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

YEARLY UPDATE FORM

Patient Name:_____

Period: January 1, 2019 to January 1, 2020

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	
☐	☐	Was a **Bone Marrow Evaluation** done between January 1, 2019 and January 1, 2020? → *If Yes, please attach **pathology report***
☐	☐	Was a **Cytogenetic Evaluation** done between January 1, 2019 and January 1, 2020? → *If Yes, please attach **hematology report***
☐	☐	Was a **Bone Density Evaluation** done between January 1, 2019 and January 1, 2020? → *If Yes, please attach **radiology report***
☐	☐	Were complete blood counts (CBCs) / full blood counts (FBCs) – **with differentials** – done between January 1, 2019 and January 1, 2020? → *If Yes, please attach ALL CBC with differentials **lab reports***
☐	☐	Was a **Bone Marrow Transplant** done between January 1, 2019 and January 1, 2020? → *If Yes, please provide date of BMT:* _____/_____/_____ Month Day Year
☐	☐	Is the patient **pregnant**? → *If Yes, please provide expected/actual date of delivery:* _____/_____/_____ Month Day Year
☐	☐	Did the patient have their **spleen removed** between January 1, 2019 and January 1, 2020**?** → *If Yes, please provide date done:* _____/_____/_____ Month Day Year
☐	☐	Was the patient **hospitalized** between January 1, 2019 and January 1, 2020? → *If Yes, please submit admission/discharge notes that summarize the details of the hospitalization.*
☐	☐	Did the patient **die** between January 1, 2019 and January 1, 2020? → *If Yes, please send date of death, cause of death, and a copy of the autopsy report or death certificate.*

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

YEARLY UPDATE FORM

Period: January 1, 2019 to January 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
EXAMPLE:	***Jan / 1 / 2019*** ***Month Day Year***	***Jan / 1 / 2020*** ***Month Day Year***	***0.55***	***ml***	***QD***	***Neutrophil Recovery***
G-CSF (Neupogen® or Biosimilar): *Specify type if Biosimilar:* _____	_____/_____/_____ Month Day Year	_____/_____/_____ Month Day Year				
	_____/_____/_____ Month Day Year	_____/_____/_____ Month Day Year				
_____	_____/_____/_____ Month Day Year	_____/_____/_____ Month Day Year				

OTHER MEDICATIONS FOR NEUTROPENIA

Yes	No	Have any of the following medications been taken to treat neutropenia? (Specify dose, frequency, duration)
☐	☐	**Steroids** (ex. Corticosteroid, Prednisone, Methylprednisolone, etc.)_____
☐	☐	**Gamma Globulin:** _____
☐	☐	**Other** (ex: Methotrexate, Cyclosporine, etc.)_____

NON-INFECTIOUS EVENTS

	Was this a problem during time period? Yes	No
Enlarged Spleen	☐	☐
Enlarged Liver	☐	☐
Inflamed blood vessels-Kidney (Glomerulonephritis)	☐	☐
Arthritis	☐	☐
Inflamed blood vessels (Vasculitis)	☐	☐
Cancer	☐	☐
Other (specify)	☐	☐

PHYSICAL ASSESSMENT

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

Height: _____ cm or _____ ft _____ in

Weight: _____ kg or _____ lb _____ oz

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

YEARLY UPDATE FORM

Period: January 1, 2019 to January 1, 2020

Patient Name:_____

Date of Birth:_____ **SCNIR:**_____

INFECTIONS

	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)	☐	☐	☐	☐
Cellulitis	☐	☐	☐	☐
Skin Infection (Abscess/other)	☐	☐	☐	☐
Sinusitis	☐	☐	☐	☐
Ear ache (Otitis)	☐	☐	☐	☐
Upper Respiratory Infection (Pharyngitis, Bronchitis, Common cold)	☐	☐	☐	☐
Pneumonia	☐	☐	☐	☐
Blood Stream Infection (Specify:)	☐	☐	☐	☐
Stomach/Intestinal Infection (Specify:)	☐	☐	☐	☐
Peritonitis	☐	☐	☐	☐
Liver Abscess	☐	☐	☐	☐
Urinary Tract Infection	☐	☐	☐	☐
Other Infection (Specify:)	☐	☐	☐	☐

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