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

# YEARLY UPDATE FORM

**Patient Name:**_____

**Period: October 1, 2018 to October 1, 2019**

**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 October 1, 2018 and October 1, 2019?<br>→ *If Yes, please attach **pathology report*** |
| ☐ | ☐ | Was a **Cytogenetic Evaluation** done between October 1, 2018 and October 1, 2019?<br>→ *If Yes, please attach **hematology report*** |
| ☐ | ☐ | Was a **Bone Density Evaluation** done between October 1, 2018 and October 1, 2019?<br>→ *If Yes, please attach **radiology report*** |
| ☐ | ☐ | Were complete blood counts (CBCs) / full blood counts (FBCs) – **with differentials** – done between October 1, 2018 and October 1, 2019?<br>→ *If Yes, please attach ALL CBC with differentials **lab reports*** |
| ☐ | ☐ | Was a **Bone Marrow Transplant** done between October 1, 2018 and October 1, 2019?<br>→ *If Yes, please provide date of BMT:* _____/_____/_____ Month Day Year |
| ☐ | ☐ | Is the patient **pregnant**?<br>→ *If Yes, please provide expected/actual date of delivery:* _____/_____/_____ Month Day Year |
| ☐ | ☐ | Did the patient have their **spleen removed** between October 1, 2018 and October 1, 2019**?**<br>→ *If Yes, please provide date done:* _____/_____/_____ Month Day Year |
| ☐ | ☐ | Was the patient **hospitalized** between October 1, 2018 and October 1, 2019?<br>→ *If Yes, please submit admission/discharge notes that summarize the details of the hospitalization.* |
| ☐ | ☐ | Did the patient **die** between October 1, 2018 and October 1, 2019?<br>→ *If Yes, please send date of death, cause of death, and a copy of the autopsy report or death certificate.* |

| | |
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# YEARLY UPDATE FORM

**Period: October 1, 2018 to October 1, 2019**

**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:*** | ***Oct / 1 / 2018*** ***Month Day Year*** | ***Oct / 1 / 2019*** ***Month Day Year*** | ***0.55*** | ***ml*** | ***QD*** | ***Neutrophil Recovery*** |
| **G-CSF (Neupogen® or Biosimilar):** | _____/_____/_____ Month Day Year | _____/_____/_____ Month Day Year | | | | |
| *Specify type if Biosimilar:* _____ | _____/_____/_____ 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

| | | |
|---|---|---|
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# YEARLY UPDATE FORM

**Period: October 1, 2018 to October 1, 2019**

**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**