

NEWS RELEASE

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Office of the Premier
Provincial Health Services Authority
BC Women's Hospital & Health Centre

EXPANDED SCREENING TO IMPROVE HEALTH OF B.C. BABIES

VANCOUVER – Newborn babies in British Columbia will now be screened for more than three times as many disorders at birth that can be treated to avoid lifelong health issues, Premier Gordon Campbell announced today.

“Newborn babies in British Columbia deserve the very best chance to a healthy life – that is why we are increasing the number of tests at birth to screen for 19 disorders, up from six,” said Premier Campbell. “Screening newborns means earlier detection of treatable disorders. With specialized treatment, lifelong health problems such as development disorders, liver problems, brain damage, and even sudden death can be prevented, meaning a healthier life for newborns, and reduced future pressures on our health care system.”

The decision to expand the province's newborn screening is based on the recommendation from the Newborn Screening Advisory Committee, established by the Provincial Health Services Authority (PHSA). Members of the committee include medical experts from BC Women's Hospital & Health Centre and BC Children's Hospital, agencies of the PHSA.

Technological advances and improvements in diagnosis and treatment have provided an opportunity to add new conditions to the screening panel, using the same conventional filter paper blood spot card. The expanded program will include screening for cystic fibrosis and sickle cell disease. The expansion will be phased in over the next 12 months with full implementation expected by 2010.

“The decision to broaden the screening program was made after a careful review of the medical literature on newborn screening,” explained Dr. Hilary Vallance, director of the Biochemical Genetics laboratory at BC Children's Hospital and BC Women's Hospital & Health Centre and chair of the Newborn Screening Advisory Committee. “We were looking for the answers to two fundamental questions for each disorder reviewed: what is the expected health benefit to the newborn, and what is the best screening strategy to detect the most cases while minimizing the false positive rate?”

One of the positive outcomes that resulted from the review process was a strategy to minimize the recall rate or false positive rate. This will be achieved by a two-tier screening approach. B.C. will be one of the first jurisdictions in Canada to implement a suite of second tier screening tests aimed at minimizing false positive rates.

With a few drops of blood collected on a filter paper card, about 42,000 babies are screened each year. Approximately 20 children a year are identified with one of six treatable conditions. The additional screening is expected to benefit another 20 children a year.

“Expanding the new screening program is a strategic priority for the Provincial Health Services Authority,” said Wynne Powell, chair of the PHSA Board of Directors. “While the conditions are rare, the pain and suffering for the children and families can be immense.”

The implementation and operation costs for the newborn screening program will be covered by the Provincial Health Services Authority from their existing funding allocation. Implementation will cost approximately \$2.3 million in capital investment and annual operating costs of approximately \$2 million once the program is fully implemented. The implementation phase will start this year to build additional capacity, integrate a new software system, and ensure testing facilities are in place. This will include the co-ordination of regional services, including sample collection, transportation, parent education and follow up.

The program announced today builds on government’s early childhood screening program commitment. The Province has already implemented three early childhood screening programs: early hearing screening in all neonatal intensive care units and most well-baby units in hospitals across the province, with full implementation expected by year end; early childhood dental screening that includes screening surveys for kindergarten children; and vision screening for kindergarten children with an expected roll out to three-year-olds.

1 backgrounder(s) attached.

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BACKGROUND

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NEWBORN SCREENING IN BRITISH COLUMBIA

Below are the six disorders currently being screened and a list of the 13 additional disorders that will be screened for when British Columbia's Newborn Screening Program is expanded. Approximately 20 children a year are identified with the current test panel. The additional screening is expected to identify a further 20 children a year.

Current Screening Panel	
Congenital hypothyroidism	A condition in which a baby cannot make enough thyroid hormone. Without it, delayed growth and brain damage occur. With early detection and thyroid hormone treatment, these children have normal growth and intelligence. One baby in 3,500 is born with hypothyroidism.
Galactosemia	A condition that affects a person's ability to process the sugar galactose, which, if untreated, can lead to liver, brain, and eye damage. These problems are prevented with a special diet.
Phenylketonuria (PKU)	A baby with PKU is missing an enzyme that is needed to process the essential amino acid phenylalanine, found in certain foods. Without treatment, phenylalanine builds up in the baby's blood and causes mental retardation. With early diagnosis and dietary treatment, mental retardation is prevented.
Glutaric Aciduria Type I (GA-I)	A baby with GA-I is missing an enzyme used in the breakdown of several amino acids. Babies may develop normally early on but are at risk of metabolic crisis that can lead to brain damage, seizures, and cerebral palsy-like symptoms. With early diagnosis and treatment, brain damage may be prevented.
Medium-chain Acyl-CoA dehydrogenase deficiency (MCAD)	A baby with MCAD may have problems using fats stored in their body for energy. The baby is healthy when eating well. If the baby has a cold or flu, he or she may not be able to use the stored fatty acids as energy. There is a risk of sudden unexpected death (similar to SIDS), which can be prevented by using a special diet and not fasting.
Long-chain Hydroxyacyl-CoA dehydrogenase deficiency (LCHAD)	A condition that prevents the body from converting certain fats into a usable energy source. LCHAD deficiency can present in many ways, such as low blood sugar, sudden unexpected death, low muscle tone, or problems with the function of the heart. Treatment with avoidance of fasting and a special diet can improve health outcomes.

Expanded Screening Panel	
Very-long chain AcylCoA dehydrogenase deficiency (VLCAD)	Similar to LCHAD, this is a condition that prevents the body from converting certain fats into a usable energy source. Low blood sugar and muscle symptoms can be prevented with dietary treatment and avoidance of fasting.
Citrullinemia	A disorder that causes ammonia and other toxic substances to accumulate in the blood. A build-up of ammonia can cause brain damage and can be life-threatening. Treatment with a special diet can improve health outcomes.
Tyrosinemia I	A missing enzyme in the breakdown of the amino acid tyrosine leads to liver and kidney damage. The disorder is treatable with medication and, in some cases, liver transplantation.
Homocystinuria (including second-tier testing)	A missing enzyme in the processing of the amino acid, homocysteine. The resultant high homocysteine levels in blood increase the risk of stroke. Early detection and treatment prevents blood clots and strokes and developmental delay.
Argininosuccinic Acidemia	An inherited disorder that causes ammonia to accumulate in the blood. High ammonia causes brain damage and can lead to coma. Treatment with a special diet can improve health outcomes.
Isovaleric Acidemia	A condition in the processing of certain amino acids. Acute illness and chronic disability can be prevented with a special diet.
Maple Syrup Urine Disease (including second-tier testing)	A condition in the processing of certain branch chain amino acids leads to a toxic build-up in the blood. If left untreated, infants can suffer severe neurological damage. Dietary treatment improves health outcomes.
Propionic Acidemia (including second-tier testing)	These are a group of amino acid disorders that can present with acute episodes of illness during infancy and may cause progressive brain disease. Early detection and treatment offers the best chance of survival. However, developmental delay and other motor problems may occur despite treatment.
Methylmalonic Acidemia (including second-tier testing)	
Cobalamin disorders (CblA,B) (including second-tier testing)	
Cystic Fibrosis	A life-limiting disease that affects mainly the exocrine (mucus) glands of the lungs, liver and pancreas. Early detection and treatment of cystic fibrosis reduces the risk of mortality, prevents malnutrition, improves growth and may slow the progression of lung disease.
Sickle Cell Disease	A blood disorder characterized by red blood cells that assume an abnormal, rigid, sickle shape resulting in their restricted movement through blood vessels, depriving tissues of oxygen. Affected individuals experience lifelong periodic painful attacks and are at a risk of serious infections. Careful treatment and monitoring can improve health outcomes.
Congenital Adrenal Hyperplasia (including second-tier testing)	A condition of deficient production of adrenal gland hormones. Early detection and treatment can prevent life-threatening dehydration.

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