#### Kayte Spector-Bagdady Assistant Professor, Department of Obstetrics and Gynecology Chief, Research Ethics Service, Center for Bioethics & Social Sciences

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# **Education and Training**

## Education

09/2000-05/2004	BA, magna cum laude, History and Theater, Middlebury College, Middlebury, VT
01/2003-06/2003	Study abroad, Oxford University, St. Catherine's College, Oxford, United Kingdom
08/2006-05/2009	JD, Law, University of Pennsylvania School of Law, Philadelphia, PA
08/2007-05/2009	MBE, Bioethics, University of Pennsylvania School of Medicine, Philadelphia, PA

#### PostDoctoral Training

09/2015-10/2016	Postdoctoral Research Fellow, Bioethics, University of Michigan Center for Bioethics &
	Social Sciences in Medicine, Ann Arbor, MI

### Additional Education

05/2007-07/2007	Health Policy Legal Intern, Health Care for All, Boston, MA
01/2008-05/2008	JD, Clinical coursework: Interdisciplinary Child Advocacy Clinic, University of Pennsylvania Law School and the Children's Hospital of Philadelphia, Philadelphia, PA
09/2008-12/2008	JD, Clerkship: Hospital of the University of Pennsylvania, Office of General Counsel, Philadelphia, PA

## **Certification And Licensure**

#### Certification

2010-2016	New York State Bar - Law license #4769204
2010-2018	District of Columbia Bar - Law license #997285
2017-present	Michigan State Bar - Law License #P81976

### Academic, Administrative, Clinical and Military Appointments

#### Academic Appointments

09/2015-10/2016	Postdoctoral Research Fellow, University of Michigan Medical School, Ann Arbor, MI
11/2016-07/2017	Research Investigator in Obstetrics and Gynecology, University of Michigan, Ann Arbor, Michigan
08/2017-present	Assistant Professor of Obstetrics and Gynecology, University of Michigan Medical School, Ann Arbor, MI

#### Administrative Appointments

06/2004-05/2006	Corporate Legal Assistant, Mergers & Aquisitions, Cravath, Swaine & Moore LLP, New York, NY
09/2006-05/2009	Member/Co-Director/Managing Director, Penn Law Reproductive Rights Law Project, Philadelphia, PA
05/2008-07/2008	Summer Associate, Food and Drug Law, Hunton & Williams LLP, Washington, DC
09/2009-09/2010	Associate, Food and Drug Law, Hunton & Williams LLP, Washington, DC
09/2010-12/2011	Research Analyst, Presidential Commission for the Study of Bioethical Issues, US Dept. of Health and Human Services, Washington, DC
01/2012-07/2015	Associate Director, Presidential Commission for the Study of Bioethical Issues, US Dept. of Health and Human Services, Washington, DC

#### Gaps

05/2006-08/2006 Studied for law school and volunteered at camp for children with HIV/AIDS 07/2015-09/2015 Maternity leave

## Research Interests

- Genetic testing: Direct to consumer, carrier screening, informed consent, regulatory/liability concerns
- Informed consent to emerging OB/GYN technologies
- Research ethics: regulatory, historical, STD protocols

## Grants

#### **Current Grants**

The Ethics of Electronic Fetal Monitoring: The Intersection of Ethics, Law, and Everyday Medical Practice Greenwall Foundation- 18-PAF05755 Co-I with Effort (Principal Investigator: De Vries, Raymond G) 07/2018-06/2020. \$230,531 (\$107,011)

KL2: Assessing Prenatal Patient Expectations, Understanding, and Response to Expanded Carrier Screening MICHR- 00 Spector-Bagdady, K, PI 03/2018-02/2020. \$85,000 (\$42,500)

*1 R01 CA214829-01A1: The Lifecycle of Health Data: Polices and Practices* NIH-DHHS-US- 17-PAF05133 Co-I with Effort (Principal Investigator: Kardia, Sharon Reilly) 02/2018-01/2022. \$2,446,187

5 UL1 TR002240-05: Michigan Institute for Clinical and Health Research (MICHR) NIH-DHHS-US- 16-PAF04360 Co-I with Effort (Principal Investigator: Mashour, George A) 06/2017-02/2022. \$48,220,260 (\$9,644,052)

*N022893: Towards Evidence-Based Public Intellectual Life* Foundation Other (Principal Investigator: Harris, Lisa) 01/2017-12/2019. \$1,227,358

#### Submitted Grants

Genetic data partnerships: Enabling equitable access within academic/private data sharing agreements NIH-DHHS-US- 18-PAF06648 Spector-Bagdady, Kayte, PI 04/2019-03/2024. \$909,510

Making Data-driven Clinical Knowledge Nationally Scalable and Useful at the Point of Care OS-DHHS-US- 19-PAF00401 Co-I with Effort (Principal Investigator: Friedman, Charles P) 09/2018-09/2020. \$999,481

#### Past Grants

*Pilot Study:Evolution of Parental Values in Decision-Making for Critically III Infants* Dept. of Pediatrics Co-I (Principal Investigator: Kukora S) 09/2017-08/2018. \$6,372 (\$6,372)

*Understanding Disparities in Ethics Consultation* University of Michigan, Pediatric Health Disparities Award Other (Principal Investigator: Moseley, Kathryn) 01/2015-12/2016. \$20,000

## **Honors and Awards**

International	
2015	Keynote Speaker for the International Association of Clinical Research Nurses' annual conference
2016	Invited participant to Brocher Foundation in Geneva, Switzerland, Frankenstein's Shadow: A Bicentennial Assessment of the Frankenstein Narrative's Influence
2018	Invited speaker at the University of Maastricht: "Establishing an interdisciplinary research ethics consultation service in a large academic institution"
National	
2004	"The Precious Few," winner, Kennedy Center American College Theater Festival "One- Act" Play, Washington, DC
2011	Department of Health and Human Services Assistant Secretary for Health's Award for Outstanding Team Performance, for "exemplary service and commitment to delivering a full, independent accounting, within nine months, of historical research events in Guatemala from 1946-1948 as requested by the President of the United States," team member recipient, Office of the Assistant Secretary for Health, U.S. Department of Health and Human Services, Washington, DC
2012	Plenary Speaker for the Office of Research Integrity, US Dept. of Health & Human Services' annual Conference on Research Integrity
2012	Plenary Speaker for the The Science in Society Conference's annual meeting
2016	Recognition of Service, for "remarkable efforts on the Bioethics Commission's behalf to ensure comprehensive and nuanced assessments of important and challenging topics," Presidential Commission for the Study of Bioethical Issues, Office of the Assistant Secretary of Health, US Dept. of Health and Human Services, Washington, DC
2018	Invited speaker to the Risk Communication Advisory Committee (U.S. Food & Drug Administration) regarding the updated pregnancy and lactation medication labeling regulations
Regional	
2001	"next to you me her," honorable mention, Kennedy Center American College Theater Festival Region I "10-minute" Play, Washington, DC
Institutional	
2000-2004	College Scholar Award (Dean's List), Middlebury College, Middlebury, VT
2001	"next to you me her," honorable mention, Alison Fraker Prize for writing, Middlebury College, Middlebury, VT
2006-2009	Dean's Merit Scholarship, University of Pennsylvania Law School, Philadelphia, PA
2007	Equal Justice Foundation Grant Awardee, University of Pennsylvania Law School, Philadelphia, PA
2009	Outstanding Public Service Award, Toll Public Interest Center, University of Pennsylvania Law School, Philadelphia, PA
2016	Outstanding Postdoctoral Fellow Award, University of Michigan, Ann Arbor, MI
Memberships in	n Professional Societies

2012-present	Member, American Society for Bioethics and Humanities
2012-present	Member, Legal Advocates for Birth Options and Rights (LABOR)
2016-present	Junior Fellow, Society for Family Planning
2016	Member, Institute for Healthcare Policy and Innovation, University of Michigan

# Editorial Positions, Boards, and Peer-Review Service

Journal Reviewer	
2014-2018	Journal of Bioethical Inquiry (Ad Hoc)
2014-2018	Journal of Law and the Biosciences (Ad Hoc)
2016-2018	American Society of Bioethics and Humanities, Annual Meeting, Law & Research Ethics abstract reviewer (Ad Hoc)
2016	Health Affairs (Ad Hoc)
2016	Yale Journal of Health Policy, Law, and Ethics (Ad Hoc)
2017	Annals of Women's Health (Ad Hoc)
2017	Onterio Genomics, 2017 Large-Scale Applied Research Project competition in Genomics and Precision Health (Ad Hoc)
2017	Pharmacogenomics and Personalized Medicine (Ad Hoc)
2017	The Milbank Quarterly (Ad Hoc)
2018	New England Journal of Medicine (Ad Hoc)

# **Teaching Activity**

# National

2013	"Advancing Bioethics Education," Presidential Commission for the Study of Bioethical Issues Webinar Series
2013	"What about Privacy and Progress in Whole Genome Sequencing?," Genetics Alliance Webinar series
Institutional	
2012	Guest Lecturer: "An Introduction to Bioethics: Ethics and Public Sentiment," Industry Studies: Biotechnology, Industrial College of the Armed Forces
2013	Guest Lecturer: "Genomics: Privacy, Progress, and Reproduction;" Industry Studies: Biotechnology, Industrial College of the Armed Forces
2013	Guest Lecturer: "Investigating Past Maleficence and Contemporary Reflections," Seminar in Health Law: The PHS Guatemala STD Studies 1946-1948, Georgia State University, College of Law
2013	Guest Lecturer: "Ethics, Policy and Emerging Biotechnologies: a Case Study of Direct-to- Consumer Genetic Testing," Ethics, Policy, and Emerging Biomedical Technologies, Berman Institute of Bioethics, Johns Hopkins University
2014	Guest Lecturer: "Genetic Testing: Law, Policy & Ethics," Genetics, Stevenson University, School of the Sciences
2014	Guest Lecturer: "Ethically Impossible:' Staff Empirical Research into the Guatemala STD Experiment Archives," History of Bioethics, University of Pennsylvania, Perleman School of Medicine
2015-present	"M1 Ethics Small Group Sessions," University of Michigan Medical School
2016	Guest Lecturer: "The Physician as Gatekeeper," Philosophy of Medicine, University of Michigan, College of Literature, Science, and the Arts
2016-2017	"Research Ethics," Independent Study, University of Michigan School of Public Health
2016-present	Guest Lecturer: "Genetic Discrimination," Genetics, Health Behavior & Health Education, University of Michigan, School of Public Health
2016-present	M4 Ethics Essay Seminar
2016-present	Guest Lecturer: "History of Bioethics," Sociology of Bioethics, University of Michigan, School of Arts and Sciences
2016-present	"Informed Consent for Study Coordinators," Michigan Institute for Clinical & Health Research, University of Michigan
2017	Guest Lecturer: "Screening for Parenthood," Health Law Seminar, University of Michigan, School of Law

2017-present	"Responsible Conduct of Research for K Grant Awardees," Michigan Institute for Clinical & Health Research, University of Michigan
2017-present	HMP 540: Legal Rules and Ethical Issues for Clinical Research; On-Job/On-Campus Master's in Clinical Research Design and Statistical Analysis
2017-present	Guest Lecturer: "Genetics and the Law," Advanced Concepts in Medical Genetics, University of Michigan Genetic Counseling Program
2018	Guest Lecturer: "The Guatemala STD Experiments: A Case Study in Government Policy and Apology," Bioethics from D.C. to Philly, Lewis Katz School of Medicine,Temple University
2018	Medical Ethics and Informed Consent, OBGYN Residency Preparatory Course

### **Committee and Administrative Services**

#### **Committee Services**

#### National

2015-2017	Informed Consent and Governance Workgroup, Clinical Sequencing Exploratory Research (CSER) Consortium, Member
2018-2021	American Society of Bioethics & Humanities, Board of Directors, Director at Large
2018	Clinical Research Ethics Consultation Collaborative, Member
2018	Clinical Research Ethics Consultation Collaborative: Subcommittee on Consultation Competency, Member
Regional	
2011	Ethics Committee, Medstar Washington Hospital Center, Community Member
Institutional	
2015-present	Pediatric Ethics Committee, C.S. Mott Children's Hospital, University of Michigan Health System, Member
2016-present	Adult Ethics Committee, University of Michigan Health System, Member
2016-present	Ethical, Legal, and Social Implications of Learning Health Systems Steering Committee, University of Michigan, Co-Chair
2016-present	IRB Council, University of Michigan Health System, Member
2016-present	Research Ethics Service, Center for Bioethics & Social Sciences in Medicine, University of Michigan Medical School, Chief
2017-present	Health Systems Science Curriculum Committee, Member
2017-present	U-M Ad Hoc Committee on Disclosure of Individual Research Results, Member
2018-present	Data Release Committee, Member
2018-present	Early Career Faculty Advisory Council, Institute for Health Policy & Innovation, Member
2018-present	Research Ethics Committee, Chair
2018	Task Force on Pelvic Exams Under Anesthesia, Chair

## **Administrative Services**

# Volunteer

2017	Judge, Michigan High School Ethics Bowl, Ann Arbor, MI, Judge for annual Michigan High School Ethics Bowl
2018	Hosted community forum on research ethics after film, State Theater, Ann Arbor, MI, Three Identical Strangers

# Visiting Professorships and Extramural Invited Presentations

#### Visiting Professorships

- 04/2014
  - Research Ethics Series, Rock Ethics Institute, Penn State University, April 2014, College Park, PA

- 03/2015 "'Ethically Impossible:' Scientific and Ethical Violations of the Guatemala STD Experiments", Duke University, March 2015, Durham, NC
- 04/2018 "Justice and the Privatization of Health Data" (OBGYN Grand Rounds and Law School talk), University of Iowa College of Law and Carver College of Medicine, April 2018, Iowa City, IA
- 09/2018 The Google of Healthcare: Making Big Data Work for-As Opposed to Against-Our Patients' Best Interest, University of Central Florida, September 2018, Orlando, FL

#### **Extramural Invited Presentations**

- 1. **Plenary Speaker**: "Ethically Impossible:' Research Integrity in the Guatemala STD Experiments", ORI Conference on Research Integrity, Georgetown University, March 2012, Washington, DC
- 2. **Plenary Speaker**: "Ethically Impossible:' A Case Study for Ethics Education and Scholars", The Science in Society Conference, University of California, November 2012, Berkley, CA
- "A Response to the Report on Privacy and Progress in Whole Genome Sequencing", An Education for Public Inquiry and International Citizenship "Pugwash" Professional Workshop, February 2013, Tufts University
- 4. "Motherhood at Work: Break Time for Nursing Mothers under the Affordable Care Act", The Ethics of Fertility and Reproduction: Fresh Looks, March 2013, University of Pennsylvania Law School
- 5. "Motherhood at Work: Benefits and Limits for Nursing Mothers under the Affordable Care Act", Reproductive Affinity Group, American Society for Bioethics and Humanities, October 2013, Atlanta, GA
- 6. **Keynote Speaker**: "Why We've Always Needed Ethics: Grants, Research, and the Law", International Association of Clinical Research Nurses annual conference, October 2015, Baltimore, MD
- 7. "What We Have Already, and Have Still to Learn, from Historical Unethical Research", Michigan State University, Center for Ethics and Humanities in the Life Sciences, November 2015, East Lansing, MI
- 8. "Direct-to-Consumer Healthcare: 'Disrupting' Consent", Michigan State University: Bioethics for Breakfast, December 2015, East Lansing, MI
- 9. "The NPRM-Key Issues for Social, Behavioral, and Educational Research: Scoping Human Subjects Research Protections", Michigan Research Ethics Conference, Michigan State University, April 2016, East Lansing, MI
- 10. "Revising Human Subjects Research Ethics: Where we've been and where we need to go", Michigan Research Ethics Conference, Michigan State University, April 2016, East Lansing, MI
- 11. "Frankenstein's Shadow in Contemporary Bioethics and Health Policy Debates", Frankenstein's Shadow: A Bicentennial Assessment of the Frankenstein Narrative's Influence, Brocher Foundation, June 2016, Geneva, Switzerland
- 12. **Spector-Bagdady K**, Lynch HF, Brenner JC, Shuman A: "Biospecimens and Research Consent: Unique Issues for Cell Line Research", Department of Bioethics, National Institutes of Health, U.S. Department of Health and Human Services, October 2017, Bethesda, MD
- 13. Biospecimens and Research Consent: Unique Issues for Cell Line Research, U.S. National Institutes of Health, Department of Bioethics, October 2017, Washington, DC
- 14. "Establishing an interdisciplinary research ethics consultation service in a large academic institution", University of Maastricht, June 2018, Maastricht, the Netherlands

#### Other

- Accepted Presentation: Spector-Bagdady K, Groman M, Bonham V: "Staff Report from the Presidential Commission for the Study of Bioethical Issues", Public Responsibility in Medicine and Research (PRIM&R), December 2011, National Harbor, MD
- 2. Accepted Presentation: **Spector-Bagdady K**, Lombardo PA: "The View from the Archives: Recovering the PHS/Guatemala Story from Record Sources", American Society for Law, Medicine, and Ethics' Health Law Professors Conference, Arizona State University, June 2012, Tempe, AZ
- Accepted Presentation: Spector-Bagdady K, Schwartz J, Lombardo PA, Lee LM: "Responsible Stewardship: The Role of National Commissions in Shaping the Public Discourse of Bioethics", American Society for Bioethics and Humanities Annual Meeting, October 2012, Washington, DC
- 4. Accepted Presentation: **Spector-Bagdady K**, Pike E: "Device-ive Maneuvers: FDA Regulation of the Bifurcation of Direct-to-Consumer Genomic Data and Information", The Food and Drug Administration in the 21st Century, Harvard Law School, May 2013, Boston, MA

- 5. Accepted Presentation: **Spector-Bagdady K**, Lombardo PA: "Something of an Adventure:' Postwar NIH Research Ethos and the Guatemala STD Experiments", American Society for Bioethics and Humanities Annual Meeting, October 2013, Atlanta, GA
- 6. Accepted Presentation: "Whole Genome Sequencing Protections: From a Property to Privacy Legal Paradigm", American Society for Bioethics and Humanities Annual Meeting, October 2013, Atlanta, GA
- Accepted Presentation: Pike E, Spector-Bagdady K: "Enabling Privacy and Progress: Protecting Individual Participants in Big Data", American Public Health Association Annual Meeting & Exposition, November 2013, Boston, MA
- 8. Invited Speaker: "Privacy and Progress in Human Genome Research: Protecting Open-Data Sharing and the Participants that Enable It", International Working Group, Department of Health and Human Services, April 2014, Washington, DC
- 9. Invited Workshop Participant: "Inter-American Bioethics Collaborations: Prospects and Challenges", Pan American Health Organization, May 2014, Washington, DC
- 10. Accepted Presentation: **Spector-Bagdady K**, Pike E: "Consuming Genomics: Regulating Direct-to-Consumer Genetic and Genomic Information", American Society for Law, Medicine & Ethics: Health Law Professors Conference, University of California Hastings College of the Law, June 2014, San Francisco, CA
- 11. Accepted Presentation: "Reconceptualizing Consent for Direct-to-Consumer Medical Services", American Society for Bioethics and Humanities Annual Meeting, October 2014, San Diego, CA
- 12. Accepted Presentation: **Spector-Bagdady K**: "Reconceptualizing Consent for Direct-to-Consumer Medical Services", American Society for Law, Medicine & Ethics: Health Law Professors Conference, St. Louis University School of Law, June 2015, St. Louis, MO
- 13. Accepted Presentation: Hakkarinen M, Groman M, **Spector-Bagdady K**: "Public Bioethics in the New Millennium: Creatively Communicating the Work of the Presidential Bioethics Commission", American Society of Bioethics and Humanities Annual Meeting, October 2015, Houston, TX
- 14. Invited Presentation: "Motherhood at Work: Benefits and Limits for Nursing Mothers under the Affordable Care Act", American Society of Bioethics and the Humanities: Reproductive Affinity Group, October 2015, Houston, TX
- 15. Invited Speaker: "From the Guatemala STD Experiments to the NPRM for Revisions to the Common Rule: Why We Still Don't Have Human Subjects Research Ethics Right", Center for Bioethics and Social Sciences in Medicine Seminar Series, University of Michigan, December 2015, Ann Arbor, MI
- 16. Invited Speaker: "History of Bioethics", Medical Ethics and Social Stress Rounds, Department of Neonatology, University of Michigan Health System, March 2016, Ann Arbor, MI
- 17. Invited Speaker: "Expanding Your Horizons: Public Speaking Skills and Practice", Center for Bioethics and Social Sciences in Medicine, University of Michigan, March 2016, Ann Arbor, MI
- 18. Accepted Presentation: "The Google of Personalized Healthcare: 23andMe and Enabling the Privatization of Genetic Biobanking", Western Michigan University, March 2016, Kalamazoo, MI
- 19. Accepted Presentation: "Direct-to-Consumer Biobanking", Center for Bioethics & Social Sciences in Medicine Research Colloquium, April 2016, Ann Arbor, MI
- 20. Bioethics Grand Rounds: "The 'Responsible Investigator:' US-sponsored STD Exposure Experiments in Guatemala", University of Michigan Medical School, May 2016, Ann Arbor, MI
- 21. Invited Speaker: "Research Ethics, Education, and the Role of the Clinical Research Nurse", University of Michigan, June 2016, Ann Arbor, MI
- 22. Accepted Presentation: "State of the Data: Assessing the Appropriate Legal and Ethical Divide between Biospecimens and Derived Data", American Society for Law, Medicine & Ethics Health Law Professors Conference, Boston University, June 2016, Boston, MA
- 23. Accepted Presentation: Hauschildt K, Firn J, Laventhal N, **Spector-Bagdady K**: "Unintended Consequences of Clinical Ethics Consultation: Self-Reflection in the Age of Professionalization", American Society of Bioethics & Humanities Annual Meeting, October 2016, Washington, DC
- 24. Accepted Presentation: "Public Versus Private Biobanks-What's the NPRM Got to Do With It?", American Society of Bioethics & Humanities Annual Meeting, October 2016, Washington, DC
- 25. Invited abstract: "Stemming the Standard of Care Sprawl: The Ethics of Liability and Clinician Self-Interest and the Case of Electronic Fetal Monitoring", Regulatory Innovation in the Biosciences Workshop, University of Michigan Law School, May 2017, Ann Arbor, MI

- 26. Accepted presentation: Prince A, Cook-Deegan R, Evans J, **Spector-Bagdady K**: "An 'Omics' Update: Effects of Next-Generation Sequencing on Genetic Testing Law & Policy", Genomics and Society, UConn, June 2017, Farmington, CT
- 27. Accepted presentation: "Genetic Counseling, Liability, and the Precision Medicine Era", American Society of Law, Medicine & Ethics' Health Law Professors' Conference, Georgia State University, June 2017, Atlanta, GA
- 28. Accepted Presentation: "Dignitary Harms and the Privatization of Data" (https://www.youtube.com/watch? v=hayKGOjG-TA), "Data Privacy and the Digital Age" Symposium, Office of the Chief Information Office, U.S. Department of Health & Human Services, October 2017, Washington, DC
- 29. Accepted Presentation: **Spector-Bagdady K**, Lombardo PA: "From Bodies to Biospecimens: How the Guatemala STD Experiments Continued in Paraffin", American Society of Bioethics & Humanities annual conference, October 2017, Kansas City, MO
- 30. **Grand Rounds**: The Google of Healthcare: Making Big Data Work for, As Opposed to Against, Our Patients' Best Interests, University of Michigan Medical School, OBGYN, November 2017, Ann Arbor, MI
- 31. Intramural Invited Presentation: "The Google of Healthcare: Making Big Data Work for-As Opposed to Against-Our Patients' Best Interest", Emergent Research Series at the University Library, March 2018, Ann Arbor, MI
- Accepted Abstract: De Vries R, Harris LH, Low LK, Spector-Bagdady K "Embracing the Electronic Fetal Monitor: The Treacherous Pursuit of Certainty in the Uncertain World of Birth", American Society of Bioethics & Humanities, October 2018, Anaheim, CA
- 33. Accepted abstract: Platt J, De Vries R, Gornick M, Shuman AG, Kardia S, **Spector-Bagdady K** "Ethics of Big Data and Biobanking", American Public Health Association, November 2018, San Diego, CA

## Bibliography

## **Peer-Reviewed Journals and Publications**

- 1. **Spector-Bagdady K**, Lombardo PA: "Something of an adventure:' Postwar NIH research ethos and the Guatemala STD experiments" *Journal of Law, Medicine and Ethics* 41(3): 697-710, 2013. PM24088161
- 2. Meagher K, **Spector-Bagdady K**: "Present Lessons from Past Infractions: STD Research in Guatemala in the 1940s as an Ethics Case Study" *Teaching Ethics: Journal of the Society for Ethics Across the Curriculum* 53(14): 53-76, 2014.
- 3. **Spector-Bagdady K**: "Reconceptualizing consent for direct-to-consumer health services" *American Journal of Law and Medicine* 41(4): 568-616, 2015. PM26863850
- 4. **Spector-Bagdady K**: "The Google of Healthcare:' enabling the privatization of genetic bio/databanking" *Ann Epidemiol* 26(7): 515-9, 2016. PM27449572
- Kang SK, Spector-Bagdady K, Caplan AL, Braithwaite RS: "Exome and Genome Sequencing and Parallels in Radiology: Searching for Patient-Centered Management of Incidental and Secondary Findings" J Am Coll Radiol 13(12 Pt A): 1467-1472, 2016. PM27595197
- Smith JD, Birkeland AC, Goldman EB, Brenner JC, Carey TE, Spector-Bagdady K, Shuman AG: "Immortal Life of the Common Rule: Ethics, Consent, and the Future of Cancer Research." J Clin Oncol 35 (17): 1879-1883, 2017. PM28426373
- Gollust SE, Gray SW, Carere DA, Koenig BA, Lehmann LS, McGuire AL, Sharp RR, Spector-Bagdady K, Wang N, Green RC, Roberts JS: "Consumer Perspectives on Access to Direct-to-Consumer Genetic Testing: Role of Demographic Factors and the Testing Experience" *Milbank Q* 95(2): 291-318, 2017. 28589610
- 8. Smith J, **Spector-Bagdady K**, Shuman AG: "Head and Neck Cancer Research Ethics: A Primer" *Int J Head Neck Surg* 8(2): 49-56, 2017.
- Moniz MH, Spector-Bagdady K, Heisler M, Harris LHH: "Inpatient Postpartum Long-Acting Reversible Contraception: Providing Care that Promotes Reproductive Justice" *Obstet Gynecol* 130(4): 783–787, 2017. 28885401
- 10. Marchiano EJ, Birkeland AC, Swiecicki PL, **Spector-Bagdady K**, Shuman AG: "Revisiting expectations in an era of precision oncology" *Oncologist* 23(3): 386-88, 2017. 29158373
- Spector-Bagdady K, De Vries R, Harris LH, Low LK: "Stemming the Standard of Care Sprawl: Clinician Self-Interest and the Case of Electronic Fetal Monitoring" *Hastings Cent Rep* 47(6): 16-24, 2017. 29171044

- 12. Platt J, **Spector-Bagdady K**, Platt T, De Vries R, Markel DS, Hutchinson R, Manion FJ, Ziegler G, Kurdonowicz P, Rubin J, Kardia S: "Ethical, Legal, and Social Implications for Learning Health Systems" Learn Health Syst 2(1): e10051, 2018.
- 13. **Spector-Bagdady K**, Shuman A: "Reg-ENT within the Learning Health System" Otolaryngol Head Neck Surg 158(3): 405-06, 2018. 29494320
- 14. **Spector-Bagdady K**, Prince A, Yu JH, Appelbaum PS: "Analysis of state laws on informed consent for clinical genetic testing in the era of genomic sequencing" *Am J Med Genet C* 178(1): 81-88, 2018.
- 15. **Spector-Bagdady K**, Shuman A: "Broad consent for head and neck cancer research" *Otolaryngol Head Neck Surg* 158(5): 835-838, 2018. 29529925
- Spector-Bagdady K, Lombardo PA: "From in vivo to in vitro: How the Guatemala STD Experiments Transformed Bodies into Biospecimens" *Milbank Q* 96(2): 244-271, 2018. 29652094
- 17. **Spector-Bagdady K**, Jagsi R: "Big Data, Ethics, and Regulations: Implications for Consent in the Learning Health System" *J Med Phys*: 2018. (In Press) 30144096

### Non-Peer-Reviewed Journals and Publications

- 1. **Spector-Bagdady K**: "Posthumous Sperm Procurement: The Critical Condition of Autonomous Consent" *Rutgers Journal of Bioethics* 1(1): 18-21, 2009.
- 2. Sampson DK, **Spector-Bagdady K**: "The Regulation of Prescription Drug and Restricted Medical Device Advertising" *Engage: The Journal of the Federalist Society for Practice Groups* 11(1): 4-8, 2010.
- 3. **Spector-Bagdady K**: "Artificial Parentage: Screening Parents for Assisted Reproductive Technologies" *Michigan State Journal of Medicine and Law* 14: 457-476, 2010.
- 4. **Spector-Bagdady K**, Pike E: "Consuming Genomics: Regulating Direct-to-Consumer Genetic and Genomic Information" *Nebraska Law Review* 92: 677-745, 2014.

#### **Book Chapters**

- Pike E, Spector-Bagdady K: "Device-ive Maneuvers: FDA's Risk Assessment of Bifurcated Direct-to-Consumer Genetic Testing". FDA in the 21st Century: The Challenges of Regulating Drugs and New Technologies, Lynch HF, Cohen IG, eds. Columbia University Press, New York, NY, 2015.
- Lee LM, Spector-Bagdady K, Sakhuja M: "Introduction: Essential Cases in the Development of Public Health Ethics". *Global Perspectives on Public Health Ethics: A Casebook*, Barrett DH, et. al, eds. Springer Press, New York, NY, 2016. 37-58
- 3. **Spector-Bagdady K**, Lombardo PA: "Something of an adventure:' Postwar NIH research ethos and the Guatemala STD experiments". *Getting to Good: Research Integrity in the Biomedical Sciences*, Caplan AL, Redman BK (eds.) Springer, 2018. 60-73

#### Books

- 1. Government report: Presidential Commission for the Study of Bioethical Issues (contributions as Associate Director): A Study Guide to "Ethically Impossible" STD Research in Guatemala from 1946 to 1948, Presidential Commission for the Study of Bioethical Issues, Washington, DC, 2011.
- Government report: Presidential Commission for the Study of Bioethical Issues (contributions as a staff Co-Lead): "*Ethically Impossible*": STD Research in Guatemala from 1946 to 1948, Government Printing Office, Washington, DC, 2011.
- 3. Government report: Presidential Commission for the Study of Bioethical Issues (contributions as Associate Director): *Privacy and Progress in Whole Genome Sequencing*, Government Printing Office, Washington, DC, 2012.
- 4. Government report: Presidential Commission for the Study of Bioethical Issues (contributions as Associate Director): Anticipate and Communicate: Ethical Management of Incidental and Secondary Findings in the Clinical, Research, and Direct-to-Consumer Contexts, Government Printing Office, Washington, DC, 2013.
- 5. Government report: Presidential Commission for the Study of Bioethical Issues (contributions as Associate Director): *Ethics and Ebola: Public Health Planning and Response*, Government Printing Office, Washington, DC, 2015.

## **Other Media**

#### **Original contribution**

1. **Spector-Bagdady K**: "Public Health Research in Guatemala: Toward New Scholarship", A commentary on "Ever Vigilant' in 'Ethically Impossible': Structural Injustice and Responsibility in PHS Research in Guatemala," from the May-June 2013 issue, Hastings Center Report, 2013.

#### Other

- 1. Interview: "The DNA Ancestry Craze" (invited commentary), Al Jazeera The Stream, October 11, 2016.
- 2. Joy K: "To Screen or Not to Screen: The Risks of Over-Imaging and Testing" (quoted regarding the potential harm of over-disclosure), MHealth Lab, October 13, 2016.
- 3. Lagnado L: "When a Medical Test Leads to Another, and Another" (discussing "Exome and Genome Sequencing and Parallels in Radiology"), The Wall Street Journal, August 29, 2016.
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