Information for Collectors

Alberta's NMS Program Panel Expansion Frequently Asked Questions

March 2019

When is the screening panel changing?

Implementation of the new screening panel begins on April 1st and will be completed in a phased approach. Blood spot cards received in the lab after noon Saturday, March 30th, 2019, will be screened for three (3) additional conditions: tyrosinemia type 1, classic galactosemia and sickle cell disease (SCD). Severe combined immunodeficiency (SCID) will be added as of May 6th.

Will the NMS Program clinical policy suite be updated?

The NMS Program is currently working with AHS Policy to finalize the clinical policy suite and these changes have been endorsed by NMS Program key stakeholders. As the changes have not yet been finalized by AHS Policy, it is critically important that staff review the updated staff education resources on AHS.ca/newbornscreening and update their training on MyLearningLink to ensure they are following current procedures.

Why is there one blood spot by itself?

The perforated section containing circle 1 is removed by the NMS Lab for SCID testing. SCID testing is performed in the Molecular Diagnostic Lab, which is separate from the NMS Lab. Therefore, it is very important to always start from circle 1 before moving on to the next circles.

Why is feeding type important?

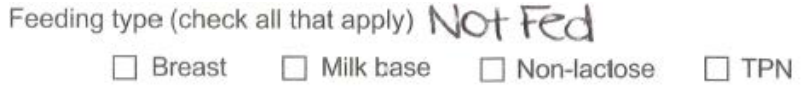
Knowing the feeding type is very important for accurately detecting galactosemia. Infants with galactosemia cannot break down galactose, which is a type of sugar that is found in breastmilk, standard infant formulas and many other foods. Infant formulas which **do not** contain galactose include:

- Soy infant formulas such as Enfamil A+ Soy, Similac Isomil or generic soy infant formulas
- Semi-elemental infant formulas such as Nutramigen A+, Pregestimil A+ or Similac Alimentum
- Elemental infant formulas such as Puramino A+ or Neocate

Infants exclusively fed any of the above formulas may result in a false negative on the newborn metabolic screen and therefore it is important that feeding type is properly documented on the blood spot card.

What if the newborn has not fed in the last 12 hours?

If the newborn has not been fed in the last 12 hours before sample collection the feeding type on the blood spot card can be left blank or written on the card as 'not fed'.



Do all infants born at <37 weeks gestational age require a recollection?

Yes, recollections will be required for all infants born at less than 37 weeks gestational age. This is required to support the detection of SCD and SCID. The NMS Program will be sending out alerts for recollections of pre-term infants as we do for all other conditions and recollection criteria. The recollection timeframe will align with recollections for low birth weight infants, i.e. 21-28 days after birth.

Are there any incidental findings with the new screening panel?

Yes, screening for SCD will also identify babies with sickle cell trait (SCT). While there are no immediate health concerns for a baby with SCT, implications may exist for other family members. Ordering healthcare providers will be notified of the baby's SCT status and will be responsible for communicating the SCT results with the family and arranging necessary follow-up in accordance with the Toward Optimized Practice guidelines for SCT, which will be available soon.

Where can screening results be accessed?

All results are available online through Netcare and the newborn screening laboratory will continue to notify ordering healthcare providers by phone in the case of abnormal results.

What if I want to confirm the NMS Lab received a blood spot card?

To confirm whether the NMS Lab has received a particular blood spot card, please contact the NMS Client Response Line at 780-407-7484

What if I have more questions about sample collection?

If you have further questions about sample collection, please contact the NMS Program at nmsprogram@ahs.ca

What if I have more questions about one of the screened conditions?

If you have questions about screened conditions, please contact the Genetic Counsellors at nmsgeneticcounsellors@ahs.ca