

## Canada lags on **newborn** screening

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As the US government prepares to recommend national core **newborn** screening for 29 conditions and disorders, testing in Canada varies widely.

| Newborn screening by province* |     |    |   |     |    |   |          |                               |
|--------------------------------|-----|----|---|-----|----|---|----------|-------------------------------|
| Province                       | PKU | CH | G | CAH | BD | T | H        | No. of other disorders tested |
| British Columbia               | X   | X  | X |     |    |   |          | 1                             |
| Alberta                        | X   | X  |   |     | X  |   |          | 0                             |
| Saskatchewan                   | X   | X  |   |     |    |   |          | 27                            |
| Manitoba †                     | X   | X  | X | X   | X  |   |          | 0                             |
| Ontario                        | X   | X  |   |     |    |   |          | 0                             |
| Quebec ‡                       | X   | X  |   |     |    | X |          | 0                             |
| Nova Scotia                    | X   | X  |   |     |    |   |          | 9                             |
| New Brunswick                  | X   | X  |   |     |    |   |          | 0                             |
| Prince Edward Island           | X   | X  |   |     |    |   |          | 9                             |
| Newfoundland and Labrador      | X   | X  |   |     |    | X | 1 region | 0                             |

Notes: PKU = phenylketonuria, CH = congenital hypothyroidism, G = galactosemia, CAH = congenital adrenal hyperplasia, BD = biotinidase deficiency, T = tyrosinemia, H = homocystinuria.

\*Yukon is covered by British Columbia, the Northwest Territories is covered by Alberta in the west and Manitoba in the east, and Nunavut is covered by Manitoba in the west and Quebec in the east.

†Manitoba also has targeted screening — glutaricacidemia type 1 (Oji-Crees), carnitinepalmitoyl transferase-1 deficiency (Hutterites).

‡Quebec has a program of urine impregnated filter paper testing at 21 days of age for amino acids and organic acids.

Source: Save Babies Through Screening Foundation Canada.

Figure.

rest of the world, are far ahead of Ontario in this field," says Dr. William Hanley, a pediatrician and founder of the PKU program at Toronto's Hospital for Sick Children. "We lack, but need, a comprehensive system for **newborn** screening."

Hanley and other physicians, including experts in sickle cell disease and thalassemia, joined the newly formed Save Babies Through Screening Foundation Canada in June. They are urging provincial governments to adopt, at minimum, screening programs for the 29 treatable conditions the US advisory committee has recommended.

John Adams, a spokesperson at the foundation, says these conditions affect about 1 baby in 800. In Ontario, 160 **newborns** are at risk annually.

Although the Canadian Pediatric Society doesn't have an official position, President Dr. Robin Walker says "The cost of doing this is not large, particularly when you recognize that the cost of treating these conditions is high."

Saskatchewan is the only jurisdiction that tests for 29 conditions, while Ontario and New Brunswick test for just 3 things — including hearing.

"The majority of developed, and an increasing number of emerging countries in the

The rarity of many of these diseases and the fact that neither patients nor professionals have lobbied prominently for these tests has contributed to Canada's lack of initiative on screening, he says.

Save Babies founder Tammy Clark also stresses the low cost of these tests. Her 9-month-old daughter, Jenna, died in 2002 after falling ill and becoming dehydrated. An autopsy diagnosed Jenna with medium-chain acyl-CoA dehydrogenase (MCAD) deficiency. While BC, Saskatchewan and Nova Scotia screen for MCAD deficiency, Ontario does not.

"A \$25-US test and a single glucose IV would have saved my daughter's life," says Clark. "This is not complicated."

The US government is preparing to respond to recommendations that all states perform [29](#) core **newborn** screening tests. See related article page [22](#).

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