

SECTION 3.4: ANNUAL FOLLOW UP DATA

Patient ID: _____

Period of Reporting: _____

Information given by: Father Mother Patient Guardian
 Date Start: _____ Date Finish: _____
 Weight: _____ kg Height: _____ cm

Inhibitor status

Screen

- Done
- Not Done
- Test not available
- Unknown

Bethesda assay

- Done
- Not done
- Test not available
- Unknown

Nijmegen modification

- Done
- Not done
- Test not available
- Unknown

Result

- Positive
- Negative
- Unknown

_____ BU/ml

Date: _____

Date: _____

Date: _____

Bleeding & other interventions requiring factor replacement

Bleeding Events

Please indicate the number of bleeds in each category, for the entire reporting period

Total number of bleeds: _____

Joints

Muscle

- Total number of bleeds
- Spontaneous bleeds
- Traumatic bleeds
- Treated bleeds
- Untreated bleeds
- Life threatening bleeds

- | | | |
|----------------------------------|---|--|
| <input type="checkbox"/> None | <input type="checkbox"/> Iliopsoas muscle | <input type="checkbox"/> Intracranial hemorrhage |
| <input type="checkbox"/> Throat | | <input type="checkbox"/> Acute GI/abdominal |
| <input type="checkbox"/> Unknown | | <input type="checkbox"/> Others |

If others, specify

Comments:



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Episodic Factor Replacement Therapy

Please record each episode in which Replacement Therapy was used during the period. Do not include data that was entered in the first 50 Exposure table.

None Unknown

| Reason for replacement therapy** | Start date of therapy | End date of therapy | #Exposures* | Product type** | Brand name | Total dose received, IU/kg or ml | #days hospitalized for this episode |
|----------------------------------|-----------------------|---------------------|-------------|----------------|------------|----------------------------------|-------------------------------------|
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Prophylaxis Factor Replacement Therapy

Please record data on Prophylaxis Replacement Therapy used during the reporting period. Do not include data that was entered in the first 50 exposure table.

None Unknown

| Type of prophylaxis** | Start date of therapy | End date of therapy | #Exposures* | Product Type | Brand name | Dose of Prophylaxis, IU/kg or ml | Frequency** |
|-----------------------|-----------------------|---------------------|-------------|--------------|------------|----------------------------------|-------------|
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¹Adapted from WBDR/WFH (www.bleedingdisorderregistry.org)

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Surgery/ Other interventions requiring Factor Replacement Therapy

Please record any other intervention that the patient underwent requiring Factor Replacement Therapy during the reporting period. Do not include data that was entered in the first 50 Exposures, Episodic or Prophylaxis tables.

None Unknown

| Procedure | Start date of therapy | End date of therapy | #Exposures* | Product type** | Brand name | Total dose received, IU/kg or ml | #days hospitalized for this episode | Reason |
|-----------|-----------------------|---------------------|-------------|----------------|------------|----------------------------------|-------------------------------------|--------|
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| **Reason for replacement therapy | **Product type | **Type of prophylaxis | **Frequency |
|----------------------------------|------------------------|-----------------------------|--------------------|
| Bleed | Plasma, ml | Prophylaxis FVIII | Once a week |
| Trauma | Plasma-derived, IU/Kg | Prophylaxis FIX | Twice a week |
| Surgery | Recombinant, IU/Kg | Immune Tolerance Induction | Three times a week |
| Prophylaxis intermittent | Cryoprecipitate, IU/Kg | Prophylaxis Bypassing Agent | Four times a week |
| Prophylaxis continuous | Unknown | Other | Five times a week |
| Immune tolerance induction | Others | Unknown | Six times a week |
| Follow up | | | Seven times a week |
| Unknown | | | |

* An exposure is defined as a 24-hour period in which FVIII/IX containing product is given to a patient. (Blanchette, VS et al.2014)