# BARBARA B. BIESECKER

## Summary of Professional Experience

Barbara Biesecker is a senior research public health analyst in the Center for Newborn Screening, Ethics, and Disability Studies in the Education and Workforce Development division with a joint appointment in the Center for Communication Science in the Social Policy, Health, and Economics Research unit. She is an expert in genetic counseling, health psychology, and clinical translation of genomic science. Dr. Biesecker has a 35-year career in genetic counseling clinical service, graduate education, and research. Her major areas of research and publication address the psychological and health care utilization outcomes of living with a genetic condition or at risk and the translation of genomics into clinical care.

## Education

PhD, Health Psychology, Kings College, London, United Kingdom, 2011.
MS, Human Genetics, University of Michigan, Ann Arbor, MI, 1981.
BA, Genetics and Psychology, St. Olaf College, Northfield, MN, 1979. Graduated cum laude.

## Certifications and Licenses

American Board of Genetic Counseling, 1993
American Board of Medical Genetics, 1984

## Selected Project Experience

***RTI Early Check Follow-Up*** (2017 to date)—*Co-Lead*. Pilot studies on parents who received fragile X premutation results on their newborns suggest little psychological distress. Yet how parents manage the uncertainties that accompany this result are unknown. Funding was received from the John Merk Foundation to develop a theoretically based intervention to help parents manage the uncertainties over time.

- Develops a theoretically informed intervention to mitigate negative psychological responses to uncertainty.
- Analyzes the data and publishes short- and long-term findings.

***ClinSeq® Social and Behavioral Studies*** (2013 to 2017)—*Team Lead*. It is critical to the effective translation of genomic technologies to identify the psychological, social, and health behavior outcomes of learning genomic information. A series of studies found that participants managed the information well with little psychological distress. Yet key areas for further research into perceptions of uncertainties and their effects on clinical outcomes were identified.

ClinSeq® is a National Institutes of Health (NIH) intramural research program on the clinical translation of genomic sequencing. There are two cohorts. One consists of 1,000 primarily white, well-educated self-referred participants, and the other consists of 500 more diverse, primarily black, self-referred participants, all of whom consented to receive results from genomic sequencing.

- Coordinated studies to assess complement and potential ways to enhance proposed efforts.
- Mentored junior investigators and trainees in designing and implementing studies.
- Led data analyses and development of papers, writing, and publication.

***Noninferiority of a Web Platform Compared with In-Person Genetic Counselor Return of Carrier Results: A Randomized Controlled Trial (RCT)*** (2013 to 2017)—*Senior Investigator*. Workforce limits in genetic counseling make return of results by a trained specialist impractical for all results from genomic sequencing. As such, noninferiority of a web-based platform as an alternative health service delivery mode for return of carrier results in ClinSeq® was assessed. The web-based platform was noninferior in both knowledge and psychological wellbeing and communication of results to relatives. This suggests that alternative educational modes may be sufficient in helping to offset some of the health care burden of returning results from genomic sequencing.

- Designed the study and trained the genetic counselor.
- Led the data analyses from multiple sources in the RCT.
- First authored the main publication and senior authored the secondary publication.

***RCT of Consent Interventions for NIH Whole Exome and Whole Genome Sequencing Studies*** (2013 to 2017)—*Principal Investigator*. Consent forms and processes for studies using genomic technologies are long and technical and exhibit a high literacy demand. An RCT was conducted of two consent forms/processes for a National Institute of Child Health and Human Development genomic sequencing intramural study of Premature Ovarian Insufficiency. An equivalence in outcomes was found, suggesting a shorter, lower literacy consent process may be as effective. A deficiency in understanding the implications of receiving secondary findings across study arms was identified, suggesting the need for more effective discussion of unanticipated sequencing outcomes.

- Designed the study and implemented the consent arms.
- Mentored a postdoctoral student in the data analysis.
- Senior authored the publication.

***Investigation into Uncertainties in Genomic Sequencing*** (2014 to 2017)—*Team Lead*. Perceptions of uncertainties and end user responses will have significant impact on the utility of genomic sequencing. ClinSeq® investigators and National Human Genome Research Institute (NHGRI) extramural Clinical Sequencing Evidence-Generating Research (CSER) investigators developed a taxonomy of uncertainties in genomic sequencing. Focus groups were run to explore perceptions of uncertainties that may come with sequence results and the data were used to inform development of a scale to assess perceptions of uncertainties in genomic sequencing. Several studies followed to assess the interpretation of variants of unknown significance that suggest participants imbue unknown variants with meaning and act accordingly. Studies to extend this work are critically important to the translation of genomic sequencing.

- Developed the Perceptions of Uncertainty in Genomic Sequencing (PUGS) scale.

- Analyzed the focus group data and senior authored the paper.
- Mentored graduate students in the design and analysis of three studies.

## Professional Experience

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| 2017 to date | RTI International, Washington, DC. |
| | Senior Research Public Health Analyst. Member of the Early Check Research Team leading a follow-up intervention for parents of infants identified with fragile X premutation. Member of the Communications Team coleading studies on the use of decision tools to enhance informed decision-making in genomics translation. |
| 1993 to 2017 | NIH/NIGRI, Social and Behavioral Research Branch, Bethesda, MD. |
| | Associate Investigator. Directed a program of research into the consequences of living at risk and with a genetic condition, decision-making and the utility of genetic/genomic testing, and RCTs of genetic counseling interventions. |
| | NHGRI and Clinical Supervisor for the NIH/NHGRI Medical Genetics Fellowship Program. Supervised and evaluated medical genetics fellows on the NHGRI Consult Service in the Clinical Center. |
| 1993 to 2017 | Johns Hopkins University/NHGRI, Social and Behavioral Research Branch, Bethesda, MD. |
| | Program Director, Genetic Counseling Training Program. Developed and directed the Genetic Counseling Program; taught courses and served as a thesis advisor. |
| 1993 to 2017 | Johns Hopkins Bloomberg School of Public Health; Health, Behavior and Society, Baltimore, MD. |
| | Adjunct Associate Professor. Taught six courses in the School of Public Health. |
| 1991 to 1993 | University of Michigan, Genetic Counseling Training Program in Molecular Medicine in Genetics, Ann Arbor, MI. |
| | Adjunct Lecturer in Human Genetics and Associate Director of the Genetic Counseling Training Program. Taught a counseling course, provided supervision to graduate students, and helped administer the program. |
| | Clinical Supervisor in Molecular Medicine and Genetics Clinic Supervised and evaluated graduate students on clinical rotation. |
| | Co-instructor in Graduate Student Seminar; Instructor of Seminar on Advanced Genetic Counseling Skills. Taught NIH campus-wide courses. |

## Honors and Awards

Natalie Weissberger Paul Leadership Award, National Society of Genetic Counselors, 2014
Inaugural Diane Baker Alumnae Lectureship, University of Michigan, 2011
"Master" Genetic Counselor, Jane Engelberg Memorial Foundation, 2010
Director's Award—Henrietta Lacks, NIH, 2014
Director's Award—Mentoring, NIH, 2006
Director's Award—Katrina Missing Persons Effort, NIH, 2006

## Professional Associations

American Society of Human Genetics
Association of Genetic Counseling Program Directors
National Society of Genetic Counselors
Society of Behavioral Medicine
Transnational Alliance of Genetic Counselors

## Professional Service

Advisory Board Member, Stanford University Genetic Counseling Graduate Program, 2009 to date
Reviewer, *American Journal of Medical Genetics, Clinical Genetics, European Journal of Medical Genetics, Genetics in Medicine, Journal of Genetic Counseling, Journal of Medical Genetics, Hastings Center Report, Health Psychology, Medical Decision Making, Nature Genetics, New England Journal of Medicine, Patient Education and Counseling, Prenatal Diagnosis, Preventive Medicine, Psychology and Health and Social Science in Medicine*, 2006 to date
Presenter, NIH Office of Intramural Training and Education Annual Career Seminar in Genetic Counseling, 2000 to date
Thesis Advisor, Johns Hopkins University/NHGRI Genetic Counseling Training Program; Griffith University Genetic Counseling Program; Dissertation committee member or referee, Johns Hopkins School of Public Health, University of Leiden, University of Cape Town, 1996 to date
Editorial Board Member, *Clinical Genetics*, 1995 to date
Planning Committee Member, World Congress in Genetic Counselling, 2017
Program Committee Member, NHGRI Ethical, Legal, and Social Implications (ELSI) Congress, 2017
Outcomes and Measures Working Group Member, Clinical Sequencing Evidence-Generating Research Consortium, 2015 to 2017
Member, NHGRI Clinical Genetics Consult Service, 2000 to 2017
Referee, Postbaccalaureate Research Symposium, NIH Division of Intramural Research, 2016
Abstract Task Force Member, National Society of Genetic Counselors, 2014 to 2016
Study Section Member, National Cancer Institute (NCI) Pharmacogenomics Trials, 2015
Study Section Member, American Association for the Advancement of Science Panel Connecticut Bioscience Innovation Fund review (Gene Council), 2015
Study Section Member, NHGRI ELSI Training Grants, 2015
Study Section Member, The Dutch Cancer Society-KWF Kankerbestrijding, 2015
Conflict of Interest Task Force Member, National Society of Genetic Counselors, 2012 to 2013
Study Section Member, NIH Societal and Ethical Issues in Research, 2011 to 2013
Study Section Member, NHGRI ELSI, 2007 to 2010
Social and Behavioral Research Section Editor, *Clinical Genetics*, 1999 to 2009
Professional Board Member, National Marfan Foundation, 1992 to 2008
Guest Editor, *American Journal of Medical Genetics*, 2006 to 2007

Professional Reviewer of the Proposed University of Utah Genetic Counseling Graduate Program, 2004
Editorial Board Member, *Journal of Genetic Counseling*, 1998 to 2002
Member, National Institute on Deafness and Other Communication Disorders Working Group on Considerations for Developing and Implementing Genetic-Diagnostic Tests for Hereditary Hearing Impairment and Other Communication Disorders, 1998
Informed Consent Subcommittee Member, NHGRI/NCI Cancer Studies Consortium, 1996 to 1998
NHGRI/NCI Cancer Studies Consortium Member, 1995 to 1998
Member, ELSI-Funded Working Group on Ensuring Privacy and Confidentiality in the Publication of Pedigrees, 1997
Professional Reviewer of the Proposed University of Toronto Genetic Counseling Graduate Program, 1997
Cancer Testing Subcommittee Member, American Society of Human Genetics, 1994
Annual Education Chair, National Society of Genetic Counselors, 1992 to1994
Human Genome Committee Member, American Society of Human Genetics, 1993
Committee on Assessing Genetic Risk Member, Institute of Medicine, 1991 to 1993
Genetic Testing in the Insurance Industry Ad Hoc Committee Member, American Society of Human Genetics, 1991 to 1993
Principal Investigator on Grants, ELSI-NIH Conference Grant, "Conference on Ethical, Legal and Social Implications of the Human Genome Initiative," 1992
Nominating Committee Member, American Society of Human Genetics, 1992
President-Elect-Past President II, National Society of Genetic Counselors, 1988 to 1992
Secretary, National Society of Genetic Counselors, 1986 to 1988
Region IV Representative, National Society of Genetic Counselors, 1984 to 1986

## Seminars and Courses Taught

Advanced Genetic Counseling, Johns Hopkins University School of Public Health, 1996 to 2017
Therapeutic Genetic Counseling, Johns Hopkins University School of Public Health, 1995 to 2017
Seminars in Genetic Counseling: Current Topics in the Field, Johns Hopkins University School of Public Health, 1995 to 2017
Professional Supervision in Genetic Counseling, Johns Hopkins University School of Public Health, 1994 to 2017
Introduction to Genetic Counseling, Johns Hopkins University School of Public Health, 1994 to 2000

## Special Courses

Qualitative Research Methods, NIH seminar, Spring, 2003
Exploratory Factor Analysis, Abt Associates, August, 2015

## Computer Skills

SPSS, N-VIVO

## Books, Book Chapters, and Monographs

Peay, H., Biesecker, B., & Austin, J. (2015). Genetic counseling for psychiatric disorders. In B. J. Sadock, V. A. Sadock, & P. Ruiz, P. (Eds.). *Kaplan and Sadock's comprehensive textbook of psychiatry* (10th ed.). New York, NY: Lippencott, Williams & Wilkens.

Biesecker, B. (2013). *Genetic counseling: Practice of. encyclopedia of bioethics* (4th ed.). Farmington Hills, MI: MacMillian Reference USA.

## Peer-Reviewed Journal Articles

Shapira, R., Turbitt, E., Erby, L. H., Biesecker, B. B., Klein, W. M. P., & Hooker, G. W. (2017, December 5). Adaptation of couples living with a high risk of breast/ovarian cancer and the association with risk-reducing surgery. *Familial Cancer*. doi: 10.1007/s10689-017-0065-z

Haakonsen Smith, C., Turbitt, E., Muschelli, J., Leonard, L., Lewis, K. L., Freedman, B., Muratori, M., & Biesecker, B. B. (2017, September 6). Feasibility of coping effectiveness training for caregivers of children with autism spectrum disorder: A genetic counseling intervention. *Journal of Genetic Counseling*. doi: 10.1007/s10897-017-0144-1

Athens, B. A., Caldwell, S. L., Umstead, K. L., Connor, P. D., Brenna, E., & Biesecker, B. (2017). A systematic review of randomized controlled trials to assess outcomes of genetic counseling. *Journal of Genetic Counseling, 26*(5), 902–933. doi: 10.1007/s10897-017-0082-y

Cameron, L. D., Biesecker, B., Peters, E., Taber, J. M., & Klein, W. M. P. (2017). Self-regulation principles underlying risk perception and decision making within the context of genomic testing. *Social and Personality Psychology Compass,* 11(5), e12315. doi: 10.1111/spc3.12315

Han, P. K. L., Umstead, K. L., Bernhardt, B. A., Green, R. C., Joffe, S., Koenig, B., Krantz, I., Waterston, L. B., Biesecker, L. G., & Biesecker, B. B. (2017). A taxonomy of medical uncertainties in genome sequencing. *Genetics in Medicine, 19*(8), 918–925. doi: 10.1038/gim.2016.212

Kohler, J., Turbitt, E., & Biesecker, B. (2017). Personal utility in genomics: A systematic literature review. *European Journal of Human Genetics, 25*, 662–668. doi: 10.1038/ejhg.10

Kohler, J., Turbitt, E., Lewis, K., Wilfond, B., Jamal, L., Peay, H., Biesecker, L., & Biesecker, B. (2017). Defining personal utility in genomics: A Delphi study. *Clinical Genetics, 92*(3), 290–297. doi: 10.1111/cge.12998

Taber, J. M., Klein, W. M. P., Lewis, K. L., Johnston, J., Biesecker, L. G., & Biesecker, B. B. (2017). Reactions to clinical reinterpretation of a gene variant by participants in a sequencing study. *Genetics in Medicine*.

Biesecker, B. B. (2016). The greatest priority for genetic counseling: Effectively meeting our client's needs. *Journal of Genetic Counseling, 25*(4), 621–624.

Biesecker, B. B. (2016). Predictive genetic testing of minors: Evidence and experience with families. *Genetics in Medicine, 18*(8), 763–764.

Biesecker, B., Austin, J., & Caleshu, C. (2016). Response to a different vantage point commentary: Psychotherapeutic genetic counseling, is it? *Journal of Genetic Counseling, 26*(2), 334–336.

Biesecker, B., Austin, J., & Caleshu, C. (2016). Theories for psychotherapeutic genetic counseling: Fuzzy trace theory and cognitive behavior theory. *Journal of Genetic Counseling, 26*(2), 322–330.

Biesecker, B. B., Woolford, S. W., Klein, W. M. P., Brothers, K. B., Umstead, K. L., Lewis, K. L., et al. (2016). PUGS: A novel scale to assess perceptions of uncertainties in genome sequencing. *Clinical Genetics, 92*(2),172–179. doi: 10.1111/cge.12949

Elrick, A., Ashida, S., Ivanovich, J., Lyons, S., Biesecker, B. B., & Goodman, M. S., et al. (2016). Psychosocial and clinical factors associated with family communication of cancer genetic test results among women diagnosed with breast cancer at a young age. *Journal of Genetic Counseling, 26*(1), 173–181.

Hooker, G., Umstead, K. L., Lewis, K. L., Koehly, L. K., Biesecker, L. G, & Biesecker, B. B. (2016). Engagement and communication among participants in the ClinSeq genomic sequencing study. *Genetics in Medicine, 19*(1), 98–103. doi:10.1038/gim.2016.71

Lamb, A. E., Biesecker, B. B., Umstead, K. L., Muratori, M., Biesecker, L. G., & Erby, L. H. (2016). Family functioning mediates adaptation in caregivers of individuals with Rett syndrome. *Patient Education Counseling, 99*(1), 1873–1879.

Peay, H. L., Scharff, H., Tibben, A., Wilfond, B., Bowie, J., Johnson, J., Nagaraju, K., Escolar, D., Piacentine, J., & Biesecker, B. B. (2016). "Watching time tick by…" Decision making for Duchenne muscular dystrophy trials. *Contemporary Clinical Trials, 46*, 1–6.doi:10.1016/j.cct.2015.11.006

Seo, J., Ivanovich, J., Goodman, M. S., Biesecker, B. B., & Kaphingst, K. A. (2016.) Information topics of greatest interest for return of genome sequencing results among women diagnosed with breast cancer at a young age. *Journal of Genetic Counseling, 26*(3), 511–521.

Turriff, A., Macnamara, E., Levy, H. P., & Biesecker, B. (2016). The impact of living with Klinefelter Syndrome: A qualitative exploration of adolescents and adults. *Journal of Genetic Counseling, 26*(4), 728–737. doi:10.1007/s10897-016-0041-z

Yanes, T., Humphreys, L., McInerney-Leo, A., & Biesecker, B. (2016). Factors associated with parental adaptation to children with an undiagnosed medical condition. *Journal of Genetic Counseling, 26*(4), 829–840. doi: 1007/s10897-016-0060-9

Bann, C. M., Abresch, R. T., Biesecker, B. B., Conway, K. C., Heatwole, C., Peay, H., et al. (2015). Measuring quality of life in muscular dystrophy. *Neurology, 84*(10),1034–1042.

Hamlington, B., Ivey, L. E., Brenna, E., Biesecker, L. G., Biesecker, B. B., & Sapp, J. C. (2015). Characterization of courtesy stigma perceived by parents of overweight children with Bardet-Biedl syndrome. *PLoS One*, *10*(10).

Kaphingst, K. A., Ivanovich, J., Biesecker, B. B., Dresser, R., Seo, J., Dressler, L. G., et al. (2015). Preferences for return of incidental findings from genome sequencing among women diagnosed with breast cancer at a young age. *Clinical Genetics*, *89*(3), 378–384.

Lewis, K. L., Hooker, G. W., Connors, P. D., Hyams, T. C., Wright, M. F., Caldwell, S., Biesecker, L. G., & Biesecker, B. B. (2015). Participant experiences receiving incidental findings through genome sequencing: A mixed-methods study. *Genetics in Medicine, 18*(6), 577–583.

Lewis, K., Klein, W. M., Han, P. K., Hooker, G., Biesecker, L. G, & Biesecker, B. B. (2015). Characterizing the ClinSeq cohort. *PLoS One, 10*(7).

Schaa, K., Roter, D., Biesecker, B., Cooper, L., & Erby, L. (2015). Genetic counselors' implicit racial attitudes and their relationship to communication. *Health Psychology, 34*(2), 111–1119.

Taber, J. M., Klein, W. M., Ferrer, R. A, Han, P. K., Lewis, K. L., Biesecker, L. G., & Biesecker, B. B. (2015). Perceived ambiguity as a barrier to receipt of genome sequencing results. *Journal of Behavioral Medicine, 38*(5), 715–726.

Turriff, A., Levy, H., & Biesecker, B. B. (2015). Factors associated with adaptation to Klinefelter syndrome: The experience of adolescents and adults. *Patient Education Counseling, 98*(1), 90–95.

Biesecker, L. G., Biesecker, B. B. (2014). An approach to pediatric exome and genome sequencing. *Current Opinion Pediatrics, 26*(6), 639–645.

Biesecker, B. B., Klein, W. M., Lewis, K., Fisher, T. C., Wright, M. F., Biesecker, L. G., et al. (2014). How do research participants perceive "uncertainty" in genome sequencing? *Genetics in Medicine, 16*(12), 977–980.

Cohen, J., Levy, H., Sloan, J., Dariotis, J., & Biesecker, B. B. (2014). Depression among adults with neurofibromatoris type 1: Prevalence and impact on quality of life. *Clinical Genetics 88*(5), 425–430.

Gray, S. W., Martins, Y., Feuerman, L. Z., Bernhardt, B. A., Biesecker, B. B., Christensen, K. D., et al. (2014). Social and behavioral research in genomic sequencing: Approaches from the Clinical Sequencing Exploratory Research Consortium Outcomes and Measures Working Group. *Genetics in Medicine, 16*, 727–735.

Hooker, G. W., Ormond, K. E., Sweet, K., & Biesecker, B. B. (2014). Teaching genomic counseling: Preparing the genetic counseling workforce for the genomic era. *Journal of Genetic Counseling, 4*, 445–451.

Hooker, G. W., Peay, H., Erby, L., Bayless, T., Biesecker, B. B., & Roter, D. L. (2014). Genetic literacy and patient perceptions of IBD testing utility and disease control: A randomized vignette study of genetic testing. *Inflammatory Bowel Diseases, 20*, 901–908.

Morgan, T., Schmidt, J., Haakonsen, C., Lewis, J., Rocha, M. D., Morrison, S., Biesecker, B., et al. (2014). Using the internet to seek information about genetic and rare diseases: A case study comparing data from 2006 and 2011. *JMIR Research Protocols, 3*(1):e10. doi: 10.2196/resprot.2916

Peay, H., Rosenstein, D., & Biesecker, B. (2014). Parenting with bipolar disease: Coping with risk of mood disorders in children. *Social Science & Medicine, 104*, 194–200.

Peay, H., Tibben, A., Fisher, T., Brenna, E., & Biesecker, B. (2014). Expectations and experiences of investigators and parents involved in a clinical trial for Duchenne/Becker muscular dystrophy. *Clinical Trials, 11*(1), 77–85.

Taber, J. M., Klein, W. M., Ferrer, R. A., Lewis, K. L., Biesecker, L. G., & Biesecker, B. B. (2014). Dispositional optimism and perceived risk interact to predict intentions to learn genome sequencing results. *Health Psychology, 34*(7), 718–728.

Biesecker, B., Erby, L., Woolford, S., Adcock, J. Y., Cohen, J. S., Lamb, A., et al. (2013). Development and validation of the Psychological Adaptation Scale (PAS): Use in six studies of adaptation to a health condition or risk. *Patient Education Counseling 93*(2), 248–254.

Biesecker, B., & Peay, H. (2013). Genomic sequencing for psychiatric disorders: Promise and challenge. *International Journal of Neuropsychopharmacology, 16*(7), 1667–1672.

Biesecker, B., Schwartz, M., & Marteau, T. M. (2013). Enhancing informed choice to undergo health-screening tests: A systematic review. *American Journal of Health Behavior 37*(3), 351–359.

Caulfield, T., Evans, J., McGuire, A., McCabe, C., Bubela, T., Cook-Degan, R., Fishman, J., Hogarth, S., Miller, F., Ravitsky, V., Biesecker, B., et al. (2013). Reflections on the cost of "low cost" whole genome sequencing: Framing the health policy debate. *PloS Biology, 11*, e1001609.

Jamal, L., Sapp, J., Lewis, K., Yanes, T., Facio, F., Biesecker, L., & Biesecker, B. (2013). Research participants' attitudes toward the confidentiality of genomic sequence information. *European Journal of Human Genetics, 22*, 964–968.

McGuire, A. L., Joffe, S., Koenig, B. A., Biesecker, B. B., McCullough, L. B., Blumenthal-Barby, J. S., et al. (2013). Point-counterpoint: Ethics and genomic incidental findings. *Science, 340*(6136), 1047–1048.

Peay, H., Rosenstein, D., & Biesecker, B. (2013). Adaptation to bipolar disease and perceived risk to children: A survey of parents affected with bipolar disorder. *BMC Psychiatry, 13*, 327. doi: 10.1186/1471-244X-13-327

Sapp, J., Dong, D., Stark, C., Ivey, L., Hooker, G., Biesecker, L., & Biesecker, B. (2013). Parental attitudes, values, and beliefs toward the return of results from exome sequencing in children. *Clinical Genetics 85*, 120–126.

Shiloh, S., Wade, C., Roberts, J. S., Hensley-Alford, S, & Biesecker, B. (2012). Associations between risk perceptions and worry about common disease: A between- and within-subjects examination. *Psychology & Health 28*(4), 434–449.

Shiloh, S., Wade, C., Roberts, J. S., Hensley-Alford, S., & Biesecker, B. (2013). On averages and peaks: How do people integrate information about multiple diseases to reach a decision about multiplex genetic testing? *Medical Decision Making, 33*(1), 71–77.

Wright, M. F., Lewis, K. L., Fisher, T., Hooker, G., Emanuel, T., Biesecker, L.,& Biesecker, B. (2013). Preferences for results delivery from Whole Exome/Whole Genome Sequencing. *Genetics in Medicine, 16*(6), 442–447.

Bemmels, H., Biesecker, B., Lowenstein, J., Krokosky, A., Guidotti, R., & Sutton E. (2012). Psychological and social factors in undergoing reconstructive surgery among individuals with craniofacial conditions: An exploratory study. *The Cleft Palate-Craniofacial Journal, 50*(2), 158–167.

Facio, F., Eidem, H., Fisher, T., Brooks, S., Linn, A., Kaphingst, K., Biesecker, L., & Biesecker, B. (2012). Intentions to receive individual results from whole genome sequencing among participants in the ClinSeq study. *European Journal of Human Genetics 21*(3), 261–265.

Kaphingst, K., Facio, F., Eidem, H., Brooks, S., Linn, A., Biesecker, B., et al. (2012). Effects of informed consent for individual genome sequencing on relevant knowledge. *Clinical Genetics, 82*(5), 408–415.

Madeo, A., O'Brien, K., Bernhardt, B., & Biesecker, B. (2012). Factors associated with perceived uncertainty among parents of children with undiagnosed medical conditions. *American Journal of Medical Genetics Part A, 158A*(8), 1877–1884.

Wade, C., Shiloh, S., Roberts, J. S., Hensley-Alford, S., Marteau, T., & Biesecker B. (2012). Preferences among diseases on a genetic susceptibility test for common health conditions: An ancillary study of the Multiplex Initiative. *Public Health Genomics, 15*(6), 322–326.

Truitt, M., Biesecker, B., Capone, G., Bailey, T., & Erby L. (2012). The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education Counseling, 87*(2), 233–238.

Wade, C., Shiloh, S., Woolford, S. W., Roberts, J. S., Alford, S. H., Marteau, T. M., & Biesecker, B. (2012). Modeling decisions to undergo genetic testing for susceptibility to common health conditions: An ancillary study of the Multiplex Initiative. *Psychology & Health, 27*(4), 430–444.

Erby, L., Roter, D., & Biesecker, B. (2011). Examination of simulated patient performance: Accuracy and consistency of six standardized patients over time. *Patient Education Counseling, 85*(2), 194–200.

Erby, L., Roter, D., & Biesecker, B. (2011). Examination of standardized patient performance: Accuracy and consistency of six standardized patients over time. *Patient Education Counseling, 85*(2), 194–200.

Facio, F., Brooks, S., Loewenstein, J., Green, S., Biesecker, L., & Biesecker B. (2011). Motivators for participation in a whole genome sequencing study: Implications for translational genomics research. *European Journal Human Genetics, 19*(12), 1213–1217.

Madeo, A., Biesecker, B., Brasington, C., Erby, L., & Peters, K. (2011). The relationship of the genetic counseling profession and the disability community: A commentary. *American Journal of Medical Genetics Part A, 155A*(8), 1777–1785.

Turriff, A., Levy, H., & Biesecker, B. (2011). Prevalence and psychosocial correlates of depressive symptoms among adolescents and adults with Klinefelter syndrome. *Genetics in Medicine, 13*(11), 966–972.

Caleshu, C., Shiloh, S., Price, C., Sapp, J., & Biesecker, B. (2010). Invasive prenatal testing decisions in pregnancy after infertility. *Prenatal Diagnosis, 30*(6), 575–581.

Cohen, J., & Biesecker, B. (2010). Quality of life in rare genetic conditions: A systematic review of the literature. *American Journal of Medical Genetics Part A,* 1*52(A),* 1136–1156.

Sapp, J. C., Hull, S. C., Duffer, S., Zornetzer, S., Sutton, E., Marteau, T., & Biesecker, B. (2010). Ambivalence toward undergoing invasive prenatal testing: An exploration of its origins. *Prenatal Diagnosis, 30*(1), 77–82.

White, B., Leib, J., Farmer, J., & Biesecker, B. (2010). Exploration of transitional life events in individuals with Fredreich Ataxia: Implications for genetic counseling. *Behavioral and Brain Functions, 6*, 65. doi: 10.1186/1744-9081-6-65

Peay, H., Hooker, G., Kassem, L., & Biesecker, B. (2009). Family risk and related education and counseling needs: Perceptions of adults with bipolar disorder and siblings of adults with bipolar disorder. *American Journal of Medical Genetics Part A, 149A*(3), 364–371.

Biesecker, B. (2008). Commentary on "My story: A genetic counselor's journey from provider to patient." *Journal of Genetic Counseling, 17*(5):419–423.

Biesecker, B., & Erby, L. (2008). Adaptation to living with a genetic condition or risk: A mini-review. *Clinical Genetics, 74*(5), 401–407.

Loewenstein, J., Sutton, E., Guidotti, R., Shapiro, K., Ball, K., McLean, D., & Biesecker, B. (2008). The art of coping with a craniofacial difference: Helping others through "Positive Exposure." *American Journal of Medical Genetics Part A, 146A*, 1547–1557.

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## Presentations and Proceedings

Biesecker, B. (2017, October). *A systematic review of randomized controlled trials assessing outcomes in genetic counseling.* Presented at the Inaugural World Congress on Genetic Counselling, Hinxton, United Kingdom.

Biesecker, B. (2017, October). *A systematic review of randomized controlled trials assessing genetic counseling outcomes.* Presented at the Translational Genomics Symposium at the American Society of Human Genetics Annual Meeting, Orlando, FL.

Biesecker, B. (2017, September). *Delivery mode sequencing carrier results: A randomized controlled trial.* Presented as the Best Member Abstract Award at the National Society of Genetic Counselors Annual Meeting, Columbus, OH.

Biesecker, B. (2017, September). *Using evidence to inform your practice: What do we know from studies to put to good use?* Presented as the Educational Breakout Session at the National Society of Genetic Counselors Annual Meeting, Columbus, OH.

Biesecker, B. (2017, May). *The evolution of genetic counseling: Effectively meeting our clients' needs.* Presented at the ESHG/ASHG Building Bridges Symposium, Copenhagen, Denmark.

Biesecker, B. (2017, May). *Delivery mode for returning sequencing carrier results: A randomized controlled trial.* Presented at Manchester Centre for Genomic Medicine, Manchester, United Kingdom.

Biesecker, B. (2017, May). *Priorities for parents undergoing prenatal genome sequencing*. Presented at The Hastings Center, Garrison, NY.

Biesecker, B. (2017, April). *Genetic counseling in the era of genomic medicine*. Presented at the Wilson Symposium, Case Western Reserve, Cleveland, OH.

Biesecker, B. (2017, February). *Client-centered prenatal genetic counseling.* Presented at The Hastings Center, New York, NY.

Biesecker, B. (2016, December). *Families rich in psychiatric disorders.* Presented at Psychiatric Genetic Counseling, Banbury Conference Center, Cold Spring Harbor, NY.

Biesecker, B. (2016, May). *Outcomes from ClinSeq social and behavioral studies*. Presented at Kennedy Kreiger Institute, Baltimore, MD.

Biesecker, B. (2016, April). *Challenges of genomics panel testing*; *Genetic and genomic epidemiology*. Presented at Johns Hopkins Bloomberg School of Public Health, Baltimore, MD.

Biesecker, B. (2016, April). *The psychosocial effects of uncertain genomic information in the prenatal context*. Presented at Columbia University Medical Center, Center for Research on Ethical, Legal and Social Implications, New York, NY.

Biesecker, B. (2016, March). *Personalized Medicine Initiative: What we can learn from oncology genetics*. Presented at Food and Drug Administration, Silver Spring, MD.

Biesecker, B. (2015, November). *Perceptions and management of uncertainty in genome sequencing*. Presented at NCI ENRICH Forum, Shady Grove, MD.

Biesecker, B. (2015, October). *Outcomes of research in genetic counseling*. Invited plenary session. Presented at National Society of Genetic Counselors, Pittsburgh, PA.

Biesecker, B. (2015, February). *Managing uncertainties in positive prenatal microarray results*. Presented at National Society of Genetic Counselors Webinar.

Biesecker, B. (2014, October). *ASHG/ESHG building bridges session: Towards finding global agreement on topical discussions in genetics: Evolving uncertainties in genomic medicine*. Presented at American Society of Human Genetics, San Diego, CA.

Biesecker, B. (2014, September). *Shared decision making in genetic counseling*. Invited plenary session. Presented at National Society of Genetic Counselors, New Orleans, LA.

Biesecker, B. (2014, September). *Our greatest priority: Genetic counseling clients and their needs*, Acceptance speech, Natalie Paul Weissberger Leadership Award. National Society of Genetic Counselors, New Orleans, LA.

Biesecker, B. (2014, July). *Fundamentals of genetic counseling: Looking toward the future.* Presented at NIH Clinical Center Social Work Department, Bethesda, MD.

Biesecker, B. (2014, April). *Genomic advances and patient decision making: Recent findings and emerging issues*. Invited symposium, Society of Behavioral Medicine, Philadelphia, PA.

Biesecker, B. (2014, February). *Social/personality psychology and genetics: A discussion on the importance of connections, critiques, and implications*. Presented at Society for Personality and Social Psychology Conference, Austin, TX.

Biesecker, B. (2013, June). *Shared decision making debate*. Presented at Behavioral and Social Science Coordinating Council, Bethesda, MD.

Biesecker, B. (2013, April). *Finding and creating opportunities for career advancement and professional development: Is a PhD your path to advancement and greater satisfaction?* Presented at National Society of Genetic Counselors Webinar.

Biesecker, B. (2012, October). *Measuring client outcomes of genetic counseling*. Invited Pre-conference, National Society of Genetic Counselors, Boston, MA.

Biesecker, B. (2012, June). *Genomics in maternal and child health*. Presented at Suburban Hospital, Bethesda, MD.

Biesecker, B. (2012, May). *Intentions to receive results from whole-genome sequencing among participants in the ClinSeq study*. Presented at Annual Virginia State Genetics Education Meeting, Charlottesville, VA.

Biesecker, B. (2012, May). *Preferences of ClinSeq participants to receive individual results from whole genome sequencing*. Presented at Department of Human Genetics, Harvard University, Boston, MA.

Biesecker, B. (2012, April). *Community perspectives on bridging the new science with decision making, including individual decision making*. Presented at Emerging Science for Environmental Health Decisions Committee, The National Academies, Washington, DC.

Biesecker, B. (2012, April). *The role of ambivalence in moderating attitudes toward invasive prenatal testing*. Presented at Law-Medicine Center, Case Western Reserve University, Cleveland, OH.

Biesecker, B. (2011, October). *Overcoming barriers to research*. Invited educational breakout session, National Society of Genetic Counselors, Annual Education Conference, San Diego, CA.

Biesecker, B. (2011, January). *Genetic counseling research: An emerging paradigm for the profession,* The Inaugural Diane Baker Alumni Lecture Award, Department of Human Genetics, University of Michigan, Ann Arbor, MI.