

Region 6 (Mountain States)

Publications

Bellcross CA, Bedrosian S, Daniels E, Duquette D, Hampel H, Jasperson K, Joseph DA, Kaye CI, Lubin I, Meyer LJ, Reyes M, Scheuner M, Schully SD, Senter-Jamieson L, Stewart S, St. Pierre J, Westman J, Wise P, Yang V, Khoury MJ. Implementing population-based screening and cascade testing for Lynch syndrome: summary of a public health/clinical collaborative meeting. *Genetics in Medicine*. October 2011; 12:152-162.

Botkin JR, Teutsch S, Kaye CI, Hayes M, Bradley LA, Szegda K, Dotson DW on behalf of the EGAPP Working Group, Outcomes of Interest in Evidence-based Evaluations of Genetic Tests. *Genetics in Medicine*. 2010; 12(4):228-35.

Hartway, S. A parent's guide to the genetics of Down Syndrome. *Advances in Neonatal Care*. Feb 2009; Vol. 9, No.1; 27-30.

Hinton CF, Feuchtbaum L, Kus C, Kempter AR, Berry SA, Levy-Fisch, J, Luedtke J, Kaye C, Boyle C. What questions should newborn screening long-term follow-up be able to answer?: A statement of the United States Secretary for Health and Human Services Advisory Committee on Heritable Disorders in Newborns and Children. *Genetics in Medicine*. June 2011; 13:861-865.

Hinton CF, Neuspiel DR, Gubernick RS, Geleske T, Healy J, Kemper AR, Lloyd-Puryear MA, Saul RA, Thompson BH, Kaye CI. Improving newborn screening follow-up in pediatric practices: Quality Improvement Innovation Network (QuIIN). *Pediatrics* 130:e1-e7; 2012.

Kaye, CI. Genetic service delivery: infrastructure, assessment, information. *Public Health Genomics*. 2012;15(3-4):164-171. Epub 2012 Apr 4.

Livingston J, Therrell BL, Mann MY, Anderson C, Christensen K, Gorski JL, Grange DK, Peck D, Roberston M, Rogers S, Taylor M, Kaye CI. Tracking clinical genetic services for newborns identified through state newborn dried bloodspot screening programs – case examples. *Journal of Community Genetics*. 2011 DOI 10.007/s12687-011-0055-z.

Lowery JT, Axell L, Vu K, Rycroft R. A novel approach to increase awareness about hereditary colon cancer using a state cancer registry. *Genet Med*. Nov 2010; 12(11):721-25

Wright, EL.; Van Hove, JLK.; Thomas, J; writing for the Mountain States Metabolic Consortium. Mountain States Genetics Regional Collaborative Center's Metabolic newborn screening long-term follow-up study: a collaborative multi-site approach to newborn screening outcomes research. *Genetics in Medicine*. 12(12):S228-S241.

Zellerino BC, Milligan SA, Gray JR, Williams MS, Brooks R. Identification and prioritization of quality indicators in clinical genetics: an international survey. *Am J Med Genet C*. 2009; 151C:179-90.

Zellerino B, Milligan SA, Brooks R, Freedenberg DL, Collingridge DS, Williams MS. Development, testing and validation of a patient satisfaction questionnaire for use in the clinical genetics setting. *Am J Med Genet C*. 2009; 151C:191-199.

Presentations

Platform Presentations

Brilliant, M, Heidenreich, R, Erickson, R, Puck, J, Garrison, N. Navajos and genetic disease: genetic, medical, and educational issues. Presented at: American College of Medical Genetics Annual Meeting; March 2010; Albuquerque, NM.

Brilliant, M. Issues in genetic testing in Navajo populations. Presented at: 2010 SERGG/SERC Annual Meeting; July 2010; Ponte Vedra Beach, FL.

Creel, L. The application of telehealth in genetic services delivery: a model for the HRSA MCHB regional genetic services collaboratives. Presented at: HRSA Office for the Advancement of Telehealth Grantee Meeting; March 2012; Washington, DC.

Creel, L, Landgren, S. MSGRC Telemedicine Projects: An Overview. Presented at: The Northwest Regional Telehealth Resource Center Annual Conference; March 2012; Billings, MT.

Garrison N, Brilliant M, Roanhorse A, Dennison J, Sandoval-Nez Y, Thomas T, et al. Perspectives of Navajo Nation officials and consumers on genetic issues. Presented at: American College of Medical Genetics Annual Meeting; March 2010; Albuquerque, NM.

Hooker J, Creel LM, Thomas J, Brilliant M, Kaye CI. MSGRCC projects promote access to genetic services. Presented at: 138th American Public Health Association Annual Meeting; November 2010; Denver, CO.

Kaye, C, Hassell, K. Mountain States Genetics Regional Collaborative: An Overview. Presented at: 2012 Bi-Regional Hemophilia Conference; April 2012; Colorado Springs, CO.

Kaye CI. Genetic service delivery: Infrastructure, assessment, information. Presented at: 4th National Conference on Genomics and Public Health; November 9, 2010; Washington, DC.

Kaye CI. Genetics workshop for the primary care provider. Presented at: Colorado AHEC Annual Meeting; October 2010; Vail, CO.

Kaye CI. MSGRCC research project update and results. Presented at: Mountain States Genetics Foundation 2010 Annual Education Conference; July 15, 2010; Denver, CO.

Lowery JT. Educational outreach to individuals at risk for hereditary colon cancer. Presented at: Annual Meeting of the Collaborative Group of the Americas on Inherited Colorectal Cancer; October 2007; San Diego, CA.

Williams, MS. Quality improvement in clinical genetics. Workshop presented at: 2008 American College of Medical Genetics Annual Clinical Genetics Meeting; March 13-16, 2008; Phoenix, AZ.

Wright E. MSGRCC metabolic newborn screening long-term follow-up project, a collaborative multi-state approach to newborn screening outcome research. Presented at: Association of Public Health Laboratories Newborn Screening and Genetic Testing Symposium; November 3-6, 2008; San Antonio, TX.

Poster Presentations

Borgfeld, L, Williams, D, Creel, L, Hooker, J, Kaye, C, writing for the MSGRC Emergency Preparedness Workgroup. Newborn screening emergency planning: understanding laboratory capacity and backup sources in the mountain states region (AZ, CO, MT, NM, NV, TX, UT, WY). Association of Public Health Laboratories 2011 Newborn Screening and Genetic Testing Symposium; November 2011; San Diego, CA.

Creel L, Eckman J, Griffin J, Harris KB, Keehn A, Stock J, Waisbren S, Whitehead S. Transition activities among the regional collaboratives. Association of Maternal and Child Health Programs Conference; February 2012; Alexandria, VA.

Creel LM, Hooker J, Kaye CI, MSGRCC Consumer Advocacy Workgroup. The life rope: engagement of diverse populations for recruitment and representation in genetics. Academy for Health Equity, 2010 Conference; August 2010; Denver, CO.

Hasegawa L, Creel L, Kubendran S, Au S. Telegenetics clinics in the United States: success, challenges, and future directions. American College of Medical Genetics Annual Clinical Genetics Meeting; March 2012; Charlotte, NC.

Hasegawa L, Creel L, Kubendran S, Andersson H, Au S. Telegenetics clinics in the United States: success, challenges, and future directions. 12th International Congress of Human Genetics; October 2011; Montreal, QC.

Perry W, Borgfeld L, Williams D, Tanksley S, Freedenberg D, Martinez D, Taylor L, Torres J, Creel L, Hooker J. Newborn screening program emergency preparedness: Texas-Florida partnership. Association of Public Health Laboratories 2011 Newborn Screening and Genetic Testing Symposium; November 2011; San Diego, CA.

