CONSENT FOR HOME INFUSION THERAPY

The purpose of a home infusion therapy program is to provide preventative and early treatment for bleeding episodes through the infusion of clotting factor concentrate. The Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation supports and recognizes the benefits of home infusion therapy programs, with appropriate precautions, as one aspect of comprehensive care for patients with clotting factor deficiencies. The IHTC Care Team provides education, counseling, and instruction on the intravenous administration of clotting factor concentrate. On-going education and regular comprehensive clinic appointments are important to maintain a safe, high-standard of health care.

Patient/Family Responsibilities for Home Infusion Therapy Program: (please initial all areas)
_____ I/my child will return to the IHTC for medical evaluation on the recommended schedule for provision of adequate medical supervision and follow-up care.
_____ I am aware of the importance of documentation of prophylactic infusions, bleeding episodes and their treatment. I agree to keep infusion logs and review these with the IHTC staff on a regular basis.
_____ I will dispose of all contaminated infusion materials in containers specifically designed for medical waste. I will make arrangements with the IHTC, local hospital, or home care company for proper disposal.
_____ I will notify the IHTC immediately if a needle stick injury occurs.

Potential Risks of Home Infusion Therapy Program:
The risks of an allergic reaction to the clotting factor concentrate utilized at home are the same as when it is infused at the IHTC or hospital. These risks may include:
- Flushing
- Fever
- Chills
- Skin rash
- Headache
- Abdominal pain
- Chest tightness
- Difficulty breathing
- Back pain

Should you or your child experience any of these symptoms during or immediately following an infusion, notify the IHTC immediately at 317-871-0000 or toll free at 1-877-CLOTTER. Seek immediate/emergent care for serious symptoms such as difficulty breathing.

As with the infusion of any intravenous medication or blood product, inadequate sterile technique, improper disposal of infusion materials, or poor cleaning of the infusion area, could result in the spread of hepatitis or other viral diseases. The risks of improper handling of the infusion materials could result in:
- Loss of clotting factor activity and infusion of an inadequate dose
- Infection secondary to poor technique
- Damage to veins
- Needle stick injury to the individual who performs the infusion with potential transmission of blood-borne diseases
Efforts to minimize the risks associated with home infusion therapy will be ongoing and include disease specific education, close contact with the IHTC, and review of the home infusion logs you are required to maintain. After completing training sessions with the IHTC staff, you or your child will be able to calculate the appropriate dosage of clotting factor concentrate, perform proper mixing and handling of the infusion materials and central/peripheral venous access. Yearly reviews of techniques may be requested.

Benefits:
1. Early treatment may lead to reduced pain and disability both short- and long-term
2. Decreased severity of acute bleeding
3. Increased personal independence and greater self-reliance through active participation in your medical care
4. Decreased time spent in the hospital, clinic or emergency room and associated costs
5. Improved lifestyle and ability to travel
6. Nutritional benefits

I understand that providing home infusion training to eligible patients is an important goal in the medical management of bleeding disorders. Home infusion training may occur in a variety of settings, including, but not limited to: at the IHTC, Hemophilia Camp, home or school.

I understand that:

_____ I will not be charged for home infusion training.
_____ The goal of home infusion training to gain increased independence and I will be an active participant in this process.
_____ The time to achieve independence often varies and specific short- and long-term goals will be discussed with me upon entry into the program.
_____ The IHTC team may ask me/my child to come to the center for treatment if I/my child develop(s) any physical or emotional problems that would alter my physician's decisions regarding further participation in a home therapy program.
_____ I have the right to remove myself/my child from this program at any time. Subsequent treatment at the IHTC is not based upon continued participation in this program.
_____ I will be dealing with potentially virally contaminated material and will follow the IHTC safety recommendations. I will dispose of contaminated supplies as instructed by the IHTC and in accordance with state law.
_____ I am responsible for sending infusion logs to the IHTC on a regular basis.

I hereby agree to follow the recommendations of the Indiana Hemophilia & Thrombosis Center regarding care, follow-up visits, and the maintaining of infusion logs so that I/my child may participate in a medically supervised home infusion therapy program.

Having fully understood and considered the above information, I hereby consent and agree to participate in the IHTC Home Infusion Therapy Program.

________________________________________              ______________________________________
Patient                                                  Parent/Guardian

________________________________________              ____________________________
Hemophilia Care Team Witness                            Date

________________________________________              ____________________________
Date of previous training if applicable