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Babies deserve better than Canada's lamentable screening record

By André Picard

Newborn screening for cystic fibrosis is the norm in every developed country except ours

"Canada is the only country in the western world where newborn screening is not a universal standard of care," says Maureen Adamson, president and CEO of Cystic Fibrosis Canada.

That is a distinction of which we should not be proud. In fact, we should be ashamed of the contempt we show for children.

One in every 3,600 babies born in Canada has CF, a genetic disease that affects the lungs and digestive system. People with CF die young and they have a punishing treatment regime, one that is well illustrated in a new video[1] entitled *A Day In the Life of a Canadian with CF*. The reality is that the earlier the condition is detected and treated, the better quality of life and life expectancy will be.

That's why newborn screening for CF is the norm in every developed country. Except this one.

Ontario, Manitoba, Alberta, Saskatchewan, British Columbia, Yukon and parts of Nunavut screen newborns for CF. Nova Scotia, after an intense campaign by parents, just announced plans to adopt newborn screening, and neighbouring New Brunswick and Prince Edward Island are expected to follow suit.

Alberta has been screening for CF since 2007, but Quebec and Newfoundland and Labrador, along with the Northwest Territories and parts of Nunavut, are still twiddling their thumbs.

Most galling of all is that there is no rhyme or reason for this patchwork of policies. (And that is true of all newborn screening for rare disorders, not just CF; for example, only two provinces screen for sickle-cell anemia.)

Health care delivery is principally a provincial responsibility. But asserting independence by denying early detection and treatment is, at best, idiotic.

Money is not an issue either. Every province does some screening – every newborn baby gets a heel prick to draw a bit of blood for testing. Adding CF to the screening panel, which ranges from two to 30 tests, depending on the jurisdiction, is a marginal cost.

That leaves the technical argument, which is that CF screening is not a diagnostic test. Rather, blood is tested for genetic markers and, if they show up, the baby undergoes further testing. The between-the-lines reasoning is that testing is pointless because CF will be detected later anyhow. That argument does not hold water.

The case of Carys Avery Nurse, a six-year-old from Middle Sackville, N.S., illustrates this well. She seemed healthy at birth, but soon started suffering cyanosis, known commonly as "blue spells" (turning blue from lack of oxygen), and a host of eating-related issues.

Baby Carys was seen by a battery of experts, who suspected acid reflux, allergies, thyroid problems and so on. At 18 months, her pediatrician did a sweat test and diagnosed CF.

Stacey Nurse, Carys's mother, said the news was both a shock and a relief. "The worst part of those 18 months was not knowing what was wrong with her," she said.

When Ms. Nurse learned that, in other provinces, CF testing was routine for newborns, she grew angry. "I really hope my daughter didn't suffer permanent lung damage in that time she went undiagnosed and untreated," she said.

Ms. Nurse joined parents in lobbying the provincial government and it came around to testing in large part because of stories like those of Carys, which demonstrate that not testing is a false economy.

Currently, only 60 per cent of children with CF are diagnosed in the first year of life. Fully 10 per cent of CF cases are not detected until after age 10, meaning some kids suffer a long time with a devastating, undiagnosed illness. That is a lamentable record.

In the coming weeks, the heat will be turned up on the two holdout provinces, Quebec and Newfoundland. The cystic fibrosis community is going to unleash the heavy artillery – Céline Dion. The singer has been an advocate for CF patients for more than 20 years, in honour of her niece Karine, who died of CF at age 16. Ms. Dion is turning her attention and star power to the screening issue.

There is no miraculous cure for CF, but there is a growing armamentarium of treatments that control symptoms and minimize damage from secondary problems like infections. These range from pancreatic enzymes to help with the digestion of food through to lung transplants. The cumulative result has been one of the great successes of modern medicine.

Until the 1960s, children with CF did not live to attend kindergarten. Today, more than half of Canadians with CF live past the age of 40.

The way to improve those numbers is to screen every baby at birth, without exception. Our children deserve no less.

References

1. www.cysticfibrosis.ca/en/aboutus/may_awareness_2013.php