
NEWS RELEASE

For immediate release
May 12, 2014

Provincial Health Services Authority
Perinatal Services BC

New home screening program for liver disease in newborns

Vancouver – Parents are being asked to check their newborn’s stool colour in an effort to detect early signs of a rare but fatal liver disease, as part of the new [Biliary Atresia Home Screening Program](#) launched by Perinatal Services BC.

Biliary atresia is a liver disease resulting from a blockage of the bile duct, which is the pipe for bile (a fluid that helps with digestion of food) to drain from the liver into the intestine. The blockage prevents bile from leaving the liver, resulting in damage and scarring that can lead to death by the age of two if not treated.

Biliary atresia begins to affect newborns in the first month of life. While it is normal to see jaundice (a yellow appearance of the skin and whites of the eyes) in the first few days after birth, some babies may have jaundice that lasts longer than two weeks as well as pale yellow, chalk white, or clay-coloured stools, an indication that very little or no bile is reaching the intestine.

The preferred treatment is the Kasai procedure, a surgical method that can help re-establish bile flow from the liver to the intestine by joining the two. The effectiveness of this surgery depends on timing. If the Kasai procedure is performed in the first two months of life, it has an 80 per cent chance of success. But after three months, it drops to 20 per cent. If the procedure is unsuccessful, a liver transplant is required.

That is why detecting biliary atresia early is so important. There is no single blood test for biliary atresia, so stool colour is the main tool for early detection.

As part of the new program, after the birth of the baby and before mom and baby leave the hospital, parents are given a stool colour card that contains photos of normal and abnormal infant stool colours. Mothers who have a home birth are given the stool colour card by their midwives. Parents are asked to check their newborn’s stool colour against the colour card every day for the first month after birth. If they see an abnormal stool colour, they are to call or email the Biliary Atresia Home Screening Program directly.

The stool colour card also has a Quick Response code, so parents can use their smartphones to sign up for weekly text or email reminders to check their baby’s stool colour. The reminders are available in English and 11 other languages (Arabic, Simplified Chinese, Traditional Chinese, French, Japanese, Korean, Persian, Portuguese, Punjabi, Spanish, and Vietnamese). Parents can sign up at www.perinatalservicesbc.ca/infantstoolcolourcard.

The Biliary Atresia Home Screening Program is the first of its kind in Canada. The program is based on best practices in Taiwan as well as research involving over 9,500 families at BC Women's Hospital, University Hospital of Northern BC, and St. Mary's Hospital in Montreal.

Facts

- Access the stool colour card at http://tiny.cc/PSBC_BA.
- The stool colour card is available in English, Arabic, Simplified Chinese, Traditional Chinese, French, Japanese, Persian, Portuguese, Punjabi, Spanish, and Vietnamese.
- The cause of biliary atresia is not known.
- It affects only newborns.
- It is not preventable.
- Biliary atresia occurs in one out of every 19,000 births per year in Canada and 1/10,000 births per year in BC (about three to five cases).
- It is the most common cause for cirrhosis and liver disease related death among children and the leading indication for liver transplantation in the pediatric population, accounting for more than 60 per cent of all pediatric hepatic transplants.
- In Canada, only eight per cent of infants with biliary atresia have the Kasai procedure done at 30 days of age or younger
- The Kasai procedure is named after Dr. Morio Kasai, the Japanese surgeon who developed the procedure in 1951. The diseased bile duct is removed, and a small segment of the small intestine is attached to the liver at the spot where bile is expected to drain.

Quotes

Terry Lake, Health Minister –

“The Biliary Atresia Home Screening Program is a great example of how BC is leading the way in disease prevention and early detection through research and collaboration. BC has a comprehensive newborn screening program, which recognizes that through early detection, we will see the greatest impact.”

Kim Williams, Provincial Executive Director, Perinatal Services BC –

“BC is the first province in Canada to implement this unique type of home screening program. There are no blood tests or samples to collect, and it is family-centered—done at home by parents or other family members. Parents can feel empowered—they are taking a proactive role in identifying a life-threatening disease and improving the health of their newborns.”

Dr. Richard Schreiber, Director, BC Pediatric Liver Transplant Program, BC Children's Hospital and Professor of Pediatrics, University of British Columbia –

“We need to build awareness among parents and healthcare providers about the need to look at stool colour as a disease indicator. Poor outcomes due to late diagnosis and surgery of infants three months of age or older remain a problem throughout Canada and elsewhere in the world. Taiwan has been using the infant stool colour card screening program for biliary atresia since 2004 and, through early referral and more timely intervention, has seen improved patient survival and a reduced need for liver transplantation. We hope to see the same improvement in health outcomes for infants in BC.”

Natalie Williams, 16-year-old with biliary atresia –

“As an infant, my biliary atresia was nearly missed. My diagnosis was on the later side due to lack of awareness of medical professionals regarding both stool colour and prolonged jaundice. I am now 16 years old and had the Kasai procedure only. However, very few children are as lucky as I am. Through my Facebook page, I have seen far too many infants have poor outcomes primarily due to late diagnosis. This is why I feel the Biliary Atresia Home Screening Program is very important as it can help diagnose an infant earlier and ultimately give them a better chance of the Kasai procedure being successful and an overall better chance of survival. The Biliary Atresia Home Screening Program is giving parents the power and knowledge to help save their babies’ lives. I don’t think it gets much better than that.”

Mitzi Mogden-Dupuis, parent of child with biliary atresia –

“It took many visits to our family doctor over the course of the first three months of our newborn son’s life to ultimately receive the biliary atresia diagnosis. Prolonged jaundice and stunted growth were clear indicators of illness, but due to a partially functioning bile duct, his stool was not yet acholic (completely void of bile and therefore white); it was still light brown and yellow in colour. We explored several possibilities, but the most important piece of the puzzle was absent simply because we did not have a reference tool to indicate and report where he registered on the scale of healthy versus unhealthy stool colour. It was not until we presented a physical stool sample that our doctors were able to establish the cause and severity of his illness. Within hours of this evidence, and just inside the window of probability to have a successful outcome through the Kasai procedure, our son was admitted into hospital. We now have a thriving five-year-old son and consider our family incredibly fortunate to have caught this in time. However, a resource such as the stool colour card could have dramatically improved the timeline of achieving the (Kasai) operation necessary to save our son's life.”

Perinatal Services BC, an agency of the Provincial Health Services Authority, provides leadership, support, and coordination for the strategic planning of perinatal services in British Columbia in collaboration with regional health authorities and other key stakeholders. PSBC is the central source in the province for evidence-based perinatal information. For more information, visit www.perinatalservicesbc.ca.

The Provincial Health Services Authority plans, manages, and evaluates selected specialty and province-wide healthcare services across BC, working with the five geographic health authorities to deliver province-wide solutions that improve the health of British Columbians. For more information, visit www.phsa.ca.

-30-

For more information or to arrange an interview:

Media Contacts

Lubna Ekramoddoullah
Communications Officer
Perinatal Services BC
lekramod@phsa.ca
604-877-2121, ext 223736

Ben Hadaway
Communications Officer
Provincial Health Services Authority
Ben.Hadaway@phsa.ca
604-675-7416
Media pager: 604-871-5699