

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

YEARLY UPDATE FORM

Period: May 1, 2020 to May 1, 2021
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 Bone Marrow Evaluation done between May 1, 2020 and May 1, 2021? <i>→ If Yes, please attach <u>pathology report</u></i>
<input type="checkbox"/>	<input type="checkbox"/>	Was a Cytogenetic Evaluation done between May 1, 2020 and May 1, 2021? <i>→ If Yes, please attach <u>hematology report</u></i>
<input type="checkbox"/>	<input type="checkbox"/>	Was a Bone Density Evaluation done between May 1, 2020 and May 1, 2021? <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) – with differentials – done between May 1, 2020 and May 1, 2021? <i>→ If Yes, please attach ALL CBC with differentials <u>lab reports</u></i>
<input type="checkbox"/>	<input type="checkbox"/>	Was a Bone Marrow Transplant done between May 1, 2020 and May 1, 2021? <i>→ If Yes, please provide date of BMT:</i> _____ / _____ / _____ Month Day Year
<input type="checkbox"/>	<input type="checkbox"/>	Is the patient pregnant ? <i>→ If Yes, please provide expected/actual date of delivery:</i> _____ / _____ / _____ Month Day Year
<input type="checkbox"/>	<input type="checkbox"/>	Did the patient have their spleen removed between May 1, 2020 and May 1, 2021? <i>→ If Yes, please provide date done:</i> _____ / _____ / _____ Month Day Year
<input type="checkbox"/>	<input type="checkbox"/>	Was the patient hospitalized between May 1, 2020 and May 1, 2021? <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 die between May 1, 2020 and May 1, 2021? <i>→ If Yes, please send date of death, cause of death, and a copy of the autopsy report or death certificate.</i>

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

YEARLY UPDATE FORM

Period: May 1, 2020 to May 1, 2021
 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
EXAMPLE:	May / 1 / 2020 <small>Month Day Year</small>	May / 1 / 2021 <small>Month Day Year</small>	0.55	ml	QD	Neutrophil Recovery
G-CSF (Neupogen® or Biosimilar): <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		
	Yes No	Have any of the following medications been taken to treat neutropenia? (Specify dose, frequency, duration)
<input type="checkbox"/>	<input type="checkbox"/>	Steroids (ex: Corticosteroid, Prednisone, Methylprednisolone, etc.) _____
<input type="checkbox"/>	<input type="checkbox"/>	Gamma Globulin: _____
<input type="checkbox"/>	<input type="checkbox"/>	Other (ex: Methotrexate, Cyclosporine, etc.) _____

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

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

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

YEARLY UPDATE FORM

Period: May 1, 2020 to May 1, 2021
 Patient Name: _____
Date of Birth: _____
SCNIR: _____

INFECTIONS

	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"/>
Cellulitis	<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 (Specify: _____)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stomach/Intestinal Infection (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 Infection (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:

Mail to: SCNIR 1107 NE 45th Street, Suite 345 Seattle, WA 98105	Or	Fax to: 206.543.3668
---	-----------	-----------------------------