Severe Chronic Neutropenia International Registry

United States Office at the University of Washington

SCNIR
1107 NE 45th St, Suite #345
Seattle, WA 98105

Phone: 206-543-9749
800-726-4463
Fax: 206-543-3668

REGISTRATION FORM

FOR OFFICE USE ONLY

Registration: ☐ Approved Date: _____/_____/_____ Month Day Year

☐ Not approved

Reviewer's Signature:

PHYSICIAN CONTACT INFORMATION

Physician Name: _____ Specialty: _____

Institution Name: _____

Institution Address: _____

City: _____ State/Province: _____ Zip Code: _____ Country: _____

Phone: _____ Fax: _____ Pager: _____

Email: _____

PATIENT CONTACT INFORMATION

Patient Name: _____

Address: _____

City: _____ State/Province: _____ Zip Code: _____ Country: _____

Phone: _____ Email: _____

Parent/Legal Guardian *(if applicable)*: _____ Relationship: _____

Phone: _____ Email: _____

Date of Birth: _____/_____/_____ Month Day Year

Sex: *(check one)* ☐ Male ☐ Female

Race: *(check one)*
☐ Caucasian
☐ Black
☐ Asian
☐ Hispanic
☐ Hawaiian/Pacific Islander
☐ Native American/Alaska Native

Date of Onset: _____/_____/_____ Month Day Year

Date of Diagnosis: _____/_____/_____ Month Day Year

Diagnosis: *(check one)*
☐ Congenital
☐ Cyclic
☐ Idiopathic
☐ Autoimmune
☐ Other (specify):

If your patient has a sub-diagnosis of **Barth Syndrome**, **Shwachman-Diamond Syndrome** (SDS), **Glycogen Storage Disease** (Type 1b), or **Myelokathexis** please submit the corresponding lab evaluations that support the sub-diagnosis (e.g., Gene Dx, laboratory reports, SDS report from the SickKids Molecular Genetics Laboratory in Toronto, Canada).

IRB Approved: 12/2/08

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Yes	No	Not Tested	
☐	☐	☐	Have **Anti-neutrophil antibodies** been detected? → *If Tested, please attach **lab report***
☐	☐		Has a **Bone Marrow Evaluation** been done? → *If Yes, please attach ALL **pathology reports***
☐	☐		Has a **Cytogenetics Evaluation** been done? → *If Yes, please attach ALL **hematology reports***
☐	☐		Has a **Bone Density Evaluation** been done? → *If Yes, please attach ALL **radiology reports***
☐	☐		Have **Bone Marrow Slides** been done? → *If Yes, please submit **one stained and one unstained slide** for the Registry to keep*
☐	☐		Have **CBC's** (complete blood counts) been done?* *If Cyclic then provide documentation of regular cycling in the form of CBCs done 3x/week for 6 weeks prior to the patient's initial exposure to cytokine (G-CSF/ Neupogen®). → *If Yes, please attach ALL **lab reports** of CBCs with differentials to date*
☐	☐		Has a **Bone Marrow Transplant** been done? → *If Yes, please provide date of BMT:* _____/_____/_____ Month Day Year

TREATMENT HISTORY

☐ Check here if cytokine (G-CSF/Neupogen®) has **never** been taken. Skip to the section entitled, "Other Medications for Neutropenia."

Cytokine (G-CSF/Neupogen®)

	Start Date:	End Date:	Quantity	mcg/ml/cc	Frequency*	Discontinue Reason
EXAMPLE:	***7 / 1 / 2008*** ***Month Day Year***	***7 / 15 / 2008*** ***Month Day Year***	***0.55***	***ml***	***QD***	***Neutrophil Recovery***
(G-CSF/ Neupogen®):	_____/_____/_____ Month Day Year	_____/_____/_____ Month Day Year				
	_____/_____/_____ Month Day Year	_____/_____/_____ Month Day Year				
Other Cytokine: *(for neutropenia such as EPO, GM-CSF)*	_____/_____/_____ Month Day Year	_____/_____/_____ Month Day Year				

OTHER MEDICATIONS FOR NEUTROPENIA

Yes	No	Have any of the following medications been taken to treat neutropenia?
☐	☐	**Steroids** (ex. Corticosteroid, Prednisone, Methylprednisolone, etc.) (specify):
☐	☐	**Gamma Globulin**
☐	☐	**Other** (specify):

** Refer to page 2 of the "Instructions for completing Registration form" for Frequency codes.*

Discontinue Reasons
- *Neutrophil Recovery*
- *Ineffective*
- *Toxicity*
- *Other (specify)*

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SIGNIFICANT CLINICAL HISTORY OF INFECTIONS

IMPORTANT: History of Infections must be **BEFORE** the initial dose of cytokine (G-CSF/Neupogen®).	**FREQUENCY OF EPISODES** *(Check one box for each Infection)*			
	None	**1-3 per Year**	**4-12 per Year**	**> 12 per Year, repeated or continuous**
Mouth Ulcers	☐	☐	☐	☐
Bleeding gums (Gingivitis/Periodontitis)	☐	☐	☐	☐
Skin Infection (Cellulitis ONLY)	☐	☐	☐	☐
Skin Infection (Abscess/other)	☐	☐	☐	☐
Sinusitis	☐	☐	☐	☐
Ear ache (Otitis)	☐	☐	☐	☐
Upper Respiratory Infection (Pharyngitis/Bronchitis, common cold)	☐	☐	☐	☐
Pneumonia	☐	☐	☐	☐
Blood Stream Infection (Bacteremia/Sepsis)	☐	☐	☐	☐
Stomach/Intestinal Infection (Please specify:)	☐	☐	☐	☐
Peritonitis	☐	☐	☐	☐
Liver Abscess	☐	☐	☐	☐
Urinary Tract Infection	☐	☐	☐	☐
Other (specify)	☐	☐	☐	☐

GROWTH AND DEVELOPMENT/PHYSICAL ASSESSMENT

Date of Assessment: _____/_____/_____
Month Day Year

Height: _____ cm or _____ ft _____ in

Weight: _____ kg or _____ lb _____ oz

IMPORTANT: These assessments must be **BEFORE** the initial dose of cytokine (G-CSF/Neupogen®).

Spleen: ☐ Palpable _____ cm bcm (below costal margin) ☐ Not Palpable ☐ Not Assessed

Liver: ☐ Palpable _____ cm bcm (below costal margin) ☐ Not Palpable ☐ Not Assessed

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REPRODUCTIVE ASSESSMENT

_____ **Number of LIVE births.**

_____ **Number of STILL births.**

_____ **Number of MISCARRIAGES/TERMINATIONS.**

☐ Yes ☐ No **Is the patient or patient's partner pregnant?**

→ If Yes, what is the estimated delivery date? _____/_____/_____ (Month Day Year)

SIGNIFICANT CLINICAL HISTORY OF NON-INFECTIOUS EVENTS

	Is this a problem <u>NOW</u>?		**Was this a problem <u>BEFORE</u> the intial dose of cytokine (G-CSF/ Neupogen®)?**	
	Yes	**No**	**Yes**	**No**
Enlarged Spleen	☐	☐	☐	☐
Enlarged Liver	☐	☐	☐	☐
Inflamed blood vessels-Kidney (Glomerulonephritis)	☐	☐	☐	☐
Arthritis	☐	☐	☐	☐
Inflamed blood vessels (Vasculitis)	☐	☐	☐	☐
Cancer	☐	☐	☐	☐
Other (specify):	☐	☐	☐	☐

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FAMILY HISTORY

☐ Yes ☐ No **Are the parents of SCN patient related to each other (e.g. 1st or 2nd cousins)?**

If Yes, please specify relationship:

Relationship to Patient		*(Check all that apply for each family member)*					
		Living	**Deceased**	**Enrolled in Registry**	**Neutropenia**	**Leukemia**	**Other Blood Disorder (specify)**
Mother:		☐	☐	☐	☐	☐	☐
Father:		☐	☐	☐	☐	☐	☐
Brothers: (fill in initials of all brothers or N/A if none)	1.	☐	☐	☐	☐	☐	☐
	2.	☐	☐	☐	☐	☐	☐
	3.	☐	☐	☐	☐	☐	☐
Sisters: (fill in initials of all sisters or N/A if none)	1.	☐	☐	☐	☐	☐	☐
	2.	☐	☐	☐	☐	☐	☐
	3.	☐	☐	☐	☐	☐	☐
Other Affected Family Member: (Specify Relationship):		☐	☐	☐	☐	☐	☐
Other Affected Family Member: (Specify Relationship):		☐	☐	☐	☐	☐	☐

☐ Check here if Family History is Unknown.

~ Stop here and submit registration form ~

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