MOLECULAR & CLINICAL MARKERS FOR THE DIAGNOSIS & MANAGEMENT OF TYPE 1 VON WILLEBRANDS DISEASE – (MCMDM – 1VWD)

1.1 Centre ☐ ☐

1.2 Family code ☐ ☐

1.3 Generation ☐

1.4 Subject code ☐ ☐

1.5 Date of birth ☐ ☐/☐ ☐/☐ ☐

1.6 Male ☐ Female ☐

1.7 ABO blood group O group ☐ non O group ☐

	Laboratory measurement	Value	Unit	Reference Range		Min.	Max.	Median
				From	To			
1.8	FVIII:C							
1.9	VWF:Ag							
1.10	VWF:RiCof							
1.11	Collagen binding assay							
1.12	Platelet count							
1.13	Bleeding time							

1.14 Multimers ……………………………………………

1.15 Other tests ………………………………………
………………………………………

1.16 Diagnosis at age ☐ ☐

Values to be registered here are those already available in the patient file

2.1	**Epistaxis**	No ☐	Yes ☐

If yes, please fill in the following boxes

Summary of Episodes

2.2	Number episodes/year	☐ less than 1 ☐ 1-5 ☐ 6-12 ☐ more than 12	
2.3	Duration of average single episode (min.)	☐ 1-5 min ☐ 5-10 min ☐ more than 10 min	
2.4	Cessation	☐ spontaneous ☐ after short compression ☐ by medical intervention	
2.5	Age of maximum severity	☐ less than 14 years ☐ 14 to 45 years ☐ more than 45 years	
2.6	Ever required medical attention ?	☐ Yes	☐ No
	If yes, please specify from the following		
2.7	Consultation only	☐ Yes	☐ No
2.8	Cauterization	☐ Yes	☐ No
2.9	Packing	☐ Yes	☐ No
2.10	Blood transfusion	☐ Yes	☐ No
2.11	Antifibrinolytic agents	☐ Yes	☐ No
2.12	Replacement therapy	☐ Yes	☐ No
2.13	If yes, please specify	…………………………………………………………………	
2.14	Desmopressin	☐ Yes	☐ No
2.15	Other therapies	☐ Yes	☐ No
	If yes, please specify	………………………………………………………………..	
2.16	Notes	………………………………………………………………… …………………………………………………………………	

 Partner No. ☐ ☐ Family Code ☐ ☐ Subject code ☐ ☐

3.1	**Cutaneous symptoms**	No ☐	Yes ☐

If yes, please fill in the following boxes

Summary of Episodes

3.2	Number episodes/year (average)	☐ ☐	
3.3	Average diameter of lesion	☐< 1 cm ☐ 1 - 3 cm ☐ >3 cm	
3.4	Type		
	Petechiae	☐ Yes	☐ No
	Bruises	☐ Yes	☐ No
	Subcutaneous hematoma	☐ Yes	☐ No
3.5	Occuring after minimal or no trauma	☐ Yes	☐ No
3.6	Ever required medical attention ?	☐ Yes	☐ No
3.7	Consultation only	☐ Yes	☐ No
3.8	Other therapies	☐ Yes	☐ No
	If yes, please specify	………………………………………………………………………	
3.9	Notes	………………………………………………………………………	
		………………………………………………………………………	

4.1	**Bleeding from minor wounds**	No ☐	Yes ☐

If yes, please fill in the following boxes

Summary of Episodes

4.2	Number episodes/year	☐ less than 1 ☐ 1-5 ☐ 6-12 ☐ more than 12	
4.3	Duration of average single episode (min.)	☐ 1-5 min ☐ more than 5 min	
4.4	Ever required medical attention ?	☐ Yes	☐ No
	If yes, please specify from the following		
4.5	Surgical hemostasis	☐ Yes	☐ No
4.6	Blood transfusion	☐ Yes	☐ No
4.7	Replacement therapy	☐ Yes	☐ No
4.8	If yes, please specify	…………………………………………………………………	
4.9	Desmopressin	☐ Yes	☐ No
4.10	Antifibrinolytic agents	☐ Yes	☐ No
4.11	Others therapies	☐ Yes	☐ No
	If yes, please specify	…………………………………………………………………	
4.12	Notes	………………………………………………………………… …………………………………………………………………	

5.1	**Oral cavity bleeding**	No ☐	Yes ☐

If yes, please fill in the following boxes

Summary of Episodes

5.2	Type of bleeding		
	Tooth eruption	☐ Yes	☐ No
	Gums, spontaneous	☐ Yes	☐ No
	Gums, after brushing	☐ Yes	☐ No
	Bites to lip & tongue	☐ Yes	☐ No
5.3	Ever required medical attention ?	☐ Yes	☐ No
	If yes, please specify from the following		
5.4	Consultation only	☐ Yes	☐ No
5.5	Surgical hemostasis	☐ Yes	☐ No
5.6	Blood transfusion	☐ Yes	☐ No
5.7	Replacement therapy	☐ Yes	☐ No
5.8	If yes, please specify	…………………………………………………………………	
5.9	Desmopressin	☐ Yes	☐ No
5.10	Antifibrinolytic agents	☐ Yes	☐ No
5.11	Others therapies	☐ Yes	☐ No
	If yes, please specify	………………………………………………………………....	
5.12	Notes	……………………………………………………………………..	
		……………………………………………………………………..	

6.1	**Gastrointestinal bleeding**	No ☐	Yes ☐

If yes, please fill in the following boxes   * IN THE BOXES, REPORT THE NUMBER OF EPISODES

Summary of Episodes

6.2	Number of episodes	☐☐	
6.3	Type of bleeding		
	Haematemesis*	☐	
	Melana*	☐	
	Hematochezia*	☐	
6.4	Presence of associated GI disease	☐ Yes	☐ No
6.5	If yes, please specify from the following		
	Ulcer	☐ Yes	☐ No
	Portal hypertension	☐ Yes	☐ No
	Angiodysplasia	☐ Yes	☐ No
	Diverticulosis	☐ Yes	☐ No
	Hemorrhoids	☐ Yes	☐ No
6.6	Ever required medical attention ? If yes, please specify from the following:	☐ Yes	☐ No
6.7	Consultation only	☐ Yes	☐ No
6.8	Surgical hemostasis	☐ Yes	☐ No
6.9	Blood transfusion	☐ Yes	☐ No
6.10	Replacement therapy	☐ Yes	☐ No
6.11	If yes, please specify	…………………………………………………………………	
6.12	Desmopressin	☐ Yes	☐ No
6.13	Antifibrinolytic agents	☐ Yes	☐ No
6.14	Others therapies	☐ Yes	☐ No
	If yes. please specify	…………………………………………………………………	
6.15	Notes	…………………………………………………………………	
		…………………………………………………………………	

7.1	**Tooth extraction**	No ☐	Yes ☐
7.2	Total number of tooth extractions	☐☐	
7.3	Number of tooth extractions followed by bleeding	☐☐	

	Type of extraction		
7.4	Permanent	……N° without hemorrhage**	……N° with hemorrhage**
7.5	Molar	……N° without hemorrhage**	……N° with hemorrhage**
7.6	Actions taken to control bleeding*:		
	None	N°…….	
	Resuturing	N°…….	
	Packing	N°…….	
	Blood transfusion	N°…….	
7.7	Replacement therapy	☐ Yes	☐ No
7.8	If yes, please specify	N°…………product …………………………………	
7.9	Desmopressin	☐ Yes	☐ No
		N°……….. specify………………………..	
7.10	Others therapies	☐ Yes	☐ No
	If yes, please specify	…………………………………………………………………………...	
7.11	Significant bleeding after decidous tooth extraction:	☐ Yes	☐ No
7.12	Notes	…………………………………………………………………………..	
		…………………………………………………………………………..	

*Specify how many times each procedure has been carried out (e.g. if 5 teeth were extracted and in all of them no action was required to control bleeding, complete None: N° ..5..; on the contrary, if for example in one of them a resuturing was required: Resuturing N° ..1.. The sum will not necessarily total to 5 because more actions could have been required for a single extraction).

** State the number as appropriate.

8.1	**Surgery**	No ☐	Yes ☐
8.2	Total number of surgeries	☐☐	
8.3	Number of surgeries followed by bleeding	☐☐	

Surgery – 1

8.4 Age at surgery ☐☐

8.5 Bleeding ☐ No ☐ Yes

8.6 Type of surgery
- ☐ Cesarean section
- ☐ Tonsillectomy/Adenoids
- ☐ Pharynx/Nose
- ☐ Circumcision
- ☐ Major-abdominal
- ☐ Major-thoracic
- ☐ Major-gynecology
- ☐ Other

8.7 Prophylaxis before surgery
- ☐ None
- ☐ Desmopressin
- ☐ Replacement therapy

8.8 If yes, please specify…………………………………………….

8.9 Action taken to control bleeding
- ☐ None
- ☐ Resuturing/surgical
- ☐ Blood transfusion
- ☐ Desmopressin
- ☐ Antifibrinolytic agents
- ☐ Replacement therapy

8.10 If yes, please specify………………………………………………

8.11 Other therapies ☐ Yes ☐ No

If yes, please specify ……………………………………………………………………

8.12 Notes ……………………………………………………………………..

……………………………………………………………………..

Surgery – 2

8.13 Age at surgery ☐☐

8.14 Bleeding ☐ No ☐ Yes

8.15 Type of surgery

- ☐ Cesarean section
- ☐ Tonsillectomy/Adenoids
- ☐ Pharynx/Nose
- ☐ Circumcision
- ☐ Major-abdominal
- ☐ Major-thoracic
- ☐ Major-gynecology
- ☐ Other

8.16 Prophylaxis before surgery

- ☐ None
- ☐ Desmopressin
- ☐ Replacement therapy

8.17 If yes, please specify……………………………………………….

8.18 Action taken to control bleeding

- ☐ None
- ☐ Resuturing/surgical
- ☐ Blood transfusion
- ☐ Desmopressin
- ☐ Antifibrinolytic agents
- ☐ Replacement therapy

8.19 If yes, please specify…………………………………………………

8.20 Other therapies ☐ Yes ☐ No

If yes, please specify ……………………………………………………………………………

8.21 Notes ……………………………………………………………………………..

……………………………………………………………………………..

Surgery – 3

8.22 Age at surgery ☐☐

8.23 Bleeding ☐ No ☐ Yes

8.24 Type of surgery
- ☐ Cesarean section
- ☐ Tonsillectomy/Adenoids
- ☐ Pharynx/Nose
- ☐ Circumcision
- ☐ Major-abdominal
- ☐ Major-thoracic
- ☐ Major-gynecology
- ☐ Other

8.25 Prophylaxis before surgery
- ☐ None
- ☐ Desmopressin
- ☐ Replacement therapy

8.26 If yes, please specify…………………………………………………

8.27 Action taken to control bleeding
- ☐ None
- ☐ Resuturing/surgical
- ☐ Blood transfusion
- ☐ Desmopressin
- ☐ Antifibrinolytic agents
- ☐ Replacement therapy

8.28 If yes, please specify…………………………………………………

8.29 Other therapies ☐ Yes ☐ No

If yes, please specify ……………………………………………………………………………

8.30 Notes ……………………………………………………………………………..

……………………………………………………………………………..

9.1	**Post-partum hemorrhage**	No ☐	Yes ☐

9.2	Total number of deliveries	☐☐
9.3	Number of deliveries followed by bleeding	☐☐

9.4	Bleeding after delivery	☐ No	☐ Yes
	If yes, please complete:		
9.5	Action taken to control bleeding*		
	None	N° ……..	
	Dilatation & curettage	N° ……..	
	Hysterectomy	N° …….	
	Blood transfusion	N° …….	
	Desmopressin	N° …….	
9.6	Replacement therapy	☐ Yes	☐ No
9.7	If yes, please specify	…………………………………………………………………………..	
9.8	Other specify	☐ Yes	☐ No
	If yes, please specify	…………………………………………………………………………..	
9.9	Notes	………………………………………………………………………… …………………………………………………………………………	

*Cross as appropriate and specify how many times each procedure has been carried out (e.g. if 3 deliveries occurred and in all of them no action was required to control bleeding: None: N° ..3..; on the contrary, if for example in one of them a blood transfusion was required: N° ..1.. The sum will not necessarily total 3 because more actions could have been required for a single delivery).

	History of Abortions		
9.11	Abortions	☐ Yes	☐ No
9.12	If yes, any profuse bleeding?	☐ Yes	☐ No
9.13	Treatment required	…………………………………………………………………..	
9.14	Notes	………………………………………………………………………… …………………………………………………………………………	

10.1	**Muscle hematomas**	No ☐	Yes ☐

If yes, please fill in the following boxes

Summary of Episodes			
10.2	Please specify type & location	……………………………………………………………………… ……………………………………………………………………… ……………………………………………………………………… ………………………………………………………………………	
10.3	Spontaneous?	☐ Yes	☐ No
10.4	Ever required medical attention?	☐ Yes	☐ No
	If yes, please specify	………………………………………………………………………..	
10.5	Blood transfusion	☐ Yes	☐ No
10.6	Desmopressin	☐ Yes	☐ No
10.7	Replacement therapy	☐ Yes	☐ No
10.8	If yes, please specify	………………………………………………………………………..	
10.9	Others	☐ Yes	☐ No
	If yes, please specify	………………………………………………………………………..	
10.10	Notes	……………………………………………………………………… ………………………………………………………………………	

11.1	**Hemarthrosis**	No ☐	Yes ☐

If yes, please fill in the following boxes

Summary of Episodes

11.2	Please specify type & location	……………………………………………………………… ……………………………………………………………… ……………………………………………………………… ………………………………………………………………	
11.3	Spontaneous?	☐ Yes	☐ No
11.4	Traumatic ?	☐ Yes	☐ No
11.5	Ever required medical attention?	☐ Yes	☐ No
	If yes, please specify	………………………………………………………	
11.6	Blood transfusion	☐ Yes	☐ No
11.7	Desmopressin	☐ Yes	☐ No
11.8	Replacement therapy	☐ Yes	☐ No
11.9	If yes, please specify	……………………………………………………………….	
11.10	Other therapies	☐ Yes	☐ No
	If yes, please specify	………………………………………………………………	
11.11	Notes	……………………………………………………………… ………………………………………………………………	

12.1	**Other bleeding**	No ☐	Yes ☐

If yes, please fill in the following boxes

Summary of Episodes			
12.2	Please specify type of bleeding - 1	……………………………………………………………………… ……………………………………………………………………… ……………………………………………………………………… ………………………………………………………………………	
12.3	Actions taken to control bleeding*		
12.4	Blood transfusion	N° …….	
12.5	Iron therapy	N° …….	
12.6	Desmopressin	N° …….	
12.7	Replacement therapy	☐ Yes	☐ No
12.8	If yes, please specify	……………………………………………………………..	
12.9	Antifibrinolytics agents	N° …….	
12.10	Other therapies	☐ Yes	☐ No
	If yes, please specify	………………………………………………………………………	
12.11	Please specify type of bleeding - 2	……………………………………………………………………… ……………………………………………………………………… ………………………………………………………………………	
12.12	Actions taken to control bleeding*		
12.13	Blood transfusion	N° …….	
12.14	Iron therapy	N° …….	
12.15	Desmopressin	N° …….	
12.16	Replacement therapy	☐ Yes	☐ No
12.17	If yes, please specify	……………………………………………………………..	
12.18	Antifibrinolytics agents	N° …….	
12.19	Other therapies	☐ Yes	☐ No
	If yes, please specify	………………………………………………………………………	

* Specify how many times each procedure has been carried out.

13.1	**Menorrhagia**	No ☐	Yes ☐

If history of menorrhagia, fill in the following boxes

Summary of Episodes			
13.2	Age of menarche	☐☐	
13.3	Present duration of average mentstruation (days)	☐☐	
13.4	Duration of heavy days	☐☐	
13.5	Age when menstruation became heavy	☐☐	
13.6	Ever required medical attention If yes, please specify from the following	☐ Yes	☐ No
13.7	Consultation only	☐ Yes	☐ No
13.8	Pill use	☐ Yes	☐ No
13.9	Dilatation & curettage	☐ Yes	☐ No
13.10	Hysterectomy	☐ Yes	☐ No
13.11	Blood transfusion	☐ Yes	☐ No
13.12	Iron therapy	☐ Yes	☐ No
13.13	Tranexamic	☐ Yes	☐ No
13.14	Desmopressin*	☐ Yes	☐ No
13.15	Replacement therapy**	☐ Yes	☐ No
13.16	Notes	…………………………………………………………………… …………………………………………………………………… ……………………………………………………………………	

* specify approximately number of cycles treated with desmopressin ☐☐

** specify approximately number of cycles treated with replacement therapy ☐☐