

Medical Condition

Barth Syndrome



Barth Syndrome
Foundation

Description: Barth syndrome is a rare but serious genetic disorder that affects males. The characteristics (signs and symptoms) of Barth syndrome consist of the following in varying degrees:

♥ **Neutropenia:** Weakness in the immune system, specifically a reduction in the number of “neutrophils”, a type of white blood cell that is most important for fighting bacterial infections. Neutropenia places Barth boys at an increased risk of acquiring serious infections such as bacterial pneumonia and skin abscesses.

♥ **Cardiomyopathy:** Enlarged heart and heart pumping weakness

♥ **Arrhythmia:** Abnormal life threatening and potentially fatal heart rhythm

♥ **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.

♥ **Small Stature:** Most children with Barth syndrome are also below average in weight and height, often substantially so. The poor growth of Barth boys is often due to the secondary effects of a chronic illness.



Contact parent if any of the following symptoms appear:

- ♥ Grey pallor
- ♥ Vomiting or nausea
- ♥ Signs of heart failure
- ♥ Persistent cough
- ♥ Extreme fatigue
- ♥ Chest pain
- ♥ Fever
- ♥ Persistent sweating
- ♥ Tightening in chest
- ♥ Diarrhea
- ♥ Increased irritability
- ♥ Signs of potential infection

NEVER:

- ♥ Force child to eat: Forcing child to eat may worsen child’s condition.
- ♥ Forbid child to contact parents when he states he does not feel well: Child knows his own body and will be at a heightened awareness of symptoms that may not be apparent to others.
- ♥ Prohibit child from going to restroom: Medications and actual condition may cause child to have BM or urinate more frequently than his peers.
- ♥ Force child to participate in physical exercise

Tips for Care:

- ♥ Child should be kept in cool environment. Child will worsen when overheated.
- ♥ Child should be kept away from other children who appear to be ill. Children who have Barth syndrome are at increased risk of infections. A common cold can be catastrophic to a child with Barth syndrome.
- ♥ Those who have Barth syndrome appear deceptively healthy, even in times when they are very ill.