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## Canada has no national standard for newborn screening. Here's why it should

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*Provincial and territorial disparities in testing methods prompt calls for guidance from a federal authority. Here's how the scene currently looks across the country*

Like all Canadian newborns, Patrice Dailey was welcomed into the world four years ago with a heel-prick test, in which a few drops of blood are screened for rare genetic disorders.

The test picked up her sickle cell anemia, an inherited disease in which red blood cells are unable to properly carry oxygen. Placed on a twice-daily regimen of amoxicillin to prevent infection, Patrice is "growing normally" but battles bouts of illness that require hospitalization, said her mother, Marsha Davis.

Had Patrice been born outside her native Ontario, the consequences could have been disastrous. Most provinces do not screen for sickle cell anemia. The disease might not have been detected by doctors for months, or even years. Untreated, sickle cell anemia can lead to organ damage and, in extreme cases, death. That provincial and territorial disparities exist in many areas of health care is nothing new. But the gap in newborn screening is so pronounced that calls for reform are growing to include members of Parliament, rare-disorder patient support groups and medical professionals. Unlike the United States and Britain, Canada does not have a national benchmark for newborn screening.

The result is a nationwide patchwork of testing programs that leaves some newborns with rare disorders vulnerable to going undetected before damage is done.

"The way it's being done in Canada makes no sense," said Durhane Wong-Rieger, president of the Canadian Organization for Rare Disorders, which advocates for a national strategy on newborn screening. "What we're trying to do is, quite frankly, catch up with the rest of the world."

The disparities were highlighted last week when Ontario became the first province to add severe combined immunodeficiency syndrome, or SCID, an uncommon but treatable disease that knocks out the body's immune system, to its list of 28 disorders for which it screens newborns.

The number of tests administered varies wildly across the country. Nova Scotia, which currently screens babies for 13 disorders, has plans to add SCID to its battery of tests, which is expected to grow to 30 over the next two years. No other province has publicly shown any intention to screen for SCID. British Columbia and Yukon test for 22 disorders, while Alberta and Northwest Territories test for 17. At least 30 disorders are screened in Saskatchewan, while Manitoba tests for upward of 40.

While there is no international consensus on an ideal number of tests, the Organization for Rare Disorders recommends the creation of a national list of diseases to be screened.

The United Kingdom's national program screens newborns for five disorders, but it is uniform across all jurisdictions with an exception for Northern Ireland, which tests for two additional disorders.

Newborn screening varies so much in Canada, observers say, because unlike in other countries there is no guidance from a federal authority. Provinces decide what tests to administer based on a variety of factors, including costs and the likelihood of their residents being afflicted.

For instance, most Maritime provinces do not screen their newborns for Type 1 tyrosinemia, a genetic disorder that can lead to kidney and liver failure and is thought to affect just one in 100,000 people worldwide. But in Quebec, which tests for the disease, the ratio was found to be one in 16,000. In some parts of the province, the ratio was as high as one in 1,900. In Manitoba, the isolated Hutterite population has been shown to be susceptible to a deadly, genetic disorder known as Bowen-Conradi syndrome; the province tests for the disorder.

Testing in the United States is organized in much the same way as Canada, with screening decisions falling to the states. But most states take their direction from a federal advisory group that in 2005 endorsed a call from the American College of Medical Genetics that all newborns be screened for 29 disorders. That list has since grown to 32, and most states meet or exceed it.

Kirsty Duncan, a Liberal MP from Toronto, has championed national standards for newborn screening. She says the federal government should act on screenings with the same sense of urgency that compelled it to support reducing hospital wait times.

"Every Canadian should have access to the same high-quality health care no matter where they live," Duncan said. "At this point the biggest obstacle we face in establishing universal screening standards is the lack of leadership from the federal government."

Newborn screening lies at the intersection of health care services, which are constitutionally a provincial matter, and the public health system, which is a shared jurisdiction. Pranesh Chakraborty, director of Newborn Screening Ontario, has argued for a national screening program on the basis of equal access. He suggests a federal panel like the National Advisory Committee on Immunization, which develops guidelines on vaccinations.

"We could work within the federal system to better harmonize across the country," Chakraborty said.

Stéphane Shank, a spokesman for the Public Health Agency of Canada, said that the agency has no plans to take on the issue.

There are many obstacles to a national system – funding, provincial pride, determining which diseases to screen, recognizing regional variations in population, among them. Transferring testing to regional screening centres could also make transporting the blood samples more complicated and costly, said Rasoul Koupaie, who runs the newborn screening lab in Nova Scotia.

"As long as it is based on provincial costs, there will be provinces saying we don't have the money for it."

Lauryn Atugonza, a Ugandan immigrant who lives in Ontario, shudders to think what might have been had the province not detected sickle cell anemia in her two-year-old son, Bryant, at birth.

"I don't know how he'd be today without the screening," Atugonza said. "He might be dead."

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