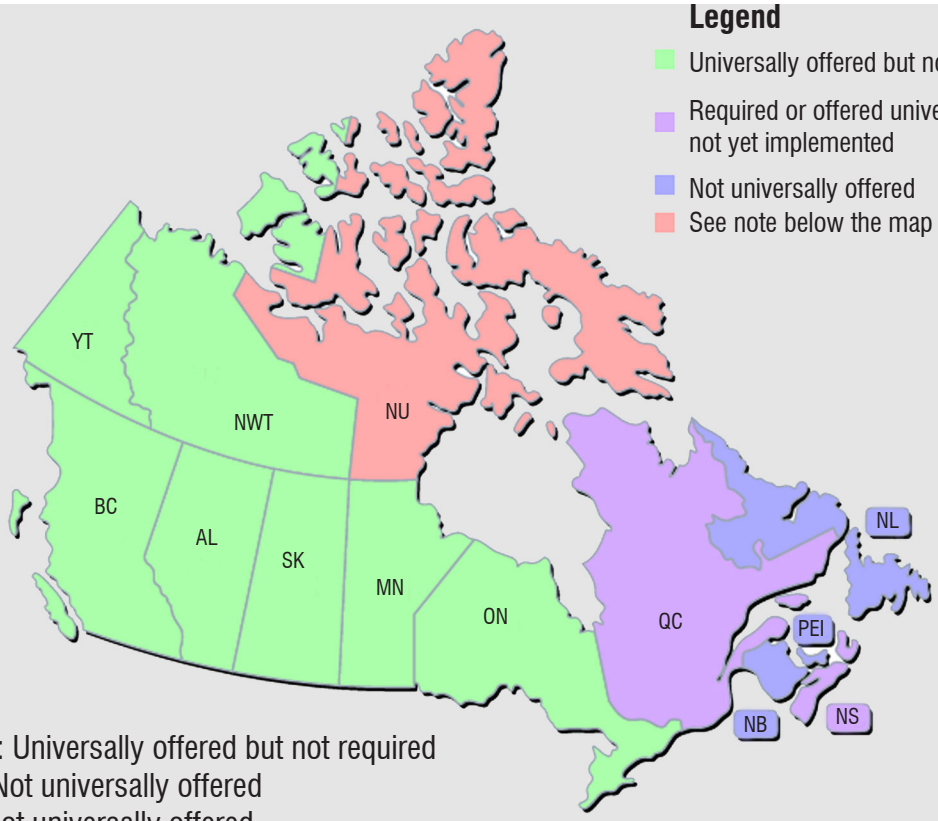
4.3.14 Specific Conditions – Newborn Screening for Cystic Fibrosis



Note:

Nunavut regions:

- Kitimeot region: Universally offered but not required
- Kivilliq region: Not universally offered
- Baffin region: Not universally offered

Source: Newborn Screening in Canada Status Report. Updated June 21, 2013. Canadian Organization for Rare Disorders. http://raredisorders.ca/documents/CanadaJune21.pdf

Eight provinces/territories offer newborn screening for cystic fibrosis.

Early diagnosis and early treatment of cystic fibrosis can reduce hospitalizations and improve the quality of life and life expectancy of cystic fibrosis patients. Without newborn screening, most people are not diagnosed until they present with symptoms. By that time, early damage to the lungs and digestive system may be difficult to reverse. Research demonstrates that a newborn diagnosed early with cystic fibrosis will have an improved height, weight, nutritional status, lung function, and cognitive ability.[1,2,3]

[1] Newborn Screening for Cystic Fibrosis. Cystic Fibrosis Canada. http://www.cysticfibrosis.ca/?lang=en

[2] Farrell PM, Kosorok MR, Rock MJ, Laxova A, Zeng L, Lai HC, Hoffman G, et al. Early diagnosis of cystic fibrosis through neonatal screening prevents severe malnutrition and improves long-term growth. Wisconsin Cystic Fibrosis Neonatal Screening Study Group. Pediatrics. 2001;107(1):1–13

[3] Southern KW, Merelle MM, Dankert-Roelse JE, Nagelkerke AF. Newborn screening for cystic fibrosis. Cochrane Database Syst Rev. 2009;(1):CD001402

Implications

Newborn screening for cystic fibrosis raises a number of ethical questions. Because it can ultimately identify a child who is just a carrier but not affected, there are pros and cons to communicating this information to parents. If parents discover that their child is a carrier, they will have numerous questions about the long-term implications for their child and about their own health. This can be very stressful.