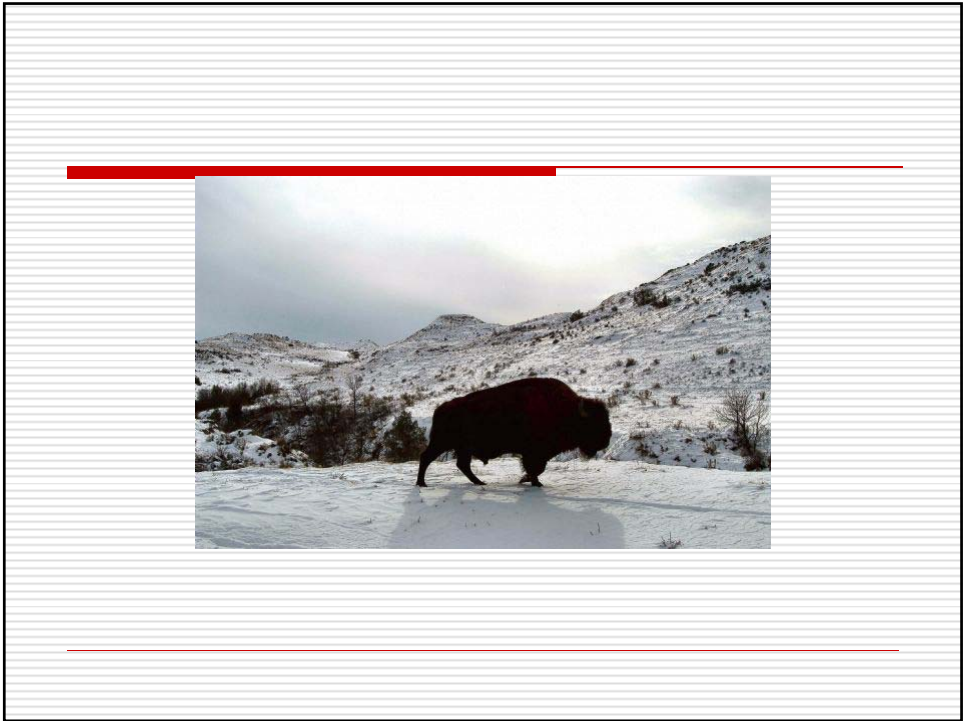
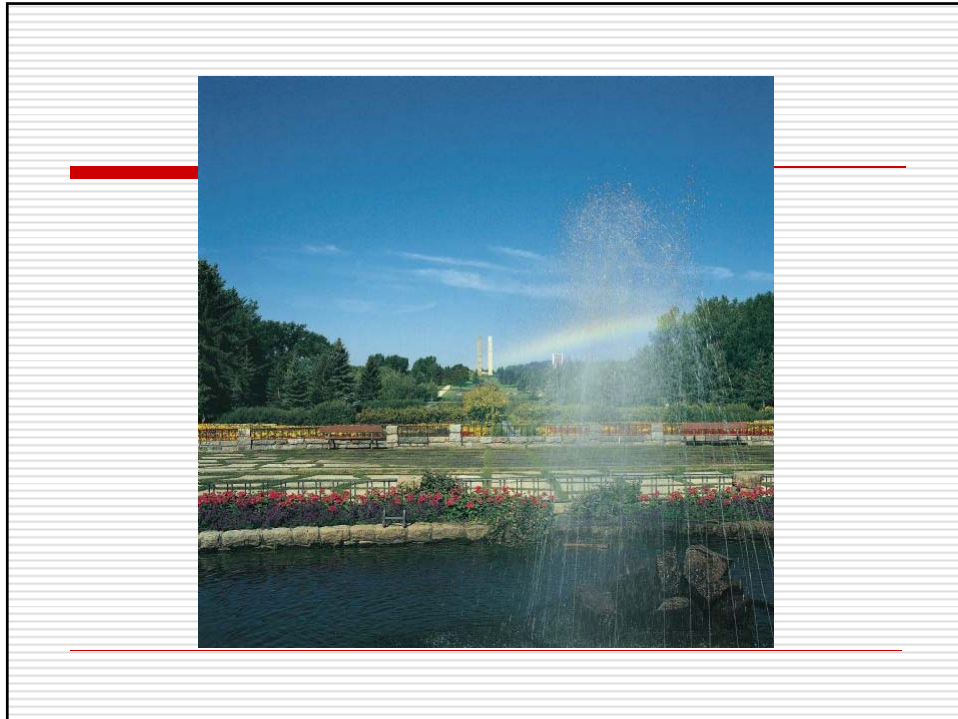


North Dakota







North Dakota population profile

Population: 672,591

Live Births: 9,088

Caucasian 90.0%
Native American 5.4%
Hispanic 2.0%
Asian 1.0%
African American 1.2%

2010 US Census Bureau

Largest Cities



Reservations



Brief History of Genetic Services

When

Before 1978:
Muscular Dystrophy Clinic
Cytogenetics Lab at UND
1978: Clinical Geneticist hired
by State & University ND

Initial Sites

1978: Grand Forks, Fargo,
Bismarck, Williston
1979: Minot, Anne Carlsen School
1980-85: Dickinson, Fort Totten
Turtle Mt. Fort Berthold
1989: Fort Yates, Grafton State
School

Funding

1978-1980 Maternal Child Health
1979-1986 March of Dimes
1980-1984 SPRANS Grant
1984-current Private Funds
1985-current Maternal & Child
Health Federal Matching
Funds
2009-Sanford Health funded a
part time geneticist
2010-Sanford Health funded a
genetic counselor

1978

First genetic patients were seen in September



Governor Link and Dr. Robert Wentz were instrumental to the establishment of the Statewide Clinical Genetics Services. Dr. Wentz was the Director of the Division of Maternal and Child Health in the State Health Department.

Mission of the State Genetic Services System

- Offer
 - Information
 - Diagnostic Services
 - Education
 - Support
 - Research opportunities

Promote

- Genomic Activities with Public Health System



Clinical Genetic Staff in ND

- Clinical Geneticists:
 - John T. Martsolf, MD FACMG
 - University of ND
 - Pamela McGrann, MD
 - Sanford Health

Clinical Genetic Staff in ND

- Genetic Nurses:
 - Shana Wiley RN, MS
 - University of ND
 - Mary Riske, RN MS CNS
 - Sanford Health
-

Clinical Genetic Staff in ND

- Genetic Counselors
 - Larissa Hansen, MS
 - Sanford Health
 - Marie Schuetzle, MS
 - Informed DNA
-

Clinical Genetic Staff in ND

- Larry Burd, Ph. D.
 - University of N D
 - Candace Skavlem, Admin. Secretary
 - University of ND
-

Current Genetic Clinic Sites

- Dr. Martsolf-Grand Forks, Minot, Bismarck
 - Dr. McGrann & Larissa Hansen-Fargo and all Sanford Clinics
 - Marie Schuetzle-Statewide Phone genetic counseling
 - Telegenetics – Grand Forks UND (counseling only)
-

Multidisciplinary Clinics

- Metabolic – Fargo
- Down Syndrome – Fargo
- Cystic Fibrosis – Fargo & Bismarck
- Hemophilia & Bleeding Disorders – Fargo
- Muscular Dystrophy – Fargo
- Myelodysplasia – Grand Forks & Fargo
Bismarck
- Cleft Lip & Palate – Bismarck, Fargo,
Grand Forks, Minot

Sites of Clinics



Reservations



Clinical Genetics in Grand Forks per Dr. Martsolf

- ❑ Provides general genetic practice with clinics in Grand Forks, Minot, and Bismarck
 - ❑ Patients range from pediatric to adult
 - ❑ Majority patients in the pediatric age span
 - ❑ 7% of patients are non-white
 - ❑ See about 3-4% of the ND birth rate
 - ❑ Practice since 1978 has involved about 13,000 patients
-

Dr. Martsof continued

- Medical School Faculty Responsibilities
 - Provides a senior elective in clinical genetics
 - Provides several lectures to medical students concerning birth defects and genetic disorders
 - Functions as wrap up physician in several genetic cases as part of the problem based learning system for medical students
-

Clinical Genetics in Fargo-per Dr. McGrann & Larissa

- 50-60 patients per month
 - 2/3 are pediatric
 - 1/3 patients have Medical Assistance
 - 1/2 of pediatric patients have Medical Assistance
 - 25% of patients are non-white
 - Larissa also provides genetic counseling at:
 - Maternal-Fetal Medicine Clinics
 - Reproductive Endocrinology Clinics
 - Cancer Risk Assessment Clinics
-

Clinical Genetics per Marie Schuetzle

Provides statewide telephone genetic counseling services for:

Informed Medical Decisions– a nationwide-network of genetics experts based out of St. Petersburg, FL available by telephone to help patients and providers harness the power of genetics to achieve the promise of personalized healthcare.

Informed continued

- Includes 40+ independent genetic counselors covering all subspecialties
 - Follows National Guidelines & Standards
 - Compliant Data & TeleCom Networks
 - Provide day, evening and weekend appointments
 - Insurance, patient, and institutional billing available
-

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.
-

Educational Activities

Include

- Undergraduates
- Graduates
- Medical Students
- Professional Groups
- Conferences
- Consumers



Educational Programs
offered throughout the
state

North Dakota Teratogen Information Service

- ❑ A statewide service offering information on harmful exposures during pregnancy and breastfeeding to health care professionals, utilizing current information from Reprotox, professional articles and current texts.
-

Network of Services

- ❑ Our comprehensive statewide clinical genetic/birth defects program provides and utilizes an extensive network of services through local, regional, and national affiliations.
-

Advisory Committees:

- Genetics Advisory Committee
 - Newborn Screening Advisory Committee
 - CSHS Medical/Family Advisory Council
 - Heartland Genetics & Newborn Screening Collaborative
-

Collaborative Agencies

- ND State Health Department
 - Newborn Screening
 - Hearing Screening
 - Cancer Prevention & Control
 - Chronic Disease
 - Childrens Special Health Services
 - State System Development (Birth Defects)
 - Fetal Alcohol Syndrome Center
-

Collaborative Agencies

- Infant Development
 - Right Tracks
 - Family Voices/Family to Family
 - March of Dimes
 - Parent Advocates
 - Legislative Advocate
 - ND Departments of Human Services
across the state for variety of services
-

Goals

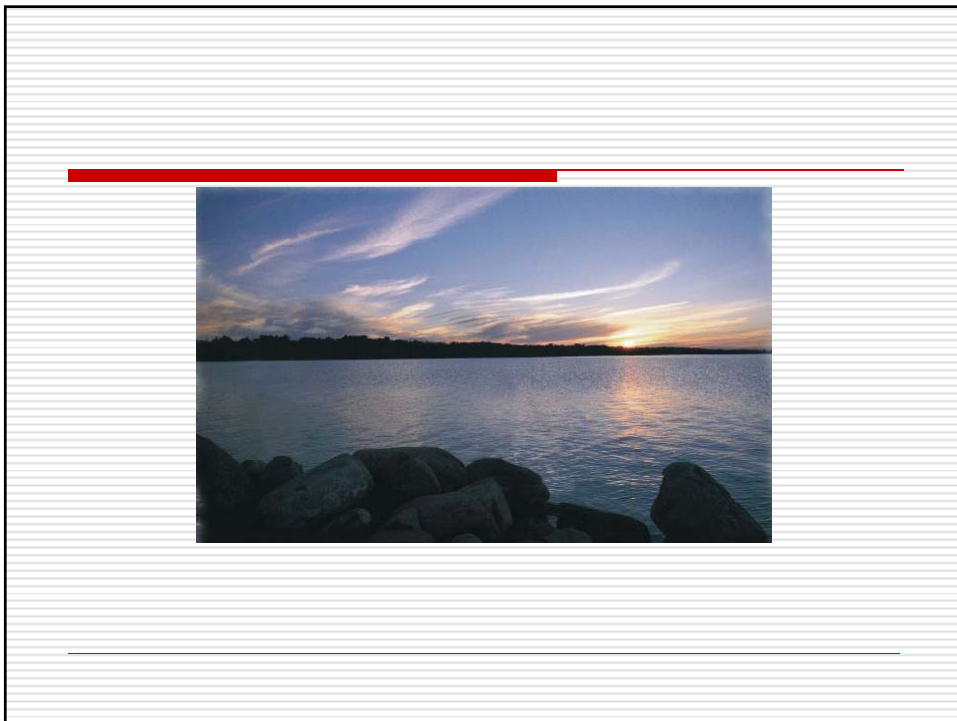
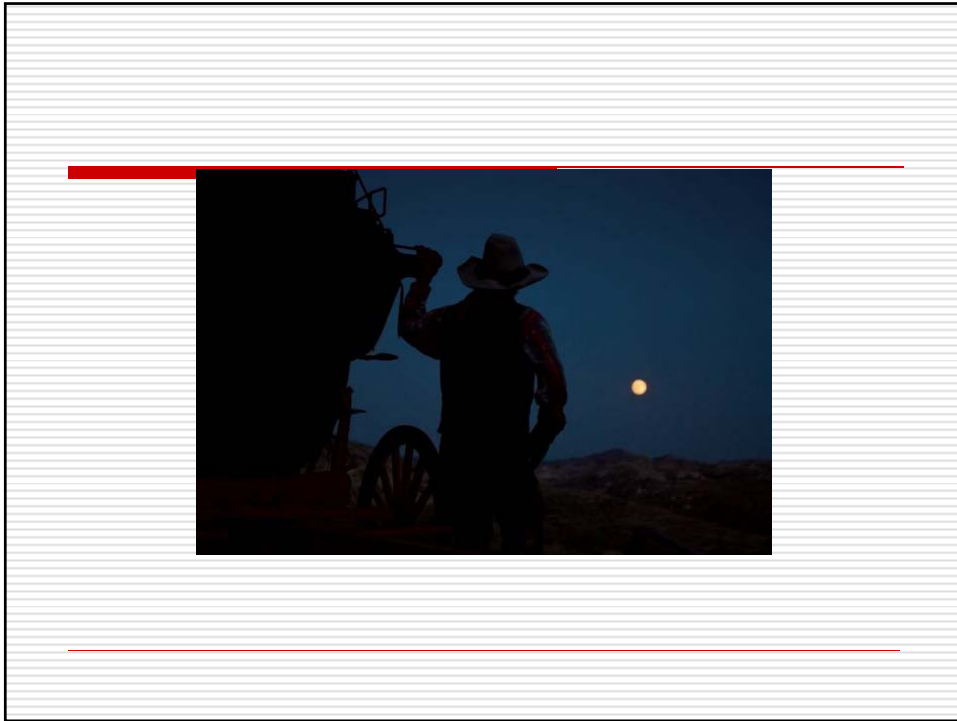
- Assure and enhance the availability and accessibility of quality and comprehensive clinical genetic services for all North Dakotans
 - Promote early identification and treatment of individuals with birth defects, heritable disorders or genetic susceptibilities throughout the life cycle.
-

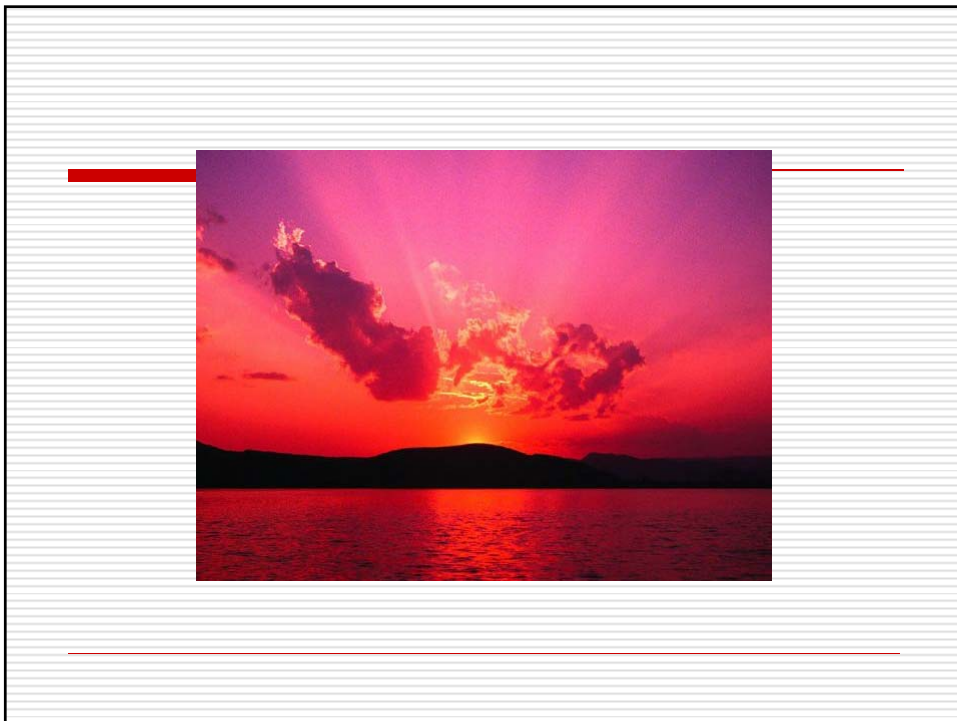
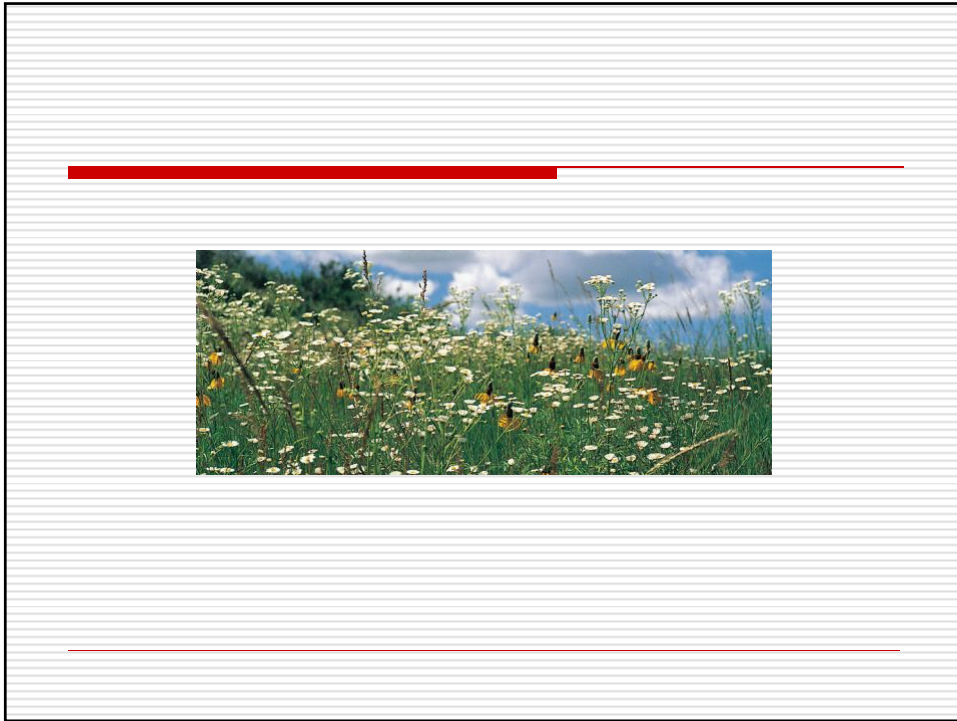
Goals

- Increase public and professional awareness of genetics, including services and resources.
 - Expand and enhance partnerships to support genetic service systems.
-

Goals

- Promote the development of public policy that protects individual and family health and privacy while supporting advancements in genetic science and technology.
-







Activities and Events



