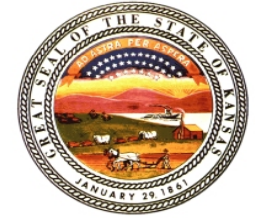


Medical and Human Genetics in KANSAS

Jamey Kendall and Linda Williams

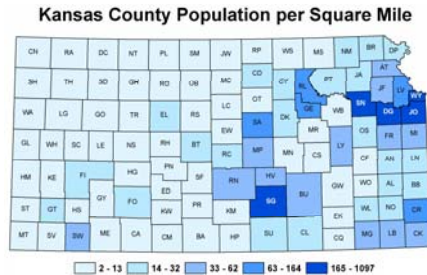
Kansas Department of Health and Environment



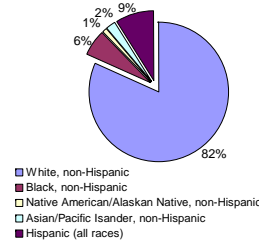
State Profile (2008)

Total Population: 2,802,134

- Wichita (357,698)
- Overland Park (166,722)
- Kansas City (143,801)
- Topeka (122,113)
- Olathe (114,662)
- Lawrence (88,605)



Racial and Ethnic Composition of Kansas Population (2007)



Personnel

State Health Department	Linda Kenney, MPH Carolyn Nelson Jamey Kendall, RN, BSN Linda Williams, MT (ASCP) Colleen Peterson, BS Janet Neff, BS
Clinical Geneticists	R. Neil Schimke, MD Majed Dasouki, MD Merlin Butler, MD, PhD University of Kansas Medical Center Kansas City, KS
Genetic Counselors	Debra Collins, MS, CGC (Adult/Cancer/Pediatrics) Lisa Butterfield, MS CGC (Prenatal) Erin Youngs, MS (Pediatrics/Psychiatry) University of Kansas Medical Center Lenna Levitch, MS, CGC (Cancer/ Prenatal/ Pediatrics) Molly Lund, MS,CGC (Cancer/ Prenatal/ Pediatrics) Cotton O'Neil Clinics at Stormont Vail, Topeka, KS & Menorah Medical Center, Overland Park, KS Shobana Kubendran KUMC-Wichita, KS

Newborn Screening

41,951 Live births (2007)

1965 Phenylketonuria	1977 Congenital hypothyroidism
1986 Galactosemia	1990 Hemoglobinopathies
1999 Hearing	2008 29 tests in ACMG core panel

Newborn Screening Progress

- 2005 – NNSGRC TA Site visit and review of NBS Program
- 2006—Final Report received
- 2006 Legislative Session
 - Newborn Screening legislation proposed
 - Initiation of Governor's Child Health Advisory Committee charged to address Newborn Screening
 - Secretary of Health convenes Financial Advisory Committee for Newborn Screening—report to legislature due in 2007
- 2007 – Initiation of State Genetics Plan with provider survey
- 2007 Legislative Session
 - Passage of SB 11 mandating expansion to ACMG core panel
- 2008 – Implementation of ACMG recommended core panel of tests
- 2009 – Draft of State Genetics Plan completed

Facilities

KS Department of Health & Environment, Topeka

- KHEL – Newborn Screening Testing
- Newborn Screening Follow-up
- Sound Beginnings – EDHI
- Children and Youth with Special Healthcare Needs
- State Genetics Coordinator
- Cancer and Prevention Control Program

University of Kansas Medical Center, Kansas City

- Adult Genetics
- Prenatal Genetics
- Pediatric Genetics
- Cystic Fibrosis Center
- Pediatric Endocrinology
- Pediatric Hematology
- Metabolic Genetics
- Dysmorphology
- Cancer Genetics

Wichita, KS

- Cystic Fibrosis Center
- Pediatric Endocrinology

Topeka, KS

- Pediatric Endocrinology

Training

ABGC programs (provisional accreditation)

MS in Genetic Counseling, MidAmerica Education Consortium (MAGEC)

Resources

- www.kdheks.gov/newborn_screening
- www.kdheks.gov/edw