

Severe Chronic Neutropenia International Registry United States Office at the University of Washington	SCNIR 600 Stewart Street, Suite #1503 Seattle, WA 98101	Phone: 206-543-9749 800-726-4463 Fax: 206-543-3668
	REGISTRATION FORM	

Yes	No	Not Tested	Have Anti-neutrophil antibodies been detected?	→ If Tested, please attach lab report
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
<input type="checkbox"/>	<input type="checkbox"/>		Has a Bone Marrow Evaluation been done?	→ If Yes, please attach ALL pathology reports
<input type="checkbox"/>	<input type="checkbox"/>		Has a Cytogenetics Evaluation been done?	→ If Yes, please attach ALL hematology reports
<input type="checkbox"/>	<input type="checkbox"/>		Has a Bone Density Evaluation been done?	→ If Yes, please attach ALL radiology reports
<input type="checkbox"/>	<input type="checkbox"/>		Have Bone Marrow Slides been done?	→ If Yes, please submit one stained and one unstained slide for the Registry to keep
<input type="checkbox"/>	<input type="checkbox"/>		Have CBC's (complete blood counts) been done?*	→ If Yes, please attach ALL lab reports of CBCs with differentials to date
			*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®).	
<input type="checkbox"/>	<input type="checkbox"/>		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®)							Discontinue Reason
	Start Date:	End Date:	Quantity	mcg/ml/cc	Frequency*		
EXAMPLE:	7 / 1 / 2008 <small>Month Day Year</small>	7 / 15 / 2008 <small>Month Day Year</small>	0.55	ml	QD		Neutrophil Recovery
(G-CSF/ Neupogen®):	____ / ____ / ____ <small>Month Day Year</small>	____ / ____ / ____ <small>Month Day Year</small>					
	____ / ____ / ____ <small>Month Day Year</small>	____ / ____ / ____ <small>Month Day Year</small>					
Other Cytokine: <small>(for neutropenia such as EPO, GM-CSF)</small>	____ / ____ / ____ <small>Month Day Year</small>	____ / ____ / ____ <small>Month Day Year</small>					

OTHER MEDICATIONS FOR NEUTROPENIA

<table> <tr> <td>Yes</td> <td>No</td> <td>Have any of the following medications been taken to treat neutropenia?</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>Steroids (ex. Corticosteroid, Prednisone, Methylprednisolone, etc.) (specify):</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>Gamma Globulin</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>Other (specify):</td> </tr> </table>	Yes	No	Have any of the following medications been taken to treat neutropenia?	<input type="checkbox"/>	<input type="checkbox"/>	Steroids (ex. Corticosteroid, Prednisone, Methylprednisolone, etc.) (specify):	<input type="checkbox"/>	<input type="checkbox"/>	Gamma Globulin	<input type="checkbox"/>	<input type="checkbox"/>	Other (specify):	<p>* Refer to page 2 of the "Instructions for completing Registration form" for Frequency codes.</p> <p>Discontinue Reasons</p> <ul style="list-style-type: none"> • Neutrophil Recovery • Ineffective • Toxicity • Other (specify)
Yes	No	Have any of the following medications been taken to treat neutropenia?											
<input type="checkbox"/>	<input type="checkbox"/>	Steroids (ex. Corticosteroid, Prednisone, Methylprednisolone, etc.) (specify):											
<input type="checkbox"/>	<input type="checkbox"/>	Gamma Globulin											
<input type="checkbox"/>	<input type="checkbox"/>	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 <i>(Check one box for each Infection)</i>			
	None	1-3 per Year	4-12 per Year	> 12 per Year, repeated or continuous
Mouth Ulcers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bleeding gums (Gingivitis/Periodontitis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin Infection (Cellulitis ONLY)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin Infection (Abscess/other)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sinusitis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ear ache (Otitis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Upper Respiratory Infection (Pharyngitis/Bronchitis, common cold)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pneumonia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blood Stream Infection (Bacteremia/Sepsis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stomach/Intestinal Infection (Please specify:)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Peritonitis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Liver Abscess	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urinary Tract Infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

GROWTH AND DEVELOPMENT/PHYSICAL ASSESSMENT

Date of Assessment: ___/___/___ <small>Month Day Year</small>	IMPORTANT: These assessments must be BEFORE the initial dose of cytokine (G-CSF/Neupogen®).		
Height: ___ or ___ ___ <small> cm ft in</small>			
Weight: ___ or ___ ___ <small> kg lb oz</small>			
Spleen: <input type="checkbox"/> Palpable _____ cm bcm <small>(below costal margin)</small> <input type="checkbox"/> Not Palpable <input type="checkbox"/> Not Assessed			
Liver: <input type="checkbox"/> Palpable _____ cm bcm <small>(below costal margin)</small> <input type="checkbox"/> Not Palpable <input type="checkbox"/> Not Assessed			

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REPRODUCTIVE ASSESSMENT

_____	Number of LIVE births.
_____	Number of STILL births.
_____	Number of MISCARRIAGES/TERMINATIONS.
<input type="checkbox"/> Yes <input type="checkbox"/> 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 initial dose of cytokine (G-CSF/ Neupogen®)?	
	Yes	No	Yes	No
Enlarged Spleen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enlarged Liver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inflamed blood vessels-Kidney (Glomerulonephritis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arthritis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inflamed blood vessels (Vasculitis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (specify):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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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	<i>(Check all that apply for each family member)</i>					
	Living	Deceased	Enrolled in Registry	Neutropenia	Leukemia	Other Blood Disorder (specify)
Mother:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Father:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brothers: <small>(fill in initials of all brothers or N/A if none)</small>	1.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	2.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	3.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sisters: <small>(fill in initials of all sisters or N/A if none)</small>	1.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	2.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	3.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other Affected Family Member: <small>(Specify Relationship):</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other Affected Family Member: <small>(Specify Relationship):</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Check here if Family History is Unknown.

~ Stop here and submit registration form ~

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