

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:		
<p>Diagnosis: Barth syndrome</p> <p>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.</p> <p>For a more comprehensive description of Barth syndrome visit our website at: www.barthsvndrome.org</p>			

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:				

Barth Syndrome Foundation, Inc. P.O. Box 974 Perry, FL 32348 Telephone: (850) 223-1128 Facsimile: (850) 223-3911 E-mail: bsinfo@barthsyndrome.org Website: www.barthsyndrome.org				