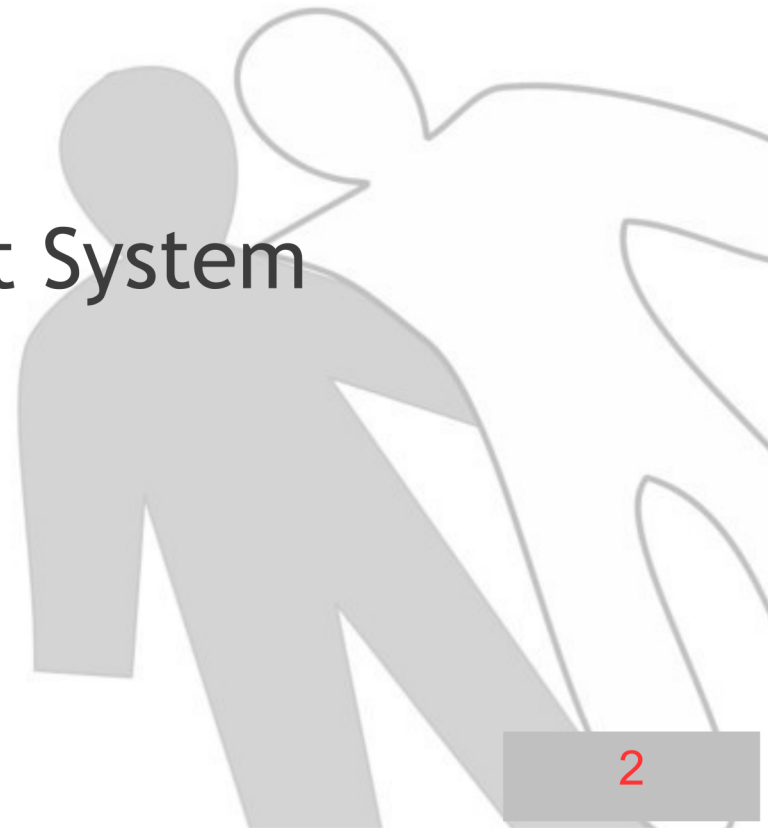


# National Hemophilia Registry Users Manual



- Accessing Registry
- Chapter Dashboard
- Viewing PWH Data
- Managing PWH Data
- Uploading Documents
- Data Verification Support System
- Contact NHR team



- Type <http://www.hemophiliaregistry.in> in your browser
- Username for chapter would be official email id provided by HFI.
  - For Example - Mysore [mysore@hemophilia.in](mailto:mysore@hemophilia.in)
  - For password please contact NHR team
  - Default password provided by NHR team needs to be changed for security reasons
  - This email id is part of registry, So all communication from registry team will be send to this official email id



## National Hemophilia Registry

User login

username

password

Login

Enter Username  
Password  
Click "Login" Button



I need Assistance

## National Hemophilia Registry (India)

NHR is a initiative of Hemophilia Federation(India) to create database of Person With Hemophilia India. Our National hemophilia organizations and hemophilia treatment centres are key partners in this network. Ours is a **Mixed systems** combining of Patient, Medical and Home Ministry registry.(WFH, National Patient Registry Guide by Bruce Evatt, MD).




- Dashboard is provides complete snapshots of chapter details.
  - **Block 1** Provides quick buttons to use registry (Page - 6)
  - **Block 2** Provides Important information about chapter (Page - 7)
  - **Block 3** Announcement help and tips (Page - 8)

# Chapter Dashboard

Header, Your Chapter name  
User who have logged in





**Hemophilia Society**  
(Affiliated to HFI and WFH)


Chapter


Welcome


Dashboard


  
PWH Members


  
Reports

  
Contact

  
Search

  
Chapter Report

  
Chapter Activity

  
DOWNLOAD

PwH Factorwise Count				
Factor 8	Factor 9	Others	Not Known	Tot Num
575	81	27	32	695

From NHR Team

Please use [Firefox](#) or [Chrome](#) to have safe browsing

Data to be Collected	
Data of Birth	115
Factor Deficiency	28
Blood Group	162
Father Name	25
Address	143
Phone number	202

View List

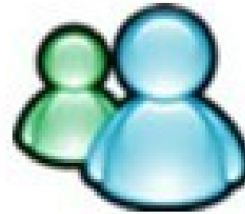
[Company](#) [Medicine Form](#)

NHR 2009

# Chapter Dash

Dashboard

Add/Modify/Upload PWH  
Details



PWH Members



Reports

Graphs/Reports

575

81

27

Mail for support in using  
Registry or other Quires



Search

Search Data

Factor Deficiency

Blood Group

Updation of chapter  
Activity and photo  
uploads

HFI Monthly Report  
Submission (only south)



Chapter Report



Chapter Activity

Phone number

Download of all PWH data  
In PDF Format



DOWNLOAD

[Company](#) [Medicine Form](#)

PwH Factorwise Count				
Factor 8	Factor 9	Others	Not Known	Tot Num
575	81	27	32	695

Glance of Chapter PWH Details  
Not Known indicates,  
data not available

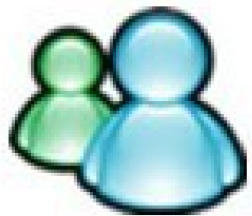
Data to be Collected	
Data of Birth	115
Factor Deficiency	28
Blood Group	162
Father Name	25
Address	143
Phone number	202
<a href="#">View List</a>	

Snapshot of data to be collected  
By chapter

This will list PWH name  
Along with data required  
By Registry

[Company](#) [Medicine Form](#)

## Dashboard



PWH Members



Reports



Search



Chapter Report



Chapter Activity



DOWNLOAD

### PwH Factorwise Count

Factor 8	Factor 9	Others	Not Known	Tot Num
575	81	27	32	695

### Data to be Collected

Data of Birth 115

Factor Deficiency 28

Blood Group 162

Father Name 25

Address 143

Phone number 202

[View List](#)

[Company](#) [Medicine Form](#)

– Can be contacted to PWH



## PWH List

### List of PWH -

[+ Select All](#)

ID	Name	Father Name	Factor	Factor Level	
1	ASHU SHARMA	ASHU KAREEM	VIII	1.6	<a href="#">Details</a>
2	ASHU AGGAR	ASHU KAREEM	VIII	< 1	<a href="#">Details</a>
3	ASHU KAREEM	ASHU KAREEM	VIII	<1	<a href="#">Details</a>
4	ASHU C. K. MOHAMMED SA	ASHU KAREEM	VIII	< 1%	<a href="#">Details</a>
5	ASHU	ASHU	VIII	1.20	<a href="#">Details</a>
6	ASHUASH SHETTY	ASHUASH SHETTY	VIII	<1	<a href="#">Details</a>
7	ASHUASH S. S. M	ASHUASH	VIII	14.7%	<a href="#">Details</a>
8	ASHUASH S. S.	ASHUASH	VIII	1.75	<a href="#">Details</a>
9	ASHUASH S. S.	ASHUASH	VIII	Nil	<a href="#">Details</a>
10	ASHUASH	ASHUASH	VIII	< 1%	<a href="#">Details</a>
11	ASHUASH AGGAR	ASHUASH	VIII	3.00	<a href="#">Details</a>
12	ASHUASH AGGAR	ASHUASH	VIII	2.00	<a href="#">Details</a>
13	ASHUASH AGGAR	ASHUASH	VIII	10.00	<a href="#">Details</a>
14	ASHUASH AGGAR	ASHUASH	IX	1.00	<a href="#">Details</a>

[Filter Missing PWH List](#) [Add New PWH](#)

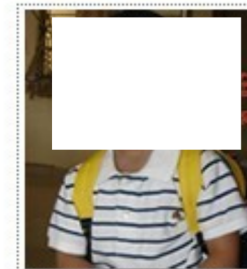
### PWH Details

Name:

Father/Gaurdin:

Clinical:

Address:



Uload Photo

Phone:

Edit

Download

SMS

Attach

PWH Details,  
Manage options



List of PWH -

+ Select All

ID	Name	Father Name	Factor	Factor Level	
1			VIII	1.6	<a href="#">Details</a>
2			VIII	< 1	<a href="#">Details</a>
3			VIII	<1	<a href="#">Details</a>
4			VIII	< 1%	<a href="#">Details</a>
5			VIII	1.20	<a href="#">Details</a>
6			VIII	<1	<a href="#">Details</a>
7			VIII	14.7%	<a href="#">Details</a>
8			VIII	1.75	<a href="#">Details</a>
9			VIII	Nil	<a href="#">Details</a>
10			VIII	< 1%	<a href="#">Details</a>
11			VIII	3.00	<a href="#">Details</a>
12			VIII	2.00	<a href="#">Details</a>
13			VIII	10.00	<a href="#">Details</a>
14			IX	1.00	<a href="#">Details</a>

15 ▾

⏮ ⏪

Page 1 of 47

⏩ ⏭

🔄

1 to 15 of 695

[Filter Missing](#)

PWH Details

Name:

F

C

Address:

Phone:

Edit

Download

SMS

Manage

Blue “Details” will Show the Details of PWH

Navigation to next set of PWH Lists

Takes to List of Missing PWH details

To Add New PWH

[Filter Missing PWH List](#)

[Add New PWH](#)

Selected PWH Details

### PWH Details

Level	
1.6	<a href="#">Details</a>
< 1	<a href="#">Details</a>
<1	<a href="#">Details</a>
< 1%	<a href="#">Details</a>
1.20	<a href="#">Details</a>
<1	<a href="#">Details</a>
14.7%	<a href="#">Details</a>
1.75	<a href="#">Details</a>
Nil	<a href="#">Details</a>
< 1%	<a href="#">Details</a>
3.00	<a href="#">Details</a>
2.00	<a href="#">Details</a>
10.00	<a href="#">Details</a>

Name:

Father/Gaurdin:

Clinical:

Address:

Phone:



Upload Photo

Edit

Download

SMS

Manage

Attach

Upload Profile Picture

Update, Transfer, Deceased, Block

Upload PWH Documents



# Managing PWH Data



**Hemophilia Society**  
(Affiliated to HFI and WFH)

Chapter

Welcome

## Patient Form



### Personal

Educational

Occupational

Medical

Other Medical

Family Details

Membership

First Name:

G

Last Name:

..

Guardian/Father Name:

Ja

Mothers Name:

mothers name

Date of Birth:

2:

Gender :

☒ Male ☐ Female

Religion :

Hindu ▼

Caste :

GL ▼

### Address

Flat/Door/Block No :

Premises/Building/Village :

Road/State/Lane/Post Office:

Area/Locality/Taluk/sub-Division:

Town/City/District:

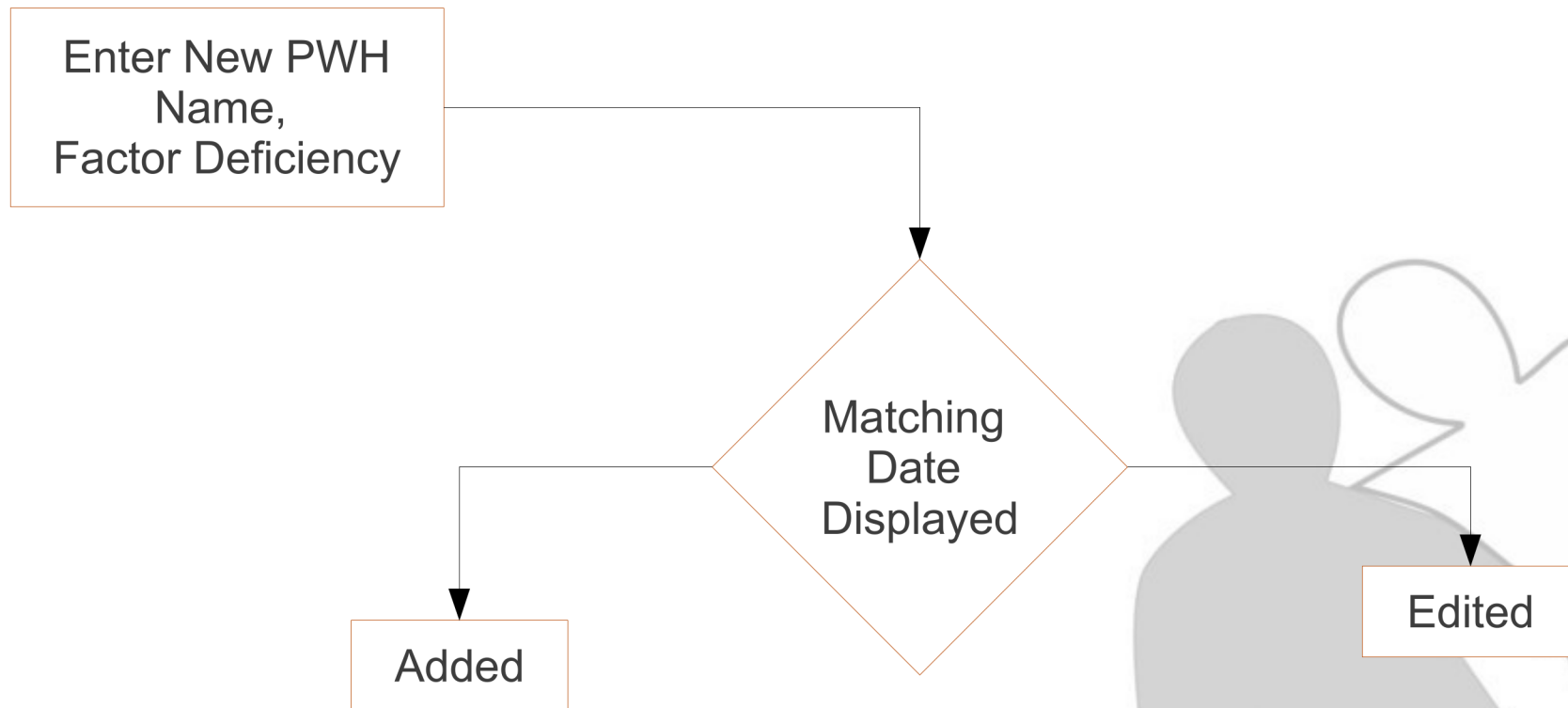
State/Union Territory :

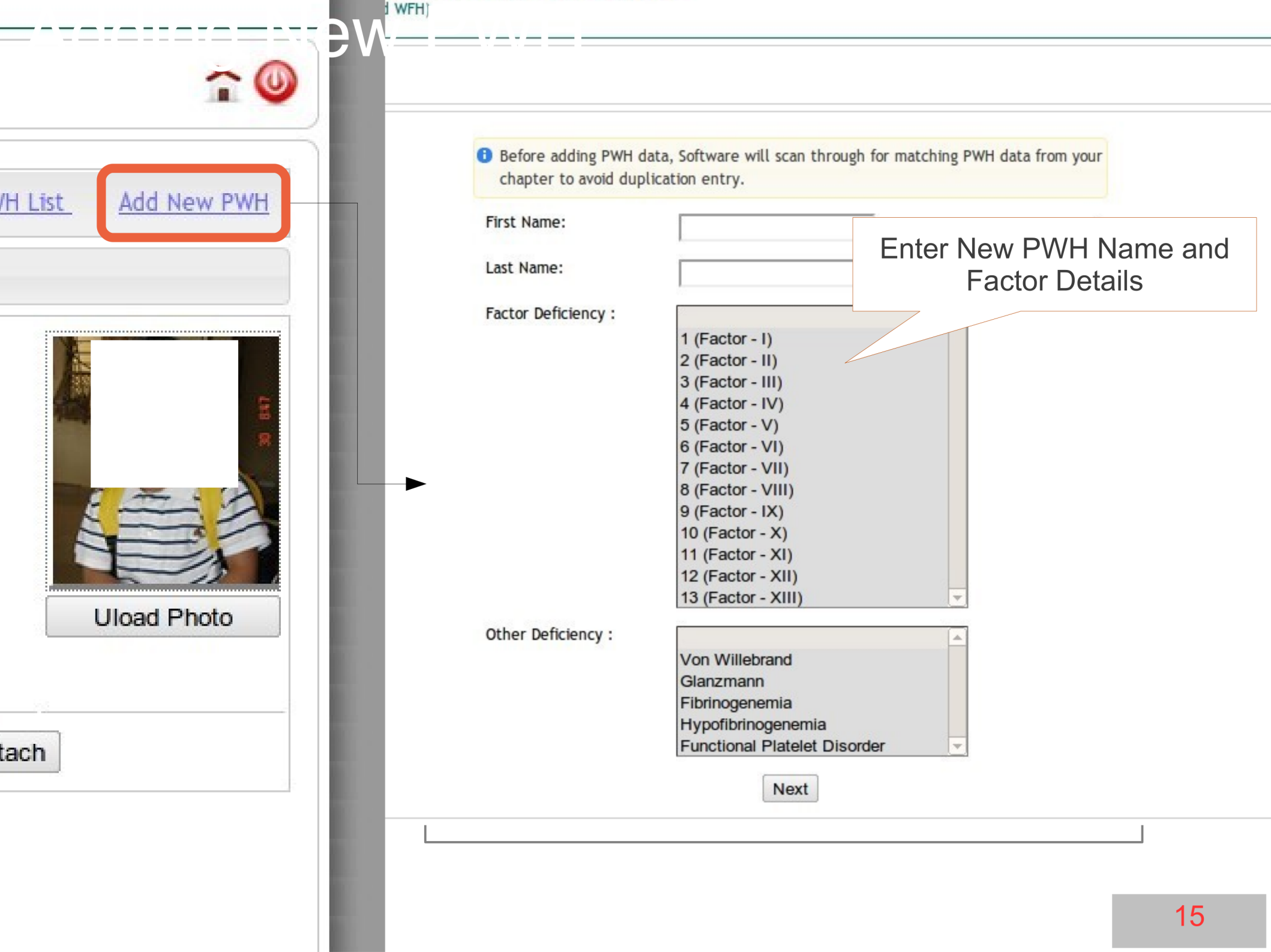
Pin Code :

Buttons, Takes  
To different Sections

Orange label data is critical  
Has to be filled

Registry will check for existing PWH details in its chapter before adding





**i** Before adding PWH data, Software will scan through for matching PWH data from your chapter to avoid duplication entry.

First Name:

Last Name:

Factor Deficiency :

- 1 (Factor - I)
- 2 (Factor - II)
- 3 (Factor - III)
- 4 (Factor - IV)
- 5 (Factor - V)
- 6 (Factor - VI)
- 7 (Factor - VII)
- 8 (Factor - VIII)
- 9 (Factor - IX)
- 10 (Factor - X)
- 11 (Factor - XI)
- 12 (Factor - XII)
- 13 (Factor - XIII)

Enter New PWH Name and Factor Details

Other Deficiency :

- Von Willebrand
- Glanzmann
- Fibrinogenemia
- Hypofibrinogenemia
- Functional Platelet Disorder

Next

# Adding New PWH



**Hemophilia Society**

(Affiliated to HFI and WFH)

**Chapter**

This link will take to add new PWH to registry

## Data Scanning



Following are list of matched PWH Entry in existing DB

1. Click on the names to view the details
2. If data match with the new PWH entry, click on edit button
3. Non of the data is matched [Click here to add](#)

Sl.No	Full Name	Factor Deficient	
1	SOMA SHEKAR S.S.	8	<a href="#">Edit</a>

Matching Data is displayed  
You can edit by clicking on it

- **Date of Birth** : Its important, has to be keyed in. If PWH doesn't know DOB and he knows age please feed as follows

PWH Says 20 Years, you can say  $2012 - 20 = 1982$ . So enter 1st Jan 1982

- **Factor Assay** : Use only numbers, less then sign (<) or full stop. Please do not write “Mild”, “Moderate”
- **BPL** : Please upload scanned bpl card and enter card number
- **ESI/CGHS/Others** : Take full details along with reference number and document of proff to assist in getting speedy treatment

# Uploading Documents

Click to Select File

Files Upload for profile ABDUL SHABAG

[Select File](#)

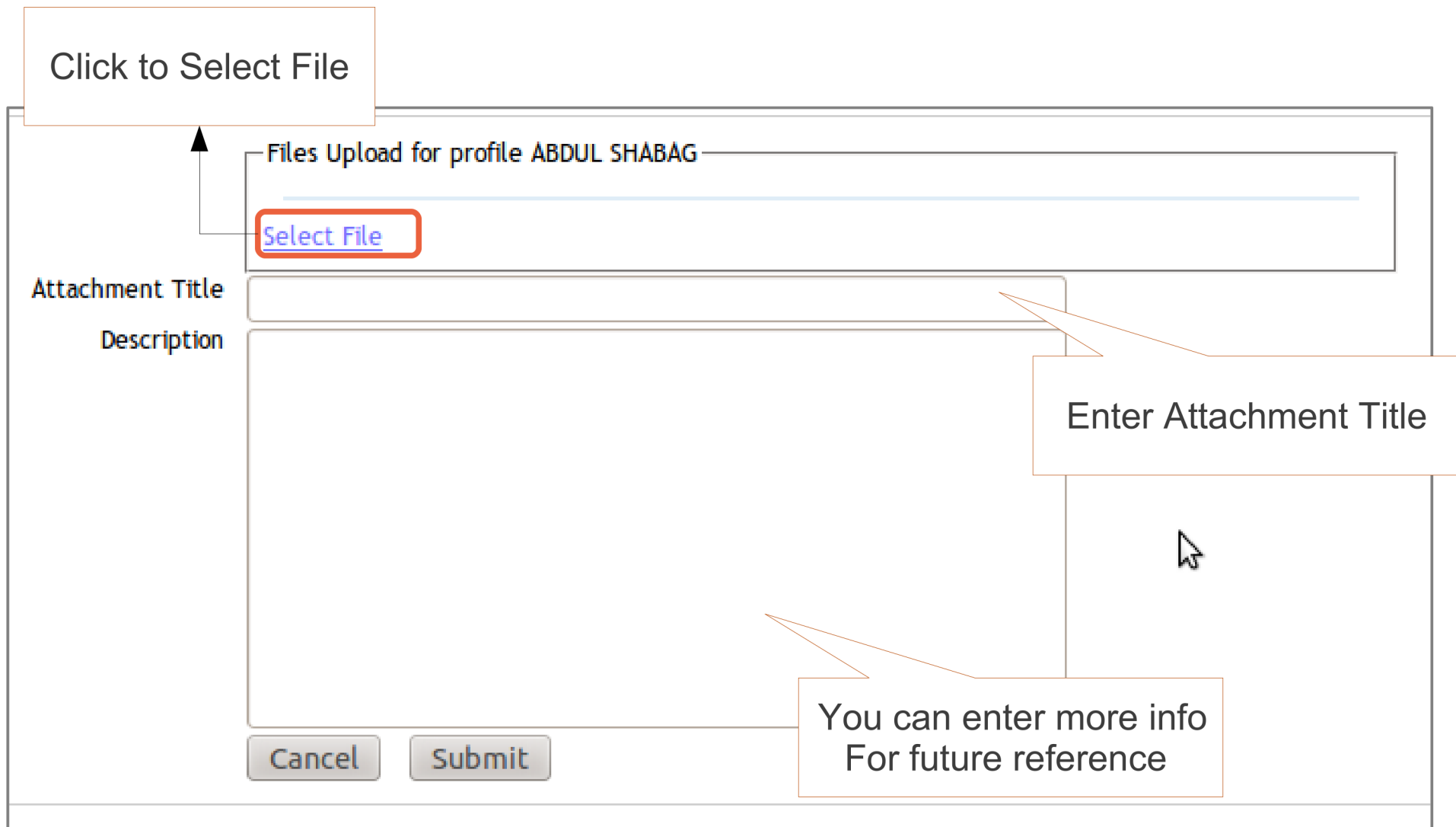
Attachment Title

Description

Enter Attachment Title

You can enter more info  
For future reference

Cancel Submit



The image shows a web form for uploading documents. At the top, a header bar contains the title 'Uploading Documents' and a Creative Commons license icon. Below the header, the form is titled 'Files Upload for profile ABDUL SHABAG'. It features a 'Select File' button, which is highlighted by a red box and a callout box labeled 'Click to Select File'. Below the button are two text input fields: 'Attachment Title' and 'Description'. A callout box labeled 'Enter Attachment Title' points to the 'Attachment Title' field. Another callout box labeled 'You can enter more info For future reference' points to the 'Description' field. At the bottom of the form are two buttons: 'Cancel' and 'Submit'.

- Keep filesize less then 2MB
- You can upload image (jpg, png), word documents (doc,docx), excel document (xls,xlsx)
- Profile Upload
  - Before upload resize photo
  - Save photo in jpg or png format
  - Keep filesize less then 2mb

**IF you have difficulty please keep in touch w  
registry team**

# Data Verification Support System



Hemophilia Society  
(Affiliated to HFI and NHR)

Chapter

Welcome somushiv

Critical Data for PWH

List of Missing Data



Sl.No	Full Name	Father Name	Sex	DOB	Address	Blood Group	Factor Deficient	Factor Assay	Comments
1		Dasaiah	*	*	*	*			
2		ASHOK SHETTY				*			
3		A.T.Srinivas				*			
4			*	*		*			
5						*			
6					*				
7		Prasanna kumar							
8		Ibrahim Sab							
9		Abdul Mazeed							
10		William	*	*					
11				*					
12		Khalil Ahmed							
13		S.Rajendran	*	*					
14		Narasimhiah							
15		H.Brahmesah		*				*	
16		Nagarai	*	*					

\* Stars Indicates Missing

Download PWH filled form

Enter Comments/notes Mailed to HFI/NHR team



# Duplication



**Hemophilia Society**  
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Chapter

Welcome

## Dashboard



PwH Members



Reports



Contact



Search



Chapter Report



Chapter Activity



[Download Excel](#)



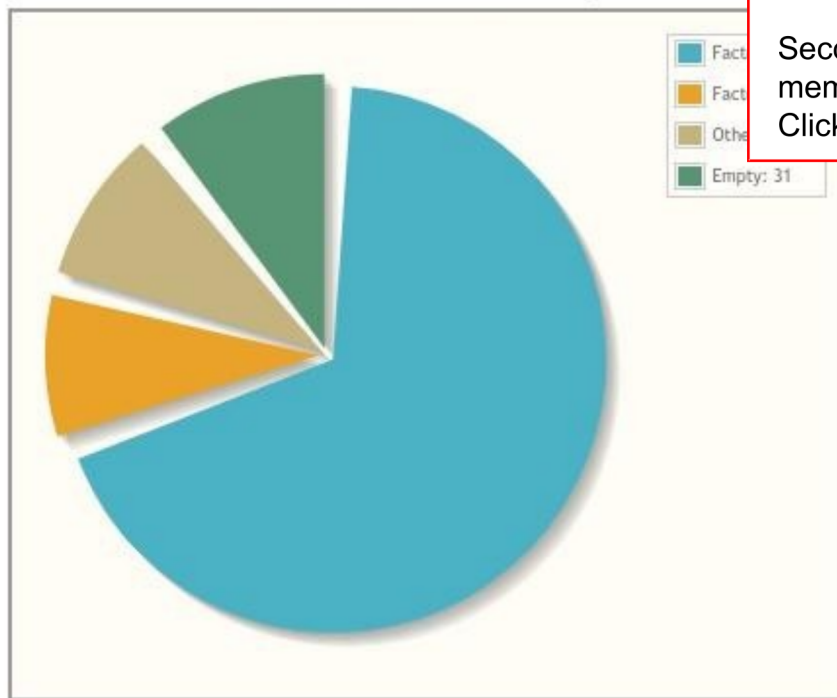
View HTC

7 of PwH are entered Duplicate.  
9 PwH found in other chapter

PwH Factorwise Count

Factor 8	Factor 9	VWD	Others	Not Known	Deceased
<a href="#">190</a>	<a href="#">26</a>	<a href="#">17</a>	<a href="#">28</a>	<a href="#">31</a>	<a href="#">5</a>

Pie Chart Factor Deficiency



First Line shows duplicate entry in your chapter.

Second Line shows dual members with other chapter. Click to check.

Incomplete Patient Data

# Duplicate entries in chapter



**Hemophilia Society**  
(Affiliated to HFI and WFH)

**Chapter**

Welcome

## Double Entries



Following PwH are entered multiple times in your chapter

Sl.No	Patient Name	Patient Father Name	Delete
1	[Redacted]	[Redacted]	<input type="checkbox"/>
2	[Redacted]	[Redacted]	<input type="checkbox"/>
3	[Redacted]	[Redacted]	<input type="checkbox"/>
4	[Redacted]	[Redacted]	<input type="checkbox"/>
5	[Redacted]	[Redacted]	<input type="checkbox"/>
6	[Redacted]	[Redacted]	<input type="checkbox"/>
7	[Redacted]	[Redacted]	<input type="checkbox"/>

Check to delete the entries from main list

# Dual / multiple membership with other chapters



PwH found in other Chapter



List of dual / multiple members with other chapters

Sl.No	Patient Name	
1	[REDACTED]	<ul style="list-style-type: none"><li>• CN : Hemophilia society Coimbatore chapter</li><li>• Patient Name : [REDACTED]</li><li>• Father Name : [REDACTED]</li><li>• Membership No : [REDACTED]</li></ul>
2	[REDACTED]	<ul style="list-style-type: none"><li>• CN : Hemophilia Society Bangalore Chapter</li><li>• Patient Name : [REDACTED]</li><li>• Father Name : [REDACTED]</li><li>• Membership No : [REDACTED]</li></ul>
3	[REDACTED]	<ul style="list-style-type: none"><li>• CN : Hemophilia Society Pondicherry centre</li><li>• Patient Name : [REDACTED]</li><li>• Father Name : [REDACTED]</li><li>• Membership No : [REDACTED]</li></ul>
4	[REDACTED]	<ul style="list-style-type: none"><li>• CN : Hemophilia society Coimbatore chapter</li><li>• Patient Name : [REDACTED]</li><li>• Father Name : [REDACTED]</li><li>• Membership No : [REDACTED]</li></ul>
5	[REDACTED]	<ul style="list-style-type: none"><li>• CN : Hemophilia Society Madras Chapter</li><li>• Patient Name : [REDACTED]</li><li>• Father Name : [REDACTED]</li><li>• Membership No : [REDACTED]</li></ul>
6	[REDACTED]	<ul style="list-style-type: none"><li>• CN : Hemophilia society Coimbatore chapter</li><li>• Patient Name : [REDACTED]</li><li>• Father Name : [REDACTED]</li><li>• Membership No : [REDACTED]</li></ul>
7	[REDACTED]	<ul style="list-style-type: none"><li>• CN : Hemophilia society Coimbatore chapter</li><li>• Patient Name : [REDACTED]</li><li>• Father Name : [REDACTED]</li><li>• Membership No : [REDACTED]</li></ul>

# Managing member status



**Hemophilia Society**  
(Affiliated to HFI and WFH)

**Chapter**

Welcome



## PWH List

### List of PWH -

[Select All](#)

ID	Name	Father Name	Factor	Factor Level	
91			VIII	0.9	<a href="#">Details</a>
92			VIII	<1	<a href="#">Details</a>
93			VIII	<1	<a href="#">Details</a>
94			VII	15.9	<a href="#">Details</a>
95			VIII	4.3	<a href="#">Details</a>
96			IX	0.9	<a href="#">Details</a>
97			VIII	<1	<a href="#">Details</a>
98			VIII	<1	<a href="#">Details</a>
99			N/A		<a href="#">Details</a>
100			VIII	4.7	<a href="#">Details</a>
101			VIII	<1	<a href="#">Details</a>
102			VIII		<a href="#">Details</a>
103			VIII	<1	<a href="#">Details</a>
104			N/A		<a href="#">Details</a>
105			N/A		<a href="#">Details</a>

15 ▼ Page 7 of 20 91 to 105 of 287

[Filter Missing PWH List](#) [Add New PWH](#)

### PWH Details

Name:

Father/Gaurdin:

Date of Birth:

Age:

Clinical:

Address:

Phone:

Chapter Membership Number:



Uload Photo

Edit

Download

Manage

Attach

# Dual / multiple membership with other chapters



**Hemophilia Society**  
(Affiliated to HFI and WFH)

**Chapter**

Welcome

Medicine Managment



PWH Details



Name:

Father/Gaurdin:

Clinical:

Address:

Phone:

PwH List

Select Option

- Select--
- Select--
- Transferred
- Deceased
- Blocked
- Duplicate
- Non-PWH
- Not Our Member
- Delete

Change the status of  
the member

- Emails
  - [nhr@hemophilia.in](mailto:nhr@hemophilia.in)

Please mark cc to your region RCC/RCS and CEO for all your queries.

