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: _____

☐ ☐ 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: mcg, mcg/kg, ml

**Freq: qd, bid, qod, qtd, qwk

☐ ☐ 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
SHWACHMAN-DIAMOND-SYNDROME

SDS RELATED SYMPTOMS

Unknown	☐ No ☐ Yes	
Asymptomatic	☐ No ☐ Yes	
Abnormal liver function	☐ No ☐ Yes	
Pancreatic insufficiency	☐ 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:	_____

PANCREATIC FUNCTION

Taking pancreatic enzymes	☐ No	☐ Yes		
Pancreatic stimulation	☐ Normal	☐ Abnormal		
Diabetes mellitus	☐ No	☐ Yes		
Faecal fat balance	_____ % of intake		Date:	_____ (DD/MON/YY)
Faecal elastase	_____ µg/g		Date:	_____ (DD/MON/YY)
Serum trypsinogen	_____ µg/L		Date:	_____ (DD/MON/YY)
Serum pancreatic isoamylase	_____ µg/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	_____		

SBDS GENOTYPE (if not reported previously)

Genotype	☐ Not tested	☐ Tested :	
Allele 1:	☐ 258+2T>C	☐ 183TA>CT	☐ [258+2T>C +183TA>CT]
	☐ Other (please specify) : _____		
Allele 2:	☐ 258+2T>C	☐ 183TA>CT	☐ [258+2T>C +183TA>CT]
	☐ Other (please specify) : _____		
Method :	☐ Panel (number of mutations in panel): _____		☐ Sequencing