Childcare Provider Information Form for Children with Barth Syndrome

Name (Last, First):	Birth Date:	Nickname:

Parent/ Guardian #1:	**Relation to Child:**
Home Address:	

Home Phone:	Work Phone:	Cell Phone:

Parent Guardian #2:	**Relation to Child:**

Home Phone:	Work Phone:	Cell Phone:

Emergency Contact #1 :	**Relation to Child:**

Home Phone:	Work Phone:	Cell Phone:

Emergency Contact #2:	**Relation to Child:**

Home Phone:	Work Phone:	Cell Phone:

Primary Language Child:	Primary Language Parent/Guardian:

Physicians:

Pediatrician:	Phone:	Fax:
Cardiologist:	Phone:	Fax:
Neurologist:	Phone:	Fax:
Hematologist:	Phone:	Fax:
Other:	Phone:	Fax:

Anticipated Primary ED:
Anticipated transfer to:

Pharmacy:	Phone:
Medic Alert # : **209-934-4917 (USA)** **www.medicalert.org**	**Medic Alert Diagnosis:**

Diagnosis: Barth syndrome

The primary symptoms of Barth syndrome are cardiomyopathy (dilated, hypertrophic and/or left ventricular noncompaction), neutropenia (chronic, cyclic, or intermittent), muscle hypoplasia and weakness, growth delay (abnormal growth pattern, similar to but more severe than constitutional growth delay), exercise intolerance, 3-methylglutaconic aciduria, and cardiolipin abnormalities.

For a more comprehensive description of Barth syndrome visit our website at: www.barthsyndrome.org

Baseline Vitals

Baseline Ejection Fraction %	Physician Signature:
Baseline Shortening Fraction %	Physician Signature:
Baseline Blood Pressure /	Physician Signature:
Baseline Pulse Rate	Physician Signature:
Baseline ANC	Physician Signature:
Chest X-Ray	Physician Signature:
ECG	Physician Signature:

Date Completed: _____

Initials: _____

Allergies, Medications to be avoided:	Why:	
Procedures to be avoided:	Why:	
Common Presenting Problems/Findings with Suggested Management		
Problem:	Suggested Diagnostic Studies	Treatment Considerations
Physician Signature:	Date:	
Antibiotic Prophylaxis :	Indication:	Medication and Dose:

Immunizations:

	Date	Date	Date	Date
DPT/DT				
OPV				
MMR				
HIB				
HepB				
Varicella				
TB status				
Other				

Comments on child, family, or other specific medical issues:

_____

_____

_____

_____

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