



# WFH World Bleeding Disorders Registry QUICK REFERENCE GUIDE

To logon go to www.wfh.org/en/wbdr access

WBDR Support Team → WBDR@WFH.org

### **Patient Registration**

#### Registering a new patient

- 1. Click on the Register New Patient / Find Patient tab on the Menu Bar
- 2. Complete the bottom section of the page, under Register New Patient
- 3. Click on Register Patient

#### Searching for an existing patient

- 1. Click on the Register New Patient / Find Patient tab on the Menu Bar
- Search for the patient by entering the Patient ID number and click on
- 3. Select the patient in the results grid by clicking on the Patient ID number

#### Finding a patient when the Patient ID is forgotten

- Click on the Register New Patient / Find Patient tab on the Menu Bar
- Search for the patient by entering the patient's date of birth (in the format DD-MM-YY) in the

Search Criteria box

OR click on the calendar to the right of the Search

Criteria box and click on the patient's date of birth

3. Select the patient in the results grid by clicking on the Patient ID number

### Adding baseline data for a patient

Baseline data is data on the patient demographics, diagnosis and medical history. These data do not change over time.

- After you have Registered a new patient, you will be automatically directed to the Baseline Data page
- The Baseline Data page can also be found by clicking on the Patient Data tab on the menu bar Patient data\*, and then clicking on the Baseline Data sub-tab
- 3. Complete this page and press SAVE/NEXT Save/Next

### Adding baseline visit data for a patient

Baseline Visit captures data on all events the patient experienced for the past 6 months. This page is completed once per patient.

- After you have completed the Baseline Data page, pressed SAVE/NEXT, you will be automatically directed to the Baseline Visit page.
- The Baseline Visit page can also be found by clicking on the Patient Data tab on the menu bar and then clicking on the Baseline Visit sub-tab
- 3. Complete the page, including the hospitalization and treatment module if applicable, and press Save  $\stackrel{\square}{\hookrightarrow}$

# Adding follow up data for a patient

At each clinic visit after the baseline visit, a Follow Up visit in the database should be completed.

- 1. Search for and select your patient (see searching for an existing patient instructions)
- Clicking on the patient ID number from the results grid, and you will be automatically directed to Follow Up Visit page
- 3. Complete the page, including all related modules if applicable, and press



## **Patient Discharge**

If a patient is withdrawn from the WBDR for any reason, a Patient Discharge must be recorded.

- 1. Search for and select your patient (see searching for an existing patient instructions)
- 2. The Patient Discharge / Transfer page can be found by clicking on the Patient Data tab in the menu bar, and then clicking on the **Patient Discharge / Transfer** sub-tab
- B. Complete this page by adding the date of discharge and the reason for discharge and press
  - If the reason for discharge was death, a Patient Mortality page must also be completed

#### **Patient Transfer**

A patient can be transferred between HTCs if they receive care at more than 1 HTC.

- .. Search for and select your patient (See searching for an existing patient instructions)
- 2. The Patient Discharge / Transfer page can be found by clicking on the Patient Data tab in the menu bar, and then clicking on the Patient Discharge / Transfer sub-tab
- 3. Choose the HTC you want to transfer the patient to in the drop down list at the bottom of the window
- 4. Click on Transfer

### **Patient Mortality**

If a patient dies while enrolled in the WBDR, a Patient Mortality must be recorded.

- Search for and select your patient (see searching for an existing patient instructions)
- 2. The Patient Mortality page can be found by clicking on the Patient Data tab in the menu bar, and then clicking on the **Patient Mortality** sub-tab
- 3. Complete this page and press Save





# WFH World Bleeding Disorders Registry QUICK REFERENCE GUIDE

### **Adding data to Different Modules**

All Modules can be completed at the Baseline Visit and all Follow Up Visits.

At **Baseline Visit**: If you have selected YES to the followings question, please enter further information in each module accordingly:

- a. 'Inhibitor assessment in the past 6 months'
- 'Admission to hospital in the past 6 months' and a a message will be displayed: 'Please enter further information in module 'Admission to Hospital' below
- c. 'Treatment received in the past 6 months' and a message will be displayed: 'Please enter further information in module Treatment below'
- d. 'Did the patient experience any adverse events in the past 6 months'
- e. Height & Weight

At any of the **Follow Up Visits**: If you have selected YES to the followings question, please enter further information in each module accordingly:

- a. 'Inhibitor tesing since last clinic visit'
- 'Admission to hospital since the last clinic visit' and a message will be displayed: 'Please enter further information in module 'Admission to Hospital' below
- c. 'Any new treatment started, or change in existing treatment, since the last clinic visit'
- d. 'Did the patient experience any adverse events since the last clinic visit'
- e. Height & Weight

To add further information in each module:

- I. Scroll down to related module and press at the bottom of the table
- 2. Enter all required data in each module (see full details on the right)
- 3. Press Save/New, to save your data and add another treatment.
  Press Save/Close to save your data and close the module.
  Press Delete, to delete the data you entered and not save it.

Press Close, to close the module, and not save the data.

Save/New Save & Close Delete Close Clo

## Adding inhibitor data to the Inhibitor assessments Module

- 1. Enter the following data:
  - a. Date of test of inhibitor
  - b. Titre (BU/ml) only required for Bethesda and Nijmegen-Bethesda
  - c. Type of test

### Adding admission to hospital data to the Hospitalization Module

- 1. Enter the following data:
  - a. Start date of hospitalization
  - b. Number of days hospitalized (this is the number of nights spent in the hospital)
  - c. Reason for hospitalization
- If the hospitalization was ongoing at the time of the clinic visit, leave the number of days hospitalized blank. This can be completed when the patient leaves the hospital.

### Adding treatment data to the Treatments Module

- 1. Enter the following data:
  - a. Start Date f. Number of intakes
  - b. Indication g. Time un
  - c. Drug h. Reason for stopping treatment (if stopped during Follow Up Period)
  - d. Dose i. End date (if stopped during Follow Up Period)
  - e. Unit
- If the treatment was not stopped during the Follow Up Period, leave the reason and end date blank. These can be completed when the treatment is stopped.

### Adding adverse data to the Adverse events Module

- . Enter the following data:
  - a. Date of onset
  - b. Event
  - c. Date of resolution
  - d. Interventions
- . If the adverse event was not resolved during the Follow Up Period, leave date of resolution blank. It can be completed when the adverse event is resolved.

### Adding height & weight data to Height & Weight Module

- 1. Enter the following data:
  - a. Height
  - b. Weight