

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

INSTRUCTIONS FOR COMPLETING YEARLY UPDATE FORM

NOTE: In this document, if you are completing this form for yourself or your dependent then the use of the terms "you/your" refers to either you or your dependent.

If you are a medical professional and you are completing this form for your patient then the use of the terms "you/your" refers to your patient.

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As a patient you have the right to your medical records. To obtain a copy of the specified evaluations please contact the physician who did the evaluation(s) for you. Request the evaluation(s) by name. For example, Anti-neutrophil antibodies report, bone marrow evaluation, etc. Your physician's office will explain to you what paperwork must be completed before your medical records can be released.

Bone Marrow Evaluation: Indicate whether a bone marrow evaluation was done during the specified time period. If yes, submit ALL corresponding pathology reports within that time period.

Cytogenetic Evaluation: Indicate whether a cytogenetic evaluation was done during the specified time period. If yes, submit ALL corresponding hematology reports within that time period.

Bone Density Report: Indicate whether a bone density evaluation was done during the specified time period. If yes, submit ALL corresponding radiology reports within that time period.

CBC's: Indicate whether CBC's (complete blood counts) with differentials have been done during the specified time period. If yes, submit ALL corresponding lab reports within that time period. A valid CBC generally contains at least the following information (see below for a sample CBC):

Complete Blood Count (CBC) with differential			
Test Results	Result	Units	Reference Interval
White Blood Count	1.5 L	x 10 ³ /mm ³	5.0-10.0
Red Blood Count	3.50 L	x 10 ⁶ /mm ³	4.1-5.3
Hemoglobin	10.8 L	g/dL	12.0-18.0
Hematocrit	31.1 L	%	37.0-52.0
MCV	84.9 L	fL	85.0-115.0
Platelets	302	x 10 ³ /mm ³	150-400
Polys (neutrophils)	23 L	%	45-76
Lymphs	68 H	%	17-44
Monocytes	7	%	3-10
Eos	2	%	0-4
Basos	0.6	%	0.2
Polys (absolute)	.34 L	x 10 ³ /mm ³	1.8-7.8
Lymphs (absolute)	1.0	x 10 ³ /mm ³	0.7-4.5
Monocytes (absolute)	0.1	x 10 ³ /mm ³	0.1-1.0
Eos (absolute)	0.1	x 10 ³ /mm ³	0.0-0.4
Basos (absolute)	0.0	x 10 ³ /mm ³	0.0-0.2

Bone Marrow Transplant: Indicate whether a bone marrow transplant was done during the specified time period. If yes, provide the date of the transplant.

Is the patient pregnant?: Indicate whether you were pregnant during the specified time period. If yes, indicate the expected date of delivery. If you had the child then indicate the actual date of delivery.

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Did the patient have their spleen removed from <Date to Date>? Indicate whether you had your spleen removed during the specified time period. If yes, indicate the date that this was done.

Was the patient hospitalized from <Date to Date>?: Indicate whether you were hospitalized during the specified time period. If Yes, please submit admission/discharge notes that summarize the details of the hospitalization.

Did the patient die between <Date to Date>? If yes, please send 1) date of death, 2) cause of death, 3) a copy of the autopsy report or death certificate, and 4) a completed death summary.

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Treatment History

NOTE: Complete this section if you have ever taken Cytokine (G-CSF/Neupogen®). Otherwise, check the box that states, "Check here if cytokine (G-CSF/Neupogen®) has never been taken." Skip to the section entitled, "Other Medications for Neutropenia."

Fill in the Start/End dates if you have stopped taking cytokine (G-CSF/Neupogen®) within the specified time period. If you took cytokine (G-CSF/Neupogen®) continuously during the specified time period then leave these date fields blank.

G-CSF/Neupogen®

Start Date*: indicate the date when you began taking cytokine (G-CSF/Neupogen®) during the specified time period.

End Date*: indicate the date when you stopped taking cytokine (G-CSF/Neupogen®) during the specified time period.

**It is common to start and stop taking cytokine (G-CSF/Neupogen®) on several occasions during a given time period. Indicate each occurrence of taking cytokine (G-CSF/Neupogen®) during the specified time period. An occurrence has a discrete beginning and an end. If you need more space to complete this section then attach a separate sheet of paper and include it with the registration form.*

Quantity: indicate how much cytokine (G-CSF/Neupogen®) you were taking between the Start and End dates specified. If you are unsure of the quantity, then please consult with the physician who prescribed you the medication or the pharmacy that filled your prescription for this information.

mcg/ml/cc: indicate the units in which your dose is measured in either micrograms (mcg), milliliters (ml), or cubic centimeters (cc). If you are unsure of the units, then please consult with the physician who prescribed you the medication or the pharmacy that filled your prescription for this information.

Frequency: indicate how often you took cytokine (G-CSF/Neupogen®) between the Start and End dates. If you are unsure of the frequency, then please consult with the physician who prescribed you the medication or the pharmacy that filled your prescription for this information. See below for a list of frequency codes.

Code:		Code:	
qd	= once a day	qtd	= every 3 rd day
bid	= twice a day	qwk	= once a week
tid	= 3 times a day	biw	= twice a week
qid	= 4 times a day	tiw	= 3 times a week
qod	= every other day	prn	= as needed

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Discontinue reason: if you have ever stopped taking cytokine (G-CSF/Neupogen®) within the specified time period then indicate the reason for discontinuing in the space provided.

Other Cytokine (for neutropenia such as GM-CSF, EPO, etc.):

Start Date: complete this section as you would for G-CSF/Neupogen®.
End Date: complete this section as you would for G-CSF/Neupogen®.
Quantity: complete this section as you would for G-CSF/Neupogen®.
mcg/ml/cc: complete this section as you would for G-CSF/Neupogen®.
Frequency: complete this section as you would for G-CSF/Neupogen®.
Discontinue Reason: complete this section as you would for G-CSF/Neupogen®.

Other medications for neutropenia: indicate whether you have taken any of the following medications to treat neutropenia. If you are asked to specify the medication then include the name of the medication in the space provided

Non-infectious events

Was this a problem during time period?: indicate whether any of the listed clinical events were a problem during the specified time period. Typically, this information is found in your medical records. If you need help interpreting your medical record or completing this section contact the Registry at 1-800-726-4463 or consult with your physician.

Physical Assessment

NOTE: You will need a physical exam from your physician that lists a height and weight to complete this section.

Date of assessment: indicate the date that height and weight were assessed.

Height: indicate your height in centimeters or feet and inches.

Weight: indicate your weight in kilograms or pounds and ounces.

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Infections

For each infection that is listed indicate the frequency of occurrences during the specified time period. Estimate the number of occurrences per year.

An episode is a discrete occurrence with a beginning and an end. For example, you may have had an earache that lasted for four (4) weeks. This would count as one (1) episode and you would check the box under, "1-3 per Year." If you were to develop an earache that lasted for one (1) week out of each month for six (6) months then each earache would count as a separate episode. In this scenario the total number of earaches is six (6) and you would check the box under, "4-12 per Year."

Select a frequency for EACH infection. Do NOT leave any infection unaccounted for. If the frequency is unknown then check "None."