



**Care Plan for School Age Children
with Barth Syndrome**

Child's Name: _____

Date of Birth: _____

Grade: _____ Section: _____

Teacher's name: _____

Contact Information:

Mother's name

Father's Name

Street Address

City

State/Province

Zip/Mailing Code

Home telephone

Mother's Work

Mother's Mobile

Father's Work

Father's Mobile

Other resources of communication with Parents:

Email address #1

Email address #2

Authorized Emergency Contacts:

Alternate Contact #1 Name

Relation to child

Telephone Number

Alternate Contact #2 Name

Relation to child

Telephone Number

Alternate Contact #3 Name

Relation to child

Telephone Number

Emergency Response Information:

Emergency Response
Such as Medic Alert

ID Number

Telephone Number

Physician Information:

Pediatrician:

Name Telephone Number

Street Address

City State/Province Mailing Code

Pediatric Cardiologist:

Name Telephone Number

Street Address

City State/Province Mailing Code

Hospital of Choice:

Name of Hospital Telephone Number

Street Address

City State/Province Mailing Code

List of Medications:

Name of drug	mg	Dosage	Time to be taken
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Name of drug	mg	Dosage	Time to be taken
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Name of drug	mg	Dosage	Time to be taken
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Medical Condition: Barth syndrome

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:** Heart muscle weakness. This, combined with a weakened immune system, represents the greatest threat to boys with Barth syndrome.

♥ **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 boys 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.

Academic Issues:

♥ A child with Barth syndrome will be at an increased risk of missing more time from school than his peers. Please remain in close contact with parents regarding make-up work.

♥ Due to the cellular level of involvement these children are at an increased risk of becoming fatigued making it difficult to concentrate. Please allow child to remain in close to instructor thereby limiting distractions.

♥ Additional testing time may be required for student.

♥ Due to chronic fatigue often associated with Barth syndrome, child may require additional time for make-up work or extended time for homework assignments. Incomplete class assignments should be sent home with child permitting additional time after rest for completion. (If this becomes a persistent problem parent should be notified immediately.)

♥ Self-limiting physical exercise may be allowed however this varies from child to child. Competitive sports should **NEVER** be forced and in many cases are considered potentially harmful to the child. Please discuss this matter with parents. Alternate activities during physical education or during a time when child will be competing in sports may be recommended.

♥ Frequent parent-teacher conferences are recommended to maintain a unified effort in child's academic endeavors.

♥ At some point an Individual Education Plan (IEP) may become necessary. Alternative options should be considered for child if he is not able to keep up with schoolwork.

♥ Poor fine motor skills are often reported with children with Barth syndrome often making adaptive technology such as lap-top computers necessary for child's education

♥ Audio tapes of reading lessons, stories and books may be a useful tool for children with Barth syndrome.

♥ Parents should remain abreast of testing dates, syllabus of course study and progress reports.

♥ Recommended Timeline for parent-teacher conferences:

o Prior to start of school year

o Mid-term of each session

o Mid-year report of students progress or delays

o Year-end meeting with current teachers-advisors (guidance counselors) parents and recommended teachers for following year

♥ Additional resource materials may be found at the official website for The Barth Syndrome Foundation (www.barthsyndrome.org).

♥ Educator-to-Educator contact may be facilitated by BSF if so requested by child's teachers.