CRF **CONGENITAL FIBRINOGEN DISORDERS**	**Dr** …… **City** …… **Center** …… **E-mail** …… **Date of report** ☐☐☐☐☐☐☐☐

Propositus:	Last name three first letters: ……..... First name three first letters: ……..... Nationality……..... Ethnic origin……	Gender:	F ☐ M ☐
		Date of birth:	☐☐☐☐☐☐☐☐
Date of diagnosis:	☐☐☐☐☐☐☐☐	Date of last follow-up:	☐☐☐☐☐☐☐☐

DIAGNOSIS

CIRCUMSTANCES OF DIAGNOSIS			
Familial screening	☐	Tooth extraction	☐
Incidental finding	☐	Other sites of bleeding	☐
Before surgery	☐	Pregnancy	☐
After surgery	☐	Thrombosis	☐
Umbilical cord bleeding	☐	Unknown	☐
Menorrhagia	☐	Other, please specify.....	

MOLECULAR DIAGNOSIS

Molecular assessment	Yes ☐ No ☐ Unknown ☐		
Date of analysis	☐☐☐☐☐☐☐☐	***Place of analysis***	……..

Heterozygous ☐ ***Homozygous*** ☐ ***NA*** ☐				
Gene	FGA ☐	FGB ☐	FGG ☐	NA ☐
Exon	……		NA ☐	
Nucleotide change (cDNA)	……		NA ☐	
Amino acid change (with peptide signal)	……		NA ☐	

LABORATORY AT DIAGNOSIS

Tests		***Tests***	
Fibrinogen clottable (g/l)	..... NA ☐	Factor V (%)	..... NA ☐
Fibrinogen antigen (g/l)	..... NA ☐	Factor VII (%)	..... NA ☐
Platelet count (G/l)	..... NA ☐	Factor VIII (%)	..... NA ☐
PT (% or ratio)	..... NA ☐	Factor IX (%)	..... NA ☐
INR	..... NA ☐	Factor X (%)	..... NA ☐
aPTT (s)	..... Range..... NA ☐	Factor VII-X (%)	..... NA ☐
Thrombin time (s)	..... NA ☐	Factor XI (%)	..... NA ☐
Reptilase time (s)	..... NA ☐	Factor XII (%)	..... NA ☐
Factor II (%)	..... NA ☐	Factor XIII (%)	..... NA ☐
PFA ADP (s)	..... NA ☐	PFA EPI (s)	..... NA ☐
FvW:Ag (%)	..... NA ☐	FvW:RCo (%)	..... NA ☐
ABO Blood group			

MEDICAL HISTORY

PAST AND RECENT MEDICAL HISTORY	Yes	No	Unknown
Heart insufficiency	☐	☐	☐
Atrial fibrillation	☐	☐	☐
Chronic obstructive pulmonary disease	☐	☐	☐
Pulmonary hypertension	☐	☐	☐
Chronic kidney disease	☐	☐	☐
HIV	☐	☐	☐
Viral hepatitis (HBV, HCV)	☐	☐	☐
Liver disease	☐	☐	☐
Amyloidosis	☐	☐	☐
Cancer, please specify ……..	☐	☐	☐

DEATH	Yes ☐ No ☐	
Date of the event (dd/mm/yr): ☐☐/☐☐/☐☐☐☐		
Cause :	Arterial thrombosis	☐
	Venous thromboembolism	☐
	Bleeding	☐
	Cancer	☐
	Infection	☐
	Unknown	☐
	Other, please specify……..	☐

VENOUS THROMBOEMBOLISM (VTE)

VTE	Yes ☐ No ☐ Unknown ☐

RISK FACTORS FOR PROVOKED VTE			
Malignancy	1	Pregnancy or post-partum	2
Surgery < 3 months	3	After fibrinogen substitution (cryoprecipitate)	4
Estrogen therapy or contraception	5	After fibrinogen substitution (concentrate)	6
Obesity	7	Prolonged immobility	8
Other (please specify).....	9	Please fill corresponding number in the list	

TYPE OF VTE	Dates (yr)	Idiopathic	Risk factors	Anticoagulation duration (months)
Deep venous thrombosis of limbs	☐☐☐☐	☐		.....NA☐
	☐☐☐☐	☐		.....NA☐
	☐☐☐☐	☐		.....NA☐
Pulmonary embolism	☐☐☐☐	☐		.....NA☐
	☐☐☐☐	☐		.....NA☐
	☐☐☐☐	☐		.....NA☐
Superficial phlebitis	☐☐☐☐	☐		.....NA☐
	☐☐☐☐	☐		.....NA☐
	☐☐☐☐	☐		.....NA☐
Cerebral sinus thrombosis	☐☐☐☐	☐		.....NA☐
	☐☐☐☐	☐		.....NA☐
	☐☐☐☐	☐		.....NA☐
Other, please specify.....	☐☐☐☐	☐		.....NA☐
.....	☐☐☐☐	☐		.....NA☐

LABORATORY EVALUATION OF THROMBOPHILIA	Yes	No	Unknown
Factor V Leiden	☐	☐	☐
Prothrombin G20210A	☐	☐	☐
Antithrombin deficiency	☐	☐	☐
Protein C deficiency	☐	☐	☐
Protein S deficiency	☐	☐	☐
JAK2V617F	☐	☐	☐
Lupus anticoagulant	☐	☐	☐
Anticardiolipin antibodies	☐	☐	☐
Anti-β2-glycoprotein antibodies	☐	☐	☐

ARTERIAL THROMBOSIS (AT)

AT	Yes ☐ No ☐ Unknown ☐

TYPE OF ARTERIAL THROMBOSIS	Dates (yr)	Under fibrinogen substitution	Treated with antiplatelet agents
Ischemic stroke	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
Acute coronary syndrome	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
Arterial occlusion of extremities	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
Mesenteric artery occlusion	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
Renal artery occlusion	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
Other, please specify ……	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
.....	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐
.....	☐☐☐☐	Yes ☐ No ☐ NA ☐	Yes ☐ No ☐ NA ☐

CVD RISK FACTOR	Yes	No	Unknown
Dyslipidemia	☐	☐	☐
Current or past smoker	☐	☐	☐
Diabetes	☐	☐	☐
Hypertension	☐	☐	☐
Obesity (BMI>30)	☐	☐	☐
Familial history	☐	☐	☐

OBSTETRIC HISTORY

Gravidity n°…………… NA ☐	***Parity n°…………… NA*** ☐

Ongoing pregnancy	Yes ☐ No ☐ Unknown ☐
Gestational Age (GA)…………………	Fibrinogen prophylaxis Yes ☐ No ☐

PAST PREGNANCY (yr)	In utero death (GA)	Succesfull deliveries (GA)	Fibrinogen prophylaxis: Fibrinogen concentrate (FC) Cryopreciptate (CR)	Bleeding complication requiring medical treatment
☐☐☐☐	☐ GA………	☐ GA………	Yes ☐ No ☐ NA ☐ CR ☐ FC ☐ Other ☐	Yes ☐ No ☐ NA ☐ <24h ☐ >24h ☐ after delivery
☐☐☐☐	☐ GA………	☐ GA………	Yes ☐ No ☐ NA ☐ CR ☐ FC ☐ Other ☐	Yes ☐ No ☐ NA ☐ <24h ☐ >24h ☐ after delivery
☐☐☐☐	☐ GA………	☐ GA………	Yes ☐ No ☐ NA ☐ CR ☐ FC ☐ Other ☐	Yes ☐ No ☐ NA ☐ <24h ☐ >24h ☐ after delivery
☐☐☐☐	☐ GA………	☐ GA………	Yes ☐ No ☐ NA ☐ CR ☐ FC ☐ Other ☐	Yes ☐ No ☐ NA ☐ <24h ☐ >24h ☐ after delivery
☐☐☐☐	☐ GA………	☐ GA………	Yes ☐ No ☐ NA ☐ CR ☐ FC ☐ Other ☐	Yes ☐ No ☐ NA ☐ <24h ☐ >24h ☐ after delivery
☐☐☐☐	☐ GA………	☐ GA………	Yes ☐ No ☐ NA ☐ CR ☐ FC ☐ Other ☐	Yes ☐ No ☐ NA ☐ <24h ☐ >24h ☐ after delivery

SURGERY

Past surgery	Yes ☐ No ☐ Unknown ☐

TYPE OF SURGERY	Dates (yr)	Fibrinogen prophylaxis: Fibrinogen concentrate (FC) Cryoprecipitate (CR)	Bleeding complication requiring medical attention
…………………………………….. ……………………………………..	☐☐☐☐	Yes ☐ No ☐ NA ☐ CR ☐ FC ☐ Other ☐	Yes ☐ No ☐ NA ☐
…………………………………….. ……………………………………..	☐☐☐☐	Yes ☐ No ☐ NA ☐ CR ☐ FC ☐ Other ☐	Yes ☐ No ☐ NA ☐
…………………………………….. ……………………………………..	☐☐☐☐	Yes ☐ No ☐ NA ☐ CR ☐ FC ☐ Other ☐	Yes ☐ No ☐ NA ☐
…………………………………….. ……………………………………..	☐☐☐☐	Yes ☐ No ☐ NA ☐ CR ☐ FC ☐ Other ☐	Yes ☐ No ☐ NA ☐
…………………………………….. ……………………………………..	☐☐☐☐	Yes ☐ No ☐ NA ☐ CR ☐ FC ☐ Other ☐	Yes ☐ No ☐ NA ☐
…………………………………….. ……………………………………..	☐☐☐☐	Yes ☐ No ☐ NA ☐ CR ☐ FC ☐ Other ☐	Yes ☐ No ☐ NA ☐

BLEEDING SYMPTOMS

Bleeding symptoms	Yes ☐ No ☐ Unknown ☐

BLEEDING SITES ***Requiring medical attention***	Present	Treatement (on demand)		Bleeding on prophylactic treatment Fibrinogen concentrate (FC) Cryoprecipitate (CR)
		Fibrinogen substitution	Other	
Umbillical cord	☐	☐ ☐ Number of events during life……		CR ☐ FC ☐ Other ☐
Cutaneous	☐	☐ ☐ Number of events during life……		CR ☐ FC ☐ Other ☐
Hematuria	☐	☐ ☐ Number of events during life……		CR ☐ FC ☐ Other ☐
Minor wounds	☐	☐ ☐ Number of events during life……		CR ☐ FC ☐ Other ☐
Oral cavity	☐	☐ ☐ Number of events during life……		CR ☐ FC ☐ Other ☐
GI bleeding	☐	☐ ☐ Number of events during life……		CR ☐ FC ☐ Other ☐
Tooth extraction	☐	☐ ☐ Number of events during life……		CR ☐ FC ☐ Other ☐
Menorrhagia	☐	☐ ☐ Number of events during life……		CR ☐ FC ☐ Other ☐
Muscle hematomas	☐	☐ ☐ Number of events during life……		CR ☐ FC ☐ Other ☐
Hemarthrosis	☐	☐ ☐ Number of events during life……		CR ☐ FC ☐ Other ☐
CNS	☐	☐ ☐ Number of events during life……		CR ☐ FC ☐ Other ☐
Epistaxis	☐	☐ ☐ Number of events during life……		CR ☐ FC ☐ Other ☐
Other, please specify…… ……				

LONG TERM PROPHYLAXIS TREATMENT

Long term prophylaxis	Yes ☐ No ☐ Unknown ☐	
Reasons for long term prophylaxis	Frequent bleeding ☐ CNS bleeding ☐ Other ☐	
Date of start (dd/mm/year)	☐☐☐☐☐☐☐☐	
Type of treatment and doses	Fibrinogen concentrate (FC) ☐ Dose ……	Cryoprecipitate (CR) ☐ Dose ……
Time interval between infusion	……	
Anti-fibrinogen antibodies	Yes ☐ No ☐ Not tested ☐	

FAMILY MEMBER

If possible, please fill a survey for each family member with fibrinogen disorder

Parents consanguinity	Yes ☐ No ☐ Unknown ☐
Other family member with fibrinogen disorder	Yes ☐ No ☐ Unknown ☐
First name three first letters:…………………… Last name three first letters:……………………… Date of birth ☐☐☐☐☐☐☐☐ Family relationship…………………………………..	Bleeding symptoms Yes ☐ No ☐ Unknown ☐ Thrombosis Yes ☐ No ☐ Unknown ☐ Death Yes ☐ No ☐ Unknown ☐
First name three first letters:…………………… Last name three first letters:……………………… Date of birth ☐☐☐☐☐☐☐☐ Family relationship…………………………………..	Bleeding symptoms Yes ☐ No ☐ Unknown ☐ Thrombosis Yes ☐ No ☐ Unknown ☐ Death Yes ☐ No ☐ Unknown ☐
First name three first letters:…………………… Last name three first letters:……………………… Date of birth ☐☐☐☐☐☐☐☐ Family relationship…………………………………..	Bleeding symptoms Yes ☐ No ☐ Unknown ☐ Thrombosis Yes ☐ No ☐ Unknown ☐ Death Yes ☐ No ☐ Unknown ☐
First name three first letters:…………………… Last name three first letters:……………………… Date of birth ☐☐☐☐☐☐☐☐ Family relationship…………………………………..	Bleeding symptoms Yes ☐ No ☐ Unknown ☐ Thrombosis Yes ☐ No ☐ Unknown ☐ Death Yes ☐ No ☐ Unknown ☐

COMMENTS
……… ……… ……… ……… ……… ……… ……… ……… ……… ……… ……… ……… ……… ……… ……… ………

Please send the completed questionnaire to:

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