

NWT Clinical Practice Information Notice

Upon receipt, please file this notice in
Section C, Clinical Practice Information Binder for future reference.

The following clinical practice has been approved for use in the Northwest Territories Health and Social Services system, and has been distributed to:

<input checked="" type="checkbox"/> Hospitals	<input checked="" type="checkbox"/> Community Health Centers	<input checked="" type="checkbox"/> Homecare	<input checked="" type="checkbox"/> LTCF	<input checked="" type="checkbox"/> Lab Directors
<input checked="" type="checkbox"/> Doctors' Offices	Social Services Offices	<input checked="" type="checkbox"/> Public Health Units		Other

The information contained in this document is a Departmental:

Policy	<input checked="" type="checkbox"/> Standard	Protocol	Procedure	Guideline
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Title: **Congenital Anomalies Registry**
Effective Date: **January 1st, 2011**

Statement of approved Clinical Practice:

The Chief Public Health Officer (CPHO) in accordance with the new *Public Health Act* (S.N.W.T. 2007, c.17), which came into force September 14, 2009. will be implementing the NWT Congenital Anomalies Registry.

Effective January 1st, 2011 all health care providers will be required to notify the Office of the Chief Public Health Officer of any newly diagnosed congenital malformations, deformations and chromosomal abnormalities in children up to age 19. This should be done within three months after the day of diagnosis. Please note that suspect congenital anomalies in stillbirths as well as fetal remains (less than 20 weeks) should also be reported.

This list is by no means comprehensive but is meant to reflect the general categories listed under the 10th edition of the WHO International Classification of Diseases

A pamphlet targeted to health professionals explaining this new reporting requirement is provided. Also included is the NWT Congenital Anomalies Reporting Form. All congenital anomalies will be reviewed by a designated Stanton paediatrician and then entered into the territorial congenital anomalies database located within Disease Registries at the Department of Health & Social Services.

Health care professionals will be required to report personal information about the patient including place of birth, ethnicity, gender and healthcare number, clinical and epidemiological details relevant to the diagnosis and treatment, test results, the health care professional's name and contact information, and any other information required by the CPHO.

Attached:

Pamphlet: NWT Notifiable Diseases: Information for the Healthcare Provider on the new Congenital Anomalies Registry

This clinical practice is approved.



(signature)

Assistant Deputy Minister

Chief Public Health Officer

Director, Child & Family Services

Director, Adoptions

NWT Notifiable Diseases

Information for the Healthcare Provider on the new
Congenital Anomalies Registry

Who should report?

Doctors, midwives, nurses.

How to report?

Download form. Attach all supporting documentation of diagnosis (results of metabolic testing, MRI, consults from specialists, etc.). This should be completed within 3 months of the diagnosis.

If in doubt, report!

**The completed form must be provided within
3 MONTHS after the day of diagnosis.**

A health care professional who suspects a congenital anomaly(ies) and/or syndrome is required to complete the NWT Disease Registry Congenital Anomalies Reporting Form and return to:

Office of the Chief Public Health Officer

Department of Health and Social Services
Box 1320 CST-6
Yellowknife, NT X1A 2L9
Phone: (867) 920-8646 • Fax: (867) 873-0442



As of January 1, 2011, the new Congenital Anomalies Registry will be in effect in the NWT.

What does this mean to you?

The reporting of the following newly diagnosed Congenital Anomaly (ies) and/or syndromes will be a requirement under the new *Public Health Act* for all children under 19 years of age, including stillbirths and fetuses less than 20 weeks.

Congenital malformations, other genetic conditions and selected disabilities

Below are a list of GENERAL categories for congenital anomalies. It is by no means comprehensive. A complete listing can be found in WHO International Classification of Disease (10th ed.) Specific ICD codes are listed in Schedule I Part 2 of the Disease Surveillance Regulations under the new *Public Health Act*.

Blood & Immune System Disorders

- Hereditary haemolytic anemias
- Disorders involving the immune mechanism

Chromosomal Abnormalities

- Chromosomal abnormalities (e.g. Trisomy 21)

Digestive System

- Congenital malformations of the upper or lower alimentary tract
- Other congenital malformations of the digestive system

Endocrine, Nutritional & Metabolic Diseases

- Congenital hypothyroidism
- Andrenogenital disorders
- Inborn Errors of Metabolism (e.g. PKU)
- Cystic Fibrosis

Eye, Ear, Face and Neck

- Cleft lip and cleft palate
- Congenital malformations of the eye, ear, face and neck

Genitourinary System

- Congenital malformations of genital organs
- Congenital abnormalities of the urinary system

Heart and Circulatory System

- Congenital malformations of the heart or circulation

Mental and Behavioural Disorders

- Childhood Autism
- Fetal alcohol spectrum disorder (FASD)
- Fetus and newborn affected by maternal use of drugs of addiction

Neuromuscular Disorders

- Anencephaly and other congenital malformations of the brain
- Cerebral palsy
- Hereditary ataxia
- Muscular dystrophies and other myopathies
- Neurofibromatosis and Tuberous Sclerosis
- Spina bifida
- Spinal muscular atrophy and related syndromes
- Other degenerative diseases and disorders of the nervous system

Musculoskeletal disorders

- Congenital malformations and deformations of the musculoskeletal system (e.g. Osteogenesis Imperfecta)

Hearing loss

- Conductive, sensorineural, or mixed

Respiratory System

- Congenital malformations of respiratory system

Skin

- Congenital malformations of the integument

Others

- Any other suspected congenital malformation

If you SUSPECT any congenital anomaly, please complete form and FAX to OCPHO (867) 873-0442



Office Use only	Registration Number	Birth Registration Number	Death Registration Number
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N.W.T. Disease Registry
Congenital Anomalies Reporting Form

**Medical
Confidential**

Fetus / Infant / Child

Please Print Clearly

Name (Last, First, Middle)		Date of Birth / Pregnancy Outcome Month by Name Day Year	
Type of Birth <input type="checkbox"/> Livebirth <input type="checkbox"/> Fetus less than 20 weeks gestation <input type="checkbox"/> Stillbirth <input type="checkbox"/> Elective termination <input type="checkbox"/> Yes <input type="checkbox"/> No		Name of Hospital of Birth / Pregnancy Outcome	
Gender <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown	Child's Health Care Number <input type="checkbox"/> Not available	Attending Physician's/Health Care Provider's Name	
Plurality of Birth <input type="checkbox"/> Single <input type="checkbox"/> Twin <input type="checkbox"/> First <input type="checkbox"/> Second <input type="checkbox"/> Triplets <input type="checkbox"/> First <input type="checkbox"/> Second <input type="checkbox"/> Third	Physician Responsible for Ongoing Care (if different from above)		
Birthweight Grams	Gestation Age (Completed Weeks)	Hospital Chart Number <input type="checkbox"/> Not available	Date of Death (if applicable) Month by Name Day Year

Parents

Biological Mother's Name (Last, First, Middle)		Mother's Date of Birth Month by Name Day Year	
Mother's Community of Residence		Postal Code	Letter Mother's Health Care Number Prefix
Father's Name (Last, First, Middle)		Father's Date of Birth Month by Name Day Year	

Reporting Hospital/Clinic/Agency

Name of Facility	Location (Community)
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Please describe congenital anomaly(ies) and/or syndrome diagnoses in as much detail as possible. Use the back of form for additional space and add confirmatory documentation if available (radiology report, consultant record etc).

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Completed by	Position	Date Month by Name Day Year
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