Caring for a baby boy with hemophilia

If your baby boy has hemophilia, the Indiana Hemophilia and Thrombosis Center (IHTC) is here to help your baby live a healthy life. Here are some plans to help you get started.

Always keep the IHTC phone number with you. Someone is always on call, so you will be able to reach someone day or night. Please call with any questions or concerns.

317.871.0000 or 877-256-8837 | website: www.ihtc.org

Call IHTC if you notice any of the following in your baby:

- 1. Symptoms of bleeding on the brain. These symptoms may include:
 - Not wanting to eat
 - Throwing up or vomiting that "shoots" out of the mouth
 - A swollen soft spot. Newborn babies have two soft spots, one at the top of the head and one at the back of the head.
 - Not being able to wake your baby
 - Repeated jerking movements (seizures)
- 2. Bleeding from the belly button (umbilical site)
- 3. Bleeding from the penis (circumcision site)
- 4. A joint or muscle that appears swollen when compared to opposite part of body
- 5. Being fussy and not wanting to move a certain part of the body
- 6. Blood in mouth, nose, throw-up or poop. A black poop may mean there is internal bleeding
- 7. A bruise that grows bigger or has a lump underneath it
- 8. Swelling or firmness at site of a shot or a heel stick

Call IHTC if your baby:

- Has any injury to the head, neck, or belly
- Falls or is dropped
- Needs any surgery or other procedure

Safety tips

- Always use safety straps when using a car seat, swing, or infant seat to prevent falls.
- Make sure anyone giving your baby their shots uses the smallest gauge needle available. They should apply pressure to the site of the shot for 3-5 minutes after the shot. You should then use an icepack to the area.
- Use a nail file instead of clippers to trim fingernails.
- If your baby needs a pain reliever or medication for a fever, talk to your baby's doctor first. Then use Tylenol (acetaminophen). Do not use ibuprofen or Motrin as these can increase bleeding.

Ongoing care

- Schedule an appointment with the IHTC as soon as possible.
- Establish care with a pediatrician or a family doctor.
- Keep a dose of any IHTC prescribed special medicine at home.
- Call the IHTC if you need to take your baby to the emergency room.
- Ask the IHTC about providing education for extended family, caregivers or daycare.
- Contact Hemophilia of Indiana (HOII) 317-570-0039 or 1-800-241-2873 web site: www.hoii.org > This is a good resource for family support and advocacy.

