



Ontario Newborn Screening Program
Children's Hospital of Eastern Ontario
Department of Genetics
401 Smyth, Ottawa Ont. K1H 8L1

BULLETIN #35 – July 30, 2009

Changes to Repeat Specimen Collection Process

On August 10, 2009 the ONSP will update the follow-up process for ensuring that every infant with an unsatisfactory newborn screening sample has a satisfactory repeat sample taken. We hope that our updated process clarifies the responsibility of both the ONSP and the submitter (i.e. the health care provider and/or institution/practice submitting a sample to the ONSP).

It is the submitter's responsibility to obtain a repeat sample once notified of an unsatisfactory sample. The submitter should attempt to communicate the need for a repeat sample directly to the infant's family or to their primary health care provider (PHCP). If a repeat sample is not received 3 weeks following notification of an unsatisfactory sample, the ONSP sends a repeat request letter to the submitter. Communication attempts to the family and/or PHCP should be documented on the repeat request letter, which is faxed back to the ONSP.

We have revised our repeat request letter so that we can clearly identify whether or not the family and/or PHCP has been informed of the need for a repeat. In addition, we have created a letter to send to parents IF a submitter indicates they have been unable to contact the infant's family OR if the infant's PHCP has been contacted but no repeat sample has been received. A copy of this letter will be cc'd to the submitting institution and the infant's PHCP (if known).

Please see the attached documents:

- 1) Updated repeat request letter
- 2) Parent letter to send IF parents have not been contacted directly by the submitting institution OR if PHCP has been informed but no repeat has been received

Ms. Shelley Kennedy, Genetic Counsellor, will be presenting a telehealth session reviewing the new process on September 17, 2009 at 12:00 pm. We invite you all to attend to enhance your knowledge of this recent change to the newborn screening process. More information on the telehealth session will follow.

Thank you for your cooperation and assistance in making the Ontario Newborn Screening Program the most effective and efficient that it can be.

Additional information about the Ontario Newborn Screening Program can be found at:
www.newbornscreening.on.ca

These bulletins are being circulated to keep you abreast of changes to the Ontario Newborn Screening program. Please share this information with any relevant personnel in your hospital / clinic. If there is someone who would like to be added to this list, contact: Shelley Kennedy or Sari Zelenietz, Genetic Counsellors
(613) 738-3222, option #1; NewbornScreening@cheo.on.ca