

<b>Severe Chronic Neutropenia International Registry</b> United States Office at the University of Washington	SCNIR 1107 NE 45 <sup>th</sup> St, Suite #345 Seattle, WA 98105	Phone: 206-543-9749 800-726-4463 Fax: 206-543-3668

**YEARLY UPDATE FORM**

Period: June 1, 2019 to June 1, 2020  
 Patient Name: \_\_\_\_\_  
 Date of Birth: \_\_\_\_\_ SCNIR: \_\_\_\_\_

**Physician Contact Information**

Physician Name: \_\_\_\_\_ Phone Number: \_\_\_\_\_  
 Institution: \_\_\_\_\_ Fax Number: \_\_\_\_\_  
 Institution or Clinic Address: \_\_\_\_\_

**Patient Contact Information**

Address: \_\_\_\_\_ Phone Number: \_\_\_\_\_  
 Address: \_\_\_\_\_ Email: \_\_\_\_\_

Yes	No	
<input type="checkbox"/>	<input type="checkbox"/>	Was a <b>Bone Marrow Evaluation</b> done between June 1, 2019 and June 1, 2020? <i>→ If Yes, please attach <u>pathology report</u></i>
<input type="checkbox"/>	<input type="checkbox"/>	Was a <b>Cytogenetic Evaluation</b> done between June 1, 2019 and June 1, 2020? <i>→ If Yes, please attach <u>hematology report</u></i>
<input type="checkbox"/>	<input type="checkbox"/>	Was a <b>Bone Density Evaluation</b> done between June 1, 2019 and June 1, 2020? <i>→ If Yes, please attach <u>radiology report</u></i>
<input type="checkbox"/>	<input type="checkbox"/>	Were complete blood counts (CBCs) / full blood counts (FBCs) – <b>with differentials</b> – done between June 1, 2019 and June 1, 2020? <i>→ If Yes, please attach ALL CBC with differentials <u>lab reports</u></i>
<input type="checkbox"/>	<input type="checkbox"/>	Was a <b>Bone Marrow Transplant</b> done between June 1, 2019 and June 1, 2020? <i>→ If Yes, please provide date of BMT:</i> _____ / _____ / _____ <div align="right">Month    Day    Year</div>
<input type="checkbox"/>	<input type="checkbox"/>	Is the patient <b>pregnant</b> ? <i>→ If Yes, please provide expected/actual date of delivery:</i> _____ / _____ / _____ <div align="right">Month    Day    Year</div>
<input type="checkbox"/>	<input type="checkbox"/>	Did the patient have their <b>spleen removed</b> between June 1, 2019 and June 1, 2020? <i>→ If Yes, please provide date done:</i> _____ / _____ / _____ <div align="right">Month    Day    Year</div>
<input type="checkbox"/>	<input type="checkbox"/>	Was the patient <b>hospitalized</b> between June 1, 2019 and June 1, 2020? <i>→ If Yes, please submit admission/discharge notes that summarize the details of the hospitalization.</i>
<input type="checkbox"/>	<input type="checkbox"/>	Did the patient <b>die</b> between June 1, 2019 and June 1, 2020? <i>→ If Yes, please send date of death, cause of death, and a copy of the autopsy report or death certificate.</i>

<b>Severe Chronic Neutropenia International Registry</b> United States Office at the University of Washington	SCNIR 1107 NE 45 <sup>th</sup> St, Suite #345 Seattle, WA 98105	Phone: 206-543-9749 800-726-4463 Fax: 206-543-3668
---	---	--

## YEARLY UPDATE FORM

Period: June 1, 2019 to June 1, 2020
 Patient Name: \_\_\_\_\_  
Date of Birth: \_\_\_\_\_
SCNIR: \_\_\_\_\_

### TREATMENT

List below all changes in dose amount or frequency or type of G-CSF (Neupogen® or Biosimilar)						
G-CSF (Neupogen® or Biosimilar)						
	Start Date:	End Date:	Quantity	mcg, ml or cc	Frequency	Discontinued
<b>EXAMPLE:</b>	<b>Jun / 1 / 2019</b> <small>Month Day Year</small>	<b>Jun / 1 / 2020</b> <small>Month Day Year</small>	<b>0.55</b>	<b>ml</b>	<b>QD</b>	<b>Neutrophil Recovery</b>
<b>G-CSF (Neupogen® or Biosimilar):</b> <small>Specify type if Biosimilar:</small>	____ / ____ / ____ <small>Month Day Year</small>	____ / ____ / ____ <small>Month Day Year</small>				
	____ / ____ / ____ <small>Month Day Year</small>	____ / ____ / ____ <small>Month Day Year</small>				
	____ / ____ / ____ <small>Month Day Year</small>	____ / ____ / ____ <small>Month Day Year</small>				

		OTHER MEDICATIONS FOR NEUTROPENIA
	<b>Yes</b> <b>No</b>	<b>Have any of the following medications been taken to treat neutropenia?</b> (Specify dose, frequency, duration)
<input type="checkbox"/>	<input type="checkbox"/>	<b>Steroids</b> (ex: Corticosteroid, Prednisone, Methylprednisolone, etc.) _____
<input type="checkbox"/>	<input type="checkbox"/>	<b>Gamma Globulin:</b> _____
<input type="checkbox"/>	<input type="checkbox"/>	<b>Other</b> (ex: Methotrexate, Cyclosporine, etc.) _____

NON-INFECTIOUS EVENTS		
	Was this a problem during time period?	
	Yes	No
<b>Enlarged Spleen</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Enlarged Liver</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Inflamed blood vessels-Kidney</b> <small>(Glomerulonephritis)</small>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Arthritis</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Inflamed blood vessels</b> <small>(Vasculitis)</small>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Cancer</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Other (specify)</b>	<input type="checkbox"/>	<input type="checkbox"/>

PHYSICAL ASSESSMENT	
<b>Date of Assessment:</b>	____ / ____ / ____ <small>Month Day Year</small>
<b>Height:</b>	____ or ____ <small>cm ft in</small>
<b>Weight:</b>	____ or ____ <small>kg lb oz</small>

<b>Severe Chronic Neutropenia International Registry</b> United States Office at the University of Washington	SCNIR 1107 NE 45 <sup>th</sup> St, Suite #345 Seattle, WA 98105	Phone: 206-543-9749 800-726-4463 Fax: 206-543-3668

**YEARLY UPDATE FORM**

Period: June 1, 2019 to June 1, 2020 Patient Name: \_\_\_\_\_  
 Date of Birth: \_\_\_\_\_ SCNIR: \_\_\_\_\_

**INFECTIONS**

	<b>FREQUENCY OF EPISODES</b> <i>(Check one box for each Infection)</i>			
	None	1-3 per Year	4-12 per Year	> 12 per Year, repeated or continuous
<b>Mouth Ulcers</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Bleeding gums</b> (Gingivitis/Periodontitis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Cellulitis</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Skin Infection</b> (Abscess/other)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Sinusitis</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Ear ache</b> (Otitis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Upper Respiratory Infection</b> (Pharyngitis, Bronchitis, Common cold)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Pneumonia</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Blood Stream Infection</b> (Specify: _____ )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Stomach/Intestinal Infection</b> (Specify: _____ )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Peritonitis</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Liver Abscess</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Urinary Tract Infection</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Other Infection</b> (Specify: _____ )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Specify additional infections below or use separate piece of paper and attach to this form:

<b>Mail to: SCNIR</b> <b>1107 NE 45<sup>th</sup> Street, Suite 345</b> <b>Seattle, WA 98105</b>	<b>Or</b>	<b>Fax to: 206.543.3668</b>
---	-----------	-----------------------------