

Medical and Human Genetics in South Dakota

SD Department of Health- Pierre, SD

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State Profile

- Population: 754,844
- 88.7% white; 9% Native American; 2.3% Other races
- 26.8% of population is under 18 years of age and 6.8% is under 4 years of age
- Area 75,955 square miles
- Population density: 9.9 people per square mile
- ½ of the 66 counties have population density of < 6 persons per square mile
- 9 Indian Reservations, many considered poorest counties in the nation
- Largest cities: Sioux Falls, 123,975; Rapid City, 59,607; Aberdeen 24,658

Newborn Screening

| January 1 to December 31, 2006 | Presumptive Positives | Confirmed with Diagnosis |
|--|-----------------------|--|
| Infants born = 12,387 Total number of infants screened = 12,336 | | |
| Amino-acyl Screen | 194 | 5 (3 – MCAD, 1 asymptomatic SCAD, 1-VLCAD) |
| Biotinidase Deficiency | 13 | 3 (2 partial, 1 carrier) |
| CAH | 59 | 0 |
| Hemoglobinopathies: | | |
| Disease | 1 | 0 |
| Trait | 64 | 63 |
| Other | 25 | 5 |
| Thyroid Screen | 12 | 5 |
| Galactosemia | 1 | 1 |
| PKU | 5 | 1 |

- ☐ Effective June 1, 2007, SD began testing for cystic fibrosis, currently testing for 28 of the 29 ACMG Core Panel and 17 secondary targets.
- ☐ Hearing Screening is not mandated – 97% of infants born in SD are screened before one month of age
- ☐ Centralized contracted laboratory system with the University of Iowa Hygienic Laboratory

MAP

Native American Reservation and Tribal Lands



Genetic Services

- ☐ New genetic counselor to start services in August, 2007 for a total number of 3 Genetic Counselors in SD
- ☐ PKU Drug Expanded Access Program (Sapropterin) – Sanford Children’s Hospital
- ☐ General Genetics – Geneticist on site
Sanford Children’s Clinic, Sioux Falls, SD
CSHS Outreach Clinics: Pierre, and Rapid City
- ☐ Hereditary Cancer Genetic Counseling Sanford Clinic – OB-GYN, Ltd.
- ☐ Maternal Fetal Medicine Sanford Clinic – Maternal Fetal Medicine
Avera McKennan Maternal-Fetal Medicine
- ☐ Multidisciplinary Genetic Clinics Comprehensive Metabolic Clinic
Down syndrome multidisciplinary
Fetal Alcohol syndrome spectrum disorder
Craniofacial multidisciplinary clinics (Rapid City and Sioux Falls)
- ☐ Cystic Fibrosis Center Sanford Children’s Clinic, Sioux Falls, SD
- ☐ Hemophilia and Blood Disorders Sanford Children’s Clinic, Sioux Falls, SD

Successes

- NBS and Hearing results are integrated with birth certificate February 2002
- Newborn Screening Laboratory Services through University of Iowa Hygienic Laboratory began June 1, 2007
- Improved turn-around-time from birth to reporting of test results – Average 5.5 days (June 2007)
- T. Denny Sanford gift of \$400 million to Sioux Valley Hospital newly named Sanford Health.
- As a result of the gift, a new children’s hospital is being built in Sioux Falls.
- H. Eugene Hoyme, MD joining Sanford Health as Chief Pediatric Medical Officer for Sanford Children’s Hospital August 1, 2007

Challenges

- Disparities of White population vs. Native American
- 27 of the 50 community hospitals deliver babies
- 1 physician (total of 1087 Ob-Gyn, Pediatrician, Internal Medicine, General and Family Practice) for every 694 people
- 1 midlevel (total of 692 PAs and CNPs) for every 1090 residents
- 29.6% of state’s population at 200% of poverty – Indian Reservation rate high 66%-79%
- 2/3 of the state is designated as Primary Medical Care Health Professional Shortage Area

References

- South Dakota Dept. of Health, Office of Data, Statistics, and Vital Records
- Quinn Stein, MS, CGC