

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 1 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:

Phone: +39-0444-993626

Fax: +39-0444-920708

E-mail: rodeghiero@hemato.ven.it

Web site: www.hemato.ven.it

CONTENT

FAMILY DATA AND PEDIGREE (WHITE)

OBLIGATORY CARRIER (GREEN)

OLDER AFFECTED (YELLOW)

YOUNGER AFFECTED (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 ¹

Total number of family members ²

Number of studied family members ³

Number of symptomatic family members ⁴

Multimeric pattern of plasma vWf ⁵

normal

abnormal

Please specify

.....

.....

Inheritance ⁶

autosomal dominant

recessive

uncertain

Mutation identified ⁷

Yes

Please specify

.....

.....

No

Additional hemostatic defects ⁸

Yes

Please specify

.....

.....

No

Not investigated

Obligatory carrier

Family code ⁹

Subject ID code ¹⁰

Date of birth ¹¹

/ /

Sex

Male

Female

ABO blood group ¹²

O group

non O group

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

Blood group adjusted reference range? ¹⁴

Yes No

Diagnosis at age

Bleeding symptoms**Before diagnosis¹⁵****Epistaxis**

No

Trivial¹⁶N.E.¹⁷ 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
(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

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

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

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

Cessation	spontaneous after short compression by medical intervention
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Required medical attention?	Yes	No
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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

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.....

Bleeding symptoms	Before diagnosis
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Bleeding from minor wounds	No	Trivial	N.E.	Yes
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If yes, please fill in the following boxes

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

MOST SEVERE PRESENTATION	
Duration of episode (min.)	<div style="display: flex; justify-content: space-between;"> one to ten minutes more than ten minutes </div>
Required medical attention?	<div style="display: flex; justify-content: space-around;"> Yes No </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 & 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 & 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 & 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 & tongue

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytics

Notes

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.....

Bleeding symptoms**Before diagnosis**

Gastrointestinal bleeding	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

.....
.....

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

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.

Bleeding after first extraction	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			

Bleeding after second extraction	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			

Bleeding after third extraction	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			

MOST SEVERE BLEEDING AFTER EXTRACTION				
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.

Bleeding after first extraction	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			

Bleeding after second extraction	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			

Bleeding after third extraction	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			

MOST SEVERE BLEEDING AFTER EXTRACTION				
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			

Bleeding symptoms	Before diagnosis
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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.

Bleeding after first surgery	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			

Bleeding after second surgery	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			

Bleeding after third surgery	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			
			

MOST SEVERE BLEEDING AFTER SURGERY				
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.

Bleeding after first surgery	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			
			

Bleeding after second surgery	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			
			

Bleeding after third surgery	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			
			

MOST SEVERE BLEEDING AFTER SURGERY				
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 & 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

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.....

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

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

Bleeding after first delivery	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			
			

Bleeding after second delivery	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			
			

Bleeding after third delivery	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			
			

MOST SEVERE BLEEDING AFTER DELIVERY		
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.

Bleeding after first delivery	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			
			

Bleeding after second delivery	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			
			

Bleeding after third delivery	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			
			

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

Bleeding symptoms	Before diagnosis
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Muscle hematomas or hemarthrosis	No	Trivial	N.E.	Yes
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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**After diagnosis****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

Desmopressin

Replacement therapy

Notes

.....

.....

MOST SEVERE PRESENTATION

Please specify type & location

.....

.....

Spontaneous ?

Yes

No

Required medical attention ?

Yes

No

if yes, please specify

Blood transfusion

Desmopressin

Replacement therapy

Notes

.....

.....

Bleeding symptoms	Before diagnosis
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Other bleedings	No	Trivial	N.E.	Yes
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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**

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

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

Older affected family member

Family code ⁹

Subject ID code ¹⁰

Date of birth ¹¹

/ /

Sex

Male

Female

ABO blood group ¹²

O group

non O group

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

Blood group adjusted reference range? ¹⁴

Yes No

Diagnosis at age

Bleeding symptoms**Before diagnosis¹⁵****Epistaxis**

No

Trivial¹⁶N.E.¹⁷ 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
(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

Desmopressin

Replacement therapy

Antifibrinolytic therapy

Notes

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.....

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

.....
.....

Bleeding symptoms	Before diagnosis
--------------------------	-------------------------

Bleeding from minor wounds	No	Trivial	N.E.	Yes
-----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

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

MOST SEVERE PRESENTATION	
Duration of episode (min.)	<div style="display: flex; justify-content: space-between;"> one to ten minutes </div> <div style="display: flex; justify-content: space-between;"> more than ten minutes </div>
Required medical attention?	<div style="display: flex; justify-content: space-around;"> Yes No </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 & 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 & 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 & 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 & 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**

Gastrointestinal bleeding	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**

Gastrointestinal bleeding	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.

Bleeding after first extraction	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			

Bleeding after second extraction	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			

Bleeding after third extraction	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			

MOST SEVERE BLEEDING AFTER EXTRACTION				
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.

Bleeding after first extraction	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			

Bleeding after second extraction	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			

Bleeding after third extraction	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			

MOST SEVERE BLEEDING AFTER EXTRACTION				
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			

Bleeding symptoms	Before 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.

Bleeding after first surgery	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			

Bleeding after second surgery	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			

Bleeding after third surgery	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			
			

MOST SEVERE BLEEDING AFTER SURGERY				
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.

Bleeding after first surgery	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			
			

Bleeding after second surgery	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			
			

Bleeding after third surgery	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			
			

MOST SEVERE BLEEDING AFTER SURGERY				
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 & 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	After 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 & curettage	
Hysterectomy	
Blood transfusion	
Desmopressin	
Replacement therapy	
Iron therapy	
Antifibrinolytics	
Notes

MOST SEVERE PRESENTATION	
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.

Bleeding after first delivery	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			
			

Bleeding after second delivery	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			
			

Bleeding after third delivery	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			
			

MOST SEVERE BLEEDING AFTER DELIVERY		
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.

Bleeding after first delivery	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			
			

Bleeding after second delivery	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			
			

Bleeding after third delivery	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			
			

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

Bleeding symptoms	Before diagnosis
--------------------------	-------------------------

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**After diagnosis****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

Desmopressin

Replacement therapy

Notes

.....

.....

MOST SEVERE PRESENTATION

Please specify type & 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****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

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

Younger affected family member

Family code ⁹

Subject ID code ¹⁰

Date of birth ¹¹

/ /

Sex

Male

Female

ABO blood group ¹²

O group

non O group

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

Blood group adjusted reference range? ¹⁴

Yes

No

Diagnosis at age

Bleeding symptoms**Before diagnosis¹⁵****Epistaxis**

No

Trivial¹⁶N.E.¹⁷ 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

.....
.....

Bleeding symptoms	Before diagnosis
--------------------------	-------------------------

Bleeding from minor wounds	No	Trivial	N.E.	Yes
-----------------------------------	----	---------	------	-----

If yes, please fill in the following boxes

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

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

Ever required medical attention ?

Yes

No

if yes, please specify

Consultation only

Surgical hemostasis

Blood transfusion

Desmopressin

Replacement therapy

Antifibrinolytics

Notes

.....
.....

Bleeding symptoms	After diagnosis
--------------------------	------------------------

Gastrointestinal bleeding	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.

Bleeding after first extraction	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			

Bleeding after second extraction	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			

Bleeding after third extraction	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			
			

MOST SEVERE BLEEDING AFTER EXTRACTION				
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.

Bleeding after first extraction	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			

Bleeding after second extraction	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			

Bleeding after third extraction	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			

MOST SEVERE BLEEDING AFTER EXTRACTION				
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			

Bleeding symptoms	Before 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.

Bleeding after first surgery	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			

Bleeding after second surgery	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			

Bleeding after third surgery	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			
			

MOST SEVERE BLEEDING AFTER SURGERY				
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.

Bleeding after first surgery	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			
			

Bleeding after second surgery	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			
			

Bleeding after third surgery	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			
			

MOST SEVERE BLEEDING AFTER SURGERY				
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 & 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	After 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 & curettage	
Hysterectomy	
Blood transfusion	
Desmopressin	
Replacement therapy	
Iron therapy	
Antifibrinolytics	
Notes

MOST SEVERE PRESENTATION	
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.

Bleeding after first delivery	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			
			

Bleeding after second delivery	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			
			

Bleeding after third delivery	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			
			

MOST SEVERE BLEEDING AFTER DELIVERY		
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.

Bleeding after first delivery	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			
			

Bleeding after second delivery	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			
			

Bleeding after third delivery	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			
			

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

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

Desmopressin

Replacement therapy

Notes

.....

.....

MOST SEVERE PRESENTATION

Please specify type & 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**

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

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 older affected)

Family code ⁹

Subject ID code ¹⁰

Date of birth ¹¹

/ /

Sex

Male

Female

ABO blood group ¹²

O group

non O group

Bleeding symptoms

Epistaxis	No	Trivial ¹⁶	N.E. ¹⁷	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

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

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	
Notes

MOST SEVERE PRESENTATION	
Duration of episode (min.)	one to ten minutes more than ten minutes
Required medical attention?	Yes No
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Notes

Bleeding symptoms

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 & 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 & tongue	
Required medical attention?	Yes	No
if yes, please specify		
Consultation only		
Surgical hemostasis		
Blood transfusion		
Notes	

Bleeding symptoms

Gastrointestinal bleeding	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

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.

Bleeding after first extraction	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			

Bleeding after second extraction	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			

Bleeding after third extraction	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			

MOST SEVERE BLEEDING AFTER EXTRACTION				
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.

Bleeding after first surgery	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			
			

Bleeding after second surgery	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			
			

Bleeding after third surgery	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			
			

MOST SEVERE BLEEDING AFTER SURGERY				
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.

Bleeding after first delivery	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			
			

Bleeding after second delivery	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			
			

Bleeding after third delivery	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			
			

MOST SEVERE BLEEDING AFTER DELIVERY		
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

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	
	

Second control subject

(matched to the younger affected)

Family code ⁹

Subject ID code ¹⁰

Date of birth ¹¹

/ /

Sex

Male

Female

ABO blood group ¹²

O group

non O group

Bleeding symptoms

Epistaxis	No	Trivial ¹⁶	N.E. ¹⁷	Yes
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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
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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
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if yes, please specify

Consultation only

Cauterization

Packing

Blood transfusion

Notes

Bleeding symptoms

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

Bleeding from minor wounds	No	Trivial	N.E.	Yes
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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	
Notes

MOST SEVERE PRESENTATION	
Duration of episode (min.)	one to ten minutes more than ten minutes
Required medical attention?	Yes No
if yes, please specify	
Surgical hemostasis	
Blood transfusion	
Notes

Bleeding symptoms

Oral cavity bleeding	No	Trivial	N.E.	Yes
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If yes, please fill in the following boxes

AVERAGE PRESENTATION		
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	

MOST SEVERE PRESENTATION		
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

Gastrointestinal bleeding	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

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.

Bleeding after first extraction	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			

Bleeding after second extraction	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			

Bleeding after third extraction	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			
			

MOST SEVERE BLEEDING AFTER EXTRACTION				
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.

Bleeding after first surgery	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			
			

Bleeding after second surgery	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			
			

Bleeding after third surgery	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			
			

MOST SEVERE BLEEDING AFTER SURGERY				
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.

Bleeding after first delivery	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			
			

Bleeding after second delivery	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			
			

Bleeding after third delivery	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			
			

MOST SEVERE BLEEDING AFTER DELIVERY		
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

Other bleedings	No	Trivial	N.E.	Yes
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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	
	

Questionnaire instructions

Important note: one single carrier should be chosen for each family, if more are available

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 chosen obligatory carrier
3. Give number of family members (first degree relatives of the chosen obligatory carrier) actually investigated at your Center; must be less or equal than the number reported in ²
4. Give number of family members (first degree relatives of the chosen obligatory carrier) identified as symptomatic; must be less or equal than the number reported in ³
5. Report if available
6. Report inheritance as based on bleeding history
7. Report if available
8. Report if available
9. Same as ¹
10. Enter the code of subjects as follows: 00=obligatory carrier; 01=older affected; 02=younger affected. Use A1, A2, A3, etc. as subject 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 members or carrier at a specialized center independently from the time on which a specific diagnosis was established (see also Section 2.2 of the 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 the 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.