International Registry for Levonorgestrel Intrauterine System
In Women with Inherited Bleeding Disorders

Please return this form to:

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# International Registry for Levonorgestrel Intrauterine System
## In Women with Inherited Bleeding Disorders

<table>
<thead>
<tr>
<th>Treatment Centre</th>
<th>Identification Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>City</td>
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<tr>
<td>Country</td>
<td></td>
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<tr>
<td>Name of Doctor/Provider</td>
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</tbody>
</table>

### Patient details:

<table>
<thead>
<tr>
<th>Initials</th>
<th>Date of Birth</th>
<th>Date / Month / Year</th>
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</thead>
</table>

### Bleeding disorder:

- Haemophilia A carrier
- Haemophilia B carrier
- Von Willebrand’s Disease
- Factor VII deficiency
- Factor IX deficiency
- Factor X deficiency
- Fibrinogen deficiency
- Prothrombin deficiency
- Factor V deficiency
- Factor V and VIII deficiency
- FXIII deficiency
- Others (please state)

### Severity:

- Severe
- Moderate
- Mild

### Relevant factor levels:

- Coagulant activity of missed factor(s) (IU/dL)
- Antigen level of missed factor(s) (IU/dL)

### Age at Diagnosis: ...........years
Levonorgestrel Intrauterine System

Accept □ Decline □ (Reason……………………………………….)

1. Date of insertion (Date / Month / Year) ...............................................................

2. Indication:  Contraception □
Menorrhagia □
Others (please specify) □
……………………………………………………………….………

3. Haemostatic cover: No □
Yes □ please state………………………………………

4. Anaesthesia:  None □
Local □
General □

5. Complication during insertion:  Bleeding □
Uterine Perforation □
Pain □
Pain scale of 1(mild) - 10(severe)…………………..

6. At time of insertion:  Haemaglobin (g/dL) .........................
Haematocrit .................................
Ferritin .................................

7. Pelvic Ultrasound:  Normal □
Abnormal □ (Please describe……………………………
…………………………………………
…………………………………………
…………………………………………
…………………………………………)

Identification Number:
8. Menstrual Cycle: Regular □ Irregular □
   Length of each cycle ............. days
   Length of each period ............. days

   Blood clots: Yes □ No □
   If yes please specify the approximate size of the blood clots:
       (you may tick more than one)
       The size of a one pence coin (1/2 inch) or smaller □
       The size of a 10 pence coin □
       The size of a 50 pence coin (1 inch) or bigger □

   Flooding: Yes □ No □

   PBAC score if available ....................... (PBAC – Pictorial Blood Assessment Chart)

   Time lost from school and/or work due to periods in the last year: ........ days

9. Previous treatment for heavy menstrual loss:

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Effective</th>
<th>Slightly Effective</th>
<th>Not Effective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tranexamic Acid</td>
<td>□</td>
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<tr>
<td>COCP</td>
<td>□</td>
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<tr>
<td>Cyclical Progesterone</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<tr>
<td>DDAVP</td>
<td>□</td>
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<tr>
<td>Other: (Please specify)</td>
<td>........................................</td>
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</tbody>
</table>

   Reason for discontinuation of previous treatment(s):
       .............................................................................................................................
       .............................................................................................................................
       .............................................................................................................................

   Concomitant use of any of the above: No □
       Yes □ please state .........................................
10. Quality of Life Baseline:

On scale of 0 (no effect) to 10 (most effect), how much does the period interfere with the following: (Please circle the appropriate number for each statement)

<table>
<thead>
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<th></th>
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<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
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<tbody>
<tr>
<td>General Activity</td>
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<td>Ability to work or go to school</td>
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<tr>
<td>Normal family activities</td>
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<td>Sleep</td>
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<tr>
<td>Ability to enjoy life</td>
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<td>Mood</td>
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</tbody>
</table>
Follow-up at 1 Month

1. Irregular bleeding/Spotting: No ☐ Yes ☐
   If yes, for how many days does it occur? ..........days
   Is it continuous? No ☐ Yes ☐
2. Menstruation since insertion: No ☐ Yes ☐
   If yes, please specify the duration of your period and a PBAC score if available:
   Duration of period:................. PBAC score:..................
3. Thread visualised: No ☐ Yes ☐
4. Expulsion: No ☐ Yes ☐
5. Removal: No ☐ Yes ☐
   Reason for removal: Irregular bleeding/spotting ☐
   Hormonal side effect ☐
   Persistent menorrhagia ☐
   Others (please specify) ☐ .............................
### Follow-up at 3 Months

1. Irregular bleeding/Spotting:  No ☐ Yes ☐
   
   If yes, for how many days does it occur? ……………….days per month

   Is it continuous?  No ☐ Yes ☐

2. Number of periods since insertion……………………………

3. Duration of period:…………………………………………

4. Most recent PBAC score if available…………………………

5. Haemaglobin (g/dL) …………………..
   
   Haematocrit …………………………….
   
   Ferritin ………………………………..

6. Expulsion:  No ☐ Yes ☐

7. Removal:  No ☐ Yes ☐
   
   Reason for removal: Irregular bleeding/spotting ☐
   
   Hormonal side effect ☐
   
   Persistent menorrhagia ☐
   
   Others (please specify) ☐ ……………………………

8. Quality of Life:

   On scale of 0 (no effect) to 10 (most effect), how much does the period interfere with the following:

<table>
<thead>
<tr>
<th>General Activity</th>
<th>Ability to work or go to school</th>
<th>Normal family activities</th>
<th>Sleep</th>
<th>Ability to enjoy life</th>
<th>Mood</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
</tbody>
</table>
## Follow-up at 12 Months

1. Irregular bleeding/Spotting □ Yes □
   If yes, for how many days does it occur? ………………days per month
   Is it continuous? □ Yes □

2. Number of periods since insertion……………………………

3. Duration of period:…………………………………………

4. Most recent PBAC score if available…………………………

5. Haemoglobin (g/dL) .........................
   Haematocrit .............................
   Ferritin .................................

6. Expulsion: □ Yes □

7. Removal: □ Yes □
   Reason for removal: Irregular bleeding/spotting □
   Hormonal side effect □
   Persistent menorrhagia □
   Others (please specify) □ ……………………. 

8. Time lost from school and/or work due to periods in the last year………………….days

9. Quality of Life:
   On scale of 0 (no effect) to 10 (most effect), how much does the period interfere with the following:
   General Activity  1  2  3  4  5  6  7  8  9  10
   Ability to work or go to school  1  2  3  4  5  6  7  8  9  10
   Normal family activities  1  2  3  4  5  6  7  8  9  10
   Sleep  1  2  3  4  5  6  7  8  9  10
   Ability to enjoy life  1  2  3  4  5  6  7  8  9  10
   Mood  1  2  3  4  5  6  7  8  9  10
Follow-up at 2 Years

1. Irregular bleeding/Spotting:  No □ Yes □
   If yes, for how many days does it occur? ………………days per month
   Is it continuous?  No □ Yes □

2. Number of periods since insertion…………………………

3. Duration of period:…………………………………………

4. Most recent PBAC score if available…………………………

5. Haemoglobin (g/dL) ……………………..
   Haematocrit ……………………………
   Ferritin ……………………………….

6. Expulsion:  No □ Yes □

7. Removal:  No □ Yes □
   Reason for removal: Irregular bleeding □
   Hormonal side effect □
   Persistent menorrhagia □
   Others (please specify) □ …………………………

8. Time lost from school and/or work due to periods in the last year…………………..days

9. Quality of Life:
   On scale of 0 (no effect) to 10 (most effect), how much does the period interfere with the following:
   General Activity 1 2 3 4 5 6 7 8 9 10
   Ability to work or go to school 1 2 3 4 5 6 7 8 9 10
   Normal family activities 1 2 3 4 5 6 7 8 9 10
   Sleep 1 2 3 4 5 6 7 8 9 10
   Ability to enjoy life 1 2 3 4 5 6 7 8 9 10
   Mood 1 2 3 4 5 6 7 8 9 10
Follow-up at 3 Years

1. Irregular bleeding/Spotting:  No □ Yes □
   If yes, for how many days does it occur? ………………days per month
   Is it continuous?  No □ Yes □

2. Number of periods since insertion……………………………

3. Duration of period:………………………………………………

4. Most recent PBAC score if available…………………………

5. Haemoglobin (g/dL) .........................
   Haematocrit .................................
   Ferritin .................................

6. Expulsion:  No □ Yes □

7. Removal:  No □ Yes □
   Reason for removal:  Irregular bleeding □
   Hormonal side effect □
   Persistent menorrhagia □
   Others (please specify) □ ……………………

8. Time lost from school and/or work due to periods in the last year………………………days

9. Quality of Life:
   On scale of 0 (no effect) to 10 (most effect), how much does the period interfere with the following:
   | General Activity | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
   | Ability to work or go to school | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
   | Normal family activities | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
   | Sleep | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
   | Ability to enjoy life | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
   | Mood | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |