

## **Leila Jamal ScM, PhD, CGC**

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### **Summary of Qualifications**

- Certified genetic counselor with seven years of clinical and teaching experience.
- Doctoral training in empirical and conceptual methods for studying ethical and policy issues genomics, with an emphasis on research ethics.

### **Education**

- 2017                      Ph.D. in Bioethics and Health Policy  
Department of Health Policy and Management  
Johns Hopkins Bloomberg School of Public Health  
Baltimore, MD
- 2012                      Sc.M. in Genetic Counseling  
Department of Health, Behavior and Society and National Human Genome  
Research Institute  
Johns Hopkins Bloomberg School of Public Health  
Baltimore, MD
- 2002                      B.A. (M.A., Oxon) in Philosophy, Politics, and Economics  
St. John's College, University of Oxford  
Oxford, United Kingdom

### **Postdoctoral Training**

- 2017-2018              Hecht-Levi Postdoctoral Fellow  
Johns Hopkins Berman Institute of Bioethics  
Baltimore, MD

### **Clinical Experience**

- 2017-Present              Genetic Counselor, Division of Intramural Research;  
Co-Investigator, Centralized Sequencing Initiative  
National Institute of Allergy and Infectious Diseases  
Bethesda, MD
- 2015-2017              Genetic Counselor, Division of Human Genetics (Oncology)  
University of Maryland  
Baltimore, MD
- 2012-2014              Genetic Counselor, Division of Neurogenetics  
Kennedy Krieger Institute  
Baltimore, MD

## Professional Service

- 2019 Chair, Public Policy Committee, National Society of Genetic Counselors
- 2018 Vice-Chair, Public Policy Committee, National Society of Genetic Counselors
- 2017-2020 Member, Social Issues Committee, American Society of Human Genetics
- 2019 Member, Centralized Institutional Review Board, National Institutes of Health

## Professional Certifications

- 2013-Present American Board of Genetic Counseling Certification

## Honors + Awards

- 2016 Dissertation Award, Center for Qualitative Studies in Health and Medicine  
Johns Hopkins Bloomberg School of Public Health
- 2011-2013 Sir Arthur Newsholme Scholarship for Doctoral Study  
Johns Hopkins Bloomberg School of Public Health
- 2011 Best Student Abstract Award  
National Society of Genetic Counselors

## Peer-Reviewed Publications (Bioethics and Genetic Counseling)

Bombard, Y, Kyle B. Brothers, Sara Fitzgerald-Butt, Nanibaa' A. Garrison, **Leila Jamal**, Cynthia A. James, Gail P. Jarvik, Jennifer B. McCormick, Tanya N. Nelson, Kelly E. Ormond, Heidi L. Rehm, Julie Richer, Emmanuelle Souzeau, Jason L. Vassy, Jennifer K. Wagner, and Howard P. Levy. "The Responsibility to Recontact Research Participants After the Reinterpretation of Genetic and Genomic Research Results". *American Journal of Human Genetics* (in press, accepted February 2019)

Li, Xin, Rachel Nusbaum, Constance Smith-Hicks, **Leila Jamal**, Shannan Dixon, and Sonal Mahida. "Caregivers' Perception of and Experience with Variants of Uncertain Significance From Whole

Exome Sequencing for Children with Undiagnosed Conditions.” *Journal of Genetic Counseling*, January 2019. doi:10.1002/jgc4.1093.

**Jamal, Leila**, Jill O Robinson, Kurt D Christensen, Jennifer Blumenthal-Barby, Melody J Slashinski, Denise Lautenbach Perry, Jason L Vassy, Julia Wycliff, Robert C Green, and Amy L McGuire. “When Bins Blur: Patient Perspectives on Categories of Results From Clinical Whole Genome Sequencing.” *AJOB Empirical Bioethics* 8, no. 2 (April 2017): 82–88. doi:10.1080/23294515.2017.1287786.

Kohler, Jennefer N, Erin Turbitt, Katie L Lewis, Benjamin Wilfond, **Leila Jamal**, Holly L Peay, Leslie G Biesecker, and Barbara B Biesecker. “Defining Personal Utility in Genomics: a Delphi Study.” *Clinical Genetics* 92, no. 3 (April 19, 2017): 290–97. doi:10.1111/cge.12998.

Hercher, Laura, and **Leila Jamal**. “An Old Problem in a New Age: Revisiting the Clinical Dilemma of Misattributed Paternity.” *Applied & Translational Genomics* 8 (March 2016): 36–39.

Lupo, Philip J, Jill O Robinson, Pamela M Diamond, **Leila Jamal**, Heather E Danysh, Jennifer Blumenthal-Barby, Lisa Soleymani Lehmann, et al. “Patients' Perceived Utility of Whole-Genome Sequencing for Their Healthcare: Findings From the MedSeq Project.” *Personalized Medicine* 13, no. 1 (January 2016): 13–20. doi:10.2217/pme.15.45.

Mathews, Debra J H, and **Leila Jamal**. “Revisiting Respect for Persons in Genomic Research.” *Genes* 5, no. 1 (January 2014): 1–12. doi:10.3390/genes5010001.

**Jamal, Leila**, Julie C Sapp, Katie Lewis, Tatiane Yanes, Flavia M Facio, Leslie G Biesecker, and Barbara B Biesecker. “Research Participants' Attitudes Towards the Confidentiality of Genomic Sequence Information.” *European Journal of Human Genetics* 22, no. 8 (August 2014): 964–68. doi:10.1038/ejhg.2013.276.

## Peer-Reviewed Publications (Genomics)

Tunovic, Sanjin, Kristin W Barañano, James A Barkovich, Jonathan B Strober, **Leila Jamal**, and Anne M Slavotinek. “Novel KIF7 Missense Substitutions in Two Patients Presenting with Multiple Malformations and Features of Acrocallosal Syndrome.” *American Journal of Medical Genetics. Part A* 167, no. 11 (November 2015): 2767–76. doi:10.1002/ajmg.a.37249.

Srivastava, Siddharth, Julie S Cohen, Hilary Vernon, Kristin Barañano, Rebecca McClellan, **Leila Jamal**, SakkuBai Naidu, and Ali Fatemi. “Clinical Whole Exome Sequencing in Child Neurology Practice.” *Annals of Neurology* 76, no. 4 (October 2014): 473–83. doi:10.1002/ana.24251.

Gonzaga-Jauregui, Claudia, Timothy Lotze, **Leila Jamal**, Samantha Penney, Ian M Campbell, Davut Pehlivan, Jill V Hunter, et al. “Mutations in VRR1 Associated with Complex Motor and Sensory Axonal Neuropathy Plus Microcephaly.” *JAMA Neurology* 70, no. 12 (December 2013): 1491–98. doi:10.1001/jamaneurol.2013.4598.

## **Selected Conference Presentations**

2019 – “Re-Examining Nondirectiveness in the Genomic Era” (with Will Schupmann and Benjamin Berkman from the NIH Bioethics Department), Consuming Genomics: 2019 Harvard Petrie-Flom Center Annual Conference (forthcoming in May 2019)

2018 – “Return of Genomic Research Results to Participants in Research: Insights from NIAID’s Experience, at Functional Genomics: Big Data to Society Conference, Sidra Women & Children’s Hospital in Doha, Qatar

2017 – “Parental Views About Rare Disease Research and Advocacy: Implications for Patient Engagement Programs”, at the American Society of Bioethics and Humanities Annual Meeting

2017 – Plenary "Genetic Travel Agent: Exploring Medical Tourism and Genetic Counselors' Role in Discussing Controversial Treatments" (with Christopher Scott from Baylor College of Medicine), at the National Society of Genetic Counselors’ Annual Meeting

2016 – “Exploring the Role of Patient Advocacy Organizations in Research”, Office of Human Research Protections, at the National Institutes of Health

2015 - "The Crisis of Converging Disparities in Genomic Medicine", at the American Society for Bioethics and Humanities Annual Meeting

2014 - "Patient Perceptions of Whole Genome Sequencing Results and Intentions to Use Non-Actionable Findings", at the American Society for Bioethics and Humanities Annual Meeting

2014 - "Teaching and Learning Empirical Bioethics: Resources from the Presidential Bioethics Commission", at the Association for Practical and Professional Ethics Annual Meeting

2013 - "Genomic Research in Children with Neurodevelopmental Disabilities: Consent and Assent Issues", at the American Academy for Cerebral Palsy and Developmental Medicine Annual Meeting

2013 - "Implementing the Affordable Care Act in the NYMAC Region: Considerations for Families with Heritable Conditions" (with Meg Comeau from the Catalyst Center), at the New York Mid-Atlantic Newborn Screening Regional Collaborative Board Meeting

## **Selected Guest Lectures**

2017, NIH Allergy and Immunology Fellowship Program Lecturer: “Introduction to Genomic Testing in an Immunology Context”

2014-2017, Graduate Guest Lecturer: "Contemporary Issues in Genome Research Ethics"; Johns Hopkins Berman Institute of Bioethics - Intensives Series

2016, Graduate Guest Lecturer: “Research Designs for Genetic Counseling Research”; University of Maryland Genetic Counseling Training Program

2014 and 2015, Graduate Guest Lecturer: “Genomics in Public Health: An Overview of Issues in Newborn Screening”; Johns Hopkins Bloomberg School of Public Health

2013 and 2014, Undergraduate Guest Lecturer: "Genomic Counseling: Around the Field in 60 minutes"; Johns Hopkins University

2012, Graduate Guest Lecturer: “The Complexities of Communicating Genetic Risk”; Duke University Forums on Genomics & Personalized Medicine

### **Teaching Assistantships**

2014 - Graduate Teaching Assistant: "Ethical Issues in Public Health Policy"; Johns Hopkins Bloomberg School of Public Health

2014 - Graduate Teaching Assistant: "Ethical Issues in Public Health Practice in Developing Countries"; Johns Hopkins Bloomberg School of Public Health

2014 - Graduate Teaching Assistant: "Ethical Issues in Public Health"; Johns Hopkins Bloomberg School of Public Health

### **Student Advising**

2019-2020 – Thesis Committee Member, Emma Moores, University of Maryland Genetic Counseling Training Program

2018 – Student Supervisor, Chenery Lowe, Johns Hopkins/NHGRI Genetic Counseling ScM Candidate

2017-2018 – Thesis Committee Member, Xin Li, University of Maryland Genetic Counseling Training Program

2016-2017 - Student Supervisor, Xin Li, University of Maryland Genetic Counseling Training Program

2015 - Thesis Committee Member, Jenn Kohler, Johns Hopkins/NHGRI Genetic Counseling ScM Candidate

### **Skills + Training**

NSGC Leadership Trainee (2017-2018)

Statistical analysis (using STATA and SPSS)

Qualitative data analysis (using NVivo and Atlas.ti)

Grant Writers' Seminars and Workshops - NIH Version (2014)

### **Professional Society Memberships**

National Society of Genetic Counselors

American Society of Human Genetics

American Society for Bioethics and Humanities

### **Citizenship**

United States and United Kingdom