



A North Dakota Perspective

February 11, 2021

North Dakota Newborn Screening & Follow-up Program
Joyal Meyer, RN, MSN

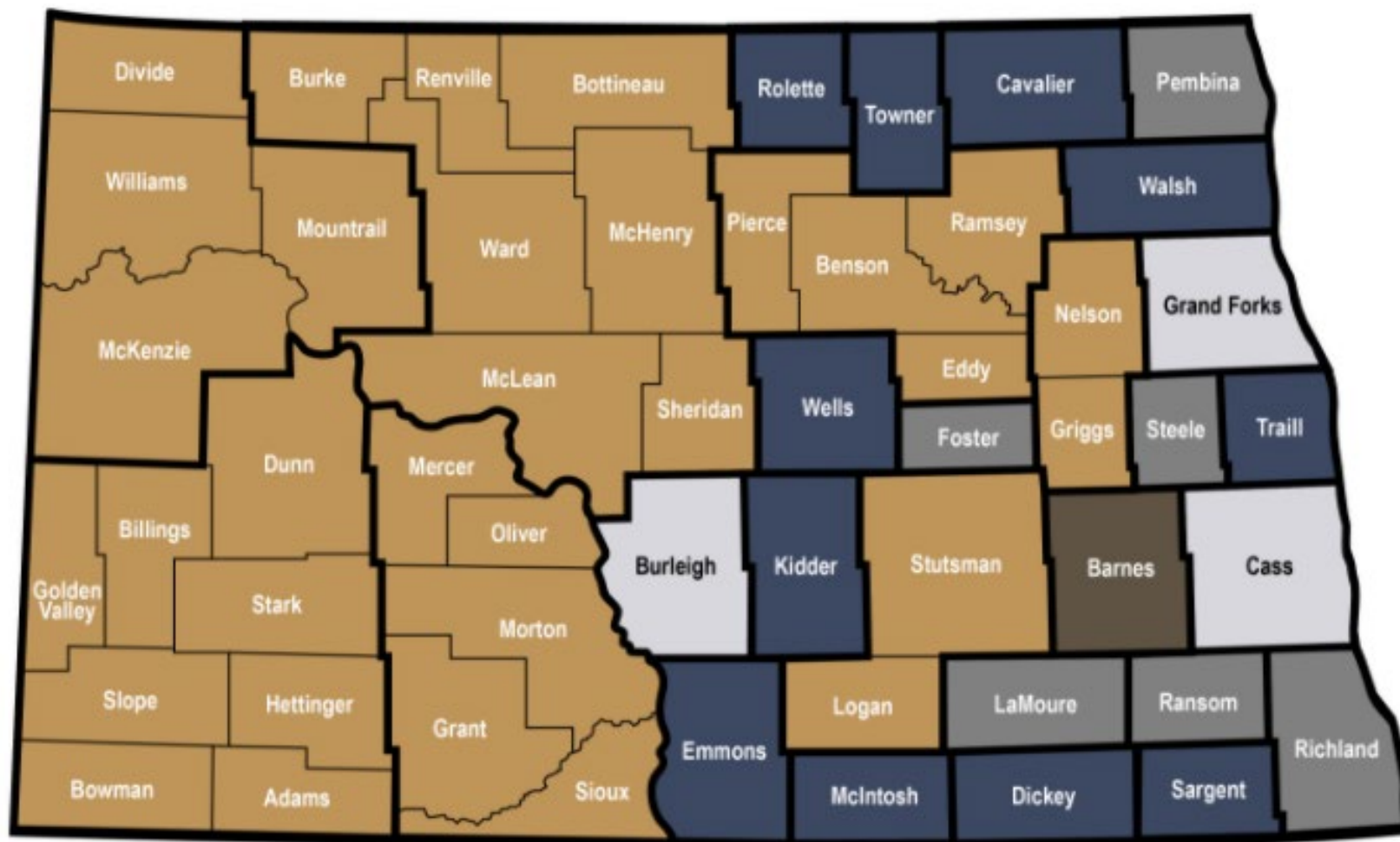
NORTH DAKOTA





UNPREDICTABLE WEATHER

North Dakota Local Public Health Units



- City/County Health Department
- Single County Health Department
- City/County Health District
- Single County Health District
- Multi-County Health District

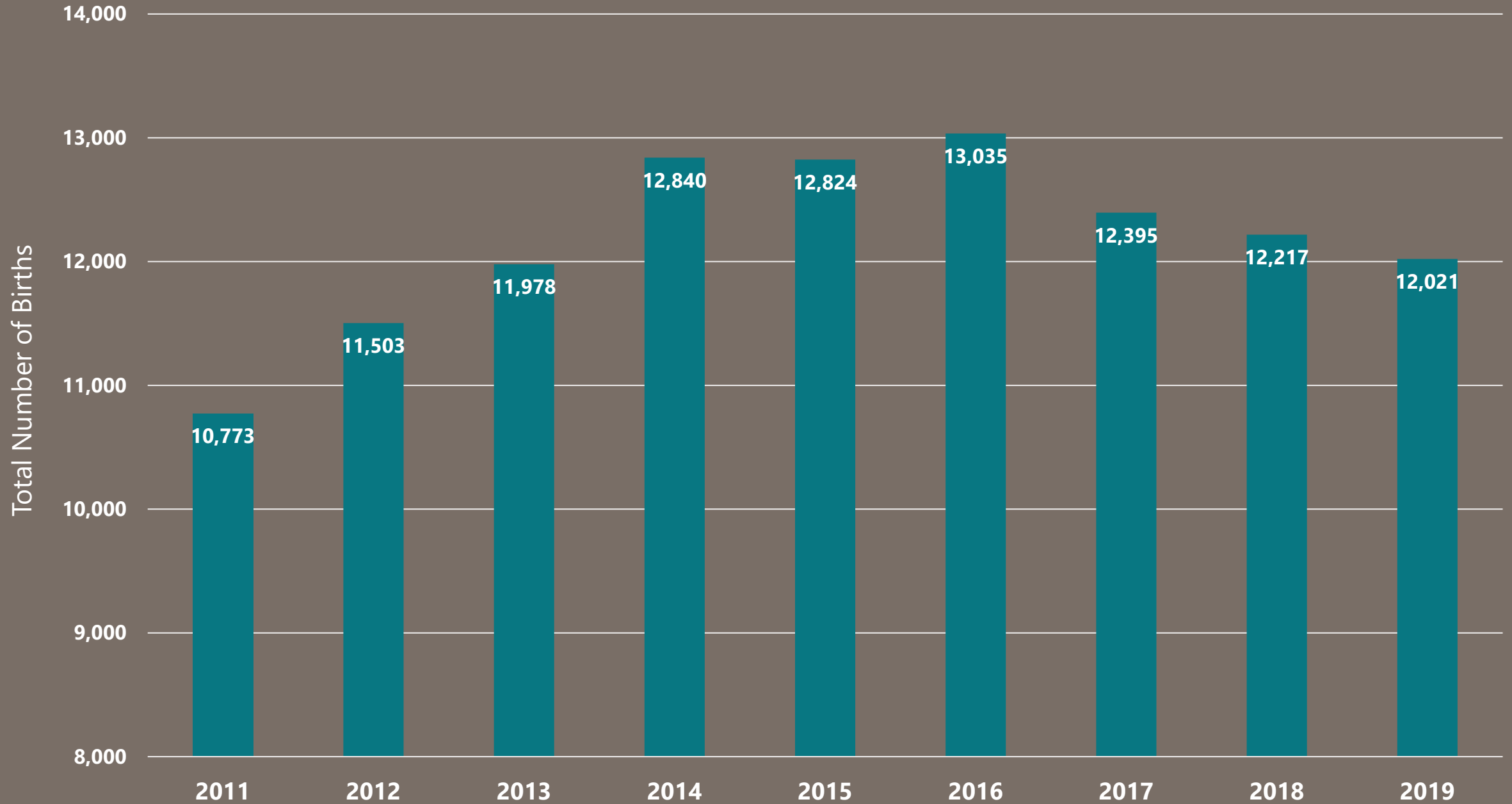


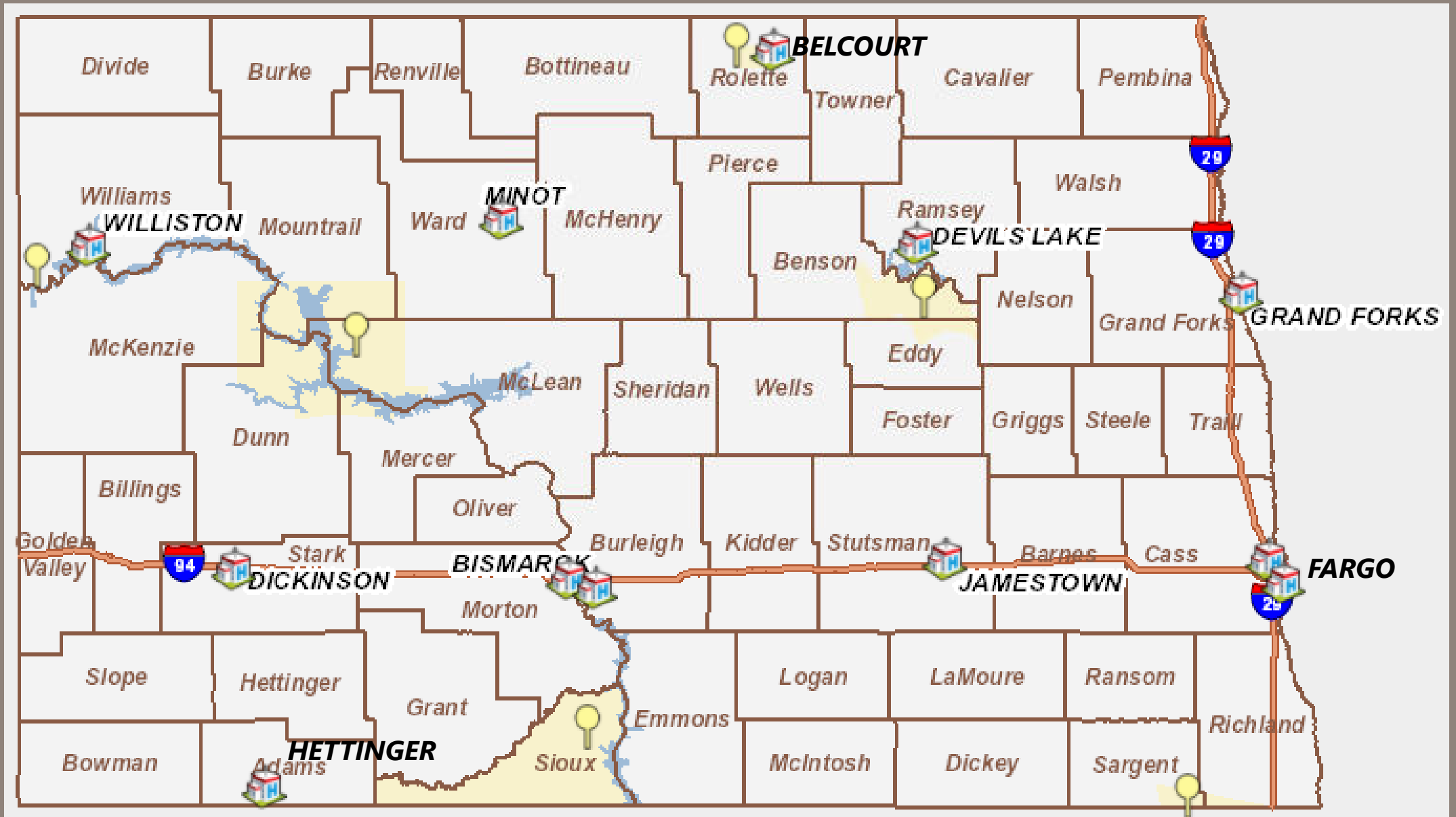
- 12,000 babies born annually
- 4 out of 12 birthing facilities deliver over 60% of babies born in ND
(2 located in central ND, 2 in eastern ND)



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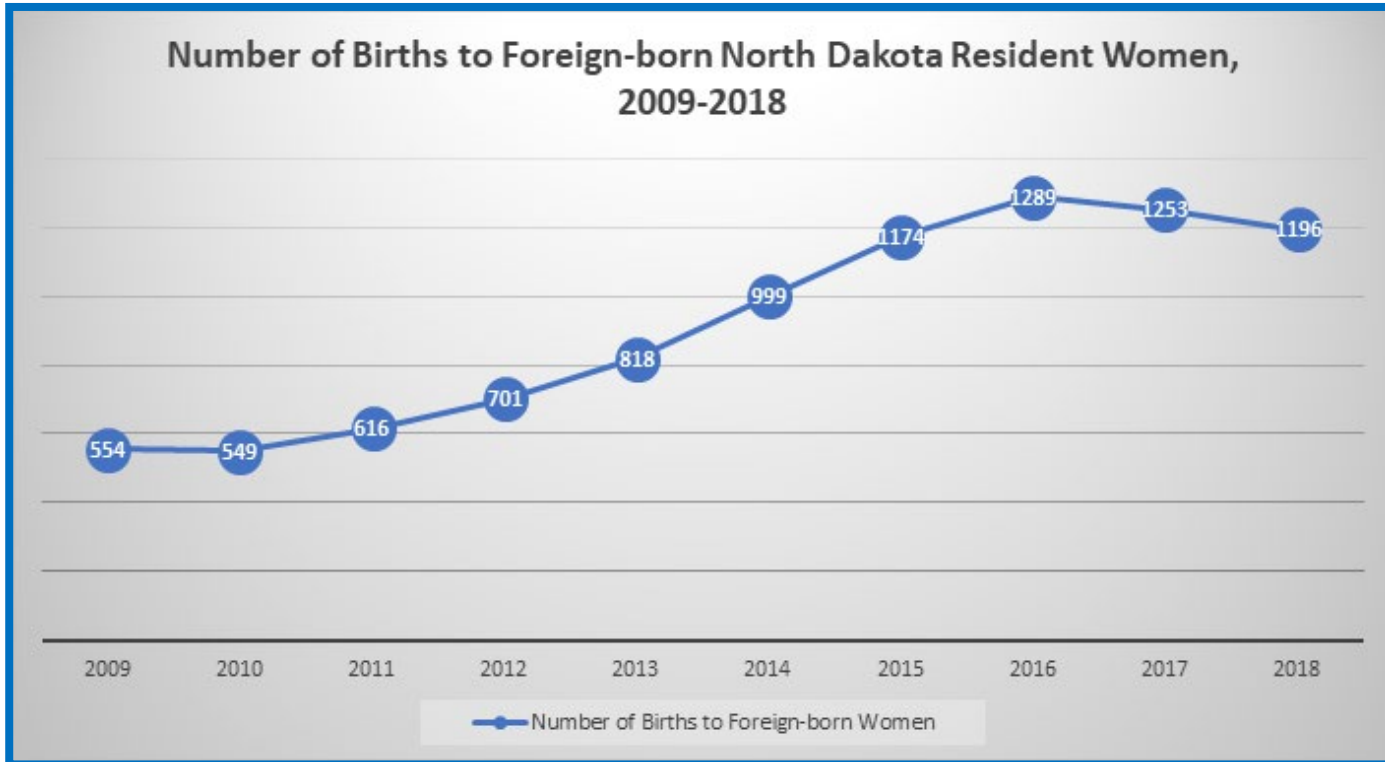
North Dakota Occurrent Birth Rate





ND Birthing Hospitals and Indian Health Service Facilities

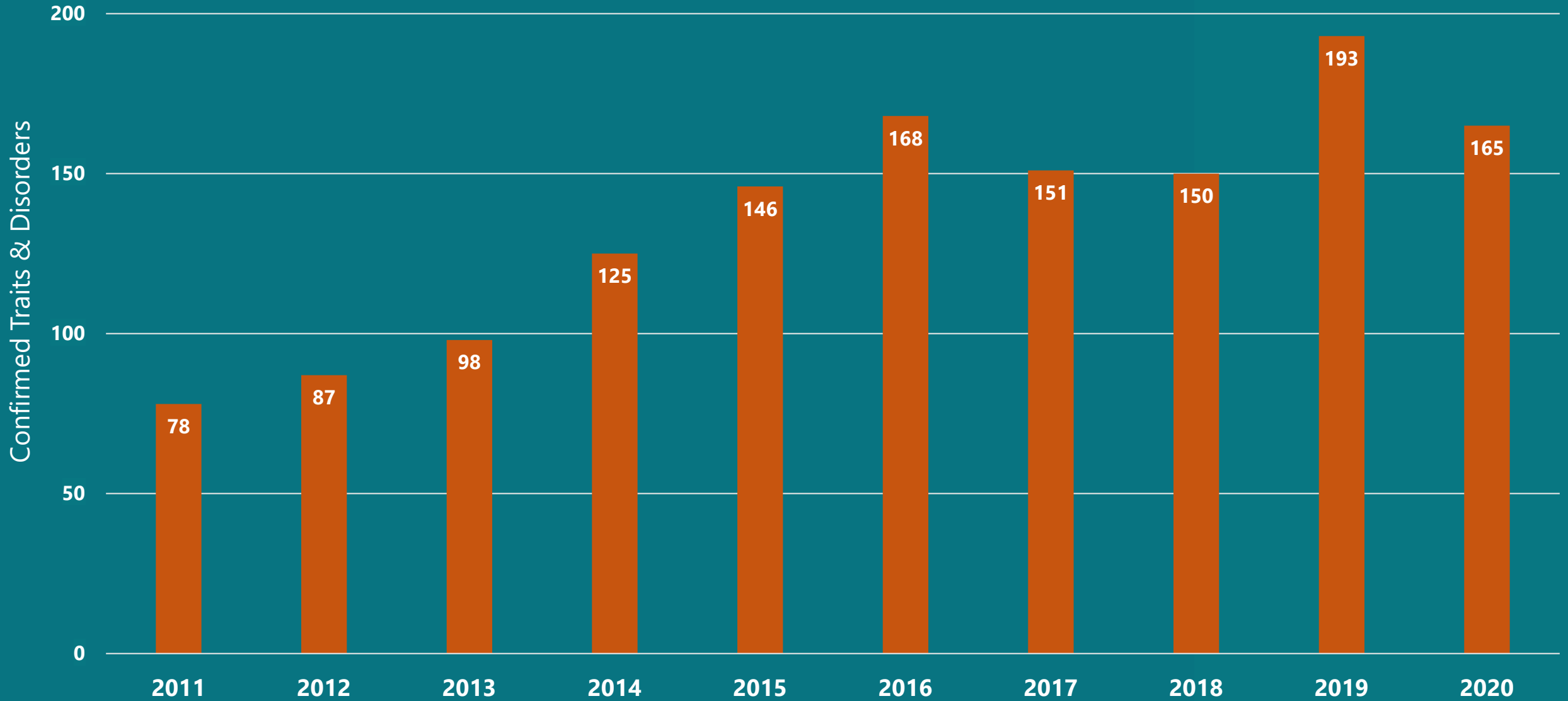
INCREASING DIVERSITY IN NORTH DAKOTA



*Data source: ND Vital Records



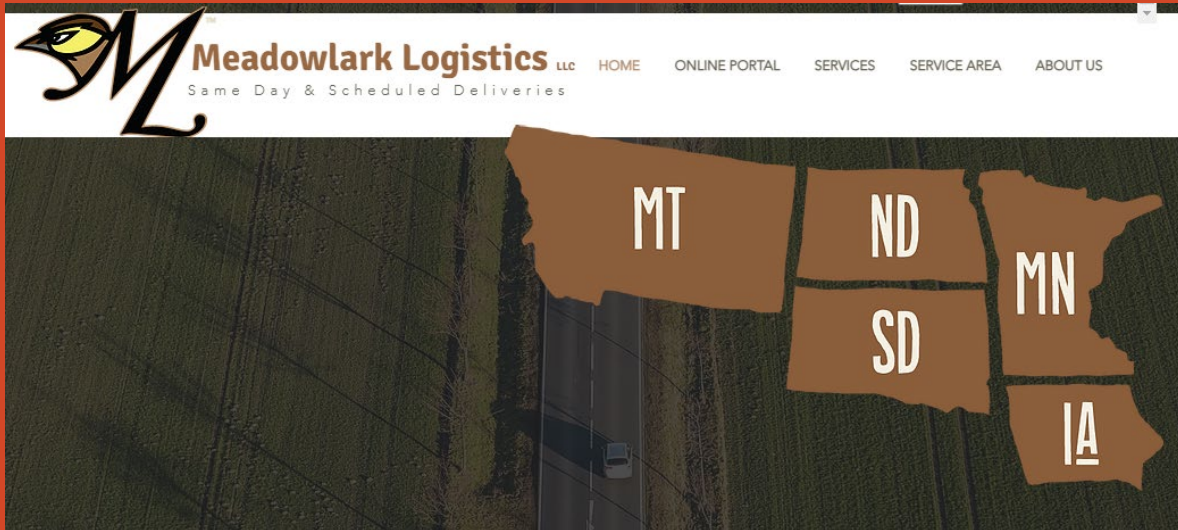
North Dakota Newborn Screening Confirmed Traits & Disorders





- University of Iowa State Hygienic Laboratory (SHL) began processing ND newborn screening specimens in 1992
- University of Iowa Hospitals and Clinics began doing ND's short-term follow-up in 2007
- In addition to ND and Iowa, University of Iowa SHL also provides screening and follow-up services to South Dakota and Alaska
- SHL collects ND's newborn screening fee which supports the lab processing, short-term follow-up and the courier service

COURIER TRANSPORTATION



- 7 days per week | 365 days per year since July 2019
- Transports from all 12 birthing facilities in ND
- Shared customers in surrounding states

NewSTEPS 360 Birth to Reporting Time Critical Results Run Chart

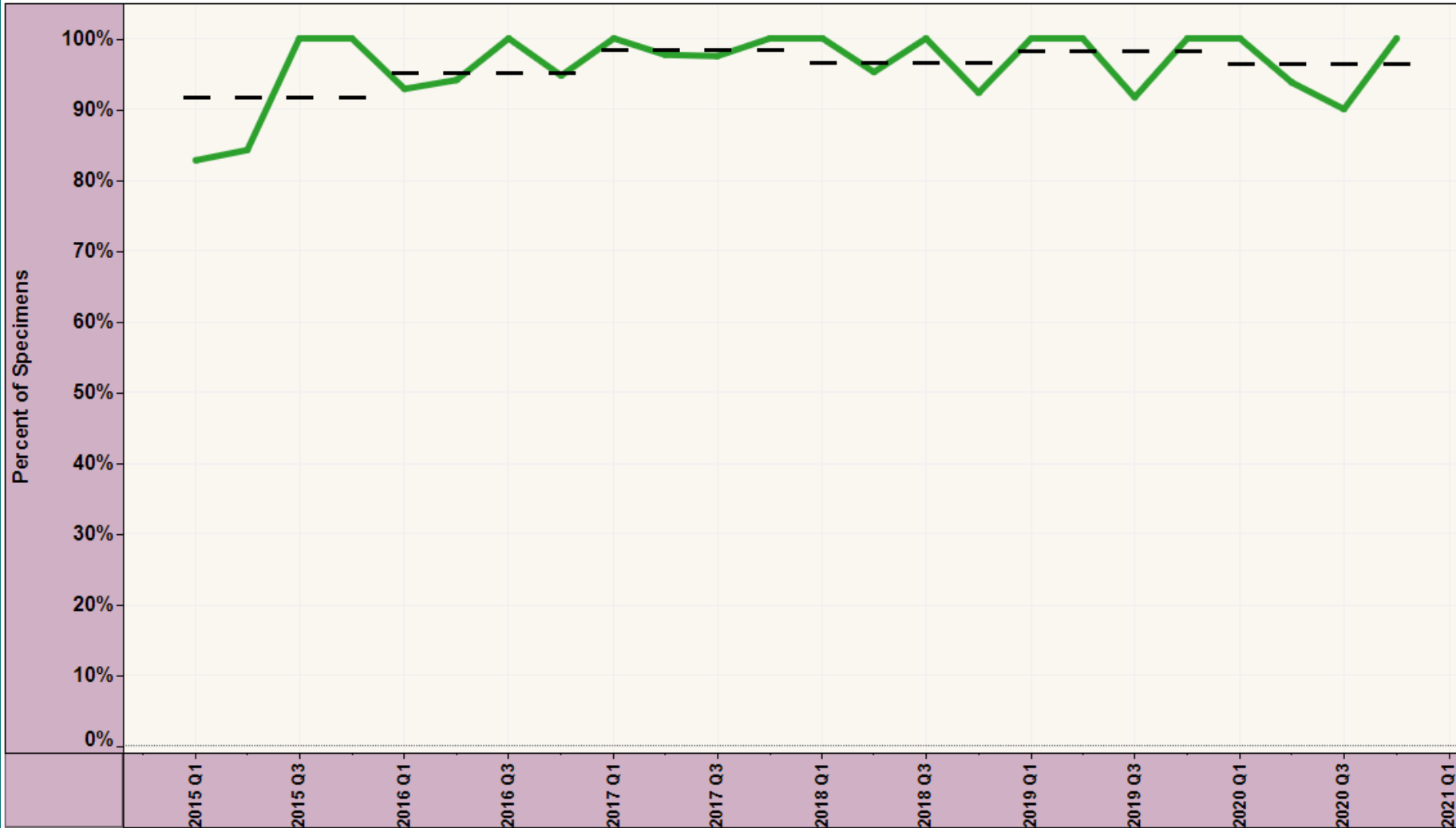
Percent of specimens with a time critical result reported on \leq Day 5 after birth

Select Time Interval
≤Day 5

Select Median
NBS Program Median

Select NBS Program ID
186

Change Date Range
2015 Q1 2020 Q4



NEWBORN SCREENING EDUCATION



- Annual in-person trainings (prior to COVID-19)
- Newborn Screening Online Toolkit Modules
- Hot Topic Lunch & Learn Sessions
- Newborn Screening Conference
- Quarterly Newborn Screening Advisory Meetings

NewSTEPS 360 Unsatisfactory Specimens Run Chart

Percent of specimens that were deemed unacceptable.

Current View = All Unsats

Select Unsat Type

All Unsats

Select Median

NBS Program Median

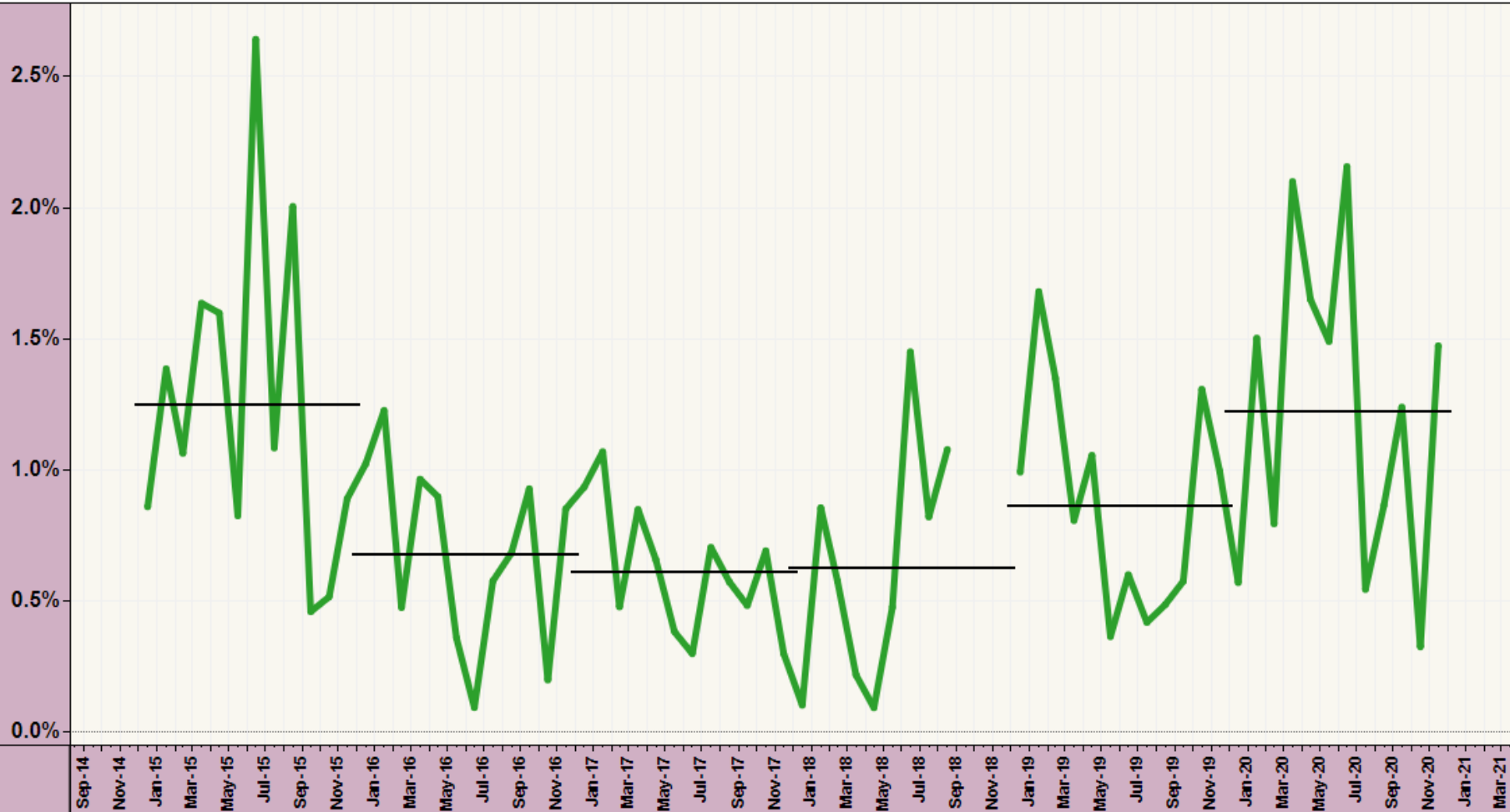
Select NBS Program ID

186

Change Date Range

January 2015

December 2020





- ND is a member of the Heartland Region
- 8 States Total
 - Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma and South Dakota
- Goal – Increase genetic services, particularly for medically underserved populations
 - Ease accessibility
 - Improve telehealth, telegenetics and quality of care



NORTH DAKOTA PUBLIC HEALTH LABORATORY

A person wearing a white lab coat and blue nitrile gloves is using a pipette to transfer liquid into a pink microplate. The background is a blurred laboratory setting with various equipment and containers.

Pre-COVID

- 18 employees (laboratory professionals & support staff)
- Operating Hours:
 - 8 am to 5 pm
 - 5 days/week
 - No weekends or holidays
- Courier transportation 5 days/week

Post-COVID

- Increase in laboratory professionals & support staff – 140 FT/PT employees (180 at peak of testing)
- Operating Hours:
 - 24 hours/day
 - 7 days/week
 - Includes weekends and holidays
- Courier transportation 7 days/week
- Limited supplies for testing (e.g., biohazard bags, pipet tips and transport media)



WHAT IS ON THE HORIZON FOR NORTH DAKOTA?

- Long-term follow-up (LTFU) in ND began in January 2019
 - Working with partners to create a LTFU database to track and provide services to children with confirmed disorders
- Open dialogue on newborn screening contingency planning with various partners (regional lab, ND state lab, border states and Heartland network)

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