

Medical and Human Genetics in South Dakota

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South Dakota Department of Health--Pierre, SD



State Profile

- Population: 754,844
- 88.7% White, 9% Native American, 2.3% other
- 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
- Number of birthing hospitals = 24
- Sanford School of Medicine, University of SD located in Vermillion, SD.



Special Features

- By 14 days of age, 97% of the metabolic laboratory results are matched to a birth certificate.
- Sanford Children's Hospital opened doors March 2009. A new regional comprehensive pediatric healthcare facility.
- Genetic Counselor licensure legislation passed and signed into law 2009.
- Long Term Follow-up Program initiated November 2007.
- Newborn Screening Specimen turn-around time from birth to reporting of results improved to 5.5 day average.
- Contract for newborn screening services with the University of Iowa Hygienic Laboratory.
- Screening for 28 of the 29 ACMG Core Panel and 17 secondary targets.
- Integrated metabolic and hearing results to birth certificates since 2002.

Newborn Screening

Year	Births	Never Tested	PKU	CH	GAL	BT	CAH	HB	Ex. Screen	CF
2000	10,589	36	0	4	1	N/A	N/A	N/A	N/A	N/A
2001	10,786	41	2	6	0	N/A	N/A	N/A	N/A	N/A
2002	11,015	41	1	3	0	N/A	N/A	N/A	N/A	N/A
2003	11,504	40	0	4	0	N/A	N/A	N/A	N/A	N/A
2004	11,805	60	1	6	1	N/A	N/A	N/A	N/A	N/A
2005	11,960	54	0	3	1	0	0	0	3	N/A
2006	12,387	51	1	5	0	0	0	2	4	N/A
2007	12,815	63	0	9	1	0	0	2	0	1
2008*	12,632	62	1	6	0	2	0	1	3	3

- 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 newborn screening system contracted with the University of Iowa Hygienic Laboratory.

Genetic Services

- Total number of Genetic Counselors in state = 4
- PKU Drug Expanded Access Program
- (Sapropterin) – Sanford Children's Hospital
- General Genetics – Geneticist on site
 - Sanford Children's Clinic, Sioux Falls, SD
 - Sanford Outreach Clinics: Pierre, Rapid City and Watertown
- Hereditary Cancer Genetic Counseling
 - Avera McKennan Cancer Institute
 - Sanford Women's Health
- 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

Personnel

Department of Health

Kayla Tinker	Administrator, Office of Family Health
Bev Duffel	Team Leader, Office of Family Health
Lucy Fossen	South Dakota Newborn Screening Program
Terry Disburg	South Dakota Newborn Hearing Program
Sarah Groeneveld	Metabolic Long-Term Follow-up, Sanford Children's Clinic

Newborn Screening Program Medical Consultants

Sanford Children's Specialty Clinic

Genetic Counselors

Jason Flanagan, MS, CGC, Sanford Clinic Women's Health
 Nicole Rose, MS, Avera Maternal Fetal Medicine
 Quinn Stein, MS, CGC, Sanford Children's Specialty Clinic
 Amy Woltanski, MS, Sanford Children's Specialty Clinic

Geneticists

Laura Davis-Keppen, MD
 H. Eugene Hoyme, MD
 Maria Palmquist, MD

Cytogenetics Laboratory

Patricia L. Crotwell, PhD Director-Sanford Clinic USD Genetics Lab

References

- South Dakota Department of Health, Office of Data Statistics, and Vital Records
- Sanford Hospital website at: <http://www.sanfordhealth.org/>
- South Dakota Newborn Screening Yearly Report
<http://doh.sd.gov/NewbornScreening/Default.aspx>