



Barth Syndrome
Foundation of Canada

Emergency Medical Information

Name: _____

Date of Birth: _____

Health Card Number: _____

Home Address

Street: _____

City: _____ Province: _____

Postal Code: _____ Phone: _____

Directions to home from major intersection:

Mother

Cell

Work

Father

Cell

Work

Emergency Contacts

Name

Relationship

Cell

Home

Name

Relationship

Cell

Home

Family Doctor:

Phone: _____

Cardiologist:

Phone: _____

Closest emergency department:

Phone: _____

Hospital most commonly used:

Phone: _____

Dentist:

Phone: _____

Description of Barth syndrome

Barth syndrome is a rare, potentially life threatening genetic disorder that affects males. Some of the cardinal characteristics of Barth syndrome are:

- Neutropenia: weakness in the immune system due to a reduction of certain white blood cells known as neutrophils, which are necessary in fighting bacterial infections. This places Barth individuals at an increased risk of acquiring serious infections.
- Cardiomyopathy: Heart muscle weakness. This, along with a weakened immune system, is the greatest threat to boys with Barth syndrome. Barth syndrome individuals are also at risk of sudden death arrhythmia.
- Muscle weakness and general fatigue: All muscles, including the heart, have a cellular deficiency which limits their ability to produce energy, causing extreme fatigue during activities requiring strength or stamina, from walking to writing to growing.
- Growth delay: Most Barth individuals are below average in weight and height. The poor growth of Barth individuals is often thought to be evidence of poor nutrition or other secondary effects of a chronic illness. This is rarely the case, and some of the common nutritional treatments are contraindicated for Barth syndrome individuals.

Baseline Vitals

Pulse:	Blood Pressure: /	Baseline Ejection Fraction:	Shortening fraction:
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Medications

Medicine:	Dosage	Time & method given
Medicine:	Dosage	Time & method given
Medicine:	Dosage	Time & method given
Medicine:	Dosage	Time & method given

Immunizations

	Date	Date	Date	Date		Date	Date	Date	Date
DTP					VAR				
Hib									
IPV									
MENI									
MMR									
PNEU									
TD									

DTP: Diphtheria, Tetanus (lockjaw) & Pertussis (whooping cough) Hib: Hemophilus influenza b/Meningitis
 IPV: Injected Polio Vaccine MENI: Meningococcal disease
 MMR: Measles, Mumps and Rubella PNEU: Pneumococcal Disease
 TD: Tetanus and Diphtheria only VAR: Varicella or Chicken Pox

Allergies and Reactions:

- 1) _____
- 2) _____
- 3) _____

Procedures and Medications to be Avoided and why (ie. Potassium)

- 1) _____
- 2) _____
- 3) _____

Notes:
