

SECTION 1.1: DEMOGRAPHY & DIAGNOSTIC INFORMATION

Centre ID: _____ Patient ID: _____

Patient Information

Name : _____

Hospital # : _____ Contact Address : _____

Phone 1: _____ Phone 2: _____

Country : _____

E-Mail : _____

Patient ID Number : _____

Centre ID Number : _____

Treater Information

Name of Hemophilia Treatment Center (HTC) : _____

Physician Responsible : _____

Institution : _____

Primary E-Mail : _____ Office Address : _____

Secondary E-Mail : _____

Phone : _____

Fax : _____

Website : _____

Baseline Characteristics

| | | |
|---|-------------------------------|--------------------------------|
| Information Given By : _____ | Date of Birth : _____ | Sex : _____ |
| Date of Baseline Data Collection : _____ | Severity : _____ | Measured Activity Date : _____ |
| Hemophilia Type : _____ | Result : % FVIII / IX:C _____ | Lab or Hosp Name : _____ |
| Measured Clotting Factor Activity : _____ | Blood Group : _____ | Rh : _____ |
| Twin with same deficiency : _____ | HCV Antibody : _____ | HCV PCR : _____ |
| HIV Status : _____ | Hemophilia A : _____ | Intron 22 Inversion : _____ |
| Mutation Known : _____ | | |

Mutation Comment

Personal Details

Weight (3 digits, 1 decimal) : _____ Height (3 digits, 1 decimal) : _____ Highest Education Completed : _____

If Primary/Secondary, Enter grade 1–12 : _____ If other, specify : _____

Employment Status : _____ If other, specify : _____

HTC Utilization : _____

¹ Adapted from WBDR / WFH (www.bleedingdisorderregistry.org)

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Centre ID: _____ Patient ID: _____

Health Insurance

Health Insurance : _____ If Others Specify : _____

Diagnostic Information

Date of Diagnosis : _____ Diagnosis : _____ If Others Specify : _____

Name of Lab / Hospital : _____

| | Test | Result | Date |
|--|-------|--------|-------|
| I. APTT (Activated partial thromboplastin time) | | | |
| 1. Control / Normal Range | _____ | _____ | _____ |
| 2. Mixing Study (1/2 + 1/2) | _____ | _____ | _____ |
| II. PT (Prothrombin time) | | | |
| 1. Control / Normal Range | _____ | _____ | _____ |
| 2. Mixing Study (1/2 + 1/2) | _____ | _____ | _____ |
| III. TT | | | |
| _____ | _____ | _____ | _____ |
| IV. Platelet Count | | | |
| _____ | _____ | _____ | _____ |

Factor assays done during coagulation workup : _____

| Factor Assay | | | |
|---------------------|-------|-------|-------|
| Factor VIII | _____ | _____ | _____ |
| Factor IX | _____ | _____ | _____ |
| VWF RCo and Ag | _____ | _____ | _____ |
| Fibrinogen | _____ | _____ | _____ |
| Others | _____ | _____ | _____ |

