

CURRICULUM VITAE

Janet Karen Williams, Ph.D., RN, FAAN
Professor of Nursing
Chair of Social and Behavioral Science Research IRB-02
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EDUCATION

1989, PhD, University of Iowa, Iowa City IA, Dissertation: Williams, Janet. (1989).
1971, MA, University of Iowa, Iowa City, IA, Fields of Study: Nursing of Children, PNP
1968, BSN, University of Iowa, Iowa City IA, Field of Study: Nursing
1966, Diploma, Iowa Methodist School of Nursing, Des Moines, IA, Field of Study: Nursing

Doctoral dissertation *Cognitive behavioral modification and visual-spatial perception in children with learning disabilities and with Turner syndrome*, University of Iowa). Abstracts International, 1, 51/04A, p. 1177. (University Microfilms AAI 9019986) Field of Study: Educational Psychology

LICENSURE

1966-present, Iowa, Registered Nurse, Iowa #039989

CERTIFICATIONS

1982-present, American Board of Human Genetics, Genetic Counselor

PROFESSIONAL EXPERIENCE

Academic Appointments

2002-present, Professor, College of Nursing, The University of Iowa
1996-2002, Associate Professor, College of Nursing, The University of Iowa
1990-1996, Assistant Professor, College of Nursing, The University of Iowa
1990, Lecturer, College of Nursing, The University of Iowa
1980-1989, Adjunct Assistant Professor, College of Nursing, The University of Iowa
1973, Instructor, College of Nursing, The University of Iowa
1969-1971, Assistant Instructor, College of Nursing, The University of Iowa
1968-1969, Instructor, St. John's Hospital School of Nursing, Brooklyn, NY

Administrative Appointments

2008-present, Chair Soc Sci & Behav Research IRB-02, The University of Iowa

Clinical Appointments

2000-present, Academic Staff Associate, Pediatrics, University of Iowa Hospitals and Clinics, Iowa City, IA
1988-1989, Research Assistant, Otolaryngology, The University of Iowa Hospitals and Clinics, Iowa City, IA
1987-1988, Graduate Assistant, Pediatric Psychology, College of Education, University of Iowa, Iowa City, IA
1978-1988, Nurse Clinician II, Division of Medical Genetics, Dept of Pediatrics, University of Iowa Hospitals and Clinics, Iowa City, IA
1974-1976, Maternal Child Health Coordinator, St. Luke's Hospital, Cedar Rapids, IA
1966-1974, Part time medical-surgical staff nurse, Mercy Hospital, Iowa City, IA

HONORS AND AWARDS

2024	UI College of Nursing Collegiate Service Award
2014	MNRS Lifetime Achievement Award
2013-2015	National Mentor, Robert Wood Johnson Faculty Scholar
2011	Regents Award for Faculty Excellence, The University of Iowa
2009-2011	Adjunct Visiting Professor, Clemson University
2006-2009	Visiting Professor, University of Plymouth, Plymouth, England
2004-2012	Kelting Professor of Nursing, The University of Iowa, Iowa City, IA
2003-2004	Adjunct Visiting Professor, School of Nursing, University of Pennsylvania
2003	Outstanding Advanced Researcher Award, Genetics section, MNRS
2000	Strategic Initiative Award, College of Nursing, The University of Iowa
2000	Founders' Outstanding Genetic Research and Scholarship Award, International Society of Nurses in Genetics, Inc
2000	Induction into American Academy of Nursing
1999	Irving Harris Visiting Professor, The University of Illinois, Chicago, IL
1998	The University of Iowa Developmental Leave
1997	Collegiate Teaching Award, The University of Iowa
1968	Gamma Chapter, Sigma Theta Tau International
1966	Dunn Award for Excellence in Nursing, Iowa Methodist School of Nursing, Des Moines, Iowa

SCHOLARSHIP

AREAS OF RESEARCH INTEREST

Psychosocial impact of genomic testing, predictive genomic testing, family management of genetic conditions, genetic discrimination, Huntington disease, research ethics

Publications

Journal articles *Data Based; Underline student or trainee author
Peer Reviewed

1. *Laures, E., **Williams, J**, McCarthy, A.M. Pain Assessment & Management Decision-Making in Pediatric Critical Care (in press) *Journal of Pediatric Nursing*
2. *Groves, P.S., Bunch, J.L., Hanrahan, K.M., Sabadosa, K., Sharp, B., & **Williams, J.K.** (2023) Patient voices in hospital safety. *Clinical Nursing Research*, 32(1), 105-114.
3. *Groves, P.S., Bunch, J.L., Sabadosa, K.A., Cannava, K.E., & **Williams, J.** (2021). A grounded theory of creating space to foster patient and family trust: A key role of hospital nurses in safety co-production. *Nursing Outlook*.69(4), 632-640
<https://doi.org/10.1016/j.outlook.2021.01.005> Epub 2021 Feb 10
4. Kurnat-Thoma, E., Fu, M.R., Henderson, W., Voss, J., Hammer, M., **Williams, J.**, Calzone, K., Conley, Y., Starkweather, A., Weaver, M., Shiao, P., & Coleman, B. (2021). U.S. Genomic Nursing Healthcare Policy- Current Status and Future Directions, *Nurs Outlook*. 2021 May-Jun;69(3):471-488. doi: 10.1016/j.outlook.2020.12.006. Epub 2021 Jan 22.
5. *Groves, P.S., Bunch, J.L., Cannava, K.E., Sbadosa, K.A., & **Williams, J.K.** (2021). Nurse sensemaking for responding to patient and family safety concerns. *Nursing Research* 70(2), 106-113 doi: 10.1097/NNR.0000000000000487
6. Tripp-Reimer, T., **Williams, J.K** Gardner, S., Rakel, B., Herr, K., McCarthy, A.M., Hand, L., Gilbertson-White, S., & Cherwin, C. (2020) Integrated model of multimorbidity and symptom science, *Nursing Outlook* 68(4), 430-439.
7. Fu, M.R., Kurnat-Thoma, E., Starkweather, A., Henderson, W.A., Cashion, A.K., **Williams, J.K.**, Katapodi, M.C., Reuter-Rice, K., Hickey, K.T., Barcelona, V. , Calzone, K., Conley, Y., Anderson, C., Lyon, D., Weaver, M., Shiao, P., Constantino, R., Wung, S.F., Hammer, M., Voss, J G., & Coleman, B. Precision health and nursing.(2019) *International Journal of Nursing Sciences* 24;7(1):5-12.
8. **Williams, J.K.**, Bonham, V.L., Wicklund, C., Coleman, B., Taylor, J.Y., & Cashion, A.K. Advocacy and actions to address disparities in access to genomic health care. (2019) *Nursing Outlook* 67(5), 605-612.
9. *Shah, L.L., Daack-Hirsch, S., Ersig, A.L., Paik, A., Ahmad, F. & **Williams, J.K.** (2019). Family Relationships Associated with Communication and Testing for Inherited Cardiac Conditions. *Western Journal of Nursing Research*. 41(11):1576-1601
10. **Williams, J.K.**, Feero, G., Veenstra, D., Starkweather, A.,& Cashion, A.(2018). Considerations in initiating genomics screening programs in health systems. *Nursing Outlook* 66 (6),570 -5 7 5
11. **Williams, J.K.**, & Anderson, C. Omics research ethics considerations, (2018.) *Nursing Outlook* 66(4), 386-393
12. Starkweather, A.R., Coleman, B., Barcelona de Mendoza V., Hickey, K., Menzies, V., Henderson, W., Cashion, A., **Williams, J.K.**, and the Genomics &Health Care Expert Panel; O’Keefe, M., and the Bioethics Expert panel, McCormick, K., Keenan, G., Harper, E., and the Informatics Expert Panel. Policy Brief: Strengthen federal and local policies to advance precision health implementation and nurses’ impact on healthcare quality and safety. (2018). *Nursing Outlook* 66 (4),101-104.
13. *Ersig, A., & **Williams, J.K.** (2018) Student and parent perspectives on severe food allergies at college. *Journal of Pediatric Health Care* 32(5), 445-454
14. Starkweather, A.R., Coleman, B., deMendoza V.B., Fu, M.R., Menzies, V., O’Keefe,M.,& **Williams J.K.** (2017). Strengthen federal regulation of laboratory-developed and direct-to-consumer genetic testing. *Nursing Outlook* 66(1) 101-104

15. *Cohn, E.G., Hamilton, N., Larson, E.L., & **Williams, J.K.** (2017) Self-reported race/ethnicity of biobank participants in the United States. *Journal of Community Genetics* 8, 229-238.
16. **Williams, J.K.**, Feero, W.G., Leonard, D., & Coleman, B. (2017) Implementation science, genomic precision medicine, and improved health: A new path forward? *Nursing Outlook* 65, 36-40.
17. **Williams, J.K.**, Tripp-Reimer, T., Daack-Hirsch, S., DeBerg, J. (2016) Five year bibliometric review of clinical genomic nursing science research. *Journal of Nursing Scholarship* 48(2):179-86. doi: 10.1111
18. **Williams, J.K.** Katapodi, M., Starkweather, A., Badzek, L., Cashion, A., Coleman, B., Fu, M., Lyon, D., Weaver, M., & Hickey, K., (2016). Advanced Nursing Practice and Research Contributions to Precision Medicine *Nursing Outlook*.64,(2) 117-123
19. **Williams, J.K.**, Cashion, A.K., Sheker, S., & Ginsburg, G.S. Genomics, clinical research, and learning health care systems: Strategies to improve patient care (2016) *Nursing Outlook*. 64(3), 225-228.
20. *Ersig, A.L., Tsalikian, E., Coffey J., & **Williams, J.K.** (2016) Immediate and Long Term Implications of Stressors in Teens With Type 1 Diabetes and Their Parents for Transition to Adult Self-Management *Journal of Pediatric Nursing*31(4):390-6. doi: 10.1016/j.pedn.2015.12.012
21. Musso, M., Westervelt, H.J., Long, J.D., Morgan, E., Woods, S.P., Smith, M.M.,..., **Williams, J.**, Downing, N.,..., Wyse, R. (2015). Intra-individual variability in prodromal Huntington disease and its relationship to genetic burden. *Journal of the International Neuropsychological Society*, 21(1), 8-21.
22. **Williams, J.K.**, & Cashion, A.K.(2015). Using clinical genomics in health care: Strategies to create a prepared workforce. *Nursing Outlook*. 63(5), 607-609.
23. Foote, J., Conley, V., **Williams, J.K.** , McCarthy, A.M., Countryman, M. (2015) DNP projects and IRB procedures. *Journal of Nursing Education* 54 (7), 372-377
24. *Kim, J.I., Long, J.D., Mills, J.A., Downing, N.R., **Williams, J.K.**, Paulsen, J.S., and the PREDICT-HD researchers. Performance of the 12-item WHODAS 2.0 in prodromal Huntington disease. (2015).*European Journal of Human Genetics* 23(11):1584-7.
25. **Williams, J.K.**, Cashion, A. K., & Veenstra, D.L.(2015). Challenges in evaluating next-generation sequence data for clinical decisions, *Nursing Outlook* 63(1):48-50
26. *Cohn, E.G., Husamudenn, M., Larson, E., & **Williams, J.K.** Increasing participation in genomic research and biobanking through community-based capacity building. (2015). *Journal of Genetic Counseling* 24(3), 491-502.
27. *Paulsen, J.S., Long, J.L., Johnson, H.J., Aylward, E.H., Ross, C.A., **Williams, J.K.**, Nance, M.A., Erwin, C.J., Wetservelt, H.K., Harrington,D.L., Bockholt,H.J., Zhang, Y., McCusker, E.A., and the PREDICT-HD Investigators and Coordinators of the Huntington Study Group. (2014). Prediction of manifest Huntington's disease with clinical and imaging measures: A prospective observational study. *Lancet Neurology* 13(12):1193-201.
28. Kim, J.I., Long, J.D., Mills, J.A., Downing, N.R., **Williams, J.K.**, Paulsen, J.S., and the PREDICT-HD researchers. Performance of the 12-item WHODAS 2.0 in prodromal Huntington disease. (2015).*European Journal of Human Genetics* 23(11):1584-7.

29. * **Williams, J.K.**, Kim, J.I., Downing, N.R., Farias, S., Harrington D., Long, J., Mills, J., Paulsen, J.S. and the PREDICT-HD researchers. Everyday Cognition in individuals with prodromal Huntington Disease (2015). *Neuropsychology* 29 (2), 255-267
30. Paulsen, J.S., Long, J.D., Johnson, H.J., Aylward, E.H., Ross, C.A., **Williams, J.K.**, Nance, M.A., Erwin, C.J., Westervelt, H.K., Harrington, D.L., Bockholt, H.J., Zhang, Y., McCusker, E.A., Chiu, E.M., Panegyres, P.K. (2014) Clinical and biomarker changes in premanifest Huntington disease show trial feasibility: a decade of the PREDICT-HD study (2014). *Frontiers in Aging Neuroscience* Apr 22, 6:78. Doi:10.3389/fnagi.2014.00078.eCollection 2014.
31. *Downing, N.R., Kim, J.I., **Williams, J.K.**, Long, J., Mills, J., Paulsen, J.S. and the PREDICT-HD researchers. WHODAS 2.0 in Prodromal Huntington disease: Measures of functioning in neuropsychiatric disease. (2014) *European Journal of Human Genetics* 22 (8), 958-963.
32. *Paulsen, J.S., Nance, M., Kim, J.I., Panagyres, P.K., Erwin, C., Goh, A., McKusker, L., **Williams, J.K.**, and the PREDICT-HD Investigators of the Huntington Study Group. (2013) A Review of Quality of Life after Predictive Testing for Neurodegenerative Diseases *Progress in Neurobiology* 110, 2-28
33. *Driessnack, M., Daack-Hirsch, S., Downing, N., Hanish, A.S., Shah, L., Alasagherin, M., Simon, C., & **Williams, J.K.** (2013) The disclosure of incidental genomic findings: An 'Ethically important moment' in pediatric research and practice. *Journal of Community Genetics* 4(4), 435-444.
34. ***Williams, J.K.**, Driessnack, M., Barnette, J., Sparbel, K.J., Leserman, A., Thompson, S., & Paulsen, J.S. (2013). Strategies used by teens growing up in families with Huntington disease. *Journal of Pediatric Nursing* 28(5):464-9.
35. *Epping, E.A., Mills, J.A., Beglinger, L.J., Fiedorowicz, J.G., Craufurd, D., Smith, M.M., Groves, M., Bijanki, K.R., Downing, N., **Williams, J.K.**, Long, J.D., Paulsen, J.S., and the PREDICT-HD Investigators and Coordinators of the Huntington Study Group (2013). *Characterization of Depression in Prodromal Huntington Disease in the Neurobiological Predictors of HD (PREDICT-HD) Study Psychiatric Research* 47, 1423-1431.
36. *Brandt, D.S., Shinkunas, L., Hillis, S.L., Daack-Hirsch, S.E., Driessnack, M., Downing, N.R., Liu, M.F., Shah, L.L., **Williams, J.K.**, & Simon, C.M (2013). A closer look at the recommended criteria for disclosing genetic results: Perspectives of medical genetics specialists, genomic researchers, and institutional review board chairs. *Journal of Genetic Counseling*. 22 (4), 544-553
37. *Daack-Hirsch, S., Driessnack, M., Hanish, A.S., Johnson, V., Shah, L., Simon, C., & **Williams, J.K.** (2013). Information is information: Public perspectives on genomic incidental findings in clinical testing and research. *Clinical Genetics* 84, 11-18
38. *Goh, A.M.H., Chiu, E., Yastrubetskaya, O., Erwin, C., **Williams, J.**, Juhl, A., & Paulsen, J. (2013) Perception, Experience and Response to Genetic Discrimination in Huntington's disease: The Australian results of the International RESPOND-HD study, *Genetic Testing and Molecular Biology* 17 (2), 115-121.
39. *Downing, N.R., **Williams, J.K.**, Daack-Hirsch, S., Driessnack, M., & Simon, C. (2013). Managing genomic incidental findings in the clinical setting. *Patient Education & Counseling* 90, 133-138.

40. *Downing, N.R. **Williams, J.K.**, Leserman, A., & Paulsen, J.S. (2012). Couple's coping in prodromal Huntington disease. *Journal of Genetic Counseling* 21(3), 662-670.
41. *Brossman, B, **Williams, J.K.**, Downing, N. & Paulsen, J.S (2012). The work function scale: Creating a patient reported outcomes measure. *Journal of Occupational and Environmental Medicine* 54(10):1300-8
42. *Simon, C., Shinkunas, L., Brandt, D., **Williams, J.K.** (2012). Institutional review board guidance for researchers on informed consent, individual genetic research results, and genomic incidental findings. *Journal of Medical Ethics* 38 (7), 417-422.
43. ***Williams, J.K.**, Daack-Hirsch, S., Driessnack, M., Downing, N., Shinkunas, L., Brandt, D., & Simon, C. (2012). Researcher and IRB chair perspectives on incidental findings in genomic research. *Genetic Testing and Biomarkers* 16(6), 508-513.
44. *Simon, C., **Williams, J.K.**, Shinkunas, L., Brandt, D., Daack-Hirsch, S., & Driessnack, M. (2011) Informed consent and genomic incidental findings: IRB chair perspectives. *Journal of Empirical Research on Human Research Ethics* 6 (4), 53-67.
45. *Driessnack, M., **Williams, J.K.**, Barnette, J.J., Sparbel, K.J.H., & Paulsen, J.S. (2012) Development of the HD-Teen Inventory *Clinical Nursing Research* 21 (2), 213-223.
46. *Vaccarino, A.L., Sills, T., Anderson, K.E., Endicott, J., Guiliano, J. Guttman, M., Ho, A.K., Kupchak, Pl, Paulsen, J.S., **Williams, J.**, & Evans, K. (2011). Assessment of Day-to-Day functioning in prodromal and early Huntington Disease. *PLoS Currents* 12(3) RRN1262
47. ***Williams, J.K.** Downing, N., Vaccarino, A., & Paulsen, J.S. (2011). Self reports of day to day function in a small cohort of people with prodromal HD. *PLoS Currents* 11 (3) RRN1254.
48. **Williams, J.K.**, Prows, C.A., Conley, Y.P., Eggert, J., Kirk, M., & Nichols, F. (2011). Strategies to prepare faculty to integrate genomics into nursing education programs. *Journal of Nursing Scholarship* 43 (3), 231-238.
49. ***Williams, J.K.**, Skirton, H., Barnette, J.J., & Paulsen, J.S. Huntington disease caregiver personal concerns. (2012). *Journal of Advanced Nursing* 68 (1), 137-146.
50. Lea, D.H., Skirton, H., Read, C., & **Williams, J.K.** (2011). Educating the Next Generation of Nurses about Genetics and Genomics. *Journal of Nursing Scholarship* 43(1), 3-12.
51. ***Williams, J.K.**, Erwin, C., Juhl, A., Mills, J., Brossman, B., & Paulsen, J.S. (2010). Personal factors associated with reported benefits of HD family history or genetic testing. *Genetic Testing: and Molecular Biomarkers* 14 (5), 629-636.
52. * Paulsen, J.S., Wang, C., Duff, K., Barker, R., Nance, M., Beglinger, L., Moser, D., **Williams, J.K.**, Simpson, S., Langbehn, D., van Kammen, D., and the Predict-HD Investigators of the Huntington Study Group. Challenges assessing clinical endpoints in early Huntington disease. (2010). *Movement Disorders* 25 (15), 2595-2603
53. ***Williams, J.K.**, Barnette, J.J., Reed, D., Sousa, V.D., Schutte, D.L., McGonigal-Kenney, M., Jarmon, L., Phillips, E., Tripp-Reimer, T., & Paulsen, J. (2010) Development of the Huntington disease family concerns and strategies survey from focus group data. *Journal of Nursing Measurement* 18 (2), 83-99.
54. ***Williams, J.K.**, Erwin, C., Juhl, A.R., Mengeling, M., Bombard, Y., Hayden, M.R., Quaid, K., Shoulson, I, Taylor, S., Paulsen, J.S., and the I-RESPOND-HD Investigators of the Huntington Study Group (2010) In their own words: Reports of stigma and

genetic discrimination by people at risk for Huntington disease in the International RESPOND study. *American Journal of Medical Genetics, Part B: Neuropsychiatric Genetics* 153B(6):1150-9.

55. *Erwin, C., Juhl, A.R., **Williams, J.K.**, Mengling, M., Mills, J.A., Paulsen, J.S., and the Investigators of the Huntington Study Group. (2010). Perception, experience, and response to genetic discrimination in Huntington disease: The RESPOND-HD study. *American Journal of Medical Genetics, Part B: Neuropsychiatric Genetics*. 153B(5):1081-93.
56. *Downing, N., **Williams J.K.**, Paulsen, J.S. (2010) Couples' illness attributions in prodromal Huntington Disease, *Journal of Genetic Counseling* 19(4):343-52
57. *Sousa, V., **Williams, J.K.**, Barnette, J.J., & Reed, D. (2010). A new scale to measure a family member's perception of community health care services for persons with Huntington disease. *Journal of Evaluation and Clinical Practice* 16(3):470-5.
58. *Skirton, H., **Williams, J.K.**, Barnette, J.J., & Paulsen, J.S. (2010). Huntington disease: families' experiences of health services *Journal of Advanced Nursing* 66 (3), 500-510.
59. Calzone, K.A, Cashion, A., Feetham, S., Jenkins, J., Prows, C., **Williams, J.K.**, & Wung, S.F. (2010) Nurses Transforming Health Care Using Genetics and Genomics. *Nursing Outlook* 58 (1), 26-35
60. Berg, A.O., Baird, M.A., Botkin, J.R., Driscoll, D.A., Fishman, P.A., Guarinao, P.D., Hiatt, R.A., Jarvik, G.P. Millon-Underwood, S., Morgan, T.M., Mulvihill, J.J., Polin, T.I., Schimmel, S.R., Stefanek, E., Vollmer, W., & **Williams, J.K.** (2009). National Institutes of Health state-of-the science conference statement: Family history and improving health. *Annals of Internal Medicine* 151 (12), 872-877.
61. *Ersig, A.L., **Williams, J.K.**, Hadley, D.W., & Koehly, L.M.(2009). Communication, Encouragement, and Cancer Screening in Families With and Without Mutations for Hereditary Non-Polyposis Colorectal Cancer. *Genetics in Medicine* 11(10):728-34.
62. *Hamilton, R.J., **Williams, J.K.**, Skirton, H., & Bowers, B.J. (2009) Living with genetic test results. *Journal of Nursing Scholarship* 41 (3), 276-283.
63. ***Williams, J.K.**, Ayres, L., Specht, J., Sparbel, K.J.H., & Klimek, M.L.(2009) Caregiving by teens for family members with Huntington disease. *Journal of Family Nursing*. 15(3), 273-294.
64. *Hamilton, R.J., **Williams, J.K.**, Bowers, B., & Calzone, K. Life trajectories, genetic testing, and risk reduction decisions in 18-39 year old women at risk for hereditary breast and ovarian cancer. (2009). *Journal of Genetic Counseling* 18(2):147-59
65. ***Williams, J.K.**, Skirton, H., Paulsen, J.S., Tripp-Reimer, T., Jarmon, L., McGonigal-Kenney, M., Birrer, E., Hennig, B., & Honeyford, J. (2009). The emotional experiences of family carers in Huntington disease. *Journal of Advanced Nursing* 65 (4), 789-798.
66. *Sparbel, K.J.H. & **Williams, J.K.** (2009). Pregnancy as foreground in cystic fibrosis carrier testing decisions in primary care. *Genetic Testing* 13 (1), 1-10
67. *Sparbel, K.J.H., Driessnack, M., **Williams J.K.**, Schutte, D., Tripp-Reimer, T., McGonigal-Kenney, M., Jarmon, L., & Paulsen, J.S. (2008). Teens' experiences living with Huntington Disease. *Journal of Genetic Counseling*. 17, 327-335.
68. *Penziner, E., **Williams, J.K.**, Erwin, C., Wallis, A., Bombard, Y., Beglinger, L., Hayden, M., & Paulsen, J. (2008). Perceptions of genetic discrimination among persons who have undergone predictive testing for Huntington disease. *American Journal of Medical Genetics Part B*. 147B, 320-325.

69. ***Williams, J.K.**, & Ayres, L. (2007). I'm like you: Establishing, confirming and contesting common ground in focus groups with Huntington disease caregivers. *Journal of Research in Nursing* 12 (6), 655-664
70. ***Williams, J.K.**, Hamilton, R.J., Nehl, C., McGonigal-Kenney, M., Schutte, D.L., Sparbel, K.J.H., Birrer, E., Tripp-Reimer, T., Friedrich, R.M., Penziner, E., Jarmon, L., & Paulsen, J. (2007) "No one else sees the difference": Family members' perceptions of changes in persons with preclinical Huntington disease. *American Journal of Medical Genetics Part B* 144B (5), 636-641
71. Beery, T., & **Williams, J.K.** (2007) Risk Modification and Health Promotion Behaviors Following Genetic Testing for Adult Onset Disorders, *Genetic Testing* 11 (2), 111-123
72. *Lea, D.H., **Williams, J.K.**, Cooksey, J Flanagan, P. Forte, G. & Blitzer, M. U.S. Genetics Nursing Advanced Practice Workforce. (2006). *Journal of Nursing Scholarship*. 38 (3), 213-218.
73. **Williams, J.K.**, Skirton, H., & Masny, A. (2006). Ethics, Policy, and Education Issues in Genetic Testing. *Journal of Nursing Scholarship* 38 (2), 119-125.
74. Lea, D.H., Cooksey, J., Flanagan, P., **Williams, J.K.**, & Forte, G (2005). Innovations in Genetics Nursing: Practice and Research, *Japan Nursing Research*. 2, 71-83.
75. Prows, C., Lea, D. H. Glass, M. Nicol, N., Callen, Skirton, H., & **Williams, J.K.** (2005) Genomics to Health: The Missing Link in Nursing Education. *Journal of Nursing Scholarship* 37(3), 196-202
76. Pestka, E.L., & **Williams, J.K.** (2005). International collaboration on genomics education for nurses. *The Journal of Continuing Education in Nursing*, 36(4)
77. Lea, D.H., **Williams, J.K.**, & Donahue, M.P. (2005) Ethical, legal, and social issues in genetic testing. *Journal of Midwifery and Women's Health* 50(3), 234-240.
78. *Hamilton, R., Bowers, B., & **Williams, J.** (2005). Disclosing genetic test results to family members. *Journal of Nursing Scholarship* 37 (1), 18-24.
79. Rolland, J., & **Williams, J.K.** (2005). Toward a family centered psychosocial model of 21st century genetics. *Family Process* 44 (1), 3-24.
80. ***Williams, J.K.**, Tripp-Reimer, T., Schutte, D., & Barnette, J.J. (2004). Advancing genetic nursing knowledge. *Nursing Outlook* 52 (2) 73-79.
81. Skirton, H., & **Williams, J.K.** (2002). Establishing international collaboration in genetics nursing, *Nursing Standard* 16 (17), 38-40
82. **Williams, J.K.** (2002). Education for genetics and nursing practice. *AACN Clinical Issues: Advanced Practice in Acute and Critical Care* 13 (4), 492-500.
83. Lea, D. H., & **Williams, J.K.** (2002). Genetic testing and screening: What every nurse needs to know for today's health care. *American Journal of Nursing* 102 (7), 36-43.
84. **Williams, J.K.**, McCarthy, A.M., Bragadottir, H., & Reed, D. (2002). Children with growth disorders. *Journal of School Nursing* 18(1), 25-32.
85. ***Williams, J, K.** Tripp-Reimer T. (2001). From ecology to base pairs: nursing and genetic science. *Biological Research for Nursing*. 3(1), 4-12.
86. **Williams, J.K.**, & Lessick, M. (2001). History of education of genetic nursing. *MEDSURG Nursing* 10(6), 301-306.
87. ***Williams, J.K.**, Skirton, H., Reed, D., Johnson, M., Maas, M., & Daack-Hirsch, S. (2001) Genetic counseling outcomes validation by UK and US genetics nurses. *Journal of Nursing Scholarship* 33(4), 369-374.

88. Jenkins, J., Prows, C., Dimond, E., Monsen, R., & **Williams, J.** (2001) Genetics Nursing Education Recommendations for Newly Graduated and Practicing Nurses. *Journal of Professional Nursing* 17(6), 283-290.
89. **Williams, J.K.** (2001). Genetics and Nursing. 21st Century message from World to World. *Nursing Research (Japan)* 34(5), 67-74.
90. **Williams, J.K.**, & Schutte, D.L. (2000). Genetic testing and mental health: The model of Huntington disease. *Online Journal of Issues in Nursing* 5(3), Manuscript 4.
91. ***Williams, J.K.**, Schutte, D.L., Evers, C., & Holkup, P.A. (2000). Redefinition: Coping with normal results from presymptomatic gene testing for neurodegenerative disorders. *Research in Nursing and Health* 23, 260-269.
92. ***Williams, J.K.**, Schutte, D.L., Holkup, P.A., Evers, C., & Muilenburg, A. (2000). Psychosocial impact of predictive testing for Huntington disease on support persons. *American Journal of Medical Genetics (Neuropsychiatric Genetics)* 96, 353-359.
93. Lea, D., **Williams, J.**, Jenkins, J., Jones, S., & Calzone, K. (2000). Genetic health care: Creating interdisciplinary partnerships with nursing in clinical practice. *National Academies of Practice Forum* 2(3), 177-186.
94. **Williams, J.K.** (2000). Impact of genome research on children and their families. *Journal of Pediatric Nursing* 15 (4), 207-211.
95. **Williams, J.K.**, Prows, C.A., & Lea, D.H. (2000). Resources in genetics for nursing education. *Journal of Nursing Education* 39(1), 45-47.
96. Prows, C.A., Latta, K.K., Hetteberg, C., **Williams, J.K.**, Kenner, C., & Monsen, R.B. (1999). Preparation of undergraduate nursing faculty to incorporate genetics content into curricula. *Biological Research for Nursing* 1(2), 108-112.
97. **Williams, J.K.** (1999) Evolution and current status of graduate programs in nursing genetics. *Biological Research for Nursing* 1(2), 103-107.
98. Welch, J., & **Williams, J.K.** (1999). Fragile X syndrome. *Neonatal Network* 18(6), 15-22.
99. McCarthy, A., **Williams, J.**, & Denehy, J. (1999). Introduction to individualized health care plans. In J. Williams & A. McCarthy (Eds.). *What school nurses can do to help children with growth disorders*. (pp 66-68) College of Nursing, The University of Iowa, Iowa City, IA
100. McCarthy, A., & **Williams, J.** (1999). Psychosocial impact of growth disorders. In J. Williams & A. McCarthy (Eds.). *What school nurses can do to help children with growth disorders*. (pp 36-45) College of Nursing, The University of Iowa, Iowa City, IA
101. ***Williams, J.K.**, Schutte, D.L, Evers, C., & Forcucci, C. (1999). Adults seeking presymptomatic gene testing for Huntington disease. *Image: Journal of Nursing Scholarship* 31(2), 109-114.
102. *McCarthy, A. M., **Williams, J.K.**, & Plumer, C. (1998). Evaluation of a school re-entry nursing intervention for children with cancer. *Journal of Pediatric Oncology Nursing* 15(3), 143-152.
103. **Williams, J. K.** (1998). Genetic testing: Implications for professional nursing. *Journal of Professional Nursing* 14(3), 184-188.
104. **Williams, J.K.**, Grant, S., Williamson, R. (1998). Genetic carrier testing for cystic fibrosis. *Hawkeye Osteopathic Journal* 15(4), 12-13.

105. **Williams, J. K.** (1998). Genetics and community health nursing. *Holistic Nursing* 12(3), 30-37.
106. Schutte, D. L., **Williams, J. K.**, Schutte, B., & Mass, M. (1998). Alzheimer disease genetics: Practice and education implications for special care unit nurses. *Journal of Gerontological Nursing* 24(1), 41-48.
107. ***Williams, J.K.**, & Schutte, D.L. (1997). Benefits and burdens of genetic carrier identification. *Western Journal of Nursing Research* 19(1), 71-81.
108. **Williams, J. K.** (1997). Principles of genetics and cancer. *Seminars in Oncology*, 13(2), 68-73.
109. *McCarthy, A. M, **Williams, J. K.**, & Eidahl, L. (1996). Children with chronic conditions: Educators' views. *Journal of Pediatric Health Care*, 10(6), 272-279.
110. Ryan, L., & **Williams, J. K.** (1996). Cystic fibrosis handbook for teachers. *Journal of Pediatric Health Care*, 10(4), 174-179.
111. **Williams, J. K.**, & Lessick, M. (1996). Genome research: Implications for children. *Pediatric Nursing*, 22(1), 40-46.
112. **Williams, J. K.** (1995). Genetics and cystic fibrosis: A focus on carrier testing. *Pediatric Nursing*, 21(5), 444-448.
113. ***Williams, J. K.**, & McCarthy, A. M. (1995). School nurses' experiences with children with chronic conditions. *Journal of School Health*, 65(6), 234-236.
114. **Williams, J. K.**, & Lea, D. H. (1995). Applying new genetic technologies: Assessment and ethical considerations. *The Nurse Practitioner*, 20(7), 16-26
115. ***Williams, J. K.** (1995). Parenting a daughter with precocious puberty or Turner syndrome. *Journal of Pediatric Health Care*, 5, 109-114.
116. Vockroch, L., & **Williams, J. K.** (1994). A reproductive option for females with Turner syndrome. *Journal of Pediatric Nursing*, 9(5), 321-325
117. Lea, D. H., **Williams, J. K.**, & Tinley, S. T. (1994). Nursing and genetic health care. *Journal of Genetic Counseling*, 3(2), 113-124.
118. Lessick, M., & **Williams, J. K.** (1994). The human genome project: Implications for nursing. *MEDSURG Nursing*, 3(1), 49-58.
119. ***Williams, J. K.** (1994). Behavioral characteristics of children with Turner syndrome and with learning disabilities. *Western Journal of Nursing Research*, 16(1), 26-39
120. **Williams, J. K.** (1993). New genetic discoveries increase counseling opportunities. *The American Journal of Maternal/Child Nursing*, 18(4), 218-222.
121. Hulsebus, D., & **Williams, J. K.** (1992). Cystic fibrosis: A new perspective in genetic counseling. *Journal of Pediatric Health Care*, 6, 338-342.
122. ***Williams, J. K.**, Richman, L., & Yarbrough, D. (1992). Comparison of visual-spatial performance strategy training in children with Turner syndrome and learning disability. *Journal of Learning Disabilities*, 25(10), 658-664.
123. ***Williams, J. K.** (1992). School aged children with Turner syndrome. *Journal of Pediatric Nursing*, 7(1), 14-19.
124. ***Williams, J. K.**, Richman, L., & Yarbrough, D. (1991). A comparison of memory and attention in Turner syndrome and learning disability. *Journal of Pediatric Psychology*, 16(5), 585-594.
125. Eliason, M. J., & **Williams J. K.** (1990). Fetal alcohol syndrome and the neonate. *The Journal of Perinatal and Neonatal Nursing*, 3(4), 64-72.

126. **Williams, J. K.** (1989). Screening for genetic disorders. *Journal of Pediatric Health Care*, 3(3), 115-121.
127. **Williams, J. K.** (1986). Genetic counseling in pediatric nursing care. *Pediatric Nursing*, 12(4), 287-290.
128. **Williams, J. K.** (1986). Counseling adolescents about environmental teratogens. *Pediatric Nursing*, 12(4), 292-295.
129. **Williams, J. K.** (1983). Understanding genetic and birth defects-An essential skill for the occupational health nurse. *Occupational Health Nursing*, 31(10), 24-27, 33-37.
130. **Williams, J. K.** (1983). Evaluating the dysmorphic child. *Pediatric Nursing*, 9(4), 241-248.
131. ***Williams, J. K.** (1983). Pediatric nurse practitioners' knowledge of genetic disease. *Pediatric Nursing*, 9(2), 119-121.
132. **Williams, J. K.** (1983). Reproductive decisions: Adolescents with Down syndrome. *Pediatric Nursing*, 9(1), 43-44, 48.
133. ***Williams, J. K.** (1977). Learning needs of new parents. *American Journal of Nursing*, Part 2, 77, 1173.

Non Peer Reviewed

1. Duree, B.K., **Williams, J.K.**, & Nelson, P. (2022, Winter) New cultural awareness and sensitivity in RN/BSN students: In their own words. *Iowa Nurse Reporter*
2. **Williams J.D.** (2018) Genomics: Data for your health. *Iowa Alumni Magazine*, March
3. **Williams, J.K.**, Cashion, A.K., & Brooks, P.J. (2015). *Return of Anticipated and Incidental Results from Next Generation Sequencing: Implications for Providers and Patients*, Discussion Paper, Institute of Medicine, Washington, DC.
<http://www.iom.edu/insertlinktoyourpaper>
4. **Williams, J.K.**, Daack-Hirsch, S., Driessnack, M., Downing, N.R., & Simon, C. (2013). The importance of patient engagement. *Genetic Testing and Molecular Biomarkers* 17(9), 1
5. **Williams, J.K.**, & Driessnack, M. (2011). We need to talk: Opening a dialogue in your family about Huntington Disease. *We Are HD*, New York: Huntington Disease Society of America, January.
6. **Williams, J.K.** (2006) Growing up in an HD family. *The Marker*, New York: Huntington Disease Society of America. October.
7. **Williams JK.** (2000) History of Genetics and Nursing. Health Resources and Services Administration and the National Institutes of Health, *Report of the Expert Panel on Genetics and Nursing: Implications for Education and Practice*, US Department of Health and Human Services, BHP 00177

Books/book chapters, monographs, edited symposia

Book Editor

1. Skirton, H., Patch, C, & **Williams, J.K.** (2005) *Applied genetics in healthcare*. New York: Taylor & Francis.
2. Van Dyke, D.C., Mattheis, P., Eberly, S., & **Williams, J. K.** (Eds.). (1995). *Medical & surgical care for children with Down syndrome*. Rockville, MD: Woodbine House.

Book Chapters

1. **Williams, J.K.**, (2017). Integration of Genomics into Nursing Research. In A.S. Hinshaw, & P.A. Grady (Eds.). *Using Nursing Research to Shape Health Policy*. Chapter 4 pp 55-71. New York: Springer
2. **Williams, J.K.**, & Sobel, S. (2006) Dementing genetic conditions. In S. Miller, S. McDaniel, J. Rolland, & S. Feetham (eds.). *Individuals, Families, and the New Genetics*, pp. 231-247, New York: Norton, W.W. & Company, Inc.
3. **Williams, J.K.**, & Skirton, H. (2009). Genomics, family nursing, and families across the life span. In J. Kaakinen, V. Gedaly-Duff, D. Coehlo, S. Hanson, (Eds.). *Family Health Care Nursing* (4th Ed.) Philadelphia: F.A.Davis.
4. **Williams, J.K.**, & Skirton, H. (2005) Genetics and families across the lifespan. In *Family Health Care Nursing*. 3rd Ed. S. Hanson, V. Gedaly-Duff, & J. Kaakinen Eds. (pp. 437-456). Philadelphia: F.A. Davis
5. **Williams, J.K.** Genetic assessment and counseling. In *Nursing Excellence for Children & Families*, (2006). M.J.Craft-Rosenberg & M. Krajicek (Eds). New York: Springer
6. **Williams, J.K.** (2016). HD Teen Caregivers. *A Caregiver Guide for Huntington Disease Families*. Huntington Disease Society of America. New York, NY
7. **Williams, J.K.** (2009). Concerns of patients and families surrounding genetic testing. In R Monsen (ed.). *Genetics and Ethics in Nursing*. (pp. 241-251), Silver Spring, MD: American Nurses Association.
8. **Williams, J. K.**, & Schutte, D.L. (1999). Genetic counseling. In G. Bulechek, & J. McCloskey. (Eds.). *Nursing Interventions: Effective Nursing Treatments* (3rd Ed.). Philadelphia, PA: Saunder
9. **Williams, J. K.** (2001). Genetic counseling. In M. Craft-Rosenberg & J. Denehy (Eds.). *Nursing Interventions for Childbearing and Childrearing Families*. (pp.201-220) St. Louis: Mosby-Year Book.
10. **Williams, J. K.** (1992). Genetics and genetic disorders. In A. Maccleran (Ed.). *Nurse's Clinical Guide to Maternity Care* (pp. 34-43). Springhouse PA: Springhouse Corporation.
11. **Williams, J. K.** (1991). Genetics and genetic disorders. In S. M. Cohen, C. A. Kenner, & A. O. Hollingsworth (Eds.). *Maternal, Neonatal, and Women's Health* (pp. 228-254). Springhouse PA: Springhouse Corporation.
12. **Williams, J. K.** (1988). Management strategies. In *Genetic Applications: A Health Perspective* (pp. 275-280). Denver, CO: University of Colorado Health Sciences Center, School of Nursing and School of Medicine, Genetics Unit.
13. **Williams, J. K.** (1988). Genetic disorders. In *Nursing Yearbook '88* (pp. 25-29). Springhouse, PA: Springhouse Corporation.
14. **Williams, J. K.** (1987). Genetic counseling and prenatal diagnosis. In B. Jennings, L. Sonstegaard, D. Kowalski (Eds.). *Women's Health: Crisis and Illness in Childbearing*. Vol. 3 (pp. 67-78). San Diego CA: Grune Stratton, Inc.
15. **Williams, J. K.** (1986). Risk assessment and screening. In G. Felton (Ed.). *Proceedings of the National Conference on Nursing Practice in Clinical Genetics: Prospects for the 21st Century* (pp. 53-70). Iowa City, IA: The University of Iowa, College of Nursing.
16. **Williams, J. K.** (1984). Surveys of nursing knowledge and roles in genetics. In J. Weiss & S. Jones (Eds.). *Education in Genetics II: Nurses and Social Workers, Proceedings of*

- a Workshop* (pp. 81-92). Washington DC, The Division of Maternal and Child Health, Department of Health and Human Services.
17. Rolland, J.S., & **Williams, J.K.** (2006) Psychosocial typology of 21st century genetics. In S. Miller, S. McDaniel, J. Rolland, & S. Feetham (eds.). *Individuals, Families, and the New Genetics*, pp. 36-78, New York: Norton, W.W. & Company, Inc.
 18. Randall, C., & **Williams, J. K.** (1985). The role of the nurse practitioner/distributive or episodic care? In J. McCloskey & H. Grace (Eds.). *Current Issues in Nursing* 2nd Ed., (pp. 321-336). Boston MA: Blackwell Scientific Publications.
 19. Hellings, P., Burns, C., & **Williams, J.K.** (2008). Genetic disorders. In C.Burns, A. Dunn, M. Brady, N Barber-Starr, & C. Blosser, Eds. *Burns: Primary Pediatric Care: A Handbook for Nurse Practitioners*. 4th Ed. St. Louis: Elsevier.

Monographs

1. **Williams, J. K.**, & Lea, D.H. (2003). *Genetic Issues for Perinatal Nurses*. 2nd Ed. ISBN 0-86525-095-2; White Plains, NY: March of Dimes Birth Defects Foundation.
2. **Williams, J. K.** (1996). *Genetic Issues for Perinatal Nurses*. White Plains, NY: March of Dimes Birth Defects Foundation.
3. **Williams, J.**, & McCarthy A. Eds. (1999). *What school nurses can do to help children with growth disorders*. College of Nursing, The University of Iowa, Iowa City, IA
4. Tarapata, K. Kogan, J., **Williams, J.** (Eds.) (2013). *Talking with Kids about HD*. Huntington Disease Society of American, New York
5. Feetham, S.L., & **Williams, J.K.** (2004). *Nursing and 21st Century Genetics: Leadership for Global Health. Monograph*. International Council of Nurses

Editorials

1. **Williams, J.K.**, Driessnack, M., Daack-Hirsch, S., Downing, N., & Simon, C. (2013) Editorial: Disclosure of incidental genomic findings involving children: Are we making progress? *Personalized Medicine* 10 (6), 519-521.
2. **Williams, J.K.** (2009). From Nightingale and Mendel to genomics in health care for children. *Journal of Pediatric Nursing*. Jun;24(3):171-2.
3. **Williams, J.K.** (2004). Nursing research linking genetics and health. *Research and Theory for Nursing Practice* 17 (4), 267-272.
4. **Williams, J.K.** (2001). Genetic nursing research. *Biological Research for Nursing*, 3(1),
5. Lea, D.H., & **Williams, J.K.** (2001). Are you ready for the genetic revolution? *American Journal of Nursing* 101(8), 11.
6. Gaff, C.L., & **Williams, J.K.D.** (2008). Genetics in health practice and education special issue. *Journal of Genetic Counseling* 17, 143-144.

Scientific and Educational Research Grants

Intramural Research Grants Funded

2019-2020, *Rapid Response System Implementation within a Long Term Acute Care Hospital (LTACH)* Bunch, J. & Dunn, H. PIs, **Williams, J.K.**, Consultant & Research Mentor, Effort

- donated, Csomay Center Woodrow W. Morris Gerontology Research Award for Faculty, The University of Iowa, \$5,000
- 2019-2020, *Evaluation of Rapid Response Systems and Resources in Rural Critical Access Hospitals to Reduce Unexpected Inpatient Injury and Mortality* Bunch, J PI, **Williams, J.K.**, Consultant & Research Mentor, Effort donated, UI Injury Prevention Research Center, College of Public Health, The University of Iowa, \$22,300
- 2007-2008, *Teen Caregivers for Family Members with Dementia and Chronic Disease*, **Williams, J.K.**, PI, Center for Advanced Studies Spelman Rockefeller Grant (CASSPR), The U of Iowa, \$8,955
- 1997-1998, *Genetic Testing in Adults and Elders*, **Williams, J.K.**, PI, Gerontological Nursing Interventions Research Center, The University of Iowa, \$10,000
- 1995, *Presymptomatic Genetic Testing: Information Disclosure and Health Behaviors*, **Williams, J.K.**, PI, Central Investment Fund for Research Enhancement, The University of Iowa, \$7,815
- 1993-1994, *Psychosocial Impact of Genetic Knowledge: Developmental Project*, **Williams, J.K.**, PI, Collaborative Human Linkage Center, The University of Iowa, \$13,687
- 1993, *Psychosocial Impact of Genetic Knowledge: Preliminary Data Analysis*, **Williams, J.K.**, PI, Old Gold Summer Fellowship, The University of Iowa, \$5,000
- 1992, *Psychosocial Impact of Genetic Knowledge: Instrument Pilot*, **Williams, J.K.**, PI, Office of Nursing Research Seed Grant, The University of Iowa, \$300
- 1991, *Parent Normalization and Children with Chronic Disorders*, **Williams, J.K.**, PI, Old Gold Summer Fellowship, The University of Iowa, \$3,500
- 1991, *Psychological adjustment of children with altered sexual maturity*, **Williams, J.K.** PI, Biomedical Seed Grant, The University of Iowa, #2SO7RR07035-26, \$9,380

Extramural Research Grants-Funded

- 2019-2020, *Keeping patients safe: Understanding how nurses recognize, evaluate, and determine the appropriate response to patient- or family-expressed safety concerns*, P Groves, PI, **Williams, J.K.** Co-Investigator, Donated, American Nurses Foundation, \$5,000
- 2018-2023, *Center for Advancing Multimorbidity Science (CAMS): Profiling risk and symptom expression to develop customized therapies for adults with multiple chronic conditions*, Gardner, S., & Rakel, B, PIs, **Williams, J.K.**, Enrichment Program Director, 2.5% Effort, 1P20 NR018081-01, \$1,905,447
- 2011-2014, *Personal Perspective and Provider Communication of Genomic Risk for T2DM*, Sandra Daack-Hirsch PI, **Williams, J.K.**, Primary Mentor K23 NR012972, \$373,631
- 2009-2011, *Managing Incidental Findings in the Genomic Era*, **Williams, J.K.** MPI NHGRI RC1 HG005786, \$868,130
- 2007-2010, *Work Function Measurement Development*, Paulsen, J.S. PI, **Williams, J.K.** Investigator, CHDI, Inc., \$262,186
- 2007-2010, *Screening for Heritable Disorders in Children: Efficacy from a Family/Consumer Perspective*, Health Resources and Services Administration, **Williams, J.K.** Co PI, U33MC07950-01-00, \$390,000

2005-2008, *Response of a Sample Population with the Deleterious HD allele (RESPOND-HD)*, **Williams, J.K.** Co- PI, National Human Genome Research Institute, Ethical, Legal, and Social Issues Research Program, # R01 HG003330, \$448,880

2005-2007, *Decision making in young women at genetic risk for HBOC*, Rebekah Hamilton, PI, **Williams, J.K.**, Consultant, R03 NR09483, University of Pittsburgh, \$100,000

2005-2006, *Living with predictive genetic test results*, Rebekah Hamilton, PI, **Williams, J.K.**, Consultant, University of Pittsburgh, PA, STT Small Grants, Rebekah Hamilton, \$4224

2001-2005, *Family Health After Predictive HD Testing*, **Williams, J.K.** PI, National Institute of Nursing Research, National Institutes of Health, R01 NR07970, \$1,470,000

2001-2005, *Parents' Interpretation and Use of Genetic Information*, Agatha Gallo, PI, **Williams, J.K.** Consultant University of Illinois, R01HG002036

1996-1998, *Growth Disorders: School Nurse Education*, **Williams, J.K.** PI, Genentech Foundation for Growth and Development, \$31,000

1995, *Evaluation of a School Re-entry Nursing Intervention for Children with Cancer*, McCarthy, A.M., Principal Investigator, **Williams, J.K.** Investigator Gamma Chapter, Sigma Theta Tau, \$750

1994-1997, *Genetic Knowledge: Psychosocial Impact*, **Williams, J.K.** PI, National Institute of Nursing Research, National Institutes of Health, R15 NR03780-01, \$109,237

1994-1995, *Educators' Questions Regarding Children with Chronic Health Conditions*. McCarthy, A.M., Principal Investigator, **Williams, J.K.** Investigator, National Association of Nurse Associates and Practitioners Foundation, \$1,674

1988-1989, *Nursing Management of Children with Birth Defects*, **Williams, J.K.** PI, National Center for Nursing Research, NIH F31-NR06221-01, \$10,552

1983-1984, *A Survey of Problems Encountered by Parents of Children with Birth Defects and Where They Sought Help in Solving Them*, **Williams, J.K.** PI, Gamma Chapter, Sigma Theta Tau and National Assn of Nurse Associates and Practitioners Foundation, \$100 and \$700

Training Grants

Extramural Training Grants-Funded (*Funded, followed by pending*)

2009-2021, *Pain and Associated Symptoms: Nurse Research Training*, Herr, K., & McCarthy, A.M. PIs, **Williams, J.K.** Senior Faculty, Effort donated. T32 NR011147, \$1,261,825

2006-2011, *Clinical Genetics Nursing Research*, **Williams, J.K.** PI, National Institute of Nursing Research, National Institutes of Health, 2 T32NR007110-06, \$1,086,071

2001-2006, *Clinical Genetics Nursing Research*, **Williams, J.K.** PI, National Institute of Nursing Research, National NIH, 1T32NR07110-01, \$1,028,000

Other Sponsored Projects -Funded

2015-2016, *Communication of genetic risk for sudden cardiac death from probands to relatives*, L Shah PI, **Williams, J.K.** Co-Sponsor, National Institute of Nursing Research, National Institutes of Health, F31NR014758, \$75,357

2004-2007, *The Spirituality of Children with Duchenne Muscular Dystrophy*, Shelley Rae Pehler PI, **Williams, J.K.**, Cosponsor, F31 Predoctoral NRSA, Shelley Rae Pehler, The University of Iowa, Iowa City

2004-2006, *Patient and Contextual Factors in CFCT Decision Making*, Kathleen Sparbel, PI, **Williams, J.K.**, Sponsor, F31 Predoctoral NRSA, The University of Iowa, Iowa City

2004-2006, *Web-based education series for nurses*, C. Prows PI, **Williams, J.K.**, Advisor, University of Cincinnati, R25-HG002663, ELSI, NHRGI,

2002-2004, *Assessing genetics services and the health workforce*, Judith Cooksey, PI, **Williams, J.K.**, Member, Advisory Council, HRSA 1 U78 HP 00016-01

2000-2003, *Nursing CD-ROM on Ethical Issues of Genetic Testing, Ethical, Legal, & Social Implications Research Program*, **Williams, J.K.**, PI, National Human Genetics Research Institute, National Institutes of Health, R25 HG02074-01, \$586,866

2000, *Midwest Genetic Nursing Research: Advancing Science*, **Williams, J.K.**, PI, Ethical, Legal & Social Implications Research Program, National Human Genetics Research Institute, National Institutes of Health, R13 HG02227-01, \$49,830

Research Presentations

***Data based**

Underlined=student or trainee

International

1. 2020. Groves, P., **Williams, J.K.**, & Bunch J. *Creating space to foster patient and family trust: A key role of hospital nurses in safety co-production* accepted by QSEN International Forum 2020, Philadelphia May 2020 .(conference cancelled due to COVID)
2. 2016. ***Williams, J.K.** *Ethics, Discrimination, Daily Function, and HD: Lessons Learned in PREDICT-HD*. Huntington Study Group, Nashville, TN, [podium, invited]
3. 2014, ***Wedderburn S**, Rae D, **Williams J**, Carey-Heaton R, & Miedzybrodzka Z. *Genetic Discrimination and predictive testing for Huntington's Disease and Familial Cancer in Northern Scotland: the I- RESPOND-UK study*. European Huntington's Disease Network conference, Sept 19-21, Barcelona, Spain [peer reviewed, poster]
4. 2013, ***Williams J.K.**, *The Evolution of Genetics Nursing Research*, ISONG Keynote, 25th anniversary conference, Oct 5, Bethesda, MD [keynote, invited]
5. 2012 ***Ungerer, L.L.**, Daack-Hirsch, S., Driessnack, M., Simon, C., & **Williams, J.K.** *It Might Lead To An Answer. Examining Views On Incidental Findings Through Caregivers' Narratives About Their Children's Diagnostic Dilemmas*, ISONG, Philadelphia [peer review, poster]
6. 2011, ***Downing, N**, **Williams J.K.**, Daack-Hirsch, S., & Simon, C. *Genomic incidental findings: What are they and what should we do about them?* American College of Medical Genetics, Vancouver, CA, [peer review, podium]
7. 2011, ***Williams, J.K.**, Daack-Hirsch, S., Downing, N., Spore, A., Johnson, V., Alasgheirin, M., Driessnack, M., & Simon, C. *Researcher and public reflections on reporting incidental findings to participants in genomic research*. ISONG, Montreal, CA, [peer review, podium]
8. 2011 ***Sparbel, K.J.**, & **Williams, J.K.** *Influences on genetic testing decisions in teens and young adults and genomic nursing implications: An exemplar with three population groups* ISONG, Montreal, CA, [peer review, podium]

9. 2011, *Downing, N., **Williams, J.K.**, & Paulsen, J.S. *Perceived Risks and Benefits of Research Results Disclosure in Huntington Disease-Related Research*. ISONG, Montreal, CA [peer reviewed, poster]
10. 2011, *Daack-Hirsch, S., Spore, A., **Williams, J.K.**, Driessnack, M., & Simon, C. *Managing incidental findings from genomic testing: A public perspective*, American Society of Human Genetics, Montreal, CA [peer reviewed, poster]
11. 2011, *Driessnack, M., Ayres, L., Barnette, J., **Williams, J.K.**, Paulsen, J.S. *I try real hard: Identifying useful strategies for teens in Huntington Disease (HD) families*. ISONG, Montreal, CA, [peer reviewed, poster]
12. 2011* Daack-Hirsch, S., Spore, A., **Williams, J.K.**, Driessnack, M., & Simon, C. *Managing incidental findings from genomic testing: A public perspective*. ASHG, Montreal [peer review, poster]
13. 2010, ***Williams, J.K.** , Easton J. *Optimizing the healthy development of children and youth*. Huntington Society of Canada, Edmonton, CA [invited, podium]
14. 2010.* Daack-Hirsch, S., **Williams, J.K.**, Simon, C., Driessnack, M., Downing, N., Johnson, V., Shinkunas, L., & Spore, A. *Ethical issues in incidental findings from genomic testing*. International Society of Nurses in Genetics, Dallas, TX. [peer reviewed, podium]
15. 2010.* Driessnack, M., **Williams, J.K.**, Barnette, J.J., & Paulsen, J.S. *Field testing of the HD teen survey: Initial findings*. ISONG, Dallas, TX, [peer reviewed, podium]
16. 2009, *Skirton, H., **Williams, J.K.**, Barnette, J.J., & Paulsen, J.S. *The experiences of families affected by Huntington disease regarding health services in the United Kingdom and United States*. World Congress on Huntington's Disease, Vancouver CA [peer reviewed, podium]
17. 2009, ***Williams, J.K.**, Skirton, H., Barnette, J.J., & Paulsen, J.S. *Personal concerns of United States and United Kingdom Huntington disease family caregivers*. World Congress on Huntington's Disease, Vancouver, CA [peer reviewed, podium]
18. 2009, ***Williams, J.K.**, Ayres, L., Specht, J., Sparbel, K., & Klimek, M.K. *Teen Caregivers of Family Members with Huntington Disease*. World Congress on Huntington's Disease, Vancouver, CA [peer reviewed, podium]
19. 2009, *Erwin, C., **Williams, J.K.**, Juhl, A.R., Mengeling, M., Mills, J.A., Bombard, Y., Hayden, M.R., Kayson, E., Shoulson, I., Quaid, K., Taylor, S., Paulsen, J.S., and the Investigators of the Huntington Study Group. *The RESPOND-HD study of genetic discrimination in persons at risk for Huntington Disease*. World Congress on Huntington's Disease, Vancouver, CA [peer reviewed, podium]
20. 2009, ***Williams, J.K.**, Erwin, C., Juhl, A. Mengeling, M., Bombard, Y., Hayden, M.R., Shoulson, I. Taylor, S., Paulsen, J.S. and the Investigators for the Huntington Study Group. *The RESPOND-HD study of genetic discrimination and stigma experiences of people at risk for HD*. World Congress on Huntington's Disease, Vancouver, CA, [peer reviewed, podium]
21. 2009, *Oster, E., Juhl, A., Erwin, C., **Williams J.K.**, Mengling, M., Mills J.A. Bombard, Y., Hayden, M., Shoulson, I. Taylor, S., Dorsey, E.R., Paulsen, J.S. and the Huntington Study Group PREDICT-HD and PHAROS Investigators. *Genetic discrimination in insurance: Attitudes, behaviors and experiences*. World Congress on Huntington's Disease, Vancouver, CA, [peer reviewed, podium]

22. 2009.* **Williams, J.K.**, Erwin, C., Juhl, A., Mengeling, M., Bombard, Y., Hayden, M.R., Paulsen, J.S., and The Huntington Study Groups PREDICT-HD and PHAROS Investigators. *Responses to Potential Genetic Discrimination by People At-risk for Huntington Disease* International Society of Nurses in Genetics, San Diego. [peer reviewed, podium]
23. 2007, ***Williams, J.K.** *A study of the needs of carers in Huntington disease: Implications for health and social care policy*. ISONG, Bristol, England, [peer reviewed, poster]
24. 2007, ***Williams, J.K.**, Pehler, S.R., Sparbel, K., HD Family Research Team. *Focus groups and teens in families with HD*. ISONG, Bristol, England, [peer reviewed, poster]
25. 2006.* Dreissnack, M. **Williams, J.**, & Sparbel, K. *There's Just Me': Teens Talk About Living In A Family with Huntington Disease* ISONG, New Orleans, [peer review, podium]
26. 2005, ***Williams, J.K** *Family caregiving research across national boundaries*. Health and Social Care Interdisciplinary Innovation and Research, University of Plymouth, Plymouth England [Invited, podium]
27. 2005* Birrer, E., Hamilton, R., McGonigal-Kenney, M., Schutte, D., Sparbel, K., & **Williams, J.K.** *Symptoms reported by family members of persons with a positive Huntington disease gene test prior to clinical diagnosis*. 18th ISONG, Salt Lake City, UT, October. [peer reviewed, poster]
28. 2004.* **Williams, J.K.**, & Hamilton, R.J. *Huntington disease: Living with predictive testing results- It's the big unknown*. ISONG, Toronto, CA [peer review, podium]
29. 2003. **Williams, J.**, *Integrating genetics and nursing science*, ISONG, Los Angeles, CA, [invited, podium]
30. 2001, ***Williams, J.K** *Living with HD: The Iowa experience*. Genetics Medical Institute, Cardiff, Wales, [invited, podium]
31. 2001. **Williams, J.**, *Family and Ethical Issues in Genetic Testing for Diabetes*. Diabetes: From Genetics to Clinical Practice. MNRS, Chicago, IL [invited, podium]
32. 2000, ***Williams, J.K.**, D. Schutte, P. Holkup, C. Evers, & A. Muilenburg, *Psychosocial impact of predictive testing for Huntington Disease on support persons*. 5th International Family Nursing Conference, Chicago, IL [peer reviewed, poster]
33. 1999* **Williams, J.K.**, Schutte, D., Evers, C., & Holkup, P. *Redefinition: Coping with negative presymptomatic HD and PPND gene test results*, ISONG, San Francisco, October [peer reviewed, poster]
34. 1999* Schutte, D., **J. Williams**, Muilenburg, A., Evers, C., & Holkup, P.; *Experience of Support Persons Participating in Presymptomatic Genetic Testing Protocols for Huntington Disease*, ISONG, San Francisco, October [peer reviewed, poster]
35. 1998, **Williams, J.K** *Practice, Education, and Research: Genetics and the Family*. 5th International Family Nursing Conference, Chicago, IL, [peer reviewed, podium]
36. 1998, ***Williams, J.K.**, *Evaluation of a school re-entry program for children with cancer*, Department of Psychology Research Seminar, Exeter University, Exeter, England [invited, poster]
37. 1998, ***Williams, J.K.**, D. Schutte, C. Evers, C. Forcucci. *Concerns of Adults Completing Presymptomatic Gene Testing for Huntington Disease* Sixth European Meeting on Psychosocial Aspects of Genetics, Paris, France [peer reviewed, poster]

38. 1998* **Williams, J.K.**, Schutte, D., Evers, C., & Forcucci, C. *Concerns of Adults Completing Presymptomatic Gene Testing for Huntington Disease*, ISONG, Denver, CO [peer reviewed, poster]
39. 1997* Grant, S., & **Williams, J.K.**, *Communication of prenatally diagnosed balanced translocation results to offspring by mothers*, ISONG, Denver, CO [peer reviewed, poster]
40. 1993* **Williams, J.K.** *Turner syndrome*. ISONG, New Orleans, LA [peer reviewed, poster]

National

1. 2017. ***Williams, J.K.** Bioethics; Bioethics and Omics Research. American Academy of Nursing Annual Meeting. [invited, panel]
2. 2015.* Ersig, A.L., Tsalikin, E. Coffey, J., & **Williams, J.K.** *Stressors of teens with type 1 diabetes and their parents: The importance of change*. CANS, Washington D.C., [peer review, poster]
3. 2014* Cohn, E., Hamilton, N., Larson, E. & **Williams, J.K.** *Who is represented in the Nation's biobanks? Why we can't wait to eliminate health disparities in genomic medicine*. Washington DC [peer review, poster]
4. 2013. ***Williams, J.K.** *Behavioral/Social Science Genomics-Based Nursing Research: State of the Science, Challenges, and Opportunities*. Genomic Nursing Science Workshop, NINR, August 20-21, 2013, Bethesda, MD [invited, podium]
5. 2013. *Downing, N.D., Kim, J.-I., **Williams, J.K.**, Long, J.L., Mills, J.A., Paulsen, J.S. and the PREDICT-HD researchers. *Measurement of function for Huntington disease clinical trials* CANS, [peer reviewed, podium]
6. 2012. *Daack-Hirsch, S., Driessnack, M., Hanish, A., Johnson, V., Simon, C., & **Williams, J.K.** *Public Expectations for Communicating Incidental Findings in Genetic Testing*. CANS, Washington DC [peer reviewed, podium]
7. 2011. ***Williams, J.K.**, Shinkunas, L., Downing, N., & Simon, C. *IRB Chair and researcher perspectives on the emergence of genomic incidental findings*. Exploring the ELSI Universe: 2001 Congress, Chapel Hill, NC [peer reviewed, podium]
8. 2011. * Simon, C., Shinkunas, L., & **Williams, J.K.** *Autonomy, Beneficence, and Genomic Incidental Findings: Perspectives from IRBs*. American Society of Bioethics + Humanities, Minneapolis [peer reviewed, podium]
9. 2011* Simon, C., Shinkunas, L., & **Williams, J.K.** *Expanding consent processes to account for the prospect of genomic incidental findings (GIFs): IRB viewpoints* Exploring the ELSI Universe: 2001 Congress, Chapel Hill, NC [peer reviewed, poster]
10. 2010.* Paulsen, J.S., Erwin, C., **Williams, J.**, Nance, M. *The PREDICT-HD Ethics Committee and the PREDICT-HD Investigators of the Huntington Study Group. Implications of PREDICT-HD for Clinical Geneticists*. American College of Medical Genetics, Albuquerque, NM [peer reviewed, podium]
11. 2010. * **Williams, J.K.** *How to cope with a parent who has HD: Youth 9-13*. Huntington Society of American, Raleigh, NC. [peer reviewed, podium]
12. 2010. * **Williams, J.K.** *Focus on the Family Care Forum: Talking to Kids about HD*. Huntington Society of American, Raleigh, NC [invited, group moderator]

13. 2010* Simon, C., **Williams, J.K.**, Shinkunas, L., & Daack-Hirsch, S. *IRB Chair Perspectives on Genomic Incidental Findings (GIFs)* PRIM&R, San Diego [peer reviewed, poster]
14. 2009* Bonhomme, N., McWalter, K., Copeland, S., **Williams, J.K.**, Piper, K.N., Terry, S.F., Au, S.M. *Integrating consumer perspectives in newborn screening: A model building approach*. 137th American Public Health Association, Philadelphia [peer reviewed, poster]
15. 2009* Erwin, C., **Williams, J.K.**, Juhl, A., Mills, J.A., Paulsen, J.S., and the I-RESPOND-HD Investigators of the Huntington Study Group. *Worry and experience of genetic discrimination in persons at risk for Huntington disease* Huntington Disease Study Group annual meeting, Baltimore [peer reviewed, poster]
16. 2008.* **Williams, J.K.**, Barnette, J.J., Skirton, H., McGonigal-Kenney, M., Jarmon, L., Twose, S., Paulsen, J., & Tripp-Reimer, T. *Personal concerns among US and UK families of persons with Huntington disease*. CANS, Washington DC [peer reviewed, podium]
17. 2008* **Williams, J.K.**, Skirton, H., Barnette, J.J., Sousa, V., Paulsen, J.S., Tripp-Reimer, T., Schutte, D., McGonigal-Kenney, M., & Jarmon, L. *Community health services for persons with Huntington disease in North America and the UK*. Translating ELSI: Ethical, Legal and Social Implications of Genomics. Cleveland Ohio [peer reviewed, poster]
18. 2008* Erwin, C., **Williams, J.**, Murray, G., Wallis, A., Bombard, Y., Hayden, M., & Paulsen, J. *Perceptions and experiences of discrimination in persons at-risk for Huntington's disease*. Translating ELSI: Ethical, Legal and Social Implications of Genomics. Cleveland Ohio [peer reviewed, poster]
19. 2008 * Erwin, C., Paulsen, J.S., & **Williams, J.K.** *RESPOND- Preliminary Data Narrative*. Huntington Study Group, St Pete Beach, Florida [peer reviewed, poster]
20. 2007.* **Williams, J.K.** *Changing roles in a HD family*. HDSA 22nd annual convention, Oklahoma City. [peer reviewed, podium]
21. 2007.* **Williams, J.K.** *Managing the HD Household*. HDSA 22nd annual convention, Oklahoma City [invited, podium]
22. 2007,* **Williams, J.K.** *Kids as caregivers*. HDSA 22nd convention, Oklahoma City, [invited, podium]
23. 2007.* **Williams, J.K.** *Family management of Huntington disease before and after diagnosis*. National Human Genome Research Institute Division of Intramural Research Seminar [invited, podium]
24. 2007* Sousa, V. D., **Williams, J. K.**, Barnette, J. J., & Reed D. *Psychometric Properties of a New Measure of Caregiver's Perception of Community Health Care Services for Persons with Huntington Disease*, Sigma Theta Tau, International, Baltimore, November [peer reviewed, poster]
25. 2007* Letocha Ersig, A., Hadley, D., **Williams, J.K.**, & Koehly, L. *Family communication, appraisal, and coping in the context of indeterminate genetic test results for hereditary non-polyposis colorectal cancer*. National Human Genome Research Institute Social and Behavioral Research Branch, September [peer reviewed, poster]
26. 2006.* **Williams, J.K.** *Dealing with Family Who Don't Understand*, 21st Annual Huntington Disease Society of America meeting, Milwaukee, WI, [invited, podium]

27. 2006.* **Williams, J.K.** *Growing up in a family with HD: Adolescent Issues* "Sometimes it just an irritable mess" 21st Annual Huntington Disease Society of America meeting, Milwaukee, WI [invited, podium]
28. 2006.* **Williams, J.K.** Hamilton, R.J., Nehl, C., Sparbel, K.J., Schutte, D.L., McGonigal-Kenney, M., Birrer, E., Friedrich, R.M., Tripp-Reimer, T., Paulsen, J. *Experiences of family of persons with Huntington Disease*. Council for the Advancement of Nursing Science (CANS) Conference, Washington D.C [peer review, podium]
29. 2006. *Sparbel, K.J. **Williams, J.K.** Driessnack, M., Pehler, S.R., Schutte, D.L., McGonigal-Kenney, M., Letocha, A., Jarmon, L., Friedrich, R.M., Paulsen, J. *Living in a Huntington disease household: Experiences from a teen perspective*. Council for the Advancement of Nursing Science (CANS) Conference, Washington D.C [peer review, podium]
30. 2006* Sparbel, K.J.H. & **Williams, J.K.** *Cystic Fibrosis Carrier Testing (CFCT): Use of Genetic Knowledge in Decision Making by Pregnant Women in Primary Care*, Council for the Advancement of Nursing Science (CANS) Conference, Washington D.C., October [peer reviewed, poster]
31. 2006* Erwin, C., Penziner, E., **Williams, J.**, Wallis, A., Bombard, Y., Hayden, M., & Paulsen, J. *Experience of Discrimination Among Persons who Have Undergone Predictive Testing for Huntington's Disease*, ASHG, New Orleans, October [peer reviewed, poster]
32. 2005.* **Williams, J.**, *Huntington Disease*. Summer Genetics Institute, National Institute of Nursing Research, Bethesda, MD [invited, podium]
33. 2005*. **Williams, J.K.** *Managing Caregiver Stress and Burden*. Huntington Disease Society Annual Meeting, Atlanta, GA [peer review, podium]
34. 2005*. **Williams, J.K.** *Family Impact of HD*. Huntington Disease Society Annual Meeting, Atlanta, GA [peer review, podium]
35. 2005* Penziner, E., **Williams, J.K.**, Erwin, C., Wallis, A., Bombard, Y., Hayden, M., & Paulsen, J. *Preliminary Investigation: Analysis of Genetic Discrimination in Persons who Have Undergone Genetic Testing for Huntington's Disease*. NCHPEG, Washington DC, January. [peer review, poster]
36. 2003.* **Williams, J.**, *Integrating genetics and nursing science to improve health*, NINR Science Symposium, Washington DC [invited, podium]
37. 2003.* **Williams, J.**, *Integrating genetics and nursing into a program of research*, NINR, Summer Genetics Institute, Bethesda MD, [invited, podium]
38. 2003. **Williams, J.**, *Genetics and Aging*, American Academy of Nursing, San Diego, CA [podium]
39. 2002 * **Williams, J.**, *Advancing nursing science related to genetics*, National Institute of Nursing Research Summer Genetics Institute, Bethesda, MD, [invited, podium]
40. 2002. **Williams, J.**, *The future for nursing and genetics*. University of Texas School of Nursing in Houston, 30th Anniversary Celebration Conference, Houston, TX, [invited, podium]
41. 2000. **Williams, J.K** *Genetic Testing: Ethical Issues*, 72nd Scientific Sessions, American Heart Association, Atlanta, GA, November. [invited, panel]

42. 2000*Schutte, D., **Williams, J.K.**, Muilenburg, A., Evers, C., & Holkup, P.; *Experience of Support Persons Participating in Presymptomatic Genetic Testing Protocols for Huntington Disease* (poster) A N A Convention, Indianapolis, IN, June [peer reviewed, poster]
43. 1999* D. Schutte, **J. Williams**, A. Muilenburg, C. Evers, & P. Holkup; *Experience of Support Persons Participating in Presymptomatic Genetic Testing Protocols for Huntington Disease* American Society of Human Genetics, San Francisco, CA [peer reviewed, poster]
44. 1999* D. Schutte, **J. Williams**, A. Muilenburg, C. Evers, & P. Holkup; *Experience of Support Persons Participating in Presymptomatic Genetic Testing Protocols for Huntington Disease* American Society of Human Genetics, San Francisco, CA [peer reviewed, poster]
45. 1999* Holkup, P. **Williams, J.K.**, D. Schutte, & C. Evers; *Redefinition: Coping with negative presymptomatic HD and PPND gene test results*, Gerontological Society of America, San Francisco, CA [peer reviewed, poster]
46. 1997* Schutte, D., Maas, M., & **Williams, J.K.**, *Family member perception and interpretation of Alzheimer disease etiology*. AJHG, Baltimore, MD [peer reviewed, poster]
47. 1995* **Williams, J.K** *Psychosocial aspects of heterozygote testing*. American Society of Human Genetics, Minneapolis, MN. [peer reviewed, poster]
48. 1995* **Williams, J.K** *Genetic knowledge: Psychosocial impact* (poster). AREA Grants Program, Indianapolis, IN [peer reviewed, poster]
49. 1990* With L. Richman & M. Eliason. *Developmental neuropsychological functions of children with cleft and two age levels*. American Cleft Palate Craniofacial Association, St. Louis, MO. [peer reviewed, poster]

State/Regional

1. *Laures, E., McCarthy, A.M., LaFond, C., St. Marie, B., **Williams, J.**, & Gilbertson-White, S. *Pain Assessment in the PICU: Assume Pain Present*, MNRS, Poster, March 2022
2. Laures, E., Gilbertson-White, S., Street, N., **Williams, J.**, & Rakel, B. *Tools to describe multiple chronic conditions and multimorbidity: A scoping review*. Poster Session, MNRS 44th Annual Research Conference, 2020.
3. *Groves, P. S., **Williams, J.**, & Bunch, J. (April 2020). *A Nurse Sensemaking Process for Responding to Patient- And Family- Reported Safety Concerns in the Hospital*. Poster. MNRS 44th Annual Research Conference, 2020
4. Gardner, S., Rakel, B., Herr, K., McCarthy, A.M., Cherwen, C., Daack-Hirsch, S., Gilbertson-White, S., Hand, L., **Williams, J.K.**, & Tripp-Reimer, T. (2019) *An integrative model of multimorbidity and symptom science*. MNRS, April 2019 [peer reviewed, podium]
5. 2012. ***Williams, J.K.**, Daack-Hirsch, S., Driessnack, M., Shinkunas, L., Downing, N., & Simon, S. *Return of Individual Incidental Findings in Genomic Research* MNRS, Dearborn, MI [peer reviewed, podium]

6. 2011. *Downing, N.R., & **Williams, J.K.** *Living in anticipation of disability from Huntington disease. Symposium. Disabilities across the lifespan.* Midwest Nursing Research Society Annual Conference, Columbus OH [peer reviewed, podium]
7. 2011. *Shinkunas, L., **Williams, J.K.**, & Simon, C. *Paternalism and Preference: Navigating the Tensions of Genomic Incidental Findings*, Annual meeting of the Central States Anthropological Society, Iowa City, IA
8. 2011* Spore, A., Daack-Hirsch, S., **Williams, J.K.**, & Simon, C. *Disclosure of incidental findings from genomic testing: A public perspective.* MNRS, Columbus, OH [peer review, poster]
9. 2010. * Downing, N., **Williams, J.K.**, & Paulsen, J.S. *Couples' attributions of work function changes in prodromal Huntington disease.* Midwest Nursing Research Society Annual Research Conference Kansas City, MO [peer reviewed, podium]
10. 2010.* **Williams, J.K.**, Brossman, B., Downing, N., & Paulsen, J.S. *Measuring the patient reported outcome of work function with people with prodromal Huntington disease.* MNRS Kansas City, MO [peer reviewed, podium]
11. 2009.* **Williams, J.K.** *Genetic Research: Pediatric Nursing The State of the Science.* Annual meeting, MNRS, Minneapolis, MN [peer reviewed. Podium]
12. 2009.* **Williams, J.K.**, & Paulsen, J.S. *Issues in multi-site US/Canadian research with families of persons with HD.* Annual meeting, MNRS, Minneapolis, MN [peer reviewed, podium]
13. 2009.* Ersig, A.L., **Williams, J.K.**, Koehly, L.M., & Hadley, D.W. *Recruitment and social network data analysis of extended family in genetics and genomics research: Lessons learned.* Annual meeting, MNRS, Minneapolis, MN [peer reviewed, podium]
14. 2009.* Porter, R., **Williams, J.K.**, & Piper, K. *"I don't know who to trust": Patterns of receiving newborn screening information among parents in non-dominant cultures.* Annual meeting, MNRS, Minneapolis, MN [peer reviewed, podium]
15. 2008. *Sparbel, K.J.H., Pehler, S.R., **Williams, J.K.**, Tripp-Reimer, T., Paulsen, J.S., McGonigal-Kenney, M., Jarmon, L., & Klimek, M.L.N. *Adaptations and lessons learned in planning and conducting focus groups with teens in Huntington disease (HD) families on sensitive topics.* MNRS, Indianapolis. [peer reviewed, podium]
16. 2008* **Williams, J.K.**, Ayers, L., & Sparbel, K. *Teens participating in caring for parents with Huntington disease.* MNRS, Indianapolis [peer reviewed, poster]
17. 2008* Letocha Ersig A., Hadley, D.W., **Williams, J.K.**, & Koehly, L.M. *Family communication and screening behaviors in the context of indeterminate genetic test results.* MNRS, Indianapolis [peer reviewed, poster]
18. 2007.* **Williams, J.K.**, Barnette, J.J., Sousa, V., Reed, D., Tripp-Reimer, T., & McGonigal-Kenney, M. *Development and psychometric analysis of HD family health concerns and management survey.* MNRS, Omaha. [peer reviewed, podium]
19. 2007 * Oldenburg, A., **Williams, J.**, M., Maas, M., & Tripp-Reimer, T. *Focus group process: Analysis of group interactions and participant insights.* MNRS, Omaha [peer reviewed, poster]
20. 2007* Pehler, S.R., Craft-Rosenberg, M., Butcher, H., Cates, D., McCarthy, A.M., & **Williams, J.K.** *Longing: The lived experience of spirituality in adolescents with Duchenne Muscular Dystrophy.* MNRS, Omaha [peer reviewed, poster]

21. 2007* **Williams, J.K.**, Barnette, J.J., Sousa, V., Tripp-Reimer, T., & Birrer, E. *Huntington Disease Family Health Concern Strategies*, MNRS, Omaha [peer reviewed, poster]
22. 2006* **Sparbel, K.**, **Pehler, S.**, **Williams, J.K.**, Jarmon, L., **Letocha, A.**, Friedrich, R., Paulsen, J., & Tripp-Reimer, T. *Concerns of teens in HD families*. MNRS, Milwaukee, April [peer reviewed, poster]
23. 2006* **Williams, J.K.**, **Hamilton, R.**, Schutte, D., **McGonigal-Kenney, M.**, **Sparbel, K.**, **Birrer, E.**, Friedrich, R., Tripp-Reimer, T., Paulsen, J., **Rehak, D.**, **Pehler, S.**, Jarmon, L., Penziner, E., & **Nehl, C.** *Nature and impact of health status in persons with mutation in the HD gene prior to clinical diagnosis*. MNRS, Milwaukee, April. [peer reviewed, poster]
24. 2005* **Sparbel, K.**, **Pehler, S.**, **Williams, J.K.**, Schutte, D., **Rehak, D.**, **McGonigal-Kenney M.**, Jarmon, L., & Paulsen, J. *HD Family Teen Data Analysis Using a Developmental Lens*. MNRS, Cincinnati, April. [peer reviewed, poster]
25. 2005* **McGonigal-Kenney, M.**, **Williams, J.K.**, Schutte, D., **Hamilton, R.**, **Rehak, D.**, **Sparbel, K.** & Jarmon, L. *Evidence of ambiguous loss experienced by families of HD*. MNRS, Cincinnati, April [peer reviewed, poster]
26. 2005* **Williams, J.K.**, **Hamilton, R.**, **Sparbel, K.**, Schutte, D., **McGonigal-Kenney, M.**, **Rehak, D.**, Tripp-Reimer, T., Paulsen, J., & Jarmon, L. *What happens when HD caregivers seek help*. MNRS, Cincinnati, April. [peer reviewed, poster]
27. 2004* Trout, C., Mathews, K., & **Williams, J.K.**, *Knowledge & concerns about respiratory illness in males with Duchenne Muscular Dystrophy and their parents*. 2nd National Center on Birth Defects and Developmental Disabilities Conference, Washington DC, July 26-28 [peer reviewed, poster]
28. 2004* **Pehler, S.**, **Williams, J.K.**, Schutte, D., **McGonigal-Kenny, M.**, **Rehak, S.**, Tripp-Reimer, T., & Paulsen, J. *Focus Group Methodology and Adolescents*, MNRS, St. Louis, February [peer reviewed, poster]
29. 2003* **Rehak, D.**, Schutte, D., **Williams, J.K.**, **McGonigal-Kenny, M.**, **Pehler, S.**, & Jarmon, L *Caregiving in families experiencing Huntington Disease*. ISONG, Los Angeles, CA
30. 2000. **Williams, J.**, Tripp-Reimer, T., *From Ecology to Base Pairs: Nursing Involvement in Genetic Science*. Midwest Genetic Nursing Research: Advancing Science Through Collaboration. Iowa City, IA [peer review, podium]
31. 2000* **Williams, J.K.**, Schutte, D., **Holkup, P.**, Evers, C., & Muilenburg, A.; *Families undergoing genetic testing for Huntington disease*. Preconference Workshop. MNRS, Dearborn, MI, April [invited, podium]
32. 1999* **Williams, J.K.**, Schutte, D., Evers, C., & **Holkup, P.**; *Redefinition: The Process of Accepting Negative Results from Presymptomatic Genetic Testing for Degenerative Neurologic Disorders* MNRS, Indianapolis, April [peer reviewed, poster]
33. 1999* Schutte, D., **Williams, J.K.**, Muilenburg, A., Evers, C., & **Holkup, P.**; *Experience of Support Persons Participating in Presymptomatic Genetic Testing Protocols for Huntington Disease* , MNRS, Indianapolis, April [peer reviewed, poster]
34. 1997* **Williams, J.K** *Seeking presymptomatic gene testing for Huntington Disease*. MNRS, Minneapolis, MN [peer reviewed, poster]
35. 1997* McCarthy, A...M., **Williams, J.K.**, *Evaluation of a school re-entry program for children with cancer*. MNRS, Minneapolis, MN [peer reviewed, poster]

36. 1996* **Williams, J.K.** *Benefits and burdens of genetic knowledge*. MNRS, Detroit, MI [peer reviewed, poster]
37. 1995* McCarthy, A.M. **Williams, J.K.**, *Concerns of educators regarding children with chronic conditions in school* MNRS Kansas City, MO [peer reviewed, poster]
38. 1995* A.M. McCarthy, **Williams, J.K.**, *Children with chronic conditions: School nurses' perceptions* MNRS, Kansas City, MO [peer reviewed, poster]
39. 1995* M. Craft-Rosenberg, S. Powell, M. Gagen, M. K. Clark, P. Willard, S. Lively, R. Freidrich, J. Roberson, **Williams, J.K.**, & K. Culp. *Health care needs of rural homeless: A pilot study* MNRS, Kansas City, MO. [peer reviewed, poster]

Local

1. **Williams, J.K.**, & Perkhounkova, Y (June 2023) *Specific Aims: Get it Right*. College of Nursing, University of Iowa Grants Workshop [invited]
2. Groves, P.S., **Williams, J.**, & Bunch, J. (March 2020). *Keeping patients safe: Creating space and making sense*. Guest Speaker. Nursing Research and EBP Grand Rounds. University of Iowa Health Care, Iowa City, Iowa. Cancelled due to COVID
3. **Williams, J.K.** *Conducting a Manuscript Review? How to Make it a Good One* Faculty Development Series, December 2019
4. 2019 **Williams, J.K.** *Specific Aims & Problems: Getting it Right*. College of Nursing Grant workshop, June, 2019 [invited, podium]
5. 2018 **Williams, J.K.** *Specific Aims Page: Getting it Right*. College of Nursing Grant workshop, June 12, 2018 [invited, podium]
6. 2016 **Williams, J.K.** *Mission or Strategic Plan: What that means when writing grants*. Grantsmanship Workshop, June [invited, podium]
7. 2014 **Williams, J.K.**, *Specific Aims: So What and Who Cares*. University of Iowa College of Nursing Grantsmanship Workshop, May 27 [invited, podium]
8. 2013. **Williams, J.K.** *Top ten list for sustaining a research program on genetics*. Virginia Commonwealth University [invited, podium]
9. 2011* **Williams J.K.** "Working in the dark": Managing incidental findings in the genomic era. University of Iowa College of Nursing Research Forum, March [invited, podium]
10. 2011* **Williams, J.K.**, *Personal genetics and ethics: Doing the right thing with your personal genetic information*, Carver College of Medicine Mini-medical school, April [invited, podium]
11. 1998* **Williams, J.K.** *Quality of life issues in adults undergoing presymptomatic genetic testing for Huntington disease*, Behavioral Medicine Research Seminar, University of Utah, Salt Lake City, UT [invited, podium]
12. 2007* **Williams J.K.**, *Families and HD*. UIHC HD Family Support Group, Iowa City, April [invited, podium]
13. 2002* **Williams, J.K.**, *Families coping with HD: The Iowa experience*. Rehabilitation department, University of Iowa Hospitals and Clinics, Iowa City, IA, [invited, podium]

CLINICAL

International

1. 2006*Jenkins, J., Calzone, K., Badzek, L., Constantin, C., Debisette, A., Feetham, S., Geolot, D., Hagan P., Hess, M., Lea, D., Lewis, J., Nesseler, K., Potempa, K., Prows, C., Thomson, E., Tinkle, M., & **Williams, J.K.** *Establishing essential nursing competencies & curricula guidelines for genetics & genomics*. NCHPEG, Bethesda, MD, February [peer reviewed, poster]
2. 2001, **Williams, J.K** *Genetic Nursing: Ethics and Clinical Practice*, Hyogo University, Japan [invited, podium]
3. 2001, **Williams, J.K** *Ethical Issues in Genetic Nursing*, Japan Academy of Nursing Science, Kobe, Japan, [invited, podium]
4. 2001, **Williams, J.K** *Ethical Issues in Genetic Nursing and Genetic Treatments*, Japan Academy of Nursing Science, Kobe, Japan [invited, podium]
5. 2001, **Williams, J.K** *Genetic Nursing Practice*, Committee on Construction of Genetic Counselor System of the Ministry of Health, Welfare and Labour, Japan, [invited, panel]

National

1. 2010. Mulvihill, J.J., Driscoll, D.A., Jarvik, G.P., Morgan, T.M., Pollin, T.I., & **Williams, J.K.** *The NIH conference statement on family history and improving health: view of the genetics panelists*. American College of Medical Genetics, Albuquerque, NM [peer reviewed, poster]
2. 2005. **Williams, J.K.** *What do genetics and genomics mean for the practice of nursing at all levels?* Minimal Nursing Competencies for Genetics and Genomics Consensus meeting, Silver Spring, MD, September [invited, podium]
3. 2005* Cooksey, J., Lea, D., Forte, G., Flanagan, P., **Williams, J.K.**, & Blitzer, M. *Advanced practice nurses in genetics: A workforce that can increase access to genetics services*. Academy Health Annual Research meeting, Boston, MA, June [peer reviewed, poster]
4. 2000. **Williams, J.**, *Complex Ethical issues in Genetic Screening*, 14th Annual North American CF Conference, Baltimore, MD [invited, podium]
5. 1996. **Williams, J.K** *Current state of providing genetic information: Nurses*. Banbury Center Conference on Human Genetics and Primary Health Care, Cold Spring Harbor, NY [invited, podium]

Local

1. 2017. **Williams, J.K.** *Precision Health: What does this have to do with my practice?* Harriet Cook Carter Distinguished Lecturer. Duke University School of Nursing, Durham, NC, [Invited , podium]
2. 2017. **Williams, J.K.** *Preclinical research and genetic testing in neurodegenerative disorders: Psychosocial impact on participants and Families*. Columbia University, NY, April 3, 2017 Invited, podium]
3. 2017. **Williams, J.K.** *Personalized Health Care*. Evidence-Based Practice Conference. 24th National. Iowa City, IA [Invited, Panel Moderator]
4. 2017. **Williams, J.K.** *Precision Health: What Does it Have to Do With My Practice?* College of Nursing Research Forum, September [invited, podium]
5. 2005. **Williams, J.K.** *Getting Ready: Preparing Health Professionals to Use Stem Cell Discoveries*. Littlefield Leadership Lecture, University of Wisconsin, Madison, WI [invited, podium]

6. 2002 **Williams, J.K.**, *Genetics and Today's Health Care*, Genetics Medical Center, Davenport, IA
7. 2001 **Williams, J.K.**, *Nursing and Genetics Research and Practice*. Center for Research on Chronic Illness. University of North Carolina, March [invited, podium]
8. 2000 **Williams, J.K.** *Basic Principles of Genetics. Genetic and Oncology Nursing: New Dimensions of Advanced Practice*. The University of Iowa, Iowa City, June [invited, podium]
9. 2000 **Williams, J.K.** *Genetic factors in health and disease: Detection, testing, and health care. Genetics and Clinical Practice*. Topeka, KS, October [invited, podium]
10. 2000 **Williams, J.K.** *Genetics and birth defects. Genetics and Clinical Practice*. Topeka, KS, October [invited, podium]
11. 1997 **Williams, J.K.** *Genetic carrier testing for cystic fibrosis*. Birth Defects Advisory Committee, Iowa Department of Health, Des Moines, IA [invited, podium]
12. 1992 **Williams, J.K.** *Professional nursing, Public forum- Developing genetic technologies: Implications for the future*. NIH-DOE Joint Working Group, Iowa City, IA [invited, podium]

EDUCATION

International

1. 2004, Floria-Santos, M., & **Williams, J.K.** *Genome based health care: Challenges to genetics education and nursing practice in Brazil*. XVI Clinical Genetics Brazilian Congress, Belem do Para, Belem, Brazil [poster]
2. 2004, **Williams, J.K.** *Nursing and Genetics Health Care: Experiences and Challenges*. Nursing in the Genomic Era: A Canadian Planning Forum Vancouver, CA [invited, podium]
3. 1998, **Williams, J.K.** *Genetics Education and Health Professionals*, Annual meeting of the Association of Genetic Nurses and Counsellors, London, England [invited, podium]

National

1. 2014. **Williams, J.K.**, *Conversations about HD*, Webinar HDSA [invited, podium]
2. 2013. **Williams, J.K.** *Managing genomic incidental findings*, Heartland Genetics & Newborn Screening Collaborative, webinar [invited, podium]
3. 2008* **Williams, J.K.**, *Challenges of growing up in a HD household*. Professional Training Day, Huntington Society of America, Pittsburgh [invited, podium]
4. 2007. **Williams, J.K.** *Issues facing children in HD homes*. HDSA Professional Training, HDSA 22nd annual convention, Oklahoma City [invited, podium]
5. 2006* **Williams, J.K.** & Hamilton, R.J. *Implementation of genetics and genomics into nursing education in the U.S.*, NCHPEG, Bethesda MD, February [peer reviewed, poster]
6. 2005* **Williams, J.K.** *Experiences and feedback on use of a CD-Rom based educational tool*. 18th ISONG conference, Salt Lake City, UT, October [peer reviewed, poster]
7. 2001. **Williams, J.**, *Innovative Specialty Education: Genetics*. American Association of Colleges of Nursing, Amelia Island, FL [invited, podium]
8. 2000. **Williams, J.K.** *History of Genetics in Nursing Education and Practice*. HRSA Genetics Initiative Expert Panel, Bethesda MD. [invited, podium]

9. 2000. Kenner, C., **Williams, J.**, Feetham, S., & Lea, D. *Issues for Leadership in Education*. Genetics Symposia, American Academy of Nursing, San Diego [invited, panel]
10. 2000 **Williams, J.K.**, Schutte, D., Berg, M., Clinton, P., Evers, C., & Judge-Ellis, T. *Integrating genetics into PNP and FNP education*. ISONG, Baltimore, MD [peer reviewed, poster]
11. 1998. **Williams, J.K** *Integrating Genetics into Nursing Curriculum: The Iowa Experience*. Summer Genetics Institute for Nursing Faculty. U of Cincinnati, Cincinnati, OH [invited, podium]
12. 1998. **Williams, J.K** *Evolution and Current Status of Graduate Programs in Nursing Genetics*, State of the Art & Science of Genetic Nursing: An Invitational Conference, Baltimore, MD [invited, podium]

Regional/Local

1. 2008. **Williams, J.K.**, *What do I do after my doctorate?* MNRS annual meeting, Indianapolis, IN. [invited, panel]

SERVICE

Editorial and Peer Review Service

Editor of journal or editorial board memberships

2006-2021 Journal of Genetic Counseling Editorial Board

Peer review of scholarly products- Manuscripts (*grant applications, journal manuscripts, book proposals, chapter drafts, conference abstracts, white papers, evidence-based guidelines or protocols, policy proposals*)

2024 Pediatric Research
 2023 Aging & Mental Health
 2023 Nursing Inquiry
 2023 J of Clinical and Translational Research
 2023 J of Community Genetics
 2022 Family Relations
 2022 Canadian Journal of Nursing Leadership
 2021 BMC Medical Ethics
 2021 Clinical Nursing Research
 2021 Journal of Pain and Symptom Management
 2020 Applied Nursing Research
 2020 Family Relations
 2020-2022 Japan Journal of Nursing Science
 2019 Cognitive and Behavioral Neurology
 2019 Frontiers in Genetics
 2019 European Journal of Medical Genetics

2019-2022 Journal of Professional Nursing
 2019 Sage Open Medicine
 2017-present Journal of Huntington Disease
 2013-2022 Personalized Medicine
 2005-present Journal of Nursing Scholarship
 2001-present Nursing Research
 1993-2021 Journal of Genetic Counseling
 2015 American Journal of Bioethics
 2015-2022 American Journal of Preventive Medicine
 2015 Journal of Nursing Measurement
 2015 Nursing & Health Sciences
 2015 Pharmacogenomics
 2015 Quality of Life in Research
 2014 Policy, Politics & Nursing Practice
 2011 Chronic Illness
 2010-2018 European Journal of Human Genetics
 2010-2018 Health Psychology
 2009 Guest Editor, Journal of Pediatric Nursing
 2009-2014 Public Health Genetics
 2008 Guest Editor, Journal of Genetic Counseling
 2007-present Journal of Pediatric Nursing
 2007-2014 Genetic Testing
 2006 Pediatrics
 2006-2021 Genetics in Medicine
 2005-2022 Nursing Outlook
 2004 Guest Editor, Research and Theory in Nursing Practice, 17 (4)
 2004 Western Journal of Nursing Research
 2003-2018 Clinical Genetics
 2002 Research and Theory for Nursing Practice
 2002-2022 Social Science & Medicine
 2001 American Journal of Nursing
 2000-2014 American Journal of Medical Genetics
 1993 Heart and Lung
 1991 Guest Editor, Journal of Pediatric Nursing, 7 (1)
 1986-present Journal of Pediatric Health Care
 1983-present Pediatric Nursing

Peer review of scholarly products- Grant review panels

2024 Stage I (mail-in) reviewer for the [2024-5 NIH Director's New Innovator Award Program \(DP2\)](#), reviewer on Special Emphasis Panel/Scientific Review Group **2025/05 ZRG1 IIDB-Q (70) R** December
 2023 Stage 1 (mail-in) reviewer 2023-2024 NIH Director's New Innovator Award Program (DP2)
 2020 Ad hoc Member, Special Emphasis Panel/Scientific Review Group 2020/05 GNOM-2 March 5

2017 Member, Special Emphasis Panel/Scientific Review Group 2017/05 ZRG1 HDM-Z (50)R, March 13

2016 Chair and member, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Special Emphasis Panel/Scientific Review Group ZHD1 DRG-D (CC) April 8

2014 Chair and member, Healthcare Delivery and Methodologies (HDM) IRG special emphasis member conflict panel, ZRG1 HDM S (03) March 10

2014 Member, National Institute of Child Health and Human Development Special Emphasis Panel, EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE OF CHILD HEALTH & HUMAN DEVELOPMENT, Post Katrina P01, ZHD1 DSR-M (MV), June 20

2014 Chair and member, Motor Function, Speech and Rehabilitation (MFSR) Study Section and Language and Communication (LCOM) Study Section. Special Emphasis Panel ZRG1 BBBP-T (59), June 27

2013 Member, NICHD Special Emphasis Panel/Scientific Review Group, Genomic Sequencing and Newborn Screening Disorders U19, 2013/05 ZHD1 DRG-H (50) 1, April 3-4

2013 Member, NHGRI GNOM-G Agenda Seq Num-00263055, June 6

2012-2013 Member, NHGRI Special Emphasis Panel, Clinical Seq Exploratory Research RFA ZHG1 HGR-N (J2), Oct 29, Jan 7

2012 Member, NHGRI Initial Review Group 2012/10 GNOM-G, June 7

2011 Member, Special Emphasis Panel, ZHG1HGR-N(01), RFA-HG-10-017, Clinical Sequencing Exploratory Research, July 11-12

2010 Member, Special Emphasis Panel/Scientific Review Group 2010/05 ZRG1 HDM-D (58) R 03/25/2010-03/26/2010.

2008 Member, CDC Special Emphasis Panel, RFA GD-08-001(U18) Genomic Applications in Practice and Prevention (GAPP): Translation Research. May

2007 Member, Special Emphasis Panel/Scientific Review Group 2007/05 ZRG1 F16-T (20) (L), Feb 15

2007 Member, Special Topics Scientific Review Group, ZRG1 GGG-J 02 M GGG, National Institutes of Health, Aug 1

2007 Member, Special Topics Scientific Review Group, ZRG1 F16-T (20) L, Nov 9

2006 Member, Special Emphasis Panel/Scientific Review Group 2007/01 ZRG1 GGG-E, Ethical, Legal and Social Implications of Genetics, Nov 13, NIH

2006 Member, Special Emphasis Panel/Scientific Review Group 2007/01 ZRG1 F16-T (20) (M), Nov 9, National Institutes of Health

2004 Member, Study section, International bioethics education and career development awards Center for Scientific Review, ZRG1 ICP-2(50) (R), March 25

2002 Member, Center for Scientific Review Special Emphasis Panel, Ethical, Legal, and Social Issues Research Program, National Institutes of Health, Bethesda, MD

2001 Outside Opinion Review, Nursing Research Study Section, Center for Scientific Review, National Institutes of Health, Bethesda, MD

2000 Reviewer, NINR Special Emphasis Panel , National Institute of Nursing Research, Bethesda, MD

2000 Temporary Reviewer, Nursing Research Study Section, Center for Scientific Review, National Institutes of Health, Bethesda,

1997-1998 Ad Hoc Member, Clinical Sciences Special Emphasis Panel, Small Business Funding Opportunities, National Institute of Nursing Research, Bethesda, MD

1996-1998 Member, Human Genome Research Initial Review Group, Ethical, Legal, and Social Implications Subcommittee, National Center for Human Genome Research, Department of Health and Human Services, Bethesda, MD

1994 Special Review Committee, National Center for Human Genome Research, Ethical, Legal, and Social Implications Program, Department of Health

1993 Abstract Review Panel, Midwest Nursing Research Society

1992-1993 Ad Hoc Review Committee, National Center for Human Genome Research, Ethical, Legal, and Social Implications Program, Department of Health and Human Services, Bethesda, MD

1987-1990 Special Review Committee, National Center for Human Genome Research, Department of Health and Human Services, Bethesda, MD

1985 Ad Hoc Review Panel for Genetic Testing and Counseling programs, Maternal and Child Health, DHHS, Rockville, MD

Professional Service (including organizational memberships and other professional activities)

Society/Association membership, participation and leadership

2019-2021 *Journal of Genetic Counseling*, Best Trainee Award committee

2017-present ISONG, Research committee

2016 ISONG, Abstract reviewer

2015 ISONG, Research committee

2014 ISONG, Research committee, Policy committee

2012 ISONG, Nursing Research Grant Program reviewer

2012 MNRS, Abstract reviewer

2010 Abstract Reviewer for State of the Science Congress

2010 ISONG, Vulnerable populations position statement committee

2009-2010 Member, Nominating Committee, MNRS

2007 ISONG Chair, Nominations committee, elected

2005 38th Biennial Convention - Scientific Sessions, Sigma Theta Tau International, Reviewer, abstracts

2001-2003 American Academy of Nursing, Co-Chair Genetics Expert Panel

2001-2002 Midwest Nursing Research Society Chair, Genetics Research Section

2001 ISONG, Program chair

2000-2001 Midwest Nursing Research Society, Genetic Research Section Chair

1999-2001 Chair-Birth Defects Advisory Committee, Iowa Department of Public Health

1999 ISONG Genetics, Chair, Credentialing subcommittee

1997-2002 Iowa Nurses Association Representative-Birth Defects Advisory Committee, Iowa Department of Public Health

1996-1997 ISONG, President, elect

1996 Iowa Nurses Association, Research Committee

1995-1996 ISONG, President Elect

1993-1994 ISONG, Chair of Education Committee

1991-1993 ISONG, Secretary

1990-1994 Sigma Theta Tau, Gamma Chapter, Recording Secretary

1989 ISONG, Chair of Nominating Committee
1988 International Society of Nurses in Genetics (ISONG), Founder and Member of Organizing Board
1971 Sigma Theta Tau, Gamma Chapter, Eligibility Committee

Advisory Panels

2024 ANA national study on Precision Health (PH) competencies for general nursing practice, expert panel Delphi member, November-December
2024, Expert panel member, [The Community Engagement Alliance Consultative Resource \(CEACR\) | Community Engagement Alliance \(nih.gov\)](#) University of Pittsburgh
2015-present Advisory Committee member. AMA, Jackson Laboratory, and Scripps Translational Medicine Institute Genomics Education Program for Health Professionals
2013-2020 AAN Representative and Member, National Academies of Science, Engineering, and Medicine (formerly Institute of Medicine), Roundtable on Genomics and Precision Health
2010-2019 Member, *Essential Competencies in Genetics and Genomics for Graduate Nurses*
2016 Reviewer for *A Framework for Genetic Testing: An Approach for the Department of Defense* for the Health and Medicine Division (HMD) of The National Academies of Sciences, Engineering, and Medicine, December, 2016.
2014-2018 Member, Genetic Nursing Science Blueprint working group, Calzone, K., Jenkins, J.
2012 Contributor, *Faces of HD*, HDSA May Awareness Month Campaign
2011-2012 Chair, *Talking about HD to kids/youth/teens* resource group, Huntington Disease Society of America
2010-2011 Advisory Board, *Journal of Nursing Scholarship* Genetics series
2010-2011 Member of the Strategic Planning Committee for the NINR Strategic Plan
2009 Member, Consultation Directory: Genetics/Genomics Education Exemplar Resources, NIH, NHGRI
2009-2013 National Advisory Council for Nursing Research, NIH
2009 Panel member, *NIH State-of-the-Science Conference: Family History and Improving Health*
2002-2009 National Coalition for Health Professional Education in Genetics
1997 Panel member, *NIH Consensus Development Conference Panel: Offering genetic testing for Cystic Fibrosis*, Bethesda, MD

Consultations

2019 Consultant: revision of ISONG *Genetic and Genomic Nursing Competencies*.
2018 Planning committee. Understanding Disparities in Access to Genomic Medicine – A Workshop. National Academy of Medicine, June, Washington DC. National
2016 Review group member, Director NINR, Bethesda, MD National
2015 Speaker. *Caregiving by and for children and adults with Huntington Disease* Workshop. “The Spectrum of Caregiving and Palliative Care in Rare Diseases.” National Institutes of Health (NIH) Office of Rare Diseases Research (ORDR), June 9, Bethesda, MD National
2013 Member. *Behavioral/Social Science Genomics-Based Nursing Research: State of the Science, Challenges, and Opportunities*. Genomic Nursing Science Workshop, NINR, August 20-21, 2013, Bethesda, MD National

2011 Member Expert Working Group, Clinical Translation of Pharmacogenetic Testing: Management of Incidental Findings & Related Issues, Susan Haga & Wylie Burke, Duke University, July. Regional

2008 Peer Reviewer, Genomics Forum, University of Edinburgh, UK Economic and Social Research Council Mid-Term Review Report. International

2006 Consultant, Clemson University Interdisciplinary PhD in Nursing and Genomics, Julie Eggert, Coordinator. Regional

2003 Consultant, Uniformed Services University, Nurse Practitioner implementation of Cystic Fibrosis carrier screening: Education and Practice. Bethesda MD, January 27. Regional

2001-2004 Consultant, Cancer genetics fellowship program, Jeffrey Weitzel, PI Regional

2001 Consultant, Center for Research on Chronic Illness, University of North Carolina Regional

1999 Irving Harris Visiting Professor, University of Illinois, Chicago, IL Regional

1998-2001 Consultant, Advanced Practice Genetics Nursing Program, University of Washington, Seattle, WA Regional

1996-1999 Consultant, Summer Genetics Program for Nursing Faculty, Children's Hospital Medical Center, Cincinnati, OH Regional

1996-1998 Advisory committee member, Genetic Education for Southeastern States project, The Institute for Disability Studies, U of Southern Mississippi, Hattiesburg, MS Regional

External Faculty reviews

2022 two reviews

2021 one review

2020 two reviews

2018 five reviews

2017 three reviews

University Service

The University of Iowa

2022 OVPR grant reviewer

2008-present Chair, Soc Sci & Behav Research IRB-02

1998-present Member Institutional Review Board 02, The University of Iowa

2011-2014 Senior Mentor, Institute for Clinical and Translational Science Clinical and Translational Biomedicine Program

2011-2013 Genetics Cluster Hire Executive Committee

2011-2012 Chair, Decanal review, Dean Rita Frantz, College of Nursing

2011 Chair Function section, member Psychiatric Section, member Program Management committee, member Cross-Correlation committee, member Steering committee for PREDICT-HD grant

2009-2010 Member, T-32 Trans-disciplinary Scholars Seminar committee

2006 Member, CIC/DEO Leadership Seminar

2001-2002 Hardin Library for the Health Sciences Advisory Committee

2001 Member, Search committee for Dean of the Graduate College

2001 External reviewer, University of Iowa, College of Medicine, Craniofacial Anomalies Research Center

2001 Member, Research Misconduct Committee

1996-1999 Parking Appeals Committee
1995-1997 Faculty Senate, The University of Iowa
1994-1996 Review Committee Old Gold Summer Fellowship & Semester Assignments
1992-1994 The University of Iowa Adv Comm in the Biological Sciences, 1993-1994, Convener
1991-1995 Hardin Library for the Health Sciences Advisory Committee, 1993-1995, Chair
1991-1995 The University of Iowa Presidential Scholarship Selection Committee

Collegiate Service

University of Iowa College of Nursing

2021-present Reviewer at ONRS grant workshop
2022 BSN candidate admissions review
2022 ONRS internal grant reviews
2022 ONRS participant and reviewer, Pitch Your Aims group
2012-present Co-convener, Writing Special Interest Group
2012-present Co-convener, Developing Scholars Group
2010-present Chair, Promotion & Tenure Committee
2010-present ad hoc member, Promotion and Tenure Task Force committee
2016 Cosponsor, Mindy Tinkle, PhD, RN Sabbatical, College of Nursing
2010 MSN/DNP Task Force
2010 PhD Task Force
2010-2011 Chair, PhD Admissions & Progression Committee
2008-2009 Faculty Research Forum Coordinator
2008-2009 Genetics committee Convener
2007-2008 Faculty Council Chair Pro Tem
2006 Faculty host for Yuko Kawasaki, University of Hyogo College of Nursing Art & Science, Hyogo, Japan
2006-2012 Scholarship Committee
2006-2008 MSN admissions Committee
2006-2008 Research courses across the curriculum faculty work group member
2004-2006 Chair, Graduate Assembly
2002-2006 Doctoral Program Advisory Committee
2001-2006 Doctoral Admissions Committee
1998-2001 Alliance for Excellence in Nursing and Genetics-Chair
1998-2000 MSN Admissions Committee
1997 Faculty Retreat for Graduate Program Planning Committee
1997 Nursing Science & Inquiry Course Committee
1997 Advanced Assessment Committee
1996-1997 Association of Graduate Nursing Students, Advisor
1995-1996 Office of Nursing Research Grant Review Panel
1993-1998 Family Interest Research Group (with University of Iowa Hospitals and Clinics)
1993-1997 Scholastic and Scholarship Committee
1992-1993 Faculty Welfare Council
1992-1993 BSN Admissions Committee
1991-1992 Planning, Development, and Coordinating Council
1990-1998 Family Interest Group

1990-1991 Chair, Grant review panel
1990 Co-Chair, Grant review panel

Community Service

Health related community organizations and groups

2016-2020, 2023-present Volunteer, Iowa City Hospice
2023-present Board member, Compeer of Johnson County

Other:

2024 Collaborated with University of Iowa Research Foundation in response to request by the CHDI (Cure Huntington Disease Initiative) to include the HDWF scale (Brossman et al., 2012) in an upcoming study

TEACHING

Course Instruction

2004-2012, Genetic Nursing Research, doctoral, sole faculty
2004-2006, Advanced Practice Genetic Nursing, graduate, sole faculty
2001-2009, Research/Evidence Based Practice, graduate, sole faculty
1990-2003, Health Promotion, didactic and practicum, undergraduate, team member

November 1, 2023, UI College of Nursing, PhD first year seminar, *Protection of Human Subjects in Research*, Guest lecture.

October 19, 2022, UI College of Nursing, PhD first year seminar, *Protection of Human Subjects in Research* Guest lecture.

March 4, 2022. UI College of Public Health graduate students, *Principles of Scholarly Inquiry*, Group discussion leader.

November, 2019. UI College of Nursing PhD students. *Protection of human subjects in research*. Guest lecture

May 15, 2019, The Ohio State University, *Ethics and Nursing Omics Research*, PhD students, guest lecture

June 20, 2017, The Ohio State University, *Ethics and Nursing Omics Research*, PhD students, guest lecture

Mentoring And Advisement

Mentoring

Faculty Mentorship

2019-2022, Brenda Krogh Duree, IT faculty, Cultural Awareness in RN/BSN graduates; quality improvement project poster, and research project and manuscript development

2019-present, Young-Eun Cho, junior TT faculty
2018-2022, Patricia Groves, TT faculty, grant writing
2018-2020, Jacinda Bunch, TT faculty, grant writing

Predoctoral Mentorship

Postdoctoral Mentorship

2010-2012, Nancy Downing, Function changes in prodromal HD, Co-Mentor/T32
2009-2011, Elisa Torres, Genetics, exercise, & depression in African American adults, Co-Mentor/T32
2009-2011, Vanessa Johnson, Health literacy and disparities in genetic testing and ethnic minorities, Co-Mentor/T32
2008-2010, Yolanda Powell Young, Intervention to reduce obesity in African American adolescents, Co-Mentor/T32
2008-2010, Anne Letocha Ersig, Transition and youth with chronic conditions, Co-Mentor/T32
2007-2009, Ida Spruill, “I ain’t claimin’ it”: Diabetes self-care intervention with Gullah families, Co-Mentor/T32
2007-2008, Kathleen Sparbel, Genetic testing decision making, Mentor/T32
2005-2007, Valmi Sousa, Perceptions of genetics, behavior, and environmental risks for T2DM, Co-Mentor/T32
2005-2007, Martha Driessnack, Exploring what children know about genetics and how they learn, Mentor/T32
2004-2006, John Twomey, Parental decisions about allowing children to enroll in genetic research studies, Co-Mentor/T32
2003-2005, Rebekah Hamilton, Decision making in young women at risk for HBOC, Mentor/T32

Advisement

BSN Honors Project

2019-2020, Erin Patchett, X-linked disorders carrier genetic testing of minors, U Iowa

DNP Project Committee

2013, Kayla Kellogg, Identification, referral, and support of elders with genetic conditions, U Iowa

Doctoral Comprehensive Examination Committee

2019, Elyse Laurens, member, U Iowa

PhD Dissertation Committee

2024, Peter Abad, *Information Management in Families with Inherited Conditions*, Member, University of Iowa.
2022-2023, Richie Paul Carreon, *Resignation, in the absence of cure: A narrative study on the illness experience of Huntington’s Disease*. External Examiner, Liverpool John Moores University

2022, Elyse Laures, *Pain Assessment in the Pediatric Intensive Care Unit*
Member, University of Iowa

2017, Lisa Shah, Family communication of genetic risk for sudden cardiac death, Member,
Nursing, U Iowa

2014, Alyson Spore Hanish, Sleep-related phenotypes: Adolescence and *PAX6*
Haploinsufficiency, Chair & NIH GPP Predoctoral Fellow mentor U Iowa

2013, Debra Brandt, What factors influence young adults' attitudes regarding willingness to
participate in future clinical research? Member, Nursing, U Iowa

2013, Stephanie Bernander, HD Caregiver access to services and quality of life, Member,
Cardinal Stritch U, Milwaukee, WI

2013, Jeanne Gottlieb, The Meaning of the Lived Experience of Hispanic Women Anticipating
Genomic Certainty after Disclosure of an Abnormal Obstetrical Ultrasound, Member,
Nursing, Florida Atlantic U, Boca Raton, FL

2010, Rebecca Porter, Nurse managers' experience of moral distress in acute care hospitals in the
United States, Chair, Nursing, U Iowa

2010, Nancy Downing, Symptom attributions in persons with pre-HD. Chair, Nursing, U Iowa

2008, Anne Letocha Ersig, Indeterminate HNPCC genetic test results: Interpretation,
communication and cancer screening, Chair, Nursing, U Iowa

2007, Kay Reeder, The impact of lay consultation on pre-hospital delay in acute myocardial
infarction, Member, Nursing, U Iowa

2007, Carissa Nehl, Psychosocial functioning and quality of life in prediagnosed Huntington
Disease, Member, Psychology, U Iowa

2006, Shelley Rae Pehler, Spirituality of children with DMD, Member, Nursing, U Iowa

2006, Kathleen Sparbel, Decision making in cystic fibrosis carrier testing for pregnant women in
a primary care setting, Chair, Nursing, U Iowa

2005, Apawan, Nookong, Familial caregivers' management behaviors and quality of life for
children with asthma. Member, Nursing, U Iowa

2003, Patricia Holkup, Native American elder mistreatment: A community concern. Member,
Nursing, U Iowa

2003, Debra Schutte, Relationship of Genotype to Cognition and Function in Late-Onset
Alzheimer Disease, Member, Nursing, U Iowa

2003, Ann Dylis, Effects of personal & environmental factors, uncertainty stress, & coping on
family functioning in parents of children with Neurofibromatosis I: A nursing path analysis,
Member, Nursing, Boston College

2001, Jane Jacobs, The perceptions of genetic self-help groups & health professionals on genetic
screening and testing: Implications for public health policy. Member, Public Health,
Queensland U, Australia