

# VALIDATION OF THE DIAGNOSTIC CRITERIA OF TYPE 1 VON WILLEBRAND

DISEASE:

AN INTERNATIONAL MULTICENTER STUDY

## DATA COLLECTION FORMS



A study fostered by the SSC Subcommittee on von Willebrand factor  
of the International Society on Thrombosis and Hemostasis

### Type 3 family

CENTER CODE\*

FAMILY CODE

\* Center code as assigned by the coordinating center

For any question or need of help, please feel free to contact us at:

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## CONTENT

FAMILY DATA AND PEDIGREE (WHITE)

AFFECTED MEMBER (GREEN)

FIRST OBLIGATORY CARRIER (YELLOW)

SECOND OBLIGATORY CARRIER (YELLOW)

FIRST CONTROL SUBJECT (BLUE)

SECOND CONTROL SUBJECT (BLUE)

INSTRUCTIONS ON LAST PAGE

## Family data

Center code \_\_\_\_\_ as assigned by the coordinating center-

Family code <sup>1</sup>

Total number of family members <sup>2</sup>

Number of studied family members <sup>3</sup>

Number of symptomatic family members <sup>4</sup>

Multimeric pattern of plasma vWf <sup>5</sup>

normal

abnormal

Please specify .....

.....

.....

Inheritance <sup>6</sup>

autosomal dominant

recessive

uncertain

Mutation identified <sup>7</sup>

Yes

Please specify .....

.....

.....

No

Additional hemostatic defects <sup>8</sup>

Yes

Please specify .....

.....

.....

No

Not investigated

## Affected member

Family code <sup>9</sup>

Subject ID code <sup>10</sup>

Date of birth <sup>11</sup>

/ /

Sex

Male

Female

ABO blood group <sup>12</sup>

O group

non O group

Laboratory measurement <sup>13</sup>	Unit	Reference Range	Min.	Max.	Median
FVIII:C		-			
vWf:Ag		-			
vWf:RiCof		-			
Bleeding Time					
Platelet count		-			

Blood group adjusted reference range? <sup>14</sup>

Yes No

Diagnosis at age

**Bleeding symptoms****Before diagnosis<sup>15</sup>****Epistaxis**

No

Trivial<sup>16</sup>N.E.<sup>17</sup> Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

less than 1  
1 - 5  
6 - 12  
more than 12

Duration of average single episode (min.)

one minute or less  
one to ten minutes  
more than ten minutes

Spontaneous ?

Yes

No

Both nostrils ?

Yes

No

After drug ingestion  
(e.g. aspirin)

Yes

No

Seasonal correlation

Yes

No

Cessation

spontaneous  
after short compression  
by medical intervention

Age of maximum severity

less than 14 years  
14 to 45 years  
more than 45 years

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Notes

.....  
.....

**Epistaxis**

**MOST SEVERE PRESENTATION**

Duration of episode (min.)	one minute or less one to ten minutes more than ten minutes	
Spontaneous ?	Yes	No
Both nostrils ?	Yes	No
After drug ingestion (e.g. aspirin)	Yes	No
Cessation	spontaneous after short compression by medical intervention	
Required medical attention?	Yes	No

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Notes

.....  
.....

**Bleeding symptoms****After diagnosis****Epistaxis**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

less than 1

1 - 5

6 - 12

more than 12

Duration of average single episode (min.)

one minute or less

one to ten minutes

more than ten minutes

Spontaneous ?

Yes

No

Both nostrils ?

Yes

No

After drug ingestion

Yes

No

(e.g. aspirin)

Seasonal correlation

Yes

No

Cessation

spontaneous

after short compression

by medical intervention

Age of maximum severity

less than 14 years

14 to 45 years

more than 45 years

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytic therapy

Notes

.....

.....

## Epistaxis

### MOST SEVERE PRESENTATION

Duration of episode (min.)	one minute or less one to ten minutes more than ten minutes
----------------------------	---

Spontaneous ?	Yes	No
---------------	-----	----

Both nostrils ?	Yes	No
-----------------	-----	----

After drug ingestion (e.g. aspirin)	Yes	No
--	-----	----

Cessation	spontaneous after short compression by medical intervention
-----------	---

Required medical attention?	Yes	No
-----------------------------	-----	----

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytic therapy

Notes .....

.....



**Bleeding symptoms****Before diagnosis****Cutaneous symptoms**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

Type

Petechiae

Bruises

Hematomas

Location of bruises (if any)

Exposed sites

Unexposed sites

Minimal or no trauma

Yes

No

Ever required medical attention ?

Yes

No

if yes, please specify

.....

.....

Consultation only

Yes

No

Notes

.....

.....

**MOST SEVERE PRESENTATION**

Type

Petechiae

Bruises

Hematomas

Location of bruises (if any)

Exposed sites

Unexposed sites

Minimal or no trauma

Yes

No

Required medical attention?

Yes

No

if yes, please specify

.....

.....

Consultation only

Yes

No

Notes

.....

.....

**Bleeding symptoms****After diagnosis****Cutaneous symptoms**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

Type

Petechiae

Bruises

Hematomas

Location of bruises (if any)

Exposed sites

Unexposed sites

Minimal or no trauma

Yes

No

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Type

Petechiae

Bruises

Hematomas

Location of bruises (if any)

Exposed sites

Unexposed sites

Minimal or no trauma

Yes

No

Required medical attention?

Yes

No

if yes, please specify

Consultation only

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....  
.....

<b>Bleeding symptoms</b>	<b>Before diagnosis</b>
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<b>Bleeding from minor wounds</b>	No	Trivial	N.E.	Yes
-----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>	
Number episodes/year	<div style="display: flex; justify-content: space-between;"> <span>less than 1</span> <span>1 - 5</span> <span>6 - 12</span> <span>more than 12</span> </div>
Duration of average single episode (min.)	<div style="display: flex; justify-content: space-between;"> <span>one to ten minutes</span> <span>more than ten minutes</span> </div>
Ever required medical attention ?	<div style="display: flex; justify-content: space-around;"> <span>Yes</span> <span>No</span> </div>
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Notes	<div style="border-top: 1px dashed black; border-bottom: 1px dashed black; height: 20px;"></div>

<b>MOST SEVERE PRESENTATION</b>	
Duration of episode (min.)	<div style="display: flex; justify-content: space-between;"> <span>one to ten minutes</span> <span>more than ten minutes</span> </div>
Required medical attention?	<div style="display: flex; justify-content: space-around;"> <span>Yes</span> <span>No</span> </div>
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Notes	<div style="border-top: 1px dashed black; border-bottom: 1px dashed black; height: 20px;"></div>

<b>Bleeding symptoms</b>	<b>After diagnosis</b>
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<b>Bleeding from minor wounds</b>	No	Trivial	N.E.	Yes
-----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>	
Number episodes/year	<div style="display: flex; justify-content: space-between;"> <span>less than 1</span> </div> <div style="display: flex; justify-content: space-between;"> <span>1 - 5</span> </div> <div style="display: flex; justify-content: space-between;"> <span>6 - 12</span> </div> <div style="display: flex; justify-content: space-between;"> <span>more than 12</span> </div>
Duration of average single episode (min.)	<div style="display: flex; justify-content: space-between;"> <span>one to ten minutes</span> </div> <div style="display: flex; justify-content: space-between;"> <span>more than ten minutes</span> </div>
Ever required medical attention ?	<div style="display: flex; justify-content: space-around;"> <span>Yes</span> <span>No</span> </div>
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Desmopressin	
Replacement therapy	
Notes	..... .....

<b>MOST SEVERE PRESENTATION</b>	
Duration of average single episode (min.)	<div style="display: flex; justify-content: space-between;"> <span>one to ten minutes</span> </div> <div style="display: flex; justify-content: space-between;"> <span>more than ten minutes</span> </div>
Required medical attention?	<div style="display: flex; justify-content: space-around;"> <span>Yes</span> <span>No</span> </div>
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Desmopressin	
Replacement therapy	
Notes	..... .....

**Bleeding symptoms****Before diagnosis****Oral cavity bleeding**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Type of bleeding

Tooth eruption

Gums, spontaneous

Gums, after brushing

Bites to lip &amp; tongue

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Type of bleeding

Tooth eruption

Gums, spontaneous

Gums, after brushing

Bites to lip &amp; tongue

Required medical attention?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Notes

.....  
.....

**Bleeding symptoms****After diagnosis****Oral cavity bleeding**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Type of bleeding

Tooth eruption

Gums, spontaneous

Gums, after brushing

Bites to lip &amp; tongue

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytics

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Type of bleeding

Tooth eruption

Gums, spontaneous

Gums, after brushing

Bites to lip &amp; tongue

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytics

Notes

.....  
.....

**Bleeding symptoms****Before diagnosis**

<b>Gastrointestinal bleeding</b>	No	Trivial	N.E.	Yes
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If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number of episodes

Type of bleeding

Hematemesis  
Melena  
Hematochezia

Presence of associated  
GI disease

Yes No

Specify:

Ulcer  
Portal hypertension  
Angiodysplasia

Ever required medical attention ?

Yes No

if yes, please specify

Consultation only  
Surgical hemostasis  
Blood transfusion

Notes

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.....

**MOST SEVERE PRESENTATION**

Type of bleeding

Hematemesis  
Melena  
Hematochezia

Presence of associated  
GI disease

Yes No

Specify:

Ulcer  
Portal hypertension  
Angiodysplasia

Required medical attention?

Yes No

if yes, please specify

Consultation only  
Surgical hemostasis  
Blood transfusion

Notes

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.....

**Bleeding symptoms****After diagnosis**

<b>Gastrointestinal bleeding</b>	No	Trivial	N.E.	Yes
----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number of episodes

Type of bleeding

Hematemesis  
Melena  
Hematochezia

Presence of associated  
GI disease

Yes No

Specify:

Ulcer  
Portal hypertension  
Angiodysplasia

Ever required medical attention ?

Yes No

if yes, please specify

Surgical hemostasis  
Blood transfusion  
Desmopressin  
Replacement therapy  
Notes

.....  
.....

**MOST SEVERE PRESENTATION**

Type of bleeding

Hematemesis  
Melena  
Hematochezia

Presence of associated  
GI disease

Yes No

Specify:

Ulcer  
Portal hypertension  
Angiodysplasia

Required medical attention?

Yes No

if yes, please specify

Surgical hemostasis  
Blood transfusion  
Desmopressin  
Replacement therapy  
Notes

.....  
.....



**Bleeding symptoms**

**Before diagnosis**

**Tooth extraction**

Total number of tooth extractions

Number of tooth extractions followed by bleeding

Please fill in a separate box for each extraction, if any; photocopy if necessary.

<b>Bleeding after first extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion			
Notes	..... .....			

<b>Bleeding after second extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion			
Notes	..... .....			

<b>Bleeding after third extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous	
			Permanent	
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None			
	Resuturing			
	Packing			
	Blood transfusion			
Notes	..... .....			

<b>MOST SEVERE BLEEDING AFTER EXTRACTION</b>				
Age at extraction	Type of extraction		Deciduous	
			Permanent	
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None			
	Resuturing			
	Packing			
	Blood transfusion			
Notes	..... .....			

**Bleeding symptoms**

**After diagnosis**

**Tooth extraction**

Total number of tooth extractions

Number of tooth extractions followed by bleeding

Please fill in a separate box for each extraction, if any; photocopy if necessary.

<b>Bleeding after first extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction		Type of extraction		Deciduous Permanent Molar
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding		None Resuturing Packing Blood transfusion	Desmopressin Replacement therapy Antifibrinolytics	
Notes	.....			

<b>Bleeding after second extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction		Type of extraction		Deciduous Permanent Molar
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding		None Resuturing Packing Blood transfusion	Desmopressin Replacement therapy Antifibrinolytics	
Notes	.....			

<b>Bleeding after third extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous	
			Permanent	
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion Desmopressin Replacement therapy Antifibrinolytics			
Notes	..... .....			

<b>MOST SEVERE BLEEDING AFTER EXTRACTION</b>				
Age at extraction	Type of extraction		Deciduous	
			Permanent	
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion Desmopressin Replacement therapy Antifibrinolytics			
Notes	..... .....			

<b>Bleeding symptoms</b>	<b>Before diagnosis</b>
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<b>Surgery</b>
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Total number of surgeries \_\_\_\_\_                      Number of surgeries followed by bleeding \_\_\_\_\_

Please fill in a separate box for each surgery, if any; photocopy if necessary.

<b>Bleeding after first surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>Bleeding after second surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Bleeding after surgery?		Yes	No	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>Bleeding after third surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>MOST SEVERE BLEEDING AFTER SURGERY</b>				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

**Bleeding symptoms**

**After diagnosis**

**Surgery**

Total number of surgeries

Number of surgeries followed by bleeding

Please fill in a separate box for each surgery, if any; photocopy if necessary.

<b>Bleeding after first surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Prophylaxis before surgery		None		
		Desmopressin		
		Replacement therapy		
Actions taken to control bleeding		None	Desmopressin	
		Resuturing/surgical	Replacement therapy	
		Blood transfusion	Antifibrinolytics	
Notes		.....		
		.....		

<b>Bleeding after second surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Prophylaxis before surgery		None		
		Desmopressin		
		Replacement therapy		
Actions taken to control bleeding		None	Desmopressin	
		Resuturing/surgical	Replacement therapy	
		Blood transfusion	Antifibrinolytics	
Notes		.....		
		.....		

<b>Bleeding after third surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Prophylaxis before surgery		None		
		Desmopressin		
		Replacement therapy		
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Desmopressin		
		Replacement therapy		
		Antifibrinolytics		
Notes		.....		
		.....		

<b>MOST SEVERE BLEEDING AFTER SURGERY</b>				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Prophylaxis before surgery		None		
		Desmopressin		
		Replacement therapy		
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Desmopressin		
		Replacement therapy		
		Antifibrinolytics		
Notes		.....		
		.....		



**Bleeding symptoms****Before diagnosis****Menorrhagia**

Duration of average menstruation (days)

Duration of heavy days

Ever suffered from menorrhagia ?

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Age of maximum severity

14 - 25

26 - 35

more than 36

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Pill use

Dilatation &amp; curettage

Hysterectomy

Blood transfusion

Iron therapy

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Age of bleeding

14 - 25

26 - 35

more than 36

Required medical attention ?

Yes

No

if yes, please specify

Consultation only

Pill use

Dilatation &amp; curettage

Hysterectomy

Blood transfusion

Iron therapy

Notes

.....  
.....

<b>Bleeding symptoms</b>	<b>After diagnosis</b>
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<b>Menorrhagia</b>
--------------------

Duration of average menstruation (days)		Duration of heavy days	
Ever suffered from menorrhagia ?	No	Trivial	N.E.    Yes

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>	
Age of maximum severity	<div style="text-align: center;">14 - 25</div> <div style="text-align: center;">26 - 35</div> <div style="text-align: center;">more than 36</div>
Ever required medical attention ?	<div style="display: flex; justify-content: space-around;"> <span>Yes</span> <span>No</span> </div>
if yes, please specify	
Consultation only	
Pill use	
Dilatation & curettage	
Hysterectomy	
Blood transfusion	
Desmopressin	
Replacement therapy	
Iron therapy	
Antifibrinolytics	
Notes	<div style="text-align: center;">.....</div> <div style="text-align: center;">.....</div>

<b>MOST SEVERE PRESENTATION</b>	
Age of bleeding	<div style="text-align: center;">14 - 25</div> <div style="text-align: center;">26 - 35</div> <div style="text-align: center;">more than 36</div>
Ever required medical attention ?	<div style="display: flex; justify-content: space-around;"> <span>Yes</span> <span>No</span> </div>
if yes, please specify	
Consultation only	
Pill use	
Dilatation & curettage	
Hysterectomy	
Blood transfusion	
Desmopressin	
Replacement therapy	
Iron therapy	
Antifibrinolytics	
Notes	<div style="text-align: center;">.....</div> <div style="text-align: center;">.....</div>

**Bleeding symptoms****Before diagnosis****Post-partum hemorrhage**

Total number of deliveries

Number of deliveries followed by bleeding

Please fill in a separate box for each delivery, if any; photocopy if necessary.

<b>Bleeding after first delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes	.....			
	.....			

<b>Bleeding after second delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes	.....			
	.....			

<b>Bleeding after third delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes	.....			
	.....			

<b>MOST SEVERE BLEEDING AFTER DELIVERY</b>		
Required medical attention?	Yes	No
if yes, please specify		
Dilatation & curettage		
Hysterectomy		
Blood transfusion		
Iron therapy		
Other		
Notes	.....	
	.....	

**Bleeding symptoms****After diagnosis****Post-partum hemorrhage**

Total number of deliveries

Number of deliveries followed by bleeding

Please fill in a separate box for each delivery, if any; photocopy if necessary.

<b>Bleeding after first delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Desmopressin				
Replacement therapy				
Other				
Notes	.....			
	.....			

<b>Bleeding after second delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Desmopressin				
Replacement therapy				
Other				
Notes	.....			
	.....			

<b>Bleeding after third delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Desmopressin				
Replacement therapy				
Other				
Notes	.....			
	.....			

<b>MOST SEVERE BLEEDING AFTER DELIVERY</b>		
Required medical attention?	Yes	No
if yes, please specify		
Dilatation & curettage		
Hysterectomy		
Blood transfusion		
Iron therapy		
Other		
Notes	.....	
	.....	

<b>Bleeding symptoms</b>	<b>Before diagnosis</b>
--------------------------	-------------------------

<b>Muscle hematomas or hemarthrosis</b>	No	Trivial	N.E.	Yes
---	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Please specify type & location		
Spontaneous ?	Yes	No
Ever required medical attention ?	Yes	No
if yes, please specify		
Blood transfusion		
Notes		

<b>MOST SEVERE PRESENTATION</b>		
Please specify type & location		
Spontaneous ?	Yes	No
Required medical attention ?	Yes	No
if yes, please specify		
Blood transfusion		
Notes		

**Bleeding symptoms****After diagnosis****Muscle hematomas or  
hemarthrosis**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Please specify type &amp; location

.....

.....

Spontaneous ?

Yes

No

Ever required medical attention ?

Yes

No

if yes, please specify

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....

.....

**MOST SEVERE PRESENTATION**

Please specify type &amp; location

.....

.....

Spontaneous ?

Yes

No

Required medical attention ?

Yes

No

if yes, please specify

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....

.....



<b>Bleeding symptoms</b>	<b>Before diagnosis</b>
--------------------------	-------------------------

<b>Other bleedings</b>	No	Trivial	N.E.	Yes
------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Please specify type of bleeding	..... .....	
Ever required medical attention?	Yes	No
if yes, please specify:		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Please specify type of bleeding	..... .....	
Ever required medical attention ?	Yes	No
if yes, please specify:		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Notes	..... .....	

<b>MOST SEVERE PRESENTATION</b>		
Please specify type of bleeding	..... .....	
Required medical attention ?	Yes	No
if yes, please specify:		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Please specify type of bleeding	..... .....	
Required medical attention ?	Yes	No
if yes, please specify		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Notes	..... .....	

**Bleeding symptoms****After diagnosis**

<b>Other bleedings</b>	No	Trivial	N.E.	Yes
------------------------	----	---------	------	-----

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Please specify type of bleeding .....

Ever required medical attention ?      Yes                                      No

specify if yes, please

- Blood transfusion
- Desmopressin
- Replacement therapy
- Iron therapy
- Antifibrinolytics
- Other

Please specify type of bleeding .....

Ever required medical attention ?      Yes                                      No

specify if yes, please

- Blood transfusion
- Desmopressin
- Replacement therapy
- Iron therapy
- Antifibrinolytics
- Other

Notes .....

**MOST SEVERE PRESENTATION**

Please specify .....

Required medical attention?      Yes                                      No

if yes, please specify

- Blood transfusion
- Desmopressin
- Replacement therapy
- Iron therapy
- Antifibrinolytics
- Other

Please specify .....

Required medical attention ?      Yes                                      No

specify if yes, please

- Blood transfusion
- Desmopressin
- Replacement therapy
- Iron therapy
- Antifibrinolytics
- Other

Notes .....

## First obligatory carrier

Family code <sup>9</sup>

Subject ID code <sup>10</sup>

Date of birth <sup>11</sup>

/ /

Sex

Male

Female

ABO blood group <sup>12</sup>

O group

non O group

Laboratory measurement <sup>13</sup>	Unit	Reference Range	Min.	Max.	Median
FVIII:C		-			
vWf:Ag		-			
vWf:RiCof		-			
Bleeding Time		<			
Platelet count		-			

Blood group adjusted reference range? <sup>14</sup>

Yes No

Diagnosis at age

**Bleeding symptoms****Before diagnosis<sup>15</sup>****Epistaxis**

No

Trivial <sup>16</sup>N.E. <sup>17</sup> Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

less than 1  
1 - 5  
6 - 12  
more than 12

Duration of average single episode (min.)

one minute or less  
one to ten minutes  
more than ten minutes

Spontaneous ?

Yes

No

Both nostrils ?

Yes

No

After drug ingestion  
(e.g. aspirin)

Yes

No

Seasonal correlation

Yes

No

Cessation

spontaneous  
after short compression  
by medical intervention

Age of maximum severity

less than 14 years  
14 to 45 years  
more than 45 years

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Notes

.....  
.....

**Epistaxis**

**MOST SEVERE PRESENTATION**

Duration of episode (min.)	one minute or less one to ten minutes more than ten minutes	
Spontaneous ?	Yes	No
Both nostrils ?	Yes	No
After drug ingestion (e.g. aspirin)	Yes	No
Cessation	spontaneous after short compression by medical intervention	
Required medical attention?	Yes	No

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Notes

.....  
.....

**Bleeding symptoms****After diagnosis****Epistaxis**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

less than 1

1 - 5

6 - 12

more than 12

Duration of average single episode (min.)

one minute or less

one to ten minutes

more than ten minutes

Spontaneous ?

Yes

No

Both nostrils ?

Yes

No

After drug ingestion

Yes

No

(e.g. aspirin)

Seasonal correlation

Yes

No

Cessation

spontaneous

after short compression

by medical intervention

Age of maximum severity

less than 14 years

14 to 45 years

more than 45 years

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytic therapy

Notes

.....

.....

# Epistaxis

## MOST SEVERE PRESENTATION

Duration of episode (min.)

one minute or less  
one to ten minutes  
more than ten minutes

Spontaneous ?

Yes

No

Both nostrils ?

Yes

No

After drug ingestion  
(e.g. aspirin)

Yes

No

Cessation

spontaneous  
after short compression  
by medical intervention

Required medical attention?

Yes

No

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytic therapy

Notes

.....  
.....

**Bleeding symptoms****Before diagnosis****Cutaneous symptoms**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

Type

Petechiae

Bruises

Hematomas

Location of bruises (if any)

Exposed sites

Unexposed sites

Minimal or no trauma

Yes

No

Ever required medical attention ?

Yes

No

if yes, please specify

.....

.....

Consultation only

Yes

No

Notes

.....

.....

**MOST SEVERE PRESENTATION**

Type

Petechiae

Bruises

Hematomas

Location of bruises (if any)

Exposed sites

Unexposed sites

Minimal or no trauma

Yes

No

Required medical attention?

Yes

No

if yes, please specify

.....

.....

Consultation only

Yes

No

Notes

.....

.....



**Bleeding symptoms****After diagnosis****Cutaneous symptoms**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

Type

Petechiae

Bruises

Hematomas

Location of bruises (if any)

Exposed sites

Unexposed sites

Minimal or no trauma

Yes

No

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Type

Petechiae

Bruises

Hematomas

Location of bruises (if any)

Exposed sites

Unexposed sites

Minimal or no trauma

Yes

No

Required medical attention?

Yes

No

if yes, please specify

Consultation only

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....  
.....

<b>Bleeding symptoms</b>	<b>Before diagnosis</b>
--------------------------	-------------------------

<b>Bleeding from minor wounds</b>	No	Trivial	N.E.	Yes
-----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>	
Number episodes/year	<div style="display: flex; justify-content: space-between;"> <span>less than 1</span> <span>1 - 5</span> <span>6 - 12</span> <span>more than 12</span> </div>
Duration of average single episode (min.)	<div style="display: flex; justify-content: space-between;"> <span>one to ten minutes</span> <span>more than ten minutes</span> </div>
Ever required medical attention ?	<div style="display: flex; justify-content: space-around;"> <span>Yes</span> <span>No</span> </div>
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Notes	..... .....

<b>MOST SEVERE PRESENTATION</b>	
Duration of episode (min.)	<div style="display: flex; justify-content: space-between;"> <span>one to ten minutes</span> <span>more than ten minutes</span> </div>
Required medical attention?	<div style="display: flex; justify-content: space-around;"> <span>Yes</span> <span>No</span> </div>
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Notes	..... .....

**Bleeding symptoms****After diagnosis****Bleeding from minor wounds**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

less than 1

1 - 5

6 - 12

more than 12

Duration of average single episode (min.)

one to ten minutes

more than ten minutes

Ever required medical attention ?

Yes

No

if yes, please specify

Surgical hemostasis

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Duration of average single episode (min.)

one to ten minutes

more than ten minutes

Required medical attention?

Yes

No

if yes, please specify

Surgical hemostasis

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....  
.....

**Bleeding symptoms****Before diagnosis****Oral cavity bleeding**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Type of bleeding

Tooth eruption

Gums, spontaneous

Gums, after brushing

Bites to lip &amp; tongue

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Type of bleeding

Tooth eruption

Gums, spontaneous

Gums, after brushing

Bites to lip &amp; tongue

Required medical attention?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Notes

.....  
.....

**Bleeding symptoms****After diagnosis****Oral cavity bleeding**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Type of bleeding

Tooth eruption

Gums, spontaneous

Gums, after brushing

Bites to lip &amp; tongue

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytics

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Type of bleeding

Tooth eruption

Gums, spontaneous

Gums, after brushing

Bites to lip &amp; tongue

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytics

Notes

.....  
.....

**Bleeding symptoms****Before diagnosis**

<b>Gastrointestinal bleeding</b>	No	Trivial	N.E.	Yes
----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number of episodes

Type of bleeding

Hematemesis  
Melena  
Hematochezia

Presence of associated  
GI disease

Yes No

Specify:

Ulcer  
Portal hypertension  
Angiodysplasia

Ever required medical attention ?

Yes No

if yes, please specify

Consultation only  
Surgical hemostasis  
Blood transfusion

Notes

.....  
.....

**MOST SEVERE PRESENTATION**

Type of bleeding

Hematemesis  
Melena  
Hematochezia

Presence of associated  
GI disease

Yes No

Specify:

Ulcer  
Portal hypertension  
Angiodysplasia

Required medical attention?

Yes No

if yes, please specify

Consultation only  
Surgical hemostasis  
Blood transfusion

Notes

.....  
.....

**Bleeding symptoms****After diagnosis**

<b>Gastrointestinal bleeding</b>	No	Trivial	N.E.	Yes
----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number of episodes

Type of bleeding

Hematemesis  
Melena  
Hematochezia

Presence of associated  
GI disease

Yes No

Specify:

Ulcer  
Portal hypertension  
Angiodysplasia

Ever required medical attention ?

Yes No

if yes, please specify

Surgical hemostasis  
Blood transfusion  
Desmopressin  
Replacement therapy  
Notes

.....  
.....

**MOST SEVERE PRESENTATION**

Type of bleeding

Hematemesis  
Melena  
Hematochezia

Presence of associated  
GI disease

Yes No

Specify:

Ulcer  
Portal hypertension  
Angiodysplasia

Required medical attention?

Yes No

if yes, please specify

Surgical hemostasis  
Blood transfusion  
Desmopressin  
Replacement therapy  
Notes

.....  
.....

**Bleeding symptoms****Before diagnosis****Tooth extraction**

Total number of tooth extractions

Number of tooth extractions followed by bleeding

Please fill in a separate box for each extraction, if any; photocopy if necessary.

<b>Bleeding after first extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion			
Notes	..... .....			

<b>Bleeding after second extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion			
Notes	..... .....			



<b>Bleeding after third extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous	
			Permanent	
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None			
	Resuturing			
	Packing			
	Blood transfusion			
Notes	..... .....			

<b>MOST SEVERE BLEEDING AFTER EXTRACTION</b>				
Age at extraction	Type of extraction		Deciduous	
			Permanent	
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None			
	Resuturing			
	Packing			
	Blood transfusion			
Notes	..... .....			

**Bleeding symptoms**

**After diagnosis**

**Tooth extraction**

Total number of tooth extractions

Number of tooth extractions followed by bleeding

Please fill in a separate box for each extraction, if any; photocopy if necessary.

<b>Bleeding after first extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction		Type of extraction		Deciduous Permanent Molar
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding		None Resuturing Packing Blood transfusion	Desmopressin Replacement therapy Antifibrinolytics	
Notes	.....			

<b>Bleeding after second extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction		Type of extraction		Deciduous Permanent Molar
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding		None Resuturing Packing Blood transfusion	Desmopressin Replacement therapy Antifibrinolytics	
Notes	.....			

<b>Bleeding after third extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous	
			Permanent	
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion Desmopressin Replacement therapy Antifibrinolytics			
Notes	..... .....			

<b>MOST SEVERE BLEEDING AFTER EXTRACTION</b>				
Age at extraction	Type of extraction		Deciduous	
			Permanent	
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion Desmopressin Replacement therapy Antifibrinolytics			
Notes	..... .....			

<b>Bleeding symptoms</b>	<b>Before diagnosis</b>
--------------------------	-------------------------

<b>Surgery</b>
----------------

Total number of surgeries Number of surgeries followed by bleeding

Please fill in a separate box for each surgery, if any; photocopy if necessary.

<b>Bleeding after first surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section Tonsillectomy/Adenoids Pharynx/Nose	Major-abdominal Major-thoracic Major-gynecology Other	
Actions taken to control bleeding		None Resuturing/surgical Blood transfusion Other		
Notes		..... .....		

<b>Bleeding after second surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section Tonsillectomy/Adenoids Pharynx/Nose	Major-abdominal Major-thoracic Major-gynecology Other	
Bleeding after surgery?		Yes	No	
Actions taken to control bleeding		None Resuturing/surgical Blood transfusion Other		
Notes		..... .....		

<b>Bleeding after third surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>MOST SEVERE BLEEDING AFTER SURGERY</b>				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

**Bleeding symptoms**

**After diagnosis**

**Surgery**

Total number of surgeries

Number of surgeries followed by bleeding

Please fill in a separate box for each surgery, if any; photocopy if necessary.

<b>Bleeding after first surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Prophylaxis before surgery		None		
		Desmopressin		
		Replacement therapy		
Actions taken to control bleeding		None	Desmopressin	
		Resuturing/surgical	Replacement therapy	
		Blood transfusion	Antifibrinolytics	
Notes		.....		
		.....		

<b>Bleeding after second surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Prophylaxis before surgery		None		
		Desmopressin		
		Replacement therapy		
Actions taken to control bleeding		None	Desmopressin	
		Resuturing/surgical	Replacement therapy	
		Blood transfusion	Antifibrinolytics	
Notes		.....		
		.....		

<b>Bleeding after third surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Prophylaxis before surgery		None		
		Desmopressin		
		Replacement therapy		
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Desmopressin		
		Replacement therapy		
		Antifibrinolytics		
Notes		.....		
		.....		

<b>MOST SEVERE BLEEDING AFTER SURGERY</b>				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Prophylaxis before surgery		None		
		Desmopressin		
		Replacement therapy		
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Desmopressin		
		Replacement therapy		
		Antifibrinolytics		
Notes		.....		
		.....		

**Bleeding symptoms****Before diagnosis****Menorrhagia**

Duration of average menstruation (days)

Duration of heavy days

Ever suffered from menorrhagia ?

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Age of maximum severity

14 - 25

26 - 35

more than 36

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Pill use

Dilatation &amp; curettage

Hysterectomy

Blood transfusion

Iron therapy

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Age of bleeding

14 - 25

26 - 35

more than 36

Required medical attention ?

Yes

No

if yes, please specify

Consultation only

Pill use

Dilatation &amp; curettage

Hysterectomy

Blood transfusion

Iron therapy

Notes

.....  
.....



<b>Bleeding symptoms</b>	<b>After diagnosis</b>
--------------------------	------------------------

<b>Menorrhagia</b>
--------------------

Duration of average menstruation (days)	Duration of heavy days
Ever suffered from menorrhagia ?	No      Trivial      N.E.      Yes

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>	
Age of maximum severity	14 - 25 26 - 35 more than 36
Ever required medical attention ?	Yes                                  No
if yes, please specify	
Consultation only	
Pill use	
Dilatation & curettage	
Hysterectomy	
Blood transfusion	
Desmopressin	
Replacement therapy	
Iron therapy	
Antifibrinolytics	
Notes	..... .....

<b>MOST SEVERE PRESENTATION</b>	
Age of bleeding	14 - 25 26 - 35 more than 36
Ever required medical attention ?	Yes                                  No
if yes, please specify	
Consultation only	
Pill use	
Dilatation & curettage	
Hysterectomy	
Blood transfusion	
Desmopressin	
Replacement therapy	
Iron therapy	
Antifibrinolytics	
Notes	..... .....

**Bleeding symptoms****Before diagnosis****Post-partum hemorrhage**

Total number of deliveries

Number of deliveries  
followed by bleeding

Please fill in a separate box for each delivery, if any; photocopy if necessary.

<b>Bleeding after first delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes		.....		
		.....		

<b>Bleeding after second delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes		.....		
		.....		

<b>Bleeding after third delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes	.....			
	.....			

<b>MOST SEVERE BLEEDING AFTER DELIVERY</b>		
Required medical attention?	Yes	No
if yes, please specify		
Dilatation & curettage		
Hysterectomy		
Blood transfusion		
Iron therapy		
Other		
Notes	.....	
	.....	

**Bleeding symptoms****After diagnosis****Post-partum hemorrhage**

Total number of deliveries

Number of deliveries followed by bleeding

Please fill in a separate box for each delivery, if any; photocopy if necessary.

<b>Bleeding after first delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Desmopressin				
Replacement therapy				
Other				
Notes	.....			
	.....			

<b>Bleeding after second delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Desmopressin				
Replacement therapy				
Other				
Notes	.....			
	.....			

<b>Bleeding after third delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Desmopressin				
Replacement therapy				
Other				
Notes	.....			
	.....			

<b>MOST SEVERE BLEEDING AFTER DELIVERY</b>		
Required medical attention?	Yes	No
if yes, please specify		
Dilatation & curettage		
Hysterectomy		
Blood transfusion		
Iron therapy		
Other		
Notes	.....	
	.....	

<b>Bleeding symptoms</b>	<b>Before diagnosis</b>
--------------------------	-------------------------

<b>Muscle hematomas or hemarthrosis</b>	No	Trivial	N.E.	Yes
---	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Please specify type & location	..... ..... ..... .....	
Spontaneous ?	Yes	No
Ever required medical attention ?	Yes	No
if yes, please specify		
Blood transfusion		
Notes	..... .....	

<b>MOST SEVERE PRESENTATION</b>		
Please specify type & location	..... .....	
Spontaneous ?	Yes	No
Required medical attention ?	Yes	No
if yes, please specify		
Blood transfusion		
Notes	..... .....	

**Bleeding symptoms****After diagnosis****Muscle hematomas or  
hemarthrosis**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Please specify type &amp; location

.....

.....

Spontaneous ?

Yes

No

Ever required medical attention ?

Yes

No

if yes, please specify

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....

.....

**MOST SEVERE PRESENTATION**

Please specify type &amp; location

.....

.....

Spontaneous ?

Yes

No

Required medical attention ?

Yes

No

if yes, please specify

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....

.....

**Bleeding symptoms****Before diagnosis****Other bleedings**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Please specify type of bleeding .....

.....

Ever required medical attention?      Yes                                      No

if yes, please specify:

Blood transfusion

Iron therapy

Antifibrinolytics

Other

Please specify type of bleeding .....

.....

Ever required medical attention ?      Yes                                      No

if yes, please specify:

Blood transfusion

Iron therapy

Antifibrinolytics

Other

Notes .....

.....

**MOST SEVERE PRESENTATION**

Please specify type of bleeding .....

.....

Required medical attention ?      Yes                                      No

if yes, please specify:

Blood transfusion

Iron therapy

Antifibrinolytics

Other

Please specify type of bleeding .....

.....

Required medical attention ?      Yes                                      No

if yes, please specify

Blood transfusion

Iron therapy

Antifibrinolytics

Other

Notes .....

.....



**Bleeding symptoms****After diagnosis**

<b>Other bleedings</b>	No	Trivial	N.E.	Yes
------------------------	----	---------	------	-----

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Please specify type of bleeding .....

Ever required medical attention ?      Yes                                      No

specify if yes, please

- Blood transfusion
- Desmopressin
- Replacement therapy
- Iron therapy
- Antifibrinolytics
- Other

Please specify type of bleeding .....

Ever required medical attention ?      Yes                                      No

specify if yes, please

- Blood transfusion
- Desmopressin
- Replacement therapy
- Iron therapy
- Antifibrinolytics
- Other

Notes .....

**MOST SEVERE PRESENTATION**

Please specify .....

Required medical attention?      Yes                                      No

if yes, please specify

- Blood transfusion
- Desmopressin
- Replacement therapy
- Iron therapy
- Antifibrinolytics
- Other

Please specify .....

Required medical attention ?      Yes                                      No

specify if yes, please

- Blood transfusion
- Desmopressin
- Replacement therapy
- Iron therapy
- Antifibrinolytics
- Other

Notes .....

## Second obligatory carrier

Family code <sup>9</sup>

Subject ID code <sup>10</sup>

Date of birth <sup>11</sup>

/ /

Sex

Male

Female

ABO blood group <sup>12</sup>

O group

non O group

Laboratory measurement <sup>13</sup>	Unit	Reference Range	Min.	Max.	Median
FVIII:C		-			
vWf:Ag		-			
vWf:RiCof		-			
Bleeding Time		<			
Platelet count		-			

Blood group adjusted reference range? <sup>14</sup>

Yes

No

Diagnosis at age

**Bleeding symptoms****Before diagnosis<sup>15</sup>****Epistaxis**

No

Trivial<sup>16</sup>N.E.<sup>17</sup> Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

less than 1  
1 - 5  
6 - 12  
more than 12

Duration of average single episode (min.)

one minute or less  
one to ten minutes  
more than ten minutes

Spontaneous ?

Yes

No

Both nostrils ?

Yes

No

After drug ingestion  
(e.g. aspirin)

Yes

No

Seasonal correlation

Yes

No

Cessation

spontaneous  
after short compression  
by medical intervention

Age of maximum severity

less than 14 years  
14 to 45 years  
more than 45 years

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Notes

.....  
.....

**Epistaxis**

**MOST SEVERE PRESENTATION**

Duration of episode (min.)	one minute or less one to ten minutes more than ten minutes	
Spontaneous ?	Yes	No
Both nostrils ?	Yes	No
After drug ingestion (e.g. aspirin)	Yes	No
Cessation	spontaneous after short compression by medical intervention	
Required medical attention?	Yes	No

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Notes

.....  
.....

**Bleeding symptoms****After diagnosis****Epistaxis**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

less than 1

1 - 5

6 - 12

more than 12

Duration of average single episode (min.)

one minute or less

one to ten minutes

more than ten minutes

Spontaneous ?

Yes

No

Both nostrils ?

Yes

No

After drug ingestion

Yes

No

(e.g. aspirin)

Seasonal correlation

Yes

No

Cessation

spontaneous

after short compression

by medical intervention

Age of maximum severity

less than 14 years

14 to 45 years

more than 45 years

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytic therapy

Notes

.....

.....

**Epistaxis**

MOST SEVERE PRESENTATION		
Duration of episode (min.)	one minute or less one to ten minutes more than ten minutes	
Spontaneous ?	Yes	No
Both nostrils ?	Yes	No
After drug ingestion (e.g. aspirin)	Yes	No
Cessation	spontaneous after short compression by medical intervention	
Required medical attention?	Yes	No
if yes, please specify		
Consultation only		
Cauterization		
Packing		
Blood transfusion		
Desmopressin		
Replacement therapy		
Antifibrinolytic therapy		
Notes	.....	
	.....	

**Bleeding symptoms****Before diagnosis****Cutaneous symptoms**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

Type

Petechiae

Bruises

Hematomas

Location of bruises (if any)

Exposed sites

Unexposed sites

Minimal or no trauma

Yes

No

Ever required medical attention ?

Yes

No

if yes, please specify

.....

.....

Consultation only

Yes

No

Notes

.....

.....

**MOST SEVERE PRESENTATION**

Type

Petechiae

Bruises

Hematomas

Location of bruises (if any)

Exposed sites

Unexposed sites

Minimal or no trauma

Yes

No

Required medical attention?

Yes

No

if yes, please specify

.....

.....

Consultation only

Yes

No

Notes

.....

.....

**Bleeding symptoms****After diagnosis****Cutaneous symptoms**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

Type

Petechiae

Bruises

Hematomas

Location of bruises (if any)

Exposed sites

Unexposed sites

Minimal or no trauma

Yes

No

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Type

Petechiae

Bruises

Hematomas

Location of bruises (if any)

Exposed sites

Unexposed sites

Minimal or no trauma

Yes

No

Required medical attention?

Yes

No

if yes, please specify

Consultation only

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....  
.....



<b>Bleeding symptoms</b>	<b>Before diagnosis</b>
--------------------------	-------------------------

<b>Bleeding from minor wounds</b>	No	Trivial	N.E.	Yes
-----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>	
Number episodes/year	<div style="display: flex; justify-content: space-between;"> <span>less than 1</span> <span>1 - 5</span> <span>6 - 12</span> <span>more than 12</span> </div>
Duration of average single episode (min.)	<div style="display: flex; justify-content: space-between;"> <span>one to ten minutes</span> <span>more than ten minutes</span> </div>
Ever required medical attention ?	<div style="display: flex; justify-content: space-around;"> <span>Yes</span> <span>No</span> </div>
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Notes	<div style="border-top: 1px dashed black; border-bottom: 1px dashed black; height: 20px;"></div>

<b>MOST SEVERE PRESENTATION</b>	
Duration of episode (min.)	<div style="display: flex; justify-content: space-between;"> <span>one to ten minutes</span> <span>more than ten minutes</span> </div>
Required medical attention?	<div style="display: flex; justify-content: space-around;"> <span>Yes</span> <span>No</span> </div>
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Notes	<div style="border-top: 1px dashed black; border-bottom: 1px dashed black; height: 20px;"></div>

**Bleeding symptoms****After diagnosis****Bleeding from minor wounds**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number episodes/year

less than 1

1 - 5

6 - 12

more than 12

Duration of average single episode (min.)

one to ten minutes

more than ten minutes

Ever required medical attention ?

Yes

No

if yes, please specify

Surgical hemostasis

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Duration of average single episode (min.)

one to ten minutes

more than ten minutes

Required medical attention?

Yes

No

if yes, please specify

Surgical hemostasis

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....  
.....

**Bleeding symptoms****Before diagnosis****Oral cavity bleeding**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Type of bleeding

Tooth eruption

Gums, spontaneous

Gums, after brushing

Bites to lip &amp; tongue

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Type of bleeding

Tooth eruption

Gums, spontaneous

Gums, after brushing

Bites to lip &amp; tongue

Required medical attention?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Notes

.....  
.....

**Bleeding symptoms****After diagnosis****Oral cavity bleeding**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Type of bleeding

Tooth eruption

Gums, spontaneous

Gums, after brushing

Bites to lip &amp; tongue

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytics

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Type of bleeding

Tooth eruption

Gums, spontaneous

Gums, after brushing

Bites to lip &amp; tongue

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytics

Notes

.....  
.....

**Bleeding symptoms****Before diagnosis**

<b>Gastrointestinal bleeding</b>	No	Trivial	N.E.	Yes
----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number of episodes

Type of bleeding

Hematemesis  
Melena  
Hematochezia

Presence of associated  
GI disease

Yes No

Specify:

Ulcer  
Portal hypertension  
Angiodysplasia

Ever required medical attention ?

Yes No

if yes, please specify

Consultation only  
Surgical hemostasis  
Blood transfusion

Notes

.....  
.....

**MOST SEVERE PRESENTATION**

Type of bleeding

Hematemesis  
Melena  
Hematochezia

Presence of associated  
GI disease

Yes No

Specify:

Ulcer  
Portal hypertension  
Angiodysplasia

Required medical attention?

Yes No

if yes, please specify

Consultation only  
Surgical hemostasis  
Blood transfusion

Notes

.....  
.....

**Bleeding symptoms****After diagnosis**

<b>Gastrointestinal bleeding</b>	No	Trivial	N.E.	Yes
----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Number of episodes		
Type of bleeding	Hematemesis Melena Hematochezia	
Presence of associated GI disease	Yes	No
	Specify:	
	Ulcer Portal hypertension Angiodysplasia	
Ever required medical attention ?	Yes	No
if yes, please specify		
Surgical hemostasis		
Blood transfusion		
Desmopressin		
Replacement therapy		
Notes	.....	
	.....	

**MOST SEVERE PRESENTATION**

Type of bleeding	Hematemesis Melena Hematochezia	
Presence of associated GI disease	Yes	No
	Specify:	
	Ulcer Portal hypertension Angiodysplasia	
Required medical attention?	Yes	No
if yes, please specify		
Surgical hemostasis		
Blood transfusion		
Desmopressin		
Replacement therapy		
Notes	.....	
	.....	

**Bleeding symptoms****Before diagnosis****Tooth extraction**

Total number of tooth extractions

Number of tooth extractions followed by bleeding

Please fill in a separate box for each extraction, if any; photocopy if necessary.

<b>Bleeding after first extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion			
Notes	..... .....			

<b>Bleeding after second extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion			
Notes	..... .....			

<b>Bleeding after third extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous	Permanent
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None			
	Resuturing			
	Packing			
	Blood transfusion			
Notes	..... .....			

<b>MOST SEVERE BLEEDING AFTER EXTRACTION</b>				
Age at extraction	Type of extraction		Deciduous	Permanent
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None			
	Resuturing			
	Packing			
	Blood transfusion			
Notes	..... .....			



**Bleeding symptoms****After diagnosis****Tooth extraction**

Total number of tooth extractions

Number of tooth extractions followed by bleeding

Please fill in a separate box for each extraction, if any; photocopy if necessary.

<b>Bleeding after first extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion		Desmopressin Replacement therapy Antifibrinolytics	
Notes	.....			

<b>Bleeding after second extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion		Desmopressin Replacement therapy Antifibrinolytics	
Notes	.....			

<b>Bleeding after third extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous	
			Permanent	
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion Desmopressin Replacement therapy Antifibrinolytics			
Notes	..... .....			

<b>MOST SEVERE BLEEDING AFTER EXTRACTION</b>				
Age at extraction	Type of extraction		Deciduous	
			Permanent	
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion Desmopressin Replacement therapy Antifibrinolytics			
Notes	..... .....			

<b>Bleeding symptoms</b>	<b>Before diagnosis</b>
--------------------------	-------------------------

<b>Surgery</b>
----------------

Total number of surgeries \_\_\_\_\_                      Number of surgeries followed by bleeding \_\_\_\_\_

Please fill in a separate box for each surgery, if any; photocopy if necessary.

<b>Bleeding after first surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>Bleeding after second surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Bleeding after surgery?		Yes	No	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>Bleeding after third surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>MOST SEVERE BLEEDING AFTER SURGERY</b>				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

**Bleeding symptoms**

**After diagnosis**

**Surgery**

Total number of surgeries

Number of surgeries followed by bleeding

Please fill in a separate box for each surgery, if any; photocopy if necessary.

<b>Bleeding after first surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Prophylaxis before surgery		None		
		Desmopressin		
		Replacement therapy		
Actions taken to control bleeding		None	Desmopressin	
		Resuturing/surgical	Replacement therapy	
		Blood transfusion	Antifibrinolytics	
Notes		.....		
		.....		

<b>Bleeding after second surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Prophylaxis before surgery		None		
		Desmopressin		
		Replacement therapy		
Actions taken to control bleeding		None	Desmopressin	
		Resuturing/surgical	Replacement therapy	
		Blood transfusion	Antifibrinolytics	
Notes		.....		
		.....		

<b>Bleeding after third surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Prophylaxis before surgery		None		
		Desmopressin		
		Replacement therapy		
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Desmopressin		
		Replacement therapy		
		Antifibrinolytics		
Notes		.....		
		.....		

<b>MOST SEVERE BLEEDING AFTER SURGERY</b>				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Prophylaxis before surgery		None		
		Desmopressin		
		Replacement therapy		
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Desmopressin		
		Replacement therapy		
		Antifibrinolytics		
Notes		.....		
		.....		

**Bleeding symptoms****Before diagnosis****Menorrhagia**

Duration of average menstruation (days)

Duration of heavy days

Ever suffered from menorrhagia ?

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Age of maximum severity

14 - 25

26 - 35

more than 36

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Pill use

Dilatation &amp; curettage

Hysterectomy

Blood transfusion

Iron therapy

Notes

.....  
.....**MOST SEVERE PRESENTATION**

Age of bleeding

14 - 25

26 - 35

more than 36

Required medical attention ?

Yes

No

if yes, please specify

Consultation only

Pill use

Dilatation &amp; curettage

Hysterectomy

Blood transfusion

Iron therapy

Notes

.....  
.....

<b>Bleeding symptoms</b>	<b>After diagnosis</b>
--------------------------	------------------------

<b>Menorrhagia</b>
--------------------

Duration of average menstruation (days)	Duration of heavy days
Ever suffered from menorrhagia ?	No      Trivial      N.E.      Yes

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>	
Age of maximum severity	14 - 25 26 - 35 more than 36
Ever required medical attention ?	Yes                                  No
if yes, please specify	
Consultation only	
Pill use	
Dilatation & curettage	
Hysterectomy	
Blood transfusion	
Desmopressin	
Replacement therapy	
Iron therapy	
Antifibrinolytics	
Notes	..... .....

<b>MOST SEVERE PRESENTATION</b>	
Age of bleeding	14 - 25 26 - 35 more than 36
Ever required medical attention ?	Yes                                  No
if yes, please specify	
Consultation only	
Pill use	
Dilatation & curettage	
Hysterectomy	
Blood transfusion	
Desmopressin	
Replacement therapy	
Iron therapy	
Antifibrinolytics	
Notes	..... .....



**Bleeding symptoms****Before diagnosis****Post-partum hemorrhage**

Total number of deliveries

Number of deliveries followed by bleeding

Please fill in a separate box for each delivery, if any; photocopy if necessary.

<b>Bleeding after first delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes		.....		
		.....		

<b>Bleeding after second delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes		.....		
		.....		

<b>Bleeding after third delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes	.....			
	.....			

<b>MOST SEVERE BLEEDING AFTER DELIVERY</b>		
Required medical attention?	Yes	No
if yes, please specify		
Dilatation & curettage		
Hysterectomy		
Blood transfusion		
Iron therapy		
Other		
Notes	.....	
	.....	

**Bleeding symptoms****After diagnosis****Post-partum hemorrhage**

Total number of deliveries

Number of deliveries followed by bleeding

Please fill in a separate box for each delivery, if any; photocopy if necessary.

<b>Bleeding after first delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Desmopressin				
Replacement therapy				
Other				
Notes	.....			
	.....			

<b>Bleeding after second delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Desmopressin				
Replacement therapy				
Other				
Notes	.....			
	.....			

<b>Bleeding after third delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Desmopressin				
Replacement therapy				
Other				
Notes	.....			
	.....			

<b>MOST SEVERE BLEEDING AFTER DELIVERY</b>		
Required medical attention?	Yes	No
if yes, please specify		
Dilatation & curettage		
Hysterectomy		
Blood transfusion		
Iron therapy		
Other		
Notes	.....	
	.....	

<b>Bleeding symptoms</b>	<b>Before diagnosis</b>
--------------------------	-------------------------

<b>Muscle hematomas or hemarthrosis</b>	No	Trivial	N.E.	Yes
---	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Please specify type & location	..... ..... ..... .....	
Spontaneous ?	Yes	No
Ever required medical attention ?	Yes	No
if yes, please specify		
Blood transfusion		
Notes	..... .....	

<b>MOST SEVERE PRESENTATION</b>		
Please specify type & location	..... .....	
Spontaneous ?	Yes	No
Required medical attention ?	Yes	No
if yes, please specify		
Blood transfusion		
Notes	..... .....	

**Bleeding symptoms****After diagnosis****Muscle hematomas or  
hemarthrosis**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Please specify type &amp; location

.....

.....

Spontaneous ?

Yes

No

Ever required medical attention ?

Yes

No

if yes, please specify

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....

.....

**MOST SEVERE PRESENTATION**

Please specify type &amp; location

.....

.....

Spontaneous ?

Yes

No

Required medical attention ?

Yes

No

if yes, please specify

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....

.....

<b>Bleeding symptoms</b>	<b>Before diagnosis</b>
--------------------------	-------------------------

<b>Other bleedings</b>	No	Trivial	N.E.	Yes
------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Please specify type of bleeding	..... .....	
Ever required medical attention?	Yes	No
if yes, please specify:		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Please specify type of bleeding	..... .....	
Ever required medical attention ?	Yes	No
if yes, please specify:		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Notes	..... .....	

<b>MOST SEVERE PRESENTATION</b>		
Please specify type of bleeding	..... .....	
Required medical attention ?	Yes	No
if yes, please specify:		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Please specify type of bleeding	..... .....	
Required medical attention ?	Yes	No
if yes, please specify		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Notes	..... .....	

**Bleeding symptoms****After diagnosis**

<b>Other bleedings</b>	No	Trivial	N.E.	Yes
------------------------	----	---------	------	-----

If yes, please fill in the following boxes

**AVERAGE PRESENTATION**

Please specify type of bleeding .....

Ever required medical attention ?      Yes                                      No

specify if yes, please

- Blood transfusion
- Desmopressin
- Replacement therapy
- Iron therapy
- Antifibrinolytics
- Other

Please specify type of bleeding .....

Ever required medical attention ?      Yes                                      No

specify if yes, please

- Blood transfusion
- Desmopressin
- Replacement therapy
- Iron therapy
- Antifibrinolytics
- Other

Notes .....

**MOST SEVERE PRESENTATION**

Please specify .....

Required medical attention?      Yes                                      No

if yes, please specify

- Blood transfusion
- Desmopressin
- Replacement therapy
- Iron therapy
- Antifibrinolytics
- Other

Please specify .....

Required medical attention ?      Yes                                      No

specify if yes, please

- Blood transfusion
- Desmopressin
- Replacement therapy
- Iron therapy
- Antifibrinolytics
- Other



Notes .....

## First control subject

(matched to the first obligatory carrier )

Family code <sup>9</sup>

Subject ID code <sup>10</sup>

Date of birth <sup>11</sup>

/ /

Sex

Male

Female

ABO blood group <sup>12</sup>

O group

non O group

**Bleeding symptoms**

<b>Epistaxis</b>	No	Trivial <sup>16</sup>	N.E. <sup>17</sup>	Yes
------------------	----	-----------------------	--------------------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Number episodes/year	less than 1 1 - 5 6 - 12 more than 12	
Duration of average single episode (min.)	one minute or less one to ten minutes more than ten minutes	
Spontaneous ?	Yes	No
Both nostrils ?	Yes	No
After drug ingestion (e.g. aspirin)	Yes	No
Seasonal correlation	Yes	No
Cessation	spontaneous after short compression by medical intervention	
Age of maximum severity	less than 14 years 14 to 45 years more than 45 years	
Ever required medical attention ?	Yes	No
if yes, please specify		
Consultation only		
Cauterization		
Packing		
Blood transfusion		
Notes	..... .....	

**Epistaxis**

**MOST SEVERE PRESENTATION**

Duration of episode (min.)	one minute or less one to ten minutes more than ten minutes	
Spontaneous ?	Yes	No
Both nostrils ?	Yes	No
After drug ingestion (e.g. aspirin)	Yes	No
Cessation	spontaneous after short compression by medical intervention	
Required medical attention?	Yes	No

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Notes

.....  
.....

## Bleeding symptoms

<b>Cutaneous symptoms</b>	No	Trivial	N.E.	Yes
---------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Number episodes/year		
Type	Petechiae Bruises Hematomas	
Location of bruises (if any)	Exposed sites Unexposed sites	
Minimal or no trauma	Yes	No
Ever required medical attention ?	Yes	No
if yes, please specify	..... .....	
Consultation only	..... Yes <span style="margin-left: 150px;">No</span>	
Notes	..... .....	

<b>MOST SEVERE PRESENTATION</b>		
Type	Petechiae Bruises Hematomas	
Location of bruises (if any)	Exposed sites Unexposed sites	
Minimal or no trauma	Yes	No
Required medical attention?	Yes	No
if yes, please specify	..... .....	
Consultation only	..... Yes <span style="margin-left: 150px;">No</span>	
Notes	..... .....	

**Bleeding symptoms**

<b>Bleeding from minor wounds</b>	No	Trivial	N.E.	Yes
-----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>	
Number episodes/year	less than 1 1 - 5 6 - 12 more than 12
Duration of average single episode (min.)	one to ten minutes more than ten minutes
Ever required medical attention ?	Yes <span style="margin-left: 150px;">No</span>
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Notes	..... .....

<b>MOST SEVERE PRESENTATION</b>	
Duration of episode (min.)	one to ten minutes more than ten minutes
Required medical attention?	Yes <span style="margin-left: 150px;">No</span>
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Notes	..... .....

## Bleeding symptoms

<b>Oral cavity bleeding</b>	No	Trivial	N.E.	Yes
-----------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Type of bleeding	Tooth eruption Gums, spontaneous Gums, after brushing Bites to lip & tongue	
Ever required medical attention ?	Yes	No
if yes, please specify		
Consultation only Surgical hemostasis Blood transfusion		
Notes	..... .....	

<b>MOST SEVERE PRESENTATION</b>		
Type of bleeding	Tooth eruption Gums, spontaneous Gums, after brushing Bites to lip & tongue	
Required medical attention?	Yes	No
if yes, please specify		
Consultation only Surgical hemostasis Blood transfusion		
Notes	..... .....	

## Bleeding symptoms

<b>Gastrointestinal bleeding</b>	No	Trivial	N.E.	Yes
----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Number of episodes		
Type of bleeding	Hematemesis Melena Hematochezia	
Presence of associated GI disease	Yes	No
	Specify:	
	Ulcer Portal hypertension Angiodysplasia	
Ever required medical attention ?	Yes	No
if yes, please specify		
Consultation only		
Surgical hemostasis		
Blood transfusion		
Notes	..... .....	

<b>MOST SEVERE PRESENTATION</b>		
Type of bleeding	Hematemesis Melena Hematochezia	
Presence of associated GI disease	Yes	No
	Specify:	
	Ulcer Portal hypertension Angiodysplasia	
Required medical attention?	Yes	No
if yes, please specify		
Consultation only		
Surgical hemostasis		
Blood transfusion		
Notes	..... .....	

## Bleeding symptoms

### Tooth extraction

Total number of tooth extractions

Number of tooth extractions followed by bleeding

Please fill in a separate box for each extraction, if any; photocopy if necessary.

<b>Bleeding after first extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion			
Notes	..... .....			

<b>Bleeding after second extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion			
Notes	..... .....			



<b>Bleeding after third extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous	Permanent
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None			
	Resuturing			
	Packing			
	Blood transfusion			
Notes	..... .....			

<b>MOST SEVERE BLEEDING AFTER EXTRACTION</b>				
Age at extraction	Type of extraction		Deciduous	Permanent
			Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None			
	Resuturing			
	Packing			
	Blood transfusion			
Notes	..... .....			

## Bleeding symptoms

### Surgery

Total number of surgeries

Number of surgeries followed by bleeding

Please fill in a separate box for each surgery, if any; photocopy if necessary.

<b>Bleeding after first surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>Bleeding after second surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>Bleeding after third surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>MOST SEVERE BLEEDING AFTER SURGERY</b>				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

## Bleeding symptoms

### Menorrhagia

Duration of average menstruation (days)

Duration of heavy days

Ever suffered from menorrhagia ?

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

#### AVERAGE PRESENTATION

Age of maximum severity

14 - 25

26 - 35

more than 36

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Pill use

Dilatation & curettage

Hysterectomy

Blood transfusion

Iron therapy

Notes

.....  
.....

#### MOST SEVERE PRESENTATION

Age of bleeding

14 - 25

26 - 35

more than 36

Required medical attention ?

Yes

No

if yes, please specify

Consultation only

Pill use

Dilatation & curettage

Hysterectomy

Blood transfusion

Iron therapy

Notes

.....  
.....

## Bleeding symptoms

### Post-partum hemorrhage

Total number of deliveries

Number of deliveries followed by bleeding

Please fill in a separate box for each delivery, if any; photocopy if necessary.

<b>Bleeding after first delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes		.....		
		.....		

<b>Bleeding after second delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes		.....		
		.....		

<b>Bleeding after third delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes	.....			
	.....			

<b>MOST SEVERE BLEEDING AFTER DELIVERY</b>		
Required medical attention?	Yes	No
if yes, please specify		
Dilatation & curettage		
Hysterectomy		
Blood transfusion		
Iron therapy		
Other		
Notes	.....	
	.....	

**Bleeding symptoms**

<b>Muscle hematomas or hemarthrosis</b>	No	Trivial	N.E.	Yes
---	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Please specify type & location	..... ..... ..... .....	
Spontaneous ?	Yes	No
Ever required medical attention ?	Yes	No
if yes, please specify		
Blood transfusion		
Notes	..... .....	

<b>MOST SEVERE PRESENTATION</b>		
Please specify type & location	..... .....	
Spontaneous ?	Yes	No
Required medical attention ?	Yes	No
if yes, please specify		
Blood transfusion		
Notes	..... .....	

**Bleeding symptoms**

<b>Other bleedings</b>	No	Trivial	N.E.	Yes
------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Please specify type of bleeding	.....	
	.....	
Ever required medical attention?	Yes	No
if yes, please specify:		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Please specify type of bleeding	.....	
	.....	
Ever required medical attention ?	Yes	No
if yes, please specify:		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Notes	.....	
	.....	

<b>MOST SEVERE PRESENTATION</b>		
Please specify type of bleeding	.....	
	.....	
Required medical attention ?	Yes	No
if yes, please specify:		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Please specify type of bleeding	.....	
	.....	
Required medical attention ?	Yes	No
if yes, please specify		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Notes	.....	
	.....	



## Second control subject

(matched to the second obligatory carrier )

Family code <sup>9</sup>

Subject ID code <sup>10</sup>

Date of birth <sup>11</sup>

/ /

Sex

Male

Female

ABO blood group <sup>12</sup>

O group

non O group

## Bleeding symptoms

<b>Epistaxis</b>	No	Trivial <sup>16</sup>	N.E. <sup>17</sup>	Yes
------------------	----	-----------------------	--------------------	-----

If yes, please fill in the following boxes

AVERAGE PRESENTATION		
Number episodes/year	less than 1 1 - 5 6 - 12 more than 12	
Duration of average single episode (min.)	one minute or less one to ten minutes more than ten minutes	
Spontaneous ?	Yes	No
Both nostrils ?	Yes	No
After drug ingestion (e.g. aspirin)	Yes	No
Seasonal correlation	Yes	No
Cessation	spontaneous after short compression by medical intervention	
Age of maximum severity	less than 14 years 14 to 45 years more than 45 years	
Ever required medical attention ?	Yes	No
if yes, please specify		
Consultation only		
Cauterization		
Packing		
Blood transfusion		
Notes	..... .....	

**Epistaxis**

**MOST SEVERE PRESENTATION**

Duration of episode (min.)

one minute or less  
one to ten minutes  
more than ten minutes

Spontaneous ?

Yes

No

Both nostrils ?

Yes

No

After drug ingestion  
(e.g. aspirin)

Yes

No

Cessation

spontaneous  
after short compression  
by medical intervention

Required medical attention?

Yes

No

if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Notes

.....  
.....

## Bleeding symptoms

<b>Cutaneous symptoms</b>	No	Trivial	N.E.	Yes
---------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Number episodes/year		
Type	Petechiae Bruises Hematomas	
Location of bruises (if any)	Exposed sites Unexposed sites	
Minimal or no trauma	Yes	No
Ever required medical attention ?	Yes	No
if yes, please specify	..... .....	
Consultation only	..... Yes <span style="margin-left: 150px;">No</span>	
Notes	..... .....	

<b>MOST SEVERE PRESENTATION</b>		
Type	Petechiae Bruises Hematomas	
Location of bruises (if any)	Exposed sites Unexposed sites	
Minimal or no trauma	Yes	No
Required medical attention?	Yes	No
if yes, please specify	..... .....	
Consultation only	..... Yes <span style="margin-left: 150px;">No</span>	
Notes	..... .....	

**Bleeding symptoms**

<b>Bleeding from minor wounds</b>	No	Trivial	N.E.	Yes
-----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>	
Number episodes/year	less than 1 1 - 5 6 - 12 more than 12
Duration of average single episode (min.)	one to ten minutes more than ten minutes
Ever required medical attention ?	Yes <span style="margin-left: 150px;">No</span>
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Notes	..... .....

<b>MOST SEVERE PRESENTATION</b>	
Duration of episode (min.)	one to ten minutes more than ten minutes
Required medical attention?	Yes <span style="margin-left: 150px;">No</span>
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Notes	..... .....

## Bleeding symptoms

<b>Oral cavity bleeding</b>	No	Trivial	N.E.	Yes
-----------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Type of bleeding	Tooth eruption Gums, spontaneous Gums, after brushing Bites to lip & tongue	
Ever required medical attention ?	Yes	No
if yes, please specify		
Consultation only		
Surgical hemostasis		
Blood transfusion		
Notes	..... .....	

<b>MOST SEVERE PRESENTATION</b>		
Type of bleeding	Tooth eruption Gums, spontaneous Gums, after brushing Bites to lip & tongue	
Required medical attention?	Yes	No
if yes, please specify		
Consultation only		
Surgical hemostasis		
Blood transfusion		
Notes	..... .....	

## Bleeding symptoms

<b>Gastrointestinal bleeding</b>	No	Trivial	N.E.	Yes
----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Number of episodes		
Type of bleeding	Hematemesis Melena Hematochezia	
Presence of associated GI disease	Yes	No
	Specify:	
	Ulcer Portal hypertension Angiodysplasia	
Ever required medical attention ?	Yes	No
if yes, please specify		
Consultation only		
Surgical hemostasis		
Blood transfusion		
Notes	..... .....	

<b>MOST SEVERE PRESENTATION</b>		
Type of bleeding	Hematemesis Melena Hematochezia	
Presence of associated GI disease	Yes	No
	Specify:	
	Ulcer Portal hypertension Angiodysplasia	
Required medical attention?	Yes	No
if yes, please specify		
Consultation only		
Surgical hemostasis		
Blood transfusion		
Notes	..... .....	

## Bleeding symptoms

### Tooth extraction

Total number of tooth extractions

Number of tooth extractions followed by bleeding

Please fill in a separate box for each extraction, if any; photocopy if necessary.

<b>Bleeding after first extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion			
Notes	..... .....			

<b>Bleeding after second extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction	Type of extraction		Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding	None Resuturing Packing Blood transfusion			
Notes	..... .....			



<b>Bleeding after third extraction</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at extraction		Type of extraction	Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding		None Resuturing Packing Blood transfusion		
Notes		..... .....		

<b>MOST SEVERE BLEEDING AFTER EXTRACTION</b>				
Age at extraction		Type of extraction	Deciduous Permanent Molar	
Prophylaxis before extraction	No	Yes	If yes, specify type: ..... ..... ..	
Actions taken to control bleeding		None Resuturing Packing Blood transfusion		
Notes		..... .....		

## Bleeding symptoms

### Surgery

Total number of surgeries

Number of surgeries followed by bleeding

Please fill in a separate box for each surgery, if any; photocopy if necessary.

<b>Bleeding after first surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>Bleeding after second surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery		
		Cesarean section	Major-abdominal	
		Tonsillectomy/Adenoids	Major-thoracic	
		Pharynx/Nose	Major-gynecology	
			Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>Bleeding after third surgery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

<b>MOST SEVERE BLEEDING AFTER SURGERY</b>				
Age at surgery		Type of surgery	Major-abdominal	
		Cesarean section	Major-thoracic	
		Tonsillectomy/Adenoids	Major-gynecology	
		Pharynx/Nose	Other	
Actions taken to control bleeding		None		
		Resuturing/surgical		
		Blood transfusion		
		Other		
Notes		.....		
		.....		

## Bleeding symptoms

### Menorrhagia

Duration of average menstruation (days)

Duration of heavy days

Ever suffered from menorrhagia ?

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

#### AVERAGE PRESENTATION

Age of maximum severity

14 - 25

26 - 35

more than 36

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Pill use

Dilatation & curettage

Hysterectomy

Blood transfusion

Iron therapy

Notes

.....  
.....

#### MOST SEVERE PRESENTATION

Age of bleeding

14 - 25

26 - 35

more than 36

Required medical attention ?

Yes

No

if yes, please specify

Consultation only

Pill use

Dilatation & curettage

Hysterectomy

Blood transfusion

Iron therapy

Notes

.....  
.....

## Bleeding symptoms

### Post-partum hemorrhage

Total number of deliveries

Number of deliveries followed by bleeding

Please fill in a separate box for each delivery, if any; photocopy if necessary.

<b>Bleeding after first delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes		.....		
		.....		

<b>Bleeding after second delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes		.....		
		.....		

<b>Bleeding after third delivery</b>	No	Trivial	N.E.	Yes
If yes, please complete:				
Ever required medical attention ?		Yes	No	
if yes, please specify				
Dilatation & curettage				
Hysterectomy				
Blood transfusion				
Iron therapy				
Other				
Notes	.....			
	.....			

<b>MOST SEVERE BLEEDING AFTER DELIVERY</b>		
Required medical attention?	Yes	No
if yes, please specify		
Dilatation & curettage		
Hysterectomy		
Blood transfusion		
Iron therapy		
Other		
Notes	.....	
	.....	

## Bleeding symptoms

**Muscle hematomas or  
hemarthrosis**

No

Trivial

N.E.

Yes

If yes, please fill in the following boxes

### AVERAGE PRESENTATION

Please specify type & location

.....  
.....  
.....  
.....

Spontaneous ?

Yes

No

Ever required medical attention ?

Yes

No

if yes, please specify

Blood transfusion

Notes

.....  
.....

### MOST SEVERE PRESENTATION

Please specify type &  
location

.....  
.....

Spontaneous ?

Yes

No

Required medical attention ?

Yes

No

if yes, please specify

Blood transfusion

Notes

.....  
.....

**Bleeding symptoms**

<b>Other bleedings</b>	No	Trivial	N.E.	Yes
------------------------	----	---------	------	-----

If yes, please fill in the following boxes

<b>AVERAGE PRESENTATION</b>		
Please specify type of bleeding	..... .....	
Ever required medical attention?	Yes	No
if yes, please specify:		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Please specify type of bleeding	..... .....	
Ever required medical attention ?	Yes	No
if yes, please specify:		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Notes	..... .....	

<b>MOST SEVERE PRESENTATION</b>		
Please specify type of bleeding	..... .....	
Required medical attention ?	Yes	No
if yes, please specify:		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Please specify type of bleeding	..... .....	
Required medical attention ?	Yes	No
if yes, please specify		
Blood transfusion		
Iron therapy		
Antifibrinolytics		
Other		
Notes	..... .....	



## Questionnaire instructions

1. Assign a family code for each family as an increasing number (e.g. 01, 02, 03, ...)
2. Give total number of family members, based on first degree relatives of the first obligatory carrier
3. Give number of family members (first degree relatives of the first obligatory carrier) actually investigated at your Center; must be less or equal than the number reported in <sup>2</sup>
4. Give number of family members (first degree relatives of the first obligatory carrier) identified as symptomatic; must be less or equal than the number reported in <sup>3</sup>
5. Report if available
6. Report inheritance as based on bleeding history
7. Report if available
8. Report if available
9. Same as <sup>1</sup>
10. Enter the code of subjects as follows: 00=affected member; 01=first obligatory carrier; 02=second obligatory carrier. Use A1, A2, A3, etc. as subjects' code to identify the additional family members (e.g. the mate). Use 03 for the first control and 04 for the second control
11. Enter birth date (dd/mm/yy)
12. Specify blood group if available
13. Laboratory measurement: give units (e.g., %, International Units), your lab reference range, the minimum, maximal and median measurement value
14. Specify if ABO-adjusted reference ranges were used for diagnosis. Please note that ABO-specific ranges are not strictly required for diagnosis
15. The date of diagnosis is based on the time of the first visit of the affected member or carrier(s) at a specialized center independently from the time on which a specific diagnosis was established (see also Section 2.2 of Study Outline and Instructions, *Study Flow-chart*)
16. Trivial symptom: check this box if the specific symptom is not clinically important. Carefully read the section 2.2 of Study Outline and Instructions (*Guidelines for History Taking*) for information on how a clinically significant cut-off should be set
17. Not Evaluated: check this box if the symptom could not be thoroughly assessed in the patient or control

Please return the completed questionnaire to:

Francesco Rodeghiero  
Department of Hematology  
S. Bortolo Hospital  
36100 Vicenza - Italy

After the arrival of the questionnaires you will be contacted for the samples shipment.

