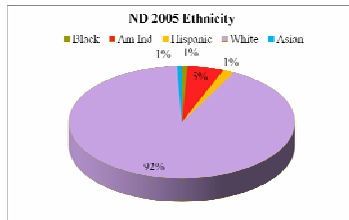


# Medical and Human Genetics in North Dakota

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## Genetic Related Clinics

**Comprehensive Metabolic Clinic (including for abnormal newborn metabolic screening)**

**Clinic:** Coordinated Treatment Center

**Site:** Fargo, ND

Description of clinic: Treatment and management of children in North Dakota with metabolic disorders.

**Down Syndrome multidisciplinary**

**Clinic:** Coordinated Treatment Center

**Site:** Fargo, ND

Description of clinic: Outpatient service to help accommodate the special medical, developmental, behavioral, family, and community needs of patients with Down syndrome.

**Cystic Fibrosis Centers**

**Clinic:** Site: Coordinated Treatment Center

**Site:** Fargo, ND

Description of clinic: Treatment and management of children identified through newborn screening and diagnostic testing for cystic fibrosis.

**Clinic:** Heart and Lung Clinic

**Site:** Bismarck, ND

Description of clinic: Treatment and management of children identified through newborn screening and diagnostic testing for cystic fibrosis.

**Hemophilia and Bleeding Disorders**

**Clinic:** North Dakota Hemophilia and Thrombosis Treatment Center

**Site:** Fargo, ND

Description of clinic: Provides a team approach and comprehensive care for people with hemophilia, von Willebrand and many other types of bleeding and clotting disorders.

**Other Multidisciplinary Clinics: Cleft Lip & Palate Clinics**

**Clinic:** Medcenter One Health Systems Ear, Nose & Throat Clinic

**Site:** Bismarck, ND

**Clinic:** Pontoppidan Lutheran Church

**Site:** Fargo, ND

**Clinic:** UND Speech, Language and Hearing Clinic

**Site:** Grand Forks, ND

**Clinic:** MSU Communications Disorders Clinic

**Site:** Minot, ND

**Muscular Dystrophy Clinic**

**Clinic:** Coordinated Treatment Center

**Site:** Fargo, ND

Description of clinic: Provides a team approach to treatment and management of children in North Dakota with muscular dystrophy.

**Myelodysplasia Clinics**

**Clinic:** Altru

**Site:** Grand Forks, ND

Description of clinic: Provides a team approach for treatment and management of children with spina bifida.

**Clinic:** Coordinated Treatment Center

**Site:** Fargo, ND

Description of clinic: Provides a team approach for treatment and management of children with spina bifida.

**Clinic:** Medcenter One Health Systems

**Site:** Bismarck, ND

Description of clinic: Provides a team approach for treatment and management of children with spina bifida.

**Hereditary Cancer Genetic Counseling**

**Clinic:** Roger Maris Cancer Center

**Site:** Fargo, ND

Description of clinic: Provides genetic counseling and coordinates testing for hereditary breast and ovarian cancer, as well as colorectal cancer.

**Cancer genetic counseling also provided at all genetic clinics throughout the State.**

**Laboratory Services**

Genetic Laboratory Services are not available in North Dakota. All newborn screening, cytogenetic studies and molecular laboratory testing are sent out of State.

**North Dakota Teratogen Information Service**

**Site:** Division of Medical Genetics

**Grand Forks, ND**

Description: A statewide service offering information on harmful exposures during pregnancy to health care professionals, utilizing up-to-date information from websites, professional articles, and recent texts.

## Special Features

**Population:** The population of North Dakota is expected to grow modestly over the next 20 years, with the most growth in the elderly population. In contrast, the young adult population is expected to continue a marked decline, along with declining birth rates. (Information from ND State Data Center)

## Genetic Clinic Sites

- Altru, Grand Forks
- Family Medicine Residency, Grand Forks
- MeritCare Southwest, Fargo
- Center of Family Medicine, Bismarck
- Center of Family Medicine, Minot
- Ft. Totten (Spirit Lake Nation)

## Collaborative Agencies

**ND State Health Dept.**

Terry Dwelle, MD, MPH/MTM; State Health Officer

Barb Schweitzer, RN, BSN; Dir. Newborn

Screening Program

Mary Ann Foss, RN; Dir. Cancer Prevention & Control

Toni Vetter, RN, BSN; Dir. Sudden Infant Death

Syndrome Program

**Children's Special Health Services**

Tammy Gallup-Millner, RN, MPA, Unit Director

Sue Burns, RN, BSN, Program Administrator

Devaiah Muccatira, MS; State System

Development Coordinator

**Infant Development**

Roxane Romanick, MSW; Early Intervention

Experienced Parent Specialist

**Right Track**

Marianne Quittshreiber; BS; Right Track Coordinator

**Family To Family**

Pat Conway, Ph.D., LCSW, Project Director

Karen Watt, LSW, Project Coordinator

**March of Dimes**

Karin Roseland, BA; State Director

**Division of Family Health**

Kim Senn, RN, BNSC Director



## Personnel

John T. Martsolf, MD FACMG,

Clinical Geneticist, **Director**

Mary Riske, RN, MS, CNS, Nurse Geneticist

Larry Burd, Ph. D., Director FAS Center

Jayne Brown, BA, LSW, Human Services

Information **Coordinator**

Candace Skavlem, Administrative Secretary

## Advisory Bodies

ND Fetal Alcohol Syndrome

Committee (FAS)

Genetics Advisory Committee

Newborn Screening Committee

ND Birth Defects Surveillance

Committee

ND Genetic State Plan Committee

## References

Division of Medical Genetics. (2007). North Dakota State Genetics Plan. Retrieved September 3, 2007, from <http://www.med.und.nodak.edu/depts/peds/genetics/NorthDakotaStateGeneticsPlan.htm>

Heartland Regional Genetics and Newborn Screening Collaborative. (2006). Clinical Genetics Resources by State. Retrieved August 3, 2007, from <http://heartland.ouhsc.edu>

Martsolf, J., Riske, M., Brown, J. (2006, Sept.) Medical and Human Genetics in North Dakota. Poster session presented at the annual meeting of Heartland Regional Genetics and Newborn Screening Collaborative, Kansas City, KA.

ND State Data Center. (2006). Population Bulletin. North Dakota State Data Center at North Dakota State University. Retrieved August 3, 2007 from [http://www.ndsu.nodak.edu/sdc/publications/population/PB\\_22\\_1press.pdf](http://www.ndsu.nodak.edu/sdc/publications/population/PB_22_1press.pdf)

U.S. Census Bureau. (2007). USA Quick Facts. Retrieved August 3, 2007, from <http://quickfacts.census.gov>.

State Genetics Plan available at: <http://www.med.und.nodak.edu/depts/peds/genetics/NorthDakotaStateGeneticsPlan.htm>

## State Population Profile

**2006 Live Births:** 8,100

**Population:** 635,867

Fargo: 91,484

Bismarck: 56,344

Grand Forks: 48,321

Minot: 35,424

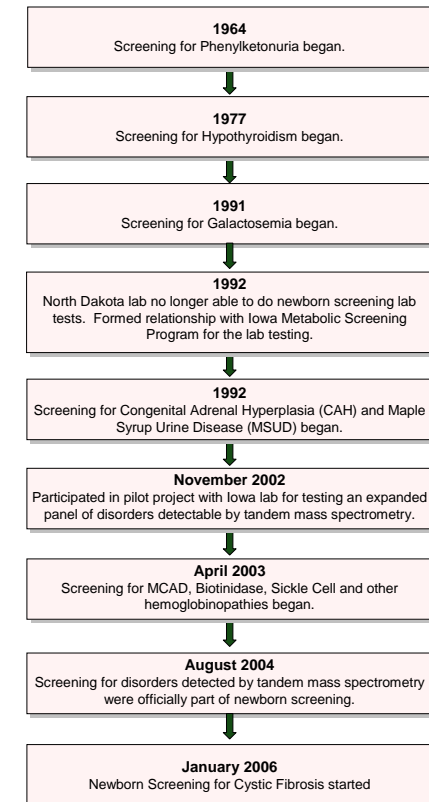
Fort Berthold Reservation 5,915

Spirit Lake Reservation 4,435

Standing Rock Reservation 4,044

Turtle Mountain Reservation 8,307

## History of ND Newborn Screening Program



B. Schweitzer (personal communication, August 10, 2006)