Nunavut Birth Defects Reporting Protocol

Although most infants born in Nunavut are healthy, Nunavut leads the country for adverse early child health outcomes such as infant mortality, prematurity, low birth weight, and in particular, rates of birth defects.

As part of the *Developing Healthy Communities Public Health Strategy for Nunavut,* the Government of Nunavut Department of Health and Social Services has established the Nutaqqavut 'Our Children' Health Information System (NHIS). The NHIS includes information on birth defects for all Nunavut infants, including those born out of territory. The collection of birth defect information is supported by a Public Health Agency of Canada initiative, which supports birth defect reporting in all jurisdictions of Canada.

Why monitor birth defects?

- To understand rates, trends and associated risk factors.
- To identify modifiable factors that can be acted upon to reduce birth defect rates.
- To identify potential areas of unmet need—including transfer needs to out of territory facilities for assessment and treatment.
- To improve outcomes for those with birth defects by making recommendations concerning special services needed in local communities.

Who should report birth defects?

- Any treating Physicians (Regular and Locums), Midwives, Community Health Nurses and Public Health Nurses.
- Screening questions are now part of all well-child visits. Community Health & Public Health Nurses are requested to complete a reporting form if screening is positive.

How do HCPs report birth defects in Nunavut?

- **Birth defects requiring medical attention are reported upon detection for all pregnancies and in children up to 5 years of age.**
- **Complete the Nunavut Birth Defects Report Form using the Nunavut List of Reportable Birth Defects (on reverse).**
- The one-page form includes fields for basic demographic information and a space to describe the birth defect(s) (ICD codes are optional).
- Describe the birth defect and attach confirmatory documentation *when available* (imaging reports, consultant records, etc.). Unless documentation is apparent, do not assume the birth defect has been previously reported.
- **If documentation is not readily available, please submit the Nunavut Birth Defects Report Form and the NHIS Data Coordinator will follow up.**
- The top/white copy stays in the chart to indicate a form has been submitted. The yellow copy is sent to NHIS.

Where are completed forms sent?

- Completed forms and attached confirmation documentation should be sent by **fax or mail to NHIS:**

Manager, Population Health Information
Nutaqqavut Health Information System (NHIS)
Government of Nunavut
P.O. Box 1000 Stn. 1033
Iqaluit, Nunavut X0A 0H0
Fax: 867-975-3190

For more information:

Please contact the NHIS Program Manager at NHIS@gov.nu.ca. For general questions about birth defects/syndromes, contact Dr. Laura Arbour, Pediatrician/Geneticist at NHIS@uvic.ca.

What should be reported?

- **Prenatally** detected birth defects:
  - Ultrasound confirmation of anencephaly
  - Hydrocephalus
  - Structural heart defects
  - Renal abnormalities such as cystic kidneys
  - Limb defects
  - Spina bifida
- Chromosome abnormalities
- **Postnatally**, see the **List of Reportable Birth Defects** (on reverse). It includes metabolic, muscular-skeletal, organ system, and handicapping conditions (i.e. cerebral palsy).

What should Not be reported?

- Soft markers found on ultrasound in pregnancy, such as nuchal thickening, echogenic foci, echogenic bowel, choroids plexus cyst, and pyelectasis.
- Prenatally detected club foot and ventriculomegaly (less than 15 mm).
- Postnatally detected hydronephrosis.

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List of Reportable Birth Defects

ICD 9	Condition Category	ICD 10
237.7	**Neurofibromatosis**	Q85.0
243	**Congenital hypothyroidism**	E03.0-E03.1
255.2	**Adrenogenital disorders**	E25
	Metabolic Disorders:	
270	Amino acid metabolic disorder	E70-E72
271.0-1	Glycogenosis and galactosemia	E74
277	Other and unspecified disorders of metabolism	E84, E88
279	**Disorders involving the immune mechanism**	D80
282	**Hereditary hemolytic anemias**	D55-D59
284	**Constitutional aplastic anemia**	D61.0
331.3-9	**Other cerebral degenerations**	G91, G93
	Neurological Disorders:	
334	Spinocerebellar disease	G11
335	Anterior horn cell disease	G12
343	**Infantile cerebral palsy**	G80
359	**Muscular dystrophies and other myopathies**	G71-G72, G73.7
362.74	**Pigmentary retinal dystrophy**	H35.52
389	**Hearing loss: conductive, sensorineural & combined**	H90-H91
	Neural Tube Defects:	
740	Anencephalus and similar anomalies	Q00
741	Spina bifida	Q05
742	Other congenital anomalies of nervous system	Q06-Q07
743	**Congenital anomalies of eye**	Q10-Q15
744	**Congenital anomalies of ear, face and neck**	Q16-Q18
	Cardiac and Circulatory System Abnormalities:	
745	Bulbus cordis and cardiac septal closure anomalies	Q21
746	Other congenital anomalies of heart	Q20, Q22-Q24
747	Other congenital anomalies of circulatory system	Q25-Q28
748	**Congenital anomalies of respiratory system**	Q30-Q34
749	**Cleft palate and cleft lip**	Q35-Q37
750	**Other congenital anomalies of upper alimentary tract**	Q38-Q40
751	**Other congenital anomalies of digestive system**	Q41-Q45
752	**Congenital anomalies of genital organs**	Q50-Q56
753	**Congenital anomalies of urinary system**	Q60-Q64
754	**Certain congenital musculoskeletal deformities**	Q65-Q66
755	**Other congenital anomalies of limbs**	Q69-Q74
756	**Other congenital musculoskeletal anomalies**	Q67-Q68, Q75-Q79
757	**Congenital anomalies of the integument**	Q80-Q84
758	**Chromosomal anomalies**	Q90-Q99
759	**Other and unspecified congenital anomalies**	Q85-Q899
760. 9	Fetus or newborn affected by maternal conditions which may be unrelated to present pregnancy	P00.9
760.71	Alcohol affecting fetus via placenta or breast milk, including **fetal alcohol syndrome**	P04.3; Q86.0