| Severe Chronic Neutropenia<br>International Registry<br>United States Office at the<br>University of Washington |  |  | SCNIR<br>1107 NE 45 <sup>th</sup> St, Suite #34<br>Seattle, WA 98105                                    | 5             | Phone:<br>Fax:  | 206-543-9749<br>800-726-4463<br>206-543-3668 |  |  |
|---|--|--|---|---------------|-----------------|--|--|--|
| YEARLY UPDATE FORM  |  |  |   |               |                 |  |  |  |
| Period <sup>.</sup> A   | Patient Name:<br>Period: August 1, 2020 to August 1, 2021  |  |   |               |                 |  |  |  |
| i onoui /   | aguet 1, 2020 to /   |  |   | rth:          |                 | SCNIR:                                       |  |  |
|   |  | I  | Physician Contact Informat  | tion          |                 |  |  |  |
| Physician   | Name:  |  |   | Phone         | Number:_        |  |  |  |
| Institution   |  |  |   | Fax Nu        | imber:          |  |  |  |
| Institution   | or Clinic Address:   |  |   |               |                 |  |  |  |
|   |  |  | Patient Contact Information   | on            |                 |  |  |  |
| Address:_   |  |  |   | Phone I       | Number:         |  |  |  |
| Address:_   |  |  |   | Email:_       |                 |  |  |  |
| Yes   | No   |  |   |               |                 |  |  |  |
|   |  |  | e Marrow Evaluation done<br>Igust 1, 2020 and August 1, 2021?<br>→ If Yes, please attach <u>patholo</u> |               |                 |  |  |  |
|   |  | Was a Cytogenetic Evaluation done between August 1, 2020 and August 1, 2021?   |   |               |                 |  |  |  |
|   |  |  | → If Yes, please attach <u>hemate</u>   | ology repo    | <u>rt</u>       |  |  |  |
|   |  | Was a <b>Bone Density Evaluation</b> done<br>between August 1, 2020 and August 1, 2021?<br>➔ If Yes, please attach <u>radiology report</u>   |   |               |                 |  |  |  |
|   |  | Were complete blood counts (CBCs) / full blood counts (FBCs) – with differentials –<br>done between August 1, 2020 and August 1, 2021?<br>→ If Yes, please attach ALL CBC with differentials lab reports |   |               |                 |  |  |  |
|   |  | Was a <b>Bone Marrow Transplant</b> done between August 1, 2020 and August 1, 2021?  |   |               |                 |  |  |  |
|   |  | between / t  | $\rightarrow$ If Yes, please provide date of  |               |                 | //<br>Month Day Year                         |  |  |
|   |  | Is the patie   | nt pregnant?  |               |                 |  |  |  |
|   |  |  | ightarrow If Yes, please provide expec  | cted/actual c | late of deliver | y://<br>Month Day Year                       |  |  |
|   |  |  | ent have their spleen removed   |               |                 | Month Day Tour                               |  |  |
|   |  | between Au   | ugust 1, 2020 and August 1, 20213<br>→ If Yes, please provide date c                                    |               |                 | //<br>Month Day Year                         |  |  |
|   |  | Was the pa   | tient <b>hospitalized</b> between Augus   | st 1, 2020    | and Augu        | st 1, 2021?                                  |  |  |
|   |  |  | ➔ If Yes, please submit admiss summarize the details of the   |               | -               |  |  |  |
|   |  | Did the pati   | ent <b>die</b> between August 1, 2020 a   | nd Augus      | st 1, 2021?     |  |  |  |
|   | → If Yes, please send date of death, cause of death,<br>and a copy of the autopsy report or death certificate. |  |   |               |                 |  |  |  |
| L   |  | S  | evere Chronic Neutropenia International R<br>Yearly Update Form   | egistry       |                 |  |  |  |

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| Severe Chronic Neutropenia  |  |  |  |  |  |
|-----------------------------|--|--|--|--|--|
| International Registry      |  |  |  |  |  |
| 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

Patient Name:

Period: August 1, 2020 to August 1, 2021

Date of Birth:\_\_\_\_\_ SCNIR:\_\_\_\_\_

## TREATMENT

| List below all changes in dose amount or frequency or type of G-CSF (Neupogen® or Biosimilar)<br>G-CSF (Neupogen® or Biosimilar) |  |  |          |                  |           |                        |  |
|--|--|--|----------|------------------|-----------|------------------------|--|
|  | Start Date:                            | End Date:                              | Quantity | mcg, ml<br>or cc | Frequency | Discontinued           |  |
| EXAMPLE:   | <b>Aug / 1 /2020</b><br>Month Day Year | <b>Aug</b> / 1 /2021<br>Month Day Year | 0.55     | ml               | QD        | Neutrophil<br>Recovery |  |
| G-CSF (Neupogen® or Biosimilar):   | //<br>Month Day Year                   | //<br>Month Day Year                   |          |                  |           |                        |  |
| Specify type if Biosimilar:  | //<br>Month Day Year                   | //<br>Month Day Year                   |          |                  |           |                        |  |
|  | //<br>Month Day Year                   | //<br>Month Day Year                   |          |                  |           |                        |  |

| OTHER MEDICATIONS FOR NEUTROPENIA |    |   |  |  |  |  |
|-----------------------------------|----|---|--|--|--|--|
| Yes                               | No | Have any of the following medications been taken to treat neutropenia?<br>(Specify dose, frequency, duration) |  |  |  |  |
|                                   |    | Steroids (ex. Corticosteroid, Prednisone, Methylprednisolone, etc.)   |  |  |  |  |
|                                   |    | Gamma Globulin:   |  |  |  |  |
|                                   |    | Other (ex: Methotrexate, Cyclosporine, etc.)  |  |  |  |  |

| NON-INFECTIOUS EVENTS                                 |     |                         | PHYSICAL ASSESSMENT             |  |  |  |
|---|-----|-------------------------|---------------------------------|--|--|--|
|   |     | a problem<br>ne period? |                                 |  |  |  |
|   | Yes | No                      |                                 |  |  |  |
| Enlarged Spleen                                       |     |                         |                                 |  |  |  |
| Enlarged Liver  |     |                         | Date of Assessment:Month'/ Year |  |  |  |
| Inflamed blood vessels-Kidney<br>(Glomerulonephritis) |     |                         | Height: Or                      |  |  |  |
| Arthritis   |     |                         | cm ft in                        |  |  |  |
| Inflamed blood vessels<br>(Vasculitis)                |     |                         | Weight: or                      |  |  |  |
| Cancer  |     |                         | kg lb oz                        |  |  |  |
| Other (specify)                                       |     |                         |                                 |  |  |  |

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| Severe Chronic Neutropenia  |  |  |  |  |  |
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## YEARLY UPDATE FORM

Period: August 1, 2020 to August 1, 2021

Patient Name:

Date of Birth:\_\_\_\_\_ SCNIR:\_\_\_\_\_

## **INFECTIONS**

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

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

Mail to:SCNIR1107 NE 45th Street, Suite 345OrSeattle, WA 98105Fax to: