Severe Chronic Neutropenia International Registry	**Patient ID Number**: ___/___ ___/___ ___/___ ___ ___ ___ **Patient Initials**: ___ ___ ___

From: ____/______/____
(DD/MON/YY)

To: ____/______/____
(DD/MON/YY)

YEARLY SUMMARY PATIENT INFORMATION

For RRC use only — Form No: _______

Status: __________

Person completing form: ____
(please print)

REFERRING PHYSICIAN

Name: ____

Institution Name: ____

Institution Address: ____

City/Village: ____

State/Province: ____

Zip/Postal Code: ____

Telephone Number: (   ) (   ) ______________ Fax Number: (   ) (   ) ______________

E-Mail Address ____

PATIENT DETAILS

Complete only if change from last information provided.

Patient: ____

Address: ____

City/Village: ____

State/Province: ____

Zip/Postal Code: ____________________ Country: ____________________

Telephone Number: (   )(   ) ______________ E-Mail: ____________________

For RRC use only

Sent: ____________________	Data Review: ____________________
Received: ____________________	Entered: ____________________
Clinical Review: ____________________	Verified: ____________________

Severe Chronic Neutropenia International Registry	**Patient ID Number**: ___/___ ___/___ ___/___ ___ ___ ___ **Patient Initials**: ___ ___ ___

From: ____/______/____ To____/______/____
(DD/MON/YY) (DD/MON/YY)

PATIENT INFORMATION YEARLY SUMMARY

EXAMINATIONS AND SIGNIFICANT NON-INFECTIOUS CLINICAL EVENTS

No	Yes	
☐	☐	**Bone marrow** evaluation done Date(s): ___________________________ (Please attach all reports)
☐	☐	AML/MDS
☐	☐	**Cytogenetics** evaluation done Date(s): ___________________________ (Please attach all reports)
☐	☐	Cytogenetic abnormality detected
☐	☐	**Bone density** evaluation done Date(s): ___________________________ (Please attach all reports)
☐	☐	Abnormal bone density/osteopenia/osteoporosis
☐	☐	**In vitro** research testing done
☐	☐	Glomerulonephritis
☐	☐	Vasculitis
☐	☐	Arthritis
☐	☐	Splenectomy Date: _______________
☐	☐	Other significant non-infectious events including all hospitalizations (specify): ____ ____ ____
☐	☐	Height assessed: __________ cm or __________ in Date: __________
☐	☐	Weight assessed: __________ kg or ___________ lbs Date: ______________
☐	☐	CBCs done during this time period (Please attach all reports)
☐	☐	Patient pregnant during this time period or currently pregnant
☐	☐	Patient died during this time period Date: _______________ Cause of death: ____

Severe Chronic Neutropenia International Registry	Patient ID Number: ___/___ ___/___ ___/___ ___ ___ ___ Patient Initials: ___ ___ ___

From: ____/______/____ To____/______/____
(DD/MON/YY) (DD/MON/YY)

PATIENT INFORMATION YEARLY SUMMARY

SIGNIFICANT INFECTIOUS EPISODES

Frequency	None √	1-3 per Year √	4-12 per Year √	> 12 per Year, Continuous √	Unknown √
Mouth ulcers	☐	☐	☐	☐	☐
Skin abscesses	☐	☐	☐	☐	☐

Other significant infections (specify):	IV Antibiotics administered (√ if yes)
________________________________	☐
________________________________	☐
________________________________	☐
________________________________	☐

TREATMENT

No	Yes	
☐	☐	Cytokine (growth factor, e.g., G-CSF) treatment during this time period

Type: ☐ G-CSF ☐ GM-CSF ☐ EPO ☐ Other (specify): ______________________
Current cytokine dose:
________ Units*: ________ Freq**: _______ Brand Name: ______________________
________ Units*: ________ Freq**: _______ Brand Name: ______________________

Indicate typical dose range for this year: ______________________________

No	Yes	
☐	☐	Was cytokine discontinued during this time period:

If yes, date discontinued: _____________
Reason: ☐ Ineffective ☐ Pt. chose to withdraw
☐ Toxicity ☐ Neutrophil recovery
☐ Non-compliant
☐ Other, specify ____

*Units	**Freq
mcg	qd
mcg/kg	bid
ml	qod
	qtd
	qwk

No	Yes	
☐	☐	Other treatments for neutropenia: ☐ Steroids ☐ Gammaglobulin ☐ Other, specify ____________
☐	☐	Bone marrow transplant

BONE MARROW CELL BANK

No	Yes	
☐	☐	Next bone marrow exam planned? If yes: _______/_______ (mo / yr)

Please plan to send bone marrow sample to cell bank every year.

Severe Chronic Neutropenia International Registry	Patient Id Number ____/____/____/__________ Patient Initials ____ ____ ____

YEARLY SUMMARY REPORT
GLYCOGENOSIS TYPE IB

BIRTH TYPE

☐ Single ☐ Identical twin ☐ Fraternal twin, gender: ☐ same ☐ different

☐ Other multiple: ____

GSD-IB RELATED SYMPTOMS

Unknown	☐ No	☐ Yes
Asymptomatic	☐ No	☐ Yes
Low birth weight	☐ No	☐ Yes
Skeletal abnormalities	☐ No	☐ Yes: ______________________________
Muscular hypotonia	☐ No	☐ Yes
Xanthomas or lipomas	☐ No	☐ Yes
Malignant adenoma	☐ No	☐ Yes
Epilepsy	☐ No	☐ Yes
Dental problems	☐ No	☐ Yes: ______________________________
Growth retardation	☐ No	☐ Yes
Failure to thrive	☐ No	☐ Yes
Hematological abnormalities	☐ No	☐ Yes: ______________________________
Malignancy	☐ No	☐ Yes: ______________________________
Other dysfunction	☐ No	☐ Yes: ______________________________
Supplementary feeding	☐ No	☐ Yes: ☐ tube feeding ☐ percutaneous endoscopic gastrostomy (PEG)

SERUM PARAMETERS

C-Gluc/GD/e	_____ mmol/L	Date [DD/MON/YY]: ____________
Lactate	_____ mmol/L	Date [DD/MON/YY]: ____________
Alanine	_____ μmol/L	Date [DD/MON/YY]: ____________
Creatinine	_____ μmol/L	Date [DD/MON/YY]: ____________
Urea	_____ mmol/L	Date [DD/MON/YY]: ____________
Cholesterol	_____ mmol/L	Date [DD/MON/YY]: ____________
Triglycerides	_____ mmol/L	Date [DD/MON/YY]: ____________

RADIOLOGY RESULTS (please attach reports)

Pancreas	☐ CT ☐ U/S	☐ Normal	☐ Abnormal: ______________________
Liver	☐ CT ☐ U/S	☐ Normal	☐ Abnormal: ______________________
Ribs		☐ Normal	☐ Abnormal: ______________________
Long bones		☐ Normal	☐ Abnormal: ______________________
Dental radiology		☐ Normal	☐ Abnormal: ______________________

PSYCHOLOGY

Overall functioning	☐ Normal	☐ Concerns: ______________________
Concentration power	☐ Normal	☐ Concerns: ______________________
Mental development	☐ Normal	☐ Concerns: ______________________
General behaviour	☐ Normal	☐ Concerns: ______________________
Social competence	☐ Normal	☐ Concerns: ______________________
Other issues	______________________	

GENOTYPE (if not reported previously)

Genotype ☐ Not tested ☐ Tested

☐ Mutation of G6P-Transporter Gene: ______________________