

# Medical and Human Genetics in KANSAS

*DL Collins<sup>1</sup>, LC Butterfield<sup>1</sup>, LL Levitch<sup>2</sup>, LR Kenney<sup>3</sup>, JP Kendall<sup>3</sup>, Michelle Leeker<sup>4</sup>*

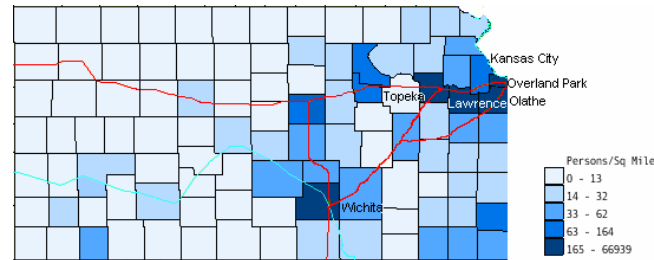
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## State Profile

Population: 2,723,507 (1/1/03)

Wichita (354,617)  
 Overland Park (160,368)  
 Kansas City (145,757)  
 Topeka (122,008)  
 Olathe (105,724)  
 Lawrence (82,120)



## Personnel

**State Health Department** Linda Kenney, MPH  
 Jamey Kendall, RN, BSN  
 Melanie Warren, 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

38,869 Births / year (2002)

1965 Phenylketouria  
 1977 Congenital hypothyroidism  
 1986 Galactosemia  
 1990 Hemoglobinopathies  
 2001 Hearing

## Newborn Screening Progress

Newborn Screening Technical Assistance Team Review  
 Sponsored by the National Newborn Screening and  
 Genetic Resource Center

August 2005—Site visit and review of Newborn  
 Screening Program

March 2006—Final Report with recommendations  
 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

## 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