

STATE HEALTH COUNCIL

February 11, 2014

A meeting of the State Health Council was called to order by Vice Chairman Wade Peterson at 9:00 a.m. on Tuesday, February 11, 2014 in AV Room 212 of the Judicial Wing, State Capitol, Bismarck, ND.

Members present:

Gordon Myerchin, Grand Forks, Chairman (*phone*)
Wade Peterson, Mandan, Vice Chairman
Mike Jones, Bismarck, Secretary (*phone*)
Howard Anderson, Turtle Lake
Greg Allen, Jamestown (*phone*)
Genny Dienstmann, Bismarck
Leona Koch, Raleigh
Marlene Kouba, Regent
Dennis Wolf, MD, Dickinson (*phone*)

Members absent:

Jerry Jurena, Bismarck
Duane Pool, Bismarck

Staff members present:

Terry Dwelle, MD, State Health Officer
Arvy Smith, Deputy State Health Officer
Tom Bachman, Division of Air Quality
Becky Bailey, Division of Family Health
Kirby Kruger, Medical Services Section
Kelly Nagel, Public Health Systems & Performance
Londa Rodahl, Recording Secretary
Steve Pickard, MD, Career Epidemiology Field Officer
Peter Wax, Division of Water Quality
Tim Wiedrich, Emergency Preparedness & Response Section

Others present:

See ATTACHMENT A

Genny Dienstmann and Leona Koch were welcomed as new Health Council members.

Minutes

MARLENE KOUBA MOVED APPROVAL OF THE NOVEMBER 12, 2013 MINUTES AS DISTRIBUTED. SECOND AND CARRIED.

Veterinarian Loan Repayment Applications

Dr. Beth Carlson, deputy state veterinarian, stated this is the seventh year of this repayment program that has had 18 recipients in 13 communities. Of those 18, only two veterinarians didn't complete their service. She presented the veterinarian loan repayment applications and the recommendations from the Board of Animal Health, which included Dr. Christina Burgard, Dr. Carla Gilbertson, Dr. Seth Nienhueser and Dr. Lindy West.

MARLENE KOUBA MOVED THE APPROVAL OF THE VETERINARIAN LOAN REPAYMENT APPLICATIONS FOR \$80,000 EACH FOR FOUR YEARS OF SERVICE TO DR. CHRISTINA BURGARD (STEELE), DR. CARLA GILBERTSON (BOTTINEAU), DR. SETH NIENHUESER (WATFORD CITY), AND DR. LINDY WEST (HETTINGER). SECOND BY LEONA KOCH.

The Chair requested a roll call vote and the MOTION CARRIED. Allen, Anderson, Dienstmann, Jones, Koch, Kouba, Myerchin, Peterson, and Wolf voted 'aye'. There were no 'nay' votes. Jurena and Pool—absent.

Dr. Carlson noted the application for Dr. Brett Webb was very strong and the Board had a difficult time deciding if he should receive the funding. Dr. Webb works as a veterinary pathologist in the NDSU Veterinary Diagnostic Laboratory and this is a difficult position to recruit, especially in North Dakota. She stated there is a national loan repayment program to which the Board of Animal Health will submit Dr. Webb's nomination for this award.

It was questioned if it would help Dr. Webb's application if the Health Council also submitted a recommendation letter for the award. Dr. Carlson thought that was a good idea.

GENNY DIENSTMANN MOVED THAT THE STATE HEALTH COUNCIL SUBMIT A LETTER OF SUPPORT FOR DR. BRETT WEBB, AT NORTH DAKOTA STATE UNIVERSITY IN FARGO, FOR THE NATIONAL VETERINARIAN LOAN REPAYMENT PROGRAM. SECOND BY MIKE JONES AND CARRIED.

Dr. Carlson also referred to the letter received from Leslie Marie Henderson, DVM, who questioned whether she'd be allowed her final loan payment since she was approved for the funds while working in New Salem and now she's working in Elgin. The Health Council approved her final loan payment.

Department Dashboard

Dr. Steve Pickard gave a website demonstration on how to access the Department's data.

NDAC 33-15, Air Pollution Control

Tom Bachman presented the proposed amendments to NDAC 33-15, Air Pollution Control. The public hearing was held November 12, 2013. The Attorney General's legality opinion was received on January 9, 2014. He requested the Council's adoption of these amendments.

HOWARD ANDERSON MOVED THE ADOPTION OF PROPOSED AMENDMENTS TO NDAC 33-15, AIR POLLUTION CONTROL. SECOND BY GENNY DIENSTMANN.

The Chair requested a roll call vote and the MOTION CARRIED. Allen, Anderson, Dienstmann, Jones, Koch, Kouba, Myerchin, Peterson, and Wolf voted 'aye'. There were no 'nay' votes. Jurena and Pool—absent.

NDAC 33-16-02.1, Standards of Quality for Waters of the State

Peter Wax presented the proposed amendments to NDAC 33-16-02.1, Standards of Quality for Waters of the State. The public hearing was held December 2, 2013. The Attorney General's legality opinion was issued on January 10, 2014. He also noted that some of the CAS numbers

have changed and those will be submitted to the Attorney General for another legality opinion prior to submittal to Legislative Council for publication. He requested the Council's adoption of these amendments, contingent upon the second approval by the Attorney General.

HOWARD ANDERSON MOVED THE ADOPTION OF THE PROPOSED AMENDMENTS TO NDAC 33-16-02.1, STANDARDS OF QUALITY FOR WATERS OF THE STATE, CONTINGENT UPON ANOTHER LEGALITY OPINION FROM THE ATTORNEY GENERAL. SECOND BY LEONA KOCH.

The Chair requested a roll call vote and the MOTION CARRIED. Allen, Anderson, Dienstmann, Jones, Koch, Kouba, Myerchin, Peterson, and Wolf voted 'aye'. There were no 'nay' votes. Jurena and Pool—absent.

Newborn Screening

Becky Bailey presented ATTACHMENT B.

Section Updates

Tim Wiedrich and Kirby Kruger gave the updates for the Emergency Preparedness & Response Section and the Medical Services Section, respectively.

Budget and Legislative Update

Arvy Smith reviewed what has taken place with the interim legislative committees the Department is tracking and a brief budget update.

Strategic Planning

Kelly Nagel reviewed what the Health Care Data Committee's subcommittee has been working on and, as a result of that work, asked for the Council's approval to change the strategic map and action plan goal from: *Develop a quality of care reporting and monitoring process to: Develop a process to inform consumers on quality of health care for informed health decisions.*

The subcommittee was appointed on August 13, 2013 and consists of Jerry Jurena, Wade Peterson, Duane Pool, John Baird, Darleen Bartz, Kelly Nagel and Steve Pickard. They will continue to function as they have been and the Council will decide later if additional Council members should be added to the Health Care Data Committee, which currently consists of Howard Anderson, Marlene Kouba and Duane Pool.

HOWARD ANDERSON MOVED THAT THE STRATEGIC MAP AND ACTION PLAN GOAL BE CHANGED TO: DEVELOP A PROCESS TO INFORM CONSUMERS ON QUALITY OF HEALTH CARE FOR INFORMED HEALTH DECISIONS. SECOND AND CARRIED.

The meeting adjourned at 12:10 p.m.



Mike Jones, Secretary



Program Update – February 11, 2014

Background

Newborn screening (NBS) is a blood test for certain metabolic and genetic disorders. North Dakota (ND) law requires that all babies are screened, unless the parent/guardian objects to testing. This lab work is collected 24 to 48 hours after birth in the form of a heel prick. Currently, ND screens for over 40 conditions. NBS is considered among the greatest public health achievements of the 21st century. By promoting early diagnosis and treatment, serious complications from these disorders may be prevented.

ND, South Dakota and Iowa (IA) newborn screening programs are able to decrease the costs of screening through shared laboratory and follow up services in our Tri-State Collaborative. The ND fee is prorated based on the percentage of births in the Tri-State Collaborative. ND specimens are delivered via private courier service to the State Hygienic Lab (SHL) at the University of Iowa. Courier services promote timely lab testing, short term follow up, medical consultation and intervention on screen positive cases. This is essential to assist in reducing the morbidity and mortality associated with some conditions ND screens for.

Newborn Screening Fees

The current fee for ND newborn screening tests is approximately \$60/baby. In order to cover the critical maintenance of implementing this program, the lab is raising the fee by \$8.08 per baby (initial screening) effective March 1, 2014. This will bring the total fee per initial screening per baby to \$68.08. This screening fee covers the cost of courier services, laboratory services, database, IA short term follow up and IA medical consultation. It is projected that this fee will be increased by three percent on an annual basis to account for inflation or increases in implementation costs.

Previously, the newborn screening fee has been increased when additional services have been required such as the addition of Cystic Fibrosis (2006) to the panel or the implementation of courier service delivery for lab specimens (2008).

Although ND Newborn Screening has been providing information and having discussions with partners regarding this issue, we will work with the SHL to develop a formal notification for birthing facilities and third party payers regarding this fee change.

In the future, the newborn screening program will continue to examine the addition of conditions to the newborn screening panel based on national recommendations from the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children along with consultation with the State Health Council, State Health Officer, ND Newborn Screening Program Advisory Committee and Tri-State Collaborative. If additional conditions are added to the panel, the newborn screening fee will need to be raised to cover the cost of implementation above the annual maintenance increase.

Newborn Screening Language Revisions

The Newborn Screening Program has been reviewing pertinent ND Century Code and Administrative Rules. Upon this review, it has been determined that revisions are needed. Some of the needed clarifications include information pertaining to:

- Newborn screening fee establishment, collection of fees and disposition of funding
- Types of conditions screened for
- Ownership, retention and destruction of dried blood spots (specimens)
- Location of the Division of Children's Special Health Services

Questions and comments can be directed to:

Becky Bailey, RN, BNSc, NCSN
Director, ND Newborn Screening
Division of Family Health
North Dakota Department of Health
600 E. Boulevard Ave., Dept. 301
Bismarck, ND 58505-0200
701.328.4526 phone 701.328.1412 fax
bbailey@nd.gov

ND Newborn Screening Advisory Committee Legislative Language Updates

ND Century Code

Chapter 23-01-03.1 Newborn metabolic and genetic disease screening tests

The language in this section only gives the state health council the authority to set rules regarding the use of newborn screening bloodspots for research. The language needs to be changed to allow them to adopt rules regarding the retention and disposal of bloodspots and the addition/deletion of any future conditions to the bloodspot panel. There are rules in place for these items at this time but the health council does not currently have the authority to adopt those rules.

- (Current language) The health council may authorize the use of newborn metabolic and genetic disease screening tests, as provided for in chapter 25-17, for research purposes. The council shall adopt rules to ensure that the results are used for legitimate research purposes and to ensure that the confidentiality of the newborns and their families is protected.

Chapter 25-17-05 Testing Charges

The language needs to be changed to reflect that the Department of Health (DoH) will designate a laboratory to perform newborn screening bloodspot testing. That laboratory will then be responsible for setting the fee for newborn screening. Fees will be collected by the designated laboratory and not the DoH, hence language should reflect the current practice. The DoH will consult with the state health council if the need for additional services is identified and a fee increase is required.

- (Current language) The state health council may adopt rules that establish reasonable fees and may impose those fees to cover the costs of administering tests under this chapter. All test fees collected by the state department of health must be deposited in the state department of health operating account.

Administrative Rules

Chapter 33-06-16-02 Testing of newborns

Language needs to be changed to reflect additions/deletions to the panel to be determined by DoH/health council (metabolic and genetic disorders). Expansion or broadening of language would be preferred to ease the addition/deletion of conditions from the panel while ensuring

adequate oversight on those additions/deletions and taking into consideration any future enhances to technology.

- (Current language) Under the newborn screening system, except as authorized by section 33-06-16-04, each newborn infant born in this state shall be tested for metabolic diseases, cystic fibrosis, hypothyroidism, galactosemia, congenital adrenal hyperplasia, biotinidase deficiency, sickle cell disease and other hemoglobinopathies, and a sample of the newborn's blood shall also be tested by tandem mass spectrometry.

Chapter 33-06-16-05 Research and testing materials

Language regarding research and testing materials needs to be updated. Children's Special Health Services (CSHS) is no longer in the Department of Human Services (DHS) but is now housed in the DoH.

- (Current language –1-b) Information may be disclosed to the individual tested, that person's parent or guardian, or that person's physician or dietitian, or to the children's special health services program of the department of human services for purposes of coordination of services and provision of medical and low-protein modified foods.

This language needs to be changed to reflect that the DoH institutional review board would need to approve all use of bloodspots for research. The bloodspots are no longer housed at UND, hence, the language should reflect current practice.

- (Current language –1-c-4) Protected health information may not be provided to a person engaged in a bona fide research project until that person has submitted a written proposal explaining and justifying the need to examine such information which is satisfactory to the state health officer. The state health officer may require the research to be approved by the university of North Dakota institutional review board.

This language needs to be changed to reflect the current practice of the bloodspot samples being retained by the DoH and no longer by UND. The bloodspots should not be stored indefinitely. The retention and disposal times should be addressed in the following subsection.

- (Current language –2-a) Information and testing materials provided to the University of North Dakota School of Medicine and Health Sciences may be retained indefinitely or destroyed according to this subsection.

Language regarding retention also needs to be updated. The period of time NBS bloodspot cards are retained before destruction needs to be addressed. Discussion is needed regarding the length of time dried blood spots are stored. The option for parents to request earlier destruction of dried blood spots or to return the dried blood spots to the family should also be discussed.

- (Current language –2-c-1,2) (1) Information and testing materials created less than ten years before the present date may be destroyed only with the state health officer’s prior written approval. (2) After ten years, information and testing materials may be destroyed without prior approval.

DRAFT