Shana L. Merrill, MS, LCGC

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EDUCATION

2016 – 2022 (anticipated)	University of Pennsylvania, PhD in Social Welfare School of Social Policy and Practice Advisor: Allison Werner-Lin, Ph.D, LCSW Dissertation Title: Unpacking Power & Positionality in Applied Clinical Genomics & Personalized Medicine
2005 - 2007	University of North Carolina Greensboro, MS in Genetic Counseling School of Health and Human Science Thesis: Development of a Web-Based Curriculum for Medical Students Addressing the Ethical, Legal, and Social Implications of Genetics
2000-2004	Lafayette College, BS in Neuroscience Honors Thesis: Factors Affecting the Use of Nondirectiveness by Genetic Counselors
1996-2000	Egg Harbor Township High School Valedictorian

ACADEMIC APPOINTMENTS, TEACHING, AND MENTORING EXPERIENCE

Fall 2017 – Present	**Graduate Adjunct Faculty** Jefferson College of Biomedical Sciences Instructor of Record for Clinical Cardiogenetics Speaker for Psychosocial Issues in Genetic Counseling Clinical Supervisor
Fall 2017	**Graduate Teaching Assistant** University of Pennsylvania School of Social Policy and Practice Illness and Family Caregiving
Fall 2016 – Spring 2017	**Curriculum Advisor & Course Content Developer** Jefferson College of Biomedical Sciences Genetic Counseling Program
Fall 2016 - Spring 2020	**Research Fellow** University of Pennsylvania School of Social Policy and Practice
Fall 2009 -	**Contracted Lecturer**

Fall 2019	Arcadia University College of Health Sciences Genetic Counseling Program (Various Courses)
Spring 2019 - Present	**Graduate Thesis Advisor & Committee Member** Jefferson College of Biomedical Sciences Genetic Counseling Program (1 mentee)
Fall 2012 – Present	**Graduate Thesis Advisor & Committee Member** Arcadia University Genetic Counseling Program (4 mentees)
Fall 2009 – Spring 2020	**Course Faculty Speaker** Perelman School of Medicine at the University of Pennsylvania Frontiers in Bioethics & Professionalism (4th yr medical students) Frontiers in Precision Medicine (1st yr medical students)
Fall 2012 – Present	**Guest Speaker** University of Pennsylvania School of Nursing Theoretical Foundations of Health Care Ethics
Summer 2015	**Webinar Speaker** National Society of Genetic Counselors "Genetic Counselors and Somatic Genetic Testing: Laboratory and Clinical Perspectives"
Fall 2013 – Spring 2014	**Faculty Instructor** National Online Board Review Course in Medical Genetics and Genetic Counseling in Oncology
Spring 2011	**Webinar Series Speaker in Cardiology** American College of Cardiology
Spring 2008 – Spring 2009	**Curriculum Development Committee Member** Virginia Tech Carilion School of Medicine and Research Institute
Fall 2006 – Spring 2007	**Graduate Research Assistant** University of North Carolina at Greensboro Guilford Genomic Medicine Initiative (DOD-funded)
Fall 2005 - Spring 2006	**Graduate Assistantship (**Competitively-Awarded) University of North Carolina at Greensboro
Spring 2009 – Fall 2019	**Lead Clinical Supervisor** Arcadia University, Genetic Counseling Program
Spring 2009 - Spring 2016	**Clinical Supervisor & Speaker** The University of Pennsylvania and Children's Hospital of Philadelphia Medical Genetics Residency Program

Fall 2007 - Fall 2019	**Frequent Grand Rounds Speaker** Clinical Genetics (majority), Pediatrics, Obstetrics & Gynecology, Cardiology, Neurology, Oncology, Bioethics
Spring 2006 – Fall 2007	**Course Content Developer**, **Programmer, & Evaluator** Online Educational Courses for Medical Students Clinical Tools Inc, of Chapel Hill, NC
Spring 2004 - Spring 2005	**Long-term Substitute High School Teacher** Egg Harbor Township Board of Education Chemistry and Spanish Teaching Placements Women's Basketball Coach
Fall 2001 - Spring 2004	**Writing Associate** Lafayette College, College Writing Program

HONORS AND AWARDS

2015	**Recipient of Janus Series Speaker Award** National Society of Genetic Counselors Annual Education Conference Session Title: Advances in the Understanding of Paragangliomas and Pheochromocytomas: Underappreciated and Highly Genetic
2005	**Recipient of Competitive Merit-Based Scholarship** University of North Carolina at Greensboro, Genetic Counseling Program
2004	**Departmental Honors in Psychology** Lafayette College
2003	**Sigma Xi**, Scientific Honor Society Nomination and Induction
2000 – 2004	**Marquis Scholar** Lafayette College's Most Distinguished Academic Scholarship

PEER-REVIEWED PUBLICATIONS

Wilsnack, C., Young, J. L, **Merrill, S**. **L.**, Groner, V., Loud, J., Bremer, R. C., Greene, M. H., Khincha, P. P., Werner-Lin, A. (in preparation) **Reproductive Decision-Making Among Families with Li-Fraumeni Syndrome: Generations of Cancer Risk.**

Werner-Lin, A., Young, J. L., Forbes Shepherd, R. Wilsnack, C., **Merrill, S**. **L.**, Groner, V., Greene, M. H., Khincha, P. P. (in preparation). **The physicality of grief and bereavement for families with Li-Fraumeni Syndrome: "Hit in the gut."**

Werner-Lin, A., Forbes Shepherd, R., Young, J. L., Wilsnack, C., **Merrill, S**. **L.**, Groner, V., Greene, M. H., Khincha, P. (under review). **Physical and aesthetic change as loss for families with a rare inherited cancer syndrome: "Like electricity through my body."**

Wilsnack, C., Young, J. L., Groner, V., **Merrill, S**. **L**, Greene, M. H., Khincha, P. P., & Werner-Lin, A. (in

press). **Family identity and role function in the context of Li-Fraumeni Syndrome: "No one's like us mutants."** Health and Social Work.

Werner-Lin, A., Young, J. L., Wilsnack, C., **Merrill, S. L**., Groner, V., Greene, M. H., & Khincha, P. P. (2020). **Waiting and "weighted down": the challenge of anticipatory loss for individuals and families with Li Fraumeni Syndrome**. Familial cancer, 19(3), 259–268. https://doi.org/10.1007/s10689-020-00173-6

Werner-Lin, A., **Merrill, S. L.**, Brandt, A. C., Barnett, R.E., Matloff, E.T. (2018). **Talking with Children About Adult-Onset Hereditary Cancer Risk: A Developmental Approach for Parents**. Journal of Genetic Counseling, 27(3), 533–548. doi: 10.1007/s10897-017-0191-7

Reza, N., Chowns, J. L., **Merrill, S. L**., Marzolf, A., Zado, E. S., Palmer, M. B., … Owens, A. T. (2018). **Frameshifts in Code and in Care.** Circulation: Genomic and Precision Medicine, 11(5). doi: 10.1161/circgen.118.002215

Reza, N., Garg, A., **Merrill, S. L**., Chowns, J. L., Rao, S., & Owens, A. T. (2018). **ACTA1 Novel Likely Pathogenic Variant in a Family With Dilated Cardiomyopathy**. Circulation: Genomic and Precision Medicine, 11(10). doi: 10.1161/circgen.118.002243

Dhifallah, S., Lancaster, E., **Merrill, S**., Leroudier, N., Mantegazza, M., & Cestèle, S. (2018). **Gain of Function for the SCN1A/hNav1.1-L1670W Mutation Responsible for Familial Hemiplegic Migraine**. Frontiers in Molecular Neuroscience, 11. doi: 10.3389/fnmol.2018.00232

Sargen, M., **Merrill, S**., Chu, E., & Nathanson, K. (2016). ***CDKN2A* mutations with p14 loss predisposing to multiple nerve sheath tumours, melanoma, dysplastic naevi and internal malignancies: a case series and review of the literature**. *British Journal of Dermatology*, *175*(4), 785–789. doi: 10.1111/bjd.14485

Merrill, S. L., & Guthrie, K. J. (2015). **Is it Time for Genomic Counseling? Retrofitting Genetic Counseling for the Era of Genomic Medicine**. Current Genetic Medicine Reports, 3(2), 57–64. doi: 10.1007/s40142-015-0068-8 (Invited Publication)

Fishbein, L, Khare, S, Wubbenhorst, B, DeSloover, D, D'Andrea, K, **Merrill, S**, Cho NW, Greenberg, R, Else, T, Montone, K, LiVolsi, V, Fraker, D, Daber, R, Cohen, D, Nathanson KL. **Whole exome sequencing identifies somatic ATRX mutations in pheochromocytomas and paragangliomas**. *Nat Commun*. 2015 Jan 21;6:6140. doi: 10.1038/ncomms7140.

Baets,J; Duan, X; Wu, Y; Smith, G; Seeley, W; Mademan, I; McGrath, N; Beadell, N; Khoury, J; Botuyan, MV; Mer, G; Worrell, G, Hojo, K; Laura, M; Liu, Y; Senderek, J; Weis, J; Van den Bergh, P; **Merrill, SL**, Reilly, M; Houlden, H; Scherer, S; De Jonghe, P; Dyck, P; Klein, C. **Maintenance methyltransferase defect causes a spectrum of neurological diseases.** *Brain*. 2015 Apr;138(Pt 4):845-61. doi: 10.1093/brain/awv010.

Bradbury, A., Patrick-Miller L, Long J, Powers J, Stopfer J, Forman A, Rybak C, Mattie K, Brandt A, Chambers R, Chung WK, Churpek J, Daly MB, Digiovanni L, Farengo-Clark D, Fetzer D, Ganschow P, Grana G, Gulden C, Hall M, Kohler L, Maxwell K, **Merrill S**, Montgomery S, Mueller R, Nielsen S, Olopade O, Rainey K, Seelaus C, Nathanson KL, Domchek S. **Development of a tiered and binned genetic counseling model for informed consent in the era of multiplex testing for cancer susceptibility**. *Genet Med.* 2015 Jun;17(6):485-92. doi: 10.1038/gim.2014.134.

Fishbein L, **Merrill S**, Fraker DL, Cohen DL, Nathanson KL. **Inherited mutations in pheochromocytoma and paraganglioma: why all patients should be offered genetic testing**. *Ann Surg Oncol*. 2013 May;20(5):1444-50.

Merrill SL, Vaidya A, Pyeritz RE. **Ethical challenges of the use of whole exome sequencing in the clinic**. *World J Pediatr Congenit Heart Surg.* 2013 Jan;4(1):58-61.

INVITED BOOK CHAPTERS

Werner-Lin, A**.**, Doyle, M., **Merrill, S**. & Gehlert, S. (2019). **Social work and genetics**. In S. Gehlert & T. Arthur Browne. *Handbook of Health Social Work, 3rd Ed.* Wiley & Sons, San Francisco, CA.

Werner-Lin, A. & **Merrill, S**. (2016). **A role for social workers in helping families with inherited cancer predisposition: A Case of Li-Fraumeni Syndrome**. In J. McCoyd (Ed). Social Work in Healthcare Settings, 2nd Edition.

ONGOING RESEARCH PROTOCOLS

Co-Investigator - "Genetics and Biochemical Studies of Tumors of the Autonomic Nervous System," sponsored by Co-I Dr. Katherine Nathanson, University of Pennsylvania

Collaborator/Staff – "A Randomized Protocol Evaluating Return of Actionable Genetic Research Results to Biobank Participants," PI Dr. Angela Bradbury, University of Pennsylvania

CONFERENCE PRESENTATIONS

Society for Social Work and Research Annual Conference **January 2020**
Werner-Lin, A., **Merrill, S**., Young, J. L., Wilsnack, C., Groner, V., Greene, M. H., Khincha, P. P. Chronic grief as an unmet need for families with rare inherited cancer syndromes: Living with and dying from Li-Fraumeni Syndrome. Symposium: "Financial and psychosocial implications of cancer."

16th International Meeting on Psychosocial Aspects of Hereditary Cancer **November 2019**
Werner-Lin, A., Young, J., **Merrill, S**., Wilsnack, C., Groner, V., Loud, J., Bremer, R, C., Peters, J. A., Greene, M., & Khincha, P.P. Complicated grief in family life with Li-Fraumeni Syndrome. Oral presentation,

16th International Meeting on Psychosocial Aspects of Hereditary Cancer **November 2019**
Wilsnack, C., Werner-Lin, A., Young, J., **Merrill, S**., Groner, V., Greene, M., & Khincha, P.P. The use of identity as a clinical tool in families with Li-Fraumeni Syndrome. Poster presentation

European Society for Human Genetics Annual Meeting **June 2019**
Werner-Lin, A., **Merrill, S.,** Young, J. L., Wilsnack, C., Groner, V., Loud, J., Bremer, R. C., Peters, J. A., Greene, M. H., Khincha, P. P. "Hit in the gut": *Grief and loss among families living with Li-Fraumeni Syndrome*.

Society for Social Work & Research Annual Conference Plenary Abstract Presentation **January 2019**
Werner-Lin, A., **Merrill, S**., Carlson, M., Zaspel, L. & Bernhardt, B. Identifying heteronormative presumptions and "breeder bias" in disclosure of pediatric genomic testing results to adolescents and their parents.

European Society for Human Genetics Conference Plenary Abstract Presentation **June 2018**
Werner-Lin, A. **Merrill, S**., Carlson, M., Zaspel, L., Walser, S. & Bernhardt, B. Reproductive and heteronormative presumptions in disclosure of pediatric whole exome sequencing results. Plenary Presentation,

Invited Speaker North American Neuroendocrine Tumor Society Annual Symposium **October 2017**
Merrill, SL. Incorporating Genetic Testing Into Clinical Practice

Invited Faculty - American College of Cardiology 66th Annual Scientific Session **March 2017**

Merrill, SL. Incorporating Genetic Testing Into Clinical Practice - The Role of the Genetic Counselor

Invited Faculty - American Heart Association's Annual Scientific Sessions **November 2016**
Instructor Clinical Genomics Bootcamp for Cardiologists

Invited Speaker 24th Annual State-of-the-Art Arrhythmia Symposium Panelist **October 2016**
Inherited Arrhythmia Disorders and Genetic Testing – Questions You Need to Ask

National Society of Genetics Counselors – Janus Series Speaker **October 2015**
Merrill, SL. **"**Advances in the Understanding of Paragangliomas and Pheochromocytomas: Underappreciated and Highly Genetic"

Invited Speaker Annual Conference Hereditary Cancers for Community Oncology Providers Sept 2015
Neuroendocrine Tumors for the Institute for Medical Education (IME) and the US Oncology Network

World Congress of Psycho-Oncology Poster Presentation **July 2015**
Werner-Lin, A and Merrill, SL. "Diagnosis of familial genetic syndrome following pediatric cancer diagnoses: The need for direct practice social workers in helping families with Li-Fraumeni Syndrome"

American Association for Cancer Research Poster Presentation **Spring 2015**
Patel V, Maxwell K, Babushok D, **Merrill S**, Wubbenhorst B, Cohen, R, Domchek, S, Sullivan L, Bessler M, Nathanson K. "Expanding the clinical paradigm of patients with biallelic BRCA2 mutations"

National Society of Genetic Counselors Annual Meeting Poster Presentation **Fall 2014**
Merrill, SL, Dolinsky, J; Witherington, S; Thompson,J; Fishbein, L; Nathanson, KL. "Cost should not be a barrier to genetic testing in patients with paragangliomas and pheochromocytomas." An industry collaboration with Ambry Genetics.

Fanconi Anemia Research Fund Scientific Symposium Abstract **Fall 2014**
Maxwell, K, Babushok, D, **Merrill, S,** Wubbenhorst, B, D'Andrea K, Domchek, S, Bessler, M, Cohen, R, Nathanson, KL. "An adult cancer patient with biallelic *BRCA2* mutations - expanding the clinical paradigm of Fanconi Anemia D1"

American Society for Bioethics and Humanities Selected Platform Paper Presentation **Fall 2013**
Merrill, SL. "Rational Suicide as a Perceived Benefit of Pre-symptomatic Genetic Testing in Patients at Risk for Huntington's Disease"

North American Neuroendocrine Tumor Society Poster Presentation **Summer 2013**

Fishbein L, Bennett B, **Merrill S**, Cohen DL, LiVolsi V, Nathanson KL, Montone K. Succinate dehydrogenase subunit B (SDHB) immunohistochemistry should not replace clinical genetic testing for SDHx mutations in patients with pheochromocytoma and paraganglioma.

The Endocrine Society Annual Meeting Poster Presentation **Summer 2013**

Fishbein, L, **Merrill, S**, Cohen, D, Loevner, L, Rosen, M, Nathanson KL. "Rapid Full Body MRI Screening is an Efficient and Effective Method for Identifying Occult Tumors in Unaffected Patients with Succinate dehydrogenase subunit B Gene Mutations"

Invited Speaker Ethics of the Heart II: Ethical Challenges of Congenital Heart Disease **Fall 2012**
Provided and discussed case examples of utility of whole exome sequencing in cardiology clinic; served as panel member for discussion of testing with cardiology staff members

Invited Speaker Focus on Neuroendocrine Tumors Conference **Fall 2012**

Merrill, SL. What to Expect from a Genetics Visit

Invited Speaker Neurofibromatosis Symposium **Fall 2011**
Reproductive Issues and NF-1

American College of Medical Genetics Platform Paper Presentation **Spring 2011**

Merrill, SL, Fishbein, L, Nathanson KL. "Prevalence of identifiable genetic etiologies in patients with pheochromocytomas and paragangliomas in a clinic-based series"

Jamestown 400th Anniversary Forum, Roanoke VA **Fall 2007**
"How shall we live together? Determining today's acceptable moral decisions in a multi-religious, multi ethnic, diverse society"

PROFESSIONAL MEMBERSHIPS, LICENSES & OTHER SERVICE

Ad-hoc Manuscript Reviewer
Genetics in Medicine
Clinical Genetics

Professional Organization Membership
Society for Social Work and Research (SSWR)
National Society of Genetic Counselors (NSGC)

Professional Licensure
Commonwealth of Pennsylvania State Genetic Counselor License

Graduate Program Admissions Committee Interviewer
Jefferson College of Health Sciences Genetic Counseling Program
Arcadia University Genetic Counseling Program

Student Government PhD Representative
University of Pennsylvania School of Social Policy and Policy

Love Hope Strength Team Leader & Recruiter
Non-Profit Organization Promoting Bone Marrow Donation Registration

Serial Interviewee for WNYC New York Public Radio
Resulting in Several Aired Interviews & Public Interest Stories, including featured on *This American Life*.

WORK EXPERIENCE

Hospital of the University of Pennsylvania, Division of Cardiology **February 2016-Present**
Senior Genetic Counselor, Inherited Cardiac Disease Program

- Provide clinical genetic counseling services for a variety of genetic indications including, but not limited to, familial cardiomyopathy, connective tissue disorders/familial aortopathies, arrhythmogenic condition, congenital heart disease, and neuromuscular diseases
- Oversee high-level coordinated patient care across multiple subdivisions and institutions
- Promote measurable growth and financial sustainability of the cardiogenetics program

- Establish and grow a telemedicine genetic counseling delivery model in cardiogenetics, including marketing and contract negotiations
- Hire, train, and supervise more junior genetic counselors and clinical staff
- Collaborate with physicians on clinical research endeavors
- Serve as a genetics resource and provide consultative services for providers in non-genetic Penn subspecialties and the regional genetics community

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Hospital of the University of Pennsylvania, Division of Medical Genetics **January 2009-January 2016**
Adult Clinical Genetic Counselor

- Provide clinical genetic counseling services for genetic indications including, but not limited to, familial cardiomyopathy, connective tissue disorders/familial aortopathies, rare cancer susceptibility syndromes, genodermatoses, neuromuscular and neurodegenerative diseases
- Oversaw high-level coordinated patient care across divisions and institutions
- Helped establish the Penn/CHOP Familial Cardiomyopathy Program with cardiologist Dr. Anjali Owens
- Negotiated funding to provide consultative genetic counseling services to other specialty departments
- Hired, trained, and acted as the primary clinical supervisor for newly hired genetic counselors and clinical staff
- Collaborated with physicians on clinical research endeavors
- Serve as a genetics resource and provide consultative services for providers in non-genetic Penn subspecialties and the regional genetics community

Carilion Clinic Prenatal Diagnostic Center; Roanoke, VA **June 2007 – January 2009**
Prenatal Genetic Counselor

- Performed prenatal and preconception genetic counseling for a variety of indications including family history concerns, advanced maternal age, pregnancy exposures, abnormal ultrasound findings, abnormal screening results, etc. in a high volume maternal fetal medicine practice serving patients in SW Virginia, SE West Virginia, and eastern Tennessee
- Performed genetic evaluation of fetal demises and infants in the neonatal intensive care unit
- Educated physicians, medical students, allied health care professionals, patient organizations, and the community
- Provided clinical supervision for 3rd and 4th year medical students from a variety of medical schools

Clinical Tools, Inc. of Chapel Hill, NC **Feb 2006 -Sept 2007**

- Worked as part of a team completing a NHGRI grant to develop online educational materials for medical students
- Served as the primary author of a 'peer-reviewed' online module focusing on prenatal genetic testing
- Scored medical student simulated patient interviews to assess effectiveness of the online genetics education intervention, specifically accuracy of information and sensitivity to ELSI issues during patient counseling regarding genetics issues
- Drafted manuscripts of educational intervention evaluations

Guilford Genomic Medicine Initiative **May 2006-July 2007**

- Recruited physician for focus groups to investigate the genetics needs of primary care physicians
- Administrated patient surveys in area physicians' offices
- Developed educational materials for a website designed to educate physicians about thrombophilia and cancer genetics
- Assisted in the design, implementation, and interpretation of data for a study investigating effective written communication strategies in patient genetic counseling letters
- Administered telephone surveys evaluating attitudes towards genetics to residents in Guilford County, NC