Hemophilia is a genetic bleeding disorder. A child born with Hemophilia will have it all his life.
About hemophilia

- Women carriers, males sufferers
- Severity as low as 1% or lower.
- Severity Classified as mild, moderate or severe depending on the deficiency of factor
- 15% of the patients have factor – IX deficiency. (Christmas disease) while the rest have Factor VIII deficiency which is called Classical hemophilia.
- One out of every 10,000 has hemophilia
INCIDENCE OF HEMOPHILIA IN INDIA

1 per 10,000 births in General Population

Expected cases in India: Over 100,000

Identified: < 12,000

I.e. 80% yet to be IDENTIFIED
Who gets hemophilia?

Can occur in any family without known history of genetic disorder

<table>
<thead>
<tr>
<th>Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>HEREDITARY</td>
<td>60-70%</td>
</tr>
<tr>
<td>NEW GENE MUTATION</td>
<td>30-40%</td>
</tr>
<tr>
<td>ACQUIRED</td>
<td>0.001%</td>
</tr>
</tbody>
</table>
What happens when a PWH bleeds?

A PWH does not bleed faster but he may bleed for a longer time.

The major problem is uncontrolled internal bleeding which can begin spontaneously without any apparent cause. If it is not stopped with proper treatment it results in pain, swelling. Over a period of time bleeding into muscles and joints can cause permanent damage.
BLEEDING IN HEMOPHILIA

Bleed more than normal people - not faster but longer

Common Sites

JOINT
MUSCLE / SOFT TISSUE
SKIN / SUB CUTANEOUS
ORAL / GUM
NOSE
GENITO URINARY
GASTRO INTESTINAL
BRAIN
TRAUMA RELATED - ANY SITE
JOINT BLEEDS

KNEE (45%)  ELBOW (30%)  ANKLE (15%)

OTHER JOINTS – 10%
Shoulder, Wrist, Hip, Spine etc.
JOINT BLEEDS
MUSCLE BLEEDS
SKIN / SUB CUTANEOUS BLEEDS
SKIN / SUB CUTANEOUS BLEEDS
ORAL / GUM BLEEDS
EYE BLEEDS
BRAIN BLEEDS
COMPLICATIONS OF BLEEDING

PSEUDO TUMOURS

CONTRACTURE and deformity
How is hemophilia treated?

Infusion of clotting factor, derived from human blood, which remains active for a short period of time.

Each time a bleed occurs additional factor is needed.

Proper treatment reduces the chance of permanent damage.

Effective controls, but no cure for hemophilia
FACTOR CONCENTRATES
FACTOR CONCENTRATES

Factor VIII

Factor IX
FACTOR CONCENTRATES
For Inhibitor to F VIII/F IX

Fieba

Factor VII (Novo seven)
<table>
<thead>
<tr>
<th>Plasma Derived</th>
<th>Recombinant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rs.22/- per Unit</td>
<td>Rs.35-40/- per Unit</td>
</tr>
<tr>
<td>I.e. 250 Iu Vial Cost</td>
<td>I.e. 250 Iu Vial Cost</td>
</tr>
<tr>
<td>About Rs.5500/-</td>
<td>About Rs.10,000/-</td>
</tr>
</tbody>
</table>

Hemophilia Federation Subsidizes rate and makes available plasma derived factor at Rs.10/- per Unit i.e. Rs.2500/- Per 250 Iu

*Cost as on Dec ‘09
# TREATMENT COST

Approximate Cost of Factor replacement in a Person With Hemophilia (PWHs) in India

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency of bleeding per year</th>
<th>Factor Requirement /bleed ( For a Body Wt. of 50 Kg)</th>
<th>Cost of Treatment/ bleed</th>
<th>Annual Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe (80%)</td>
<td>12-15/yr</td>
<td>Rs.1500-2000/-</td>
<td>Rs.15000-22000/-</td>
<td>Rs.2-2.25 lakhs</td>
</tr>
<tr>
<td>Moderate (10-15%)</td>
<td>6-8/yr</td>
<td>Rs.1000-1500/-</td>
<td>Rs.10000-15000/-</td>
<td>Rs.1-1.25 lakhs</td>
</tr>
<tr>
<td>Mild (5 – 10%)</td>
<td>3-4/yr</td>
<td>Rs.500-1000/-</td>
<td>Rs.5000-10000/-</td>
<td>Rs.50000 -70000/-</td>
</tr>
</tbody>
</table>

* Cost given here may vary depending on the Age, Body Wt., Location, Nature & Severity of bleed
Other than of Factor replacement
PWHs has to bear the Cost of

1. Frequent Hospitalization
2. Medication & Physiotherapy
3. Transportation etc.

Cost will be even more if the PWHs are Inhibitor Positive or infected with some Viruses like HIV / Hepatitis etc.
PROBLEMS OF HEMOPHILIA

• Due to repeated bleeds, the joints get affected and many get crippled.

• Attendance in school, college and at work get affected.

• The condition of the patient affects the whole family because of fear anxiety, confusion and guilt.

• Financial strain
Importance of Physiotherapy in Hemophilia

Exercises

• Improves strength of muscles & stability of joints
• Reduce the frequency of repeated joint & muscle bleeding
• Relieves Contractures & stiffness
• Prevents crippling deformity
• Reduce the factor replacement requirements
• Improves the quality of life
GOOD PHYSIOTHERAPY MAKES ALL PWHS HEALTHY!