

Medical and Human Genetics in KANSAS

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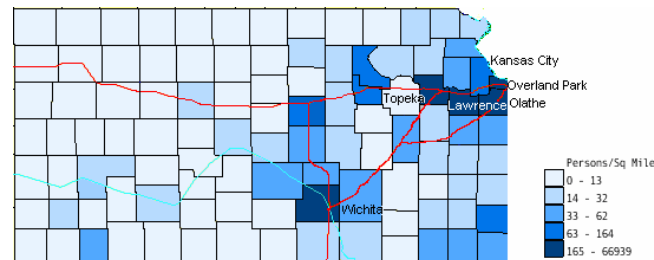
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State Profile (2005)

Population: 2,744,687

Wichita (354,865)
Overland Park (164,811)
Kansas City (144,210)
Topeka (121,946)
Olathe (111,334)
Lawrence (81,816)



Personnel

State Health Department	Linda Kenney, MPH Jamey Kendall, RN, BSN Melanie Lewis, RN
Clinical Geneticist	R. Neil Schimke, MD University of Kansas Medical Center Kansas City, KS Majed Dasouki, MD University of Kansas Medical Center Kansas City, KS
Genetic Counselors	Debra Collins, MS, CGC Adult/Cancer/Pediatric University of Kansas Medical Center Lisa Butterfield, MS, CGC Prenatal University of Kansas Medical Center Lenna Levitch, MS, CGC Cancer Genetics Cotton O'Neil Clinics, Topeka, KS
Pediatrics	Chet Johnson, MD
Endocrinology	James Lynn Casey, MD University of Kansas Medical Center
Genetic Laboratories	Diane Persons, MD Cytogenetics Laboratory University of Kansas Medical Center
Parent Advocate	Michelle Leeker Baldwin City, Kansas

Newborn Screening

39,701 Livebirths (2005)

1965	Phenylketouria
1977	Congenital hypothyroidism
1986	Galactosemia
1990	Hemoglobinopathies
2001	Hearing
2008	29 tests in ACMG core panel

Newborn Screening Progress

August 2005—NNSGRC TA Site visit and review of NBS Program; March 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 Legislative Session—passage of SB 11 mandating expansion to ACMG core panel
2007 – initiation of State Genetics Plan with provider survey

Foundations & Patient Advocacy

- National support groups started by patients in Kansas: 5p-Society, Organic Acidemia Association, Polycystic Kidney Disease Foundation, Rubinstein Taybi Syndrome, Stickler Involved People, Proteus Syndrome Foundation
- Geneticists have served as national advisors for von Hippel-Lindau Foundation, Proteus Foundation, NOAH (Albinism and Hypopigmentation), National Neurofibromatosis Foundation
- Geneticists served as local advisors for Central Star Chapter of Little People of America, Greater Kansas City Huntington Disease Group, Uriel Owens Sickle Cell Anemia Foundation, KC Cystic Fibrosis Support Group, Greater Kansas City Marfan Syndrome Support Group, Kansas City Turner Syndrome Support Group

Training

ABGC programs (provisional accreditation)

MS in Genetic Counseling, MidAmerica Education Consortium (MAGEC)

Facilities

University of Kansas Medical Center, Kansas City
Adult Genetics
Prenatal Genetics
Cancer Genetics
Pediatric Genetics
Endocrinology
Metabolic Genetics
Dysmorphology

State Health Department, Topeka
Newborn Screening