

Medical and Human Genetics in Nebraska

Julie Miller, BS, Nebraska Department of Health & Human Services

*Warren Sanger, PhD, Interim Director, Munroe Meyer Institute,
University of Nebraska Medical Center*



FACILITIES:

- **NBS Program Management & Follow-up** from State Health & Human Services Agency in Lincoln
- **General genetic clinic services** provided in Omaha at Munroe-Meyer (UNMC), Lincoln
- **Outreach clinics** Nebraska (Scottsbluff, Kearney, Winnebago); and South Dakota (Pierre, Rapid City)
- **Clinic types:** Genetics(4), Craniofacial (3), FAS (2), Cancer (3), Prenatal (3), Metabolism (3), Helmet (1), Developmental (2), Neurosensory (1), Autism (1), Teratogen IS (1), Neurogenetics (1), Neuromuscular (1)
- **MHCP Clinics** Cerebral Palsy (Scottsbluff, Grand Island), Craniofacial (North Platte)
- **Human Genetic clinical/research laboratories:** UNMC, CUMC, BTNRH

PERSONNEL

Department of Health & Human Services

Julie Miller, SGC, NBS Program Manager
Krystal Baumert NBS Follow-up Coordinator
Karen Eveans, NBS Follow-up Specialist
Jeff Hoffman, NB Hearing Scrmg Prog. Manager

Genetic Counselors cont'd

Julianne Geiser, MS (UNMC)
Danielle Bishay, MS (UNMC)
Stephanie Miller, MS, (Lincoln)

Genetic Counselors

Becky Anderson, JD, MS/CGC (UNMC)
Hope Chipman, MS (UNMC)
Beth Conover, MS/CGC/PN (UNMC)
Kelly Ferrera, MS (CUMC, Onc.)
Sara Knavel, MS/CGC (UNMC)
Shelly Nielson, MS/CGC (UNMC)
Kristal Platt, MS/CGC (BTNRH)
Gwen Reiser, MS/CGC (UNMC)
Bronson Riley, MS (Lincoln, Onc.)
Sue Tinley, MS/CGC, PhD (CUMC)
Melanie Welsh, MS (Methodist)
Teresa Castellano, MS, CGC (Linc/St. E)

Clinical Genetics

Bruce Buehler, MD(UNMC)
Richard Lutz, MD (UNMC)
Ann Olney, MD (UNMC)
William Rizzo, MD (UNMC)
Karl Roth, MD (Creighton CUMC)
Mike Schmidt, MD (Lincoln priv. practice)

Laboratory Genetics

Julia Bridge, MD (UNMC)
Amy Brower, PhD (Private-Consult)
Bhavanna Dave, PhD (UNMC)
Dana Orten, PhD (BTNRH)
Warren Sanger, PhD (UNMC)
William Kimberling, PhD (BTNRH)

NEBRASKA: SPECIAL FEATURES

History: Unicameral government

Populations: Significant increases in Hispanic, Sudanese populations, Somali, and other refugee populations with strong refugee resettlement ties.

Research Institutes: UNMC, Creighton University, BTNRH

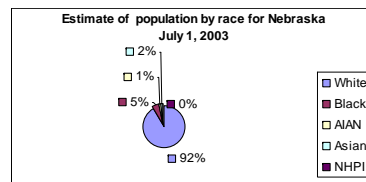
POPULATION:

State: 1,747,214 (2/3 pop. in eastern 1/3 state)

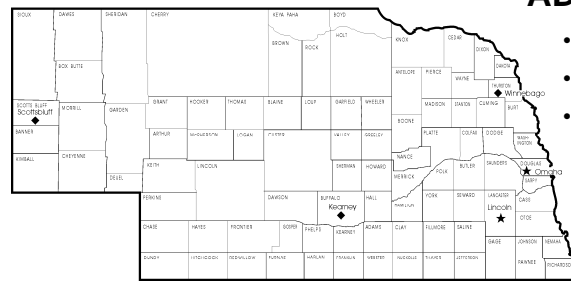
Omaha: 563,585; the greater Omaha area (4 Nebr. counties, and 4 Iowa counties) approaches 1,000,000

Lincoln: 250,291, with surrounding metro area, approaches 300,000

- Grand Island 53,534
- Kearney 42,259
- Scottsbluff 36,941



Genetic Service Sites in Nebraska



★ Genetic Service Providers
◆ Satellite Clinics

NEWBORN SCREENING -- Meets ACMG rec.

Disorder	Year Testing Began	Cases Identified (≅ per year)
PKU	1962	(≅2 per year)
Congenital Primary Hypothyroidism	1976	(6-15 per year)
Biotinidase Deficiency	1987	(2-4 / yr ¹)
Galactosemia	1996	(1 every 3-5 yrs)
Hemoglobinopathies	1996	(2-6 per year ²)
Hearing Screening	2000	(25-75 per year)
MCAD	2003	(2 per year)
MS/MS ³	2003	(3-4 per year)
Congenital Adrenal Hyperplasia	2006	(1-2 per year)
Cystic Fibrosis	2006	(13 / year)

Screening Lab: State contracts NBS lab testing with Pediatrix
Hearing screening: 2000, 100% hospitals screen, > 99% NB's screened, Incidence rate 1.6/1,000

¹ 4-6 partials treated per year

² clinically significant

³ required - full acylcarnitine and amino acid profiles, including primary succinylacetone for Tyr1, = ACMG Core Panel of recommended conditions

ADVISORY BODIES

- Newborn Screening Advisory Committee
- Newborn Hearing Screening Advisory Committee
- Munroe Meyer Institute for Genetics & Rehabilitation Consumer Advisory Board

TRAINING

- MS in Genetic Counseling (MAGEC Consortium)
- PhD in (Human) Genetics

REFERENCES

State Genetic Plan & Annual Newborn Screening Report available at: <http://www.hhss.ne.gov/nsp/>

•Munroe-Meyer Institute website at: <http://www.unmc.edu/mmi/>

•Boys Town National Research Hospital (BTNRH) website at: <http://www.boystownhospital.org>