egg and sperm donors be paid? Yes" *CQ Researcher* 2009; 19(19):465.

Josephine Johnston, "The New Stem Cell Policy and Public Opinion," *Bioethics Forum*, March 27, 2009; <a href="https://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=3306">www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=3306</a>.

Josephine Johnston, "Conflict of Interest in Biomedical Research," From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns, October 2008. www.thehastingscenter.org/publications/briefingbook.

Josephine Johnston, "Intellectual Property and Biomedicine," From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns, October 2008. <a href="https://www.thehastingscenter.org/publications/briefingbook">www.thehastingscenter.org/publications/briefingbook</a>.

Erik Parens and Josephine Johnston, "Mental Health in Children and Adolescents," From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns, October 2008.

www.thehastingscenter.org/publications/briefingbook.

Josephine Johnston, "Reprogrammed Skin Cells and Other Monkey Business," *Bioethics Forum*, November 21, 2007; <a href="https://www.bioethicsforum.org/pluripotent-stem-cells-ethical-issues.asp">www.bioethicsforum.org/pluripotent-stem-cells-ethical-issues.asp</a>.

Josephine Johnston, "Struck by Stroke, But Not Stricken," *Bioethics Forum*, October 9, 2007; www.bioethicsforum.org/socialized-medicine-New-Zealand-universal-health-care.asp.

Josephine Johnston, "Patents, Practices and the Progress of Stem Cell Research," *Bioethics Forum*, March 2, 2007; <a href="www.bioethicsforum.org/stem-cell-patents-and-scientific-progress.asp">www.bioethicsforum.org/stem-cell-patents-and-scientific-progress.asp</a>.

Josephine Johnston, "Putting Off Baby," *Bioethics Forum*, December 6, 2006; www.bioethicsforum.org/family-planning-social-policy.asp.

Erik Parens and Josephine Johnston, "Against Hyphenated Ethics," *Bioethics Forum*, September 8, 2006; www.bioethicsforum.org/genethics-neuroethics-nanoethics.asp.

Josephine Johnston, "Dirty, Filthy Love," *Bioethics Forum*, August 30, 2006; www.bioethicsforum.org/20060830jjohnston.asp.

Josephine Johnston, "The Women Behind Cloning," The Washington Post, March 8, 2004, A19.

Josephine Johnston, "Reproduction bill could curb research more than intended," *The Chronicle-Herald* (Halifax), 21 May 2002, B2.

Josephine Johnston, "Amputee Attraction: Devotees and The Amputee World," *inMotion* 2002; May-June: 20-3.

#### **Book Reviews**

Josephine Johnston, "Bioethics and the New Embryology: Springboards for Debate," *Quarterly Review of Biology* 2006; 81(2):160-161.

Josephine Johnston, "The Second Tree: Stem Cells, Clones, Chimeras, and Quests for Immortality," *Quarterly Review of Biology* 2005; 80(1):230-1.

Josephine Johnston, "Stem cell research: New frontiers in science and ethics," *Amyloid* 2005; 12(4): 263.

Josephine Johnston, "When Money Talks and Science Listens," (Review of Marcia Angell's *The Truth About the Drug Companies: How They Deceive Us and What To Do about It* and Sheldon Krimsky's *Science in the Private Interest: Has the Lure of Profits Corrupted Biomedical Research?*), *Hastings Center Report* 2004; 34 (5):44-45.

Josephine Johnston, "Human Cloning and Human Dignity: The Report of the President's Council on Bioethics," *Quarterly Review of Biology* 2003; 78(3):347.

Josephine Johnston, "Better Than Well: American Medicine Meets the American Dream," *Canadian Bioethics Society Newsletter*, August 2003:8.

#### SELECTED PRESENTATIONS

"Human Gene Editing: Is there a parental obligation to create 'better' babies?" World Conference of Science Journalists, San Francisco, October 2017.

"Beyond Safety: Ethical and Policy Issues in Human Gene Editing," *Royal Society of New Zealand*, Wellington, New Zealand, September 2017.

Prestigious speaker in series of four public panels in four New Zealand cities: "Perfectly healthy: Disease-free by technology?" (Dunedin), "Making babies: You, me and gene editing?" (Auckland), "More for all: Nature by design?" (Palmerston North), and "Editing them out: The end for pests?" (Wellington), <a href="https://royalsociety.org.nz/news/discussions-exploring-the-ethics-of-gene-editing-for-new-zealand">https://royalsociety.org.nz/news/discussions-exploring-the-ethics-of-gene-editing-for-new-zealand</a>, convened by *Royal Society of New Zealand*, September 2017.

"Beyond Safety: Ethical Issues in Gene Editing," *Bioethics Centre, University of Otago*, Dunedin, New Zealand, September 2017.

"Beyond Safety: The Place of Values in Gene Editing Policy," *Faculty of Law, University of Otago*, Dunedin, New Zealand, September 2017.

"Childrearing Ability and Fertility Services Ethical and Policy Considerations," *ASRM Ethics Webinar*, July 2017.

"Beyond Safety: Ethics and Policy Debates in Human Gene Editing," *New York City Bar*, June 2017.

"The Importance of Choice About Secondary Results: Opportunities and Challenges for Parents and Prospective Parents," *ELSI Congress*, Farmington, CT, June 2017.

- "Should Every Newborn be Sequenced at Birth? Crafting Policies to Guide Genomic Practice," *ELSI Congress*, Farmington, CT, June 2017.
- "The Bioethics of Stem Cell Research and Therapy," (panelist) *American Museum of Natural History, New York City*, May 2017.
- "No, You Probably Don't Have to Have Your Baby's Genome Sequenced—or Edited!" Association of Health Care Journalists Annual Conference, Orlando, Florida, April 2017.
- "Beyond Safety: Ethics and Policy Debates in Human Gene Editing," Association of Health Care Journalists Annual Conference, Orlando, Florida, April 2017.
- "Sequencing the Stork: Genomics and the "Good Parent," *Biomedical Ethics Unit, McGill University, Montreal, Canada*, April 2017.
- "The Future of Reproductive Autonomy," 2017 Annual Bioethics Conference: The Ethics of "Making Babies," Harvard Medical School, Cambridge, Massachusetts, April 2017.
- "Beyond Safety: Ethical Issues in Human Gene Editing," New York State Task Force on Life and the Law, New York, New York, March 2017.
- "Beyond Safety and Efficacy in Gene Editing: Understanding the Range of Ethical Issues," *AAAS 2017 Annual Meeting, Boston,* February 2017, https://livestream.com/AAASmtg/events/6979998/videos/149659178.
- "Future Tense Event: The Spawn of Frankenstein," (panelist) *New America Foundation, Washington DC*, February 2017.
- "Fixing' the Human Genome: Promises & Pitfalls," *Café Scientifique, Dalhousie University, Halifax, Nova Scotia, Canada,* January 2017.
- "Editing Human Genes: The Ethical Issues," *IFE Transdisciplinary Symposium, Genome Editing: Technical, Social and Ethical Challenges, Queensland University of Technology, Brisbane, Australia,* December 2016.
- "Human Genetic Engineering: What can we do? What should we do?" *The Hastings Center (public lecture)*, October 2016.
- "The Ethical Implications of Prenatal Whole Genome Sequencing?" *American Society for Bioethics and Humanities Annual Meeting*, Washington DC, October 2016.
- "What is Acceptable Innovation in Reproductive Medicine? The Case of Uterus transplants," *American Society for Bioethics and Humanities Annual Meeting*, Washington DC, October 2016.
- "Human Gene Editing: What are the Moral and Ethical Considerations?" *Program for Biomedical Evening Ethics Seminar Series, Yale School of Medicine, New Haven, CT*, September, 2016.
- Panelist in: "Splicing and Dicing DNA: Genome Engineering and the CRISPR Revolution," World Science Festival, New York, NY, June 2016.
- "Sequencing the Stork: Genetic Testing and the Good Parent," *Reproductive Ethics Conference*, *Albany Medical College*, *Albany NY*, *April 2016*.

- "Reducing Rates of Fertility Multiples: 6 Suggestions for Policy and Practice," *Prematurity Prevention Conference, Washington DC, November 2015.*
- "Sequencing Healthy Newborns: Critical Reflections on the Intersection of Genomics, Pediatrics, and Public Health" (Panel on Newborn Sequencing), *American Society for Bioethics and Humanities Annual Meeting*, Houston, TX, October 2015.
- "Social" Egg Freezing: Why is it that when you've got an IVF lab every problem looks like a women's body?" (Panel on Egg Freezing), *American Society for Bioethics and Humanities Annual Meeting*, Houston, TX, October 2015.
- "Reducing Rates of Fertility Multiples: 6 Suggestions for Policy and Practice" (Panel on multiple births following fertility treatment), *American Society for Reproductive Medicine Annual Meeting*, *Baltimore MD*, *October 2015*.
- "Sequencing Newborns: Ethical and Policy Considerations," *Perinatal Society of New Zealand Annual Meeting, Dunedin, New Zealand, July 3, 2015.*
- "The Ethical Challenges of Next-Generation Prenatal Testing," *Perinatal Society of New Zealand Ethics Symposium, Dunedin, New Zealand, July 2, 2015.*
- "Sequencing the Stork: How Genetic Testing is Changing Conception, Pregnancy and Parenting," *Temple University 2015 Ethics Symposium, Philadelphia, April 22, 2015.*
- "The Bioethics Project How a Research Program for High School Students Uses Bioethics to Build 21<sup>st</sup> Century Skills," *American Society for Bioethics and Humanities Annual Meeting, San Diego, October 2014.*
- "The Ethical Challenges of Next-Generation Prenatal Testing," *Occidental College, Los Angeles, USA, October 2014*.
- "The Ethical Challenges of Next-Generation Prenatal Testing," *University of Otago, Dunedin, New Zealand, July 2014.*
- "Making Difficult Decisions about the Beginning of Life: Continuing and Emerging Challenges in Technological Societies," CUHK Centre for Bioethics First Annual Summer Workshop, Chinese University of Hong Kong, Hong Kong, July 2014.
- "Bioethics," for Trailblazers in Science & Medicine panel at *Insight, Innovation, Impact: A Summit for Women, Times Center, New York City, November 2013.*
- "Towards Autonomy without Abandonment: Multiple Births and Fertility Treatment," *American Society for Bioethics and Humanities Annual Meeting*, Washington DC, October 2012.
- "Trust and Integrity in Biomedical Research: The Case of Financial Conflicts of Interest," *University of Texas Southwestern, February 2012.*
- "Psychiatric Medications for Children: Understanding the Debate" (Ethics Grand Rounds; Pediatrics Grand Rounds), *University of Texas Southwestern, February 2012*.
- "Psychiatric Medications for Children: Understanding the Debate" (Ethics Grand Rounds), *University of North Texas Health Science Center, February 2012*
- "Trust and Financial Conflicts of Interest: An Update, and A Question." *Mount Sinai School of Medicine, New York, December 2011.*

"Putting Off Baby: Reframing the Discussion about Delayed Childbearing," for panel titled "Mundane Reproductive Ethics: Beyond the Sensational Lie Everyday Ethical Problems in Abortion, IVF, Pregnancy Planning and Birth." *American Society for Bioethics and Humanities Annual Meeting, Minneapolis, October 2011.* 

Panel member: "Welche Wünsche weckt die Technisierung der Fortpflanzung?" "Eltern als Kunden –Ökonomisierung der Reproduktionsmedizin?" "Warum ist die Eizellspende bei uns verboten und in den USA erlaubt?" Wunschkinder: Die Technisierung der Menschlichen Fortpflanzung, Freiburg Theatre/University of Freiburg, Freiburg, Germany, May 20-22, 2011.

- "Do Appearances Matter? Trust and Financial Conflicts of Interest," New York Medical College, Valhalla, New York, April 14, 2011.
- "Neuroscience and Society: The Case of Criminal Responsibility," *Center for Ethics in Public Life, University of Michigan, December 7, 2010.*
- "Human Embryonic Stem Cell Research," Weil Cornell Medical College, November 10, 2010.
- "Neuroscience and Society: The Case of Criminal Responsibility," *University of Michigan, Ann Arbor, December 7, 2010.*
- "Neuroethics of Pediatric Bipolar Disorder: Phantoms in the Debate," *Neuroethics Society First Annual Meeting, Washington DC, November 2008.*
- "Trust and Financial Interests in Medical Research and Practice," *Jack Orr Memorial Lecture, Danbury Hospital, September 2008.*
- "Beyond Frankenstein: Guiding Genetic Engineering Companies to Money, Regulatory Approval and Public Acceptance," Section of Science and Technology, American Bar Association Annual Meeting, New York City, August 2008.
- "Societal Dimensions of Nanotechnology: A Comparative Analysis and Critique," *American Society for Bioethics and Humanities Annual Meeting, Washington DC, October 2007.*
- "Societal Dimensions of Nanotechnology: A Comparative Analysis and Critique," *Converging Science and Technologies: Research Trajectories and Institutional Settings, Austrian Research Promotion Agency, Vienna, Austria, May 2007.*
- "Compensation for Egg Donation," American Fertility Association meeting, New York City, April 2007.
- "The Case of Patents" in Symposium "Biotechnology and Human Rights: Industry's Responsibility?" *Keck Graduate Institute of Applied Life Sciences, April 2007.*
- "Ethical Issues and Genetic Ancestry Testing" Family Tree DNA Annual Conference, Houston, November 2006.
- "Patents, Biomedical Research, and Treatments: Debates Over Innovation and Access." *Theory-Practice Seminar, Brooklyn Law School, October 2006.*
- "Lawyers, Drugs and Money: the role of academic institutions in biomedical innovation and access," *Interrogating Boundaries Seminar Series, Fairleigh Dickinson University, October* 2006.
- "What's in a Face? Issues of Self and Identity in Facial Reconstruction," (response to the *Saving Faces* exhibition), *The College of Physicians of Philadelphia, September 2006*

"Everything is Connected: Ethical, Legal and Policy Debates in Stem Cell Research." *American University, Washington DC, April 2006.* 

Commentator: "Cornell Young Scholar Conference." Cornell University, Ithaca, April 2006.

Presenter and panel member, "2006 Ethics Symposium," *University of Mississippi Medical Center, March 2006.* 

- "Bioethics for Technology Transfer Managers," Association of University Technology Managers Annual Meeting, Orlando, March 2006.
- "Embryonic Stem Cells, Cloning, and Beyond: Challenges of Regulating Innovations at the Convergence of Genetics and Reproduction," *Connecticut College, New London, November* 2005.
- "The \$800 Million Pill: Why drugs cost so much and why price is an ethical issue," *Center for Religious Inquiry, St Bartholomew's Church, Manhattan, March 2005*
- "Integrity and Incentive in Biomedical Research: Management of Financial Conflicts of Interest in the USA," 7th World Congress of Bioethics, Sydney, Australia, November 2004.
- "Ethical Issues in the Management of Financial Conflicts of Interest in Biomedical Research," *Ethics Week, Baruch College, March, 2004.*
- "Fertility Clinics as Sources of Research Materials: Issues of Policy, Practice, and Procedure," *American Society for Bioethics and Humanities Annual Meeting, Philadelphia, October 2004.*
- "Response to Glenn McGee's Beyond Genetics," The Episcopal Diocese of Newark John E Hines Lecture on Science and Technology, Rutgers Law School, Newark, New Jersey, November 2003.
- "Frozen Embryos for Research: Results of a Survey of Canadian IVF Clinics," *Stem Cell Network Annual General Meeting, Vancouver, Canada, September 2003.*
- "If Thy Leg Offend Thee, Cut It Off: Surgery, Consent, and the Criminal Law," *Health Law Institute Seminar Series, Faculty of Law, Dalhousie University, Halifax, Canada, December* 2002.
- "Creating Alternative Families Hindrance or Assistance? A Review of Bill C-13, the Assisted Human Reproduction Act," *Canadian Bar Association, Nova Scotia Branch Meeting, Halifax, Canada, November* 2002.
- "Resisting a Genetic Identity: The Black Seminoles of Oklahoma and Genetic Tests of Ancestry," *American Society for Bioethics and Humanities Annual Meeting, Baltimore, October* 2002.
- "Convenient Distinctions: Stem cell research, policy and the sources of human embryos," *Canadian Bioethics Society Annual Conference, Victoria, Canada, October 2002.*
- "Genealogy by Genetics: Ancestry, Anthropology and the Emergence of Genetic Identities," *Canadian Bioethics Society Annual Conference, Victoria, Canada, October* 2002.
- "If thy leg offend thee, cut it off: A healthy limb amputation as an exercise of personal liberty and as treatment of a mental disorder," *Canadian Bioethics Society Annual Conference*, *Winnipeg, Canada, October 2001*