



MY BLEEDING DISORDER

Hi, my name is: _____

and here is some information you need to know about me.

My Parents: _____

My D.O.B: _____

Type of Bleeding Disorder: _____

Severity: _____

My medicine is called "factor". This is the brand name: _____

My dose is based on my weight. This is my current weight: _____

This is my current dose of factor: _____

This is how often I receive Factor: _____

This is how I give my Factor (port, central line, peripheral infusion, etc.): _____

This is where is my Factor should be kept: _____

The name and location of my Hemophilia Treatment Center are: _____

Allergies: _____

This is where I wear my medical alert tag: _____

MY EMERGENCY NUMBERS

Home: _____

Mom Cell: _____

Dad Cell: _____

Mom Work: _____

Dad Work: _____

Other Emergency Contacts: _____

Important Things to Remember in an Emergency:

1. Try your hardest to remain calm. If you are anxious, then so am I.
2. **Ice is good** - please ice area for a good 15-20 minutes with pressure.
3. You can give me **Tylenol** for pain. **NEVER** give me any aspirin products, as they are a blood thinner. Ibuprofen and NSAIDs are not recommended.

Here are the phone numbers for my doctors and nurses:

How to reach my Primary Care Doctor: _____

How to reach my Hematologist: _____

How to reach my Hemophilia Nurse Practitioner: _____



HEMOPHILIA 101: THE BASICS

- If I say something hurts, trust me – I can often feel it before it can be seen. I need to call my parents and get factor treatment IMMEDIATELY.
- Most **CUTS** are not a problem and just need basic first aid.
- Soft tissue bleeds and **BRUISES** that are tender, but not too painful, typically do not need to be treated.
- The most common type of bleeding is into **JOINTS AND MUSCLES**. In people with severe hemophilia, spontaneous joint and muscle bleeding can happen without any known trauma. I may not be able to identify a specific event that caused bleeding.
- **JOINT BLEEDS** – The early symptoms of a joint bleed are: tingling, pain, limited range of motion or stiffness. The later symptoms of a joint bleed are: heat, pain, swelling, decreased range of motion. **It's very important to treat a joint bleed as soon as possible.**
- **MUSCLE BLEEDS** – Symptoms of a muscle bleed are warmth, swelling, redness, skin tightness. I may not be able to flex or extend the area around the muscle that's bleeding, and there will probably be some pain. **Muscle bleeds should be treated as soon as possible.**

EMERGENCY SITUATIONS

There are some areas where bleeding can cause big problems. Call my parents and/or 911 immediately if I get I hurt in my:

Head

Throat

Abdomen

Eyes

There are a few things my parents would like to say....

1. _____'s blood doesn't clot like most people, and he/she may be prone to internal bleeding which would not be obvious to onlookers. Please take him/her seriously if he says he is not feeling well, and consult the school nurse.
2. Protective gear may be necessary for _____ to enjoy physical activities, but he/she should be allowed to participate. Please work with us on helping him/her be as safe and active as possible.
3. It's okay to let my child's classmates know about his/her condition as long as it is done in an appropriate way. I'd be happy to help prepare a talk or program.
4. _____ has a serious health condition, but he/she is still a child with ordinary interests and hopes and dreams. Please help us keep his/her life as normal as possible.
5. Please keep the lines of communication open. _____ needs to have all of the adults in his/her life working together.

Thank you!

PLEASE TALK WITH YOUR HTC ABOUT WHAT INFORMATION SHOULD BE ADDED TO OR DELETED FROM THIS DOCUMENT TO MAKE IT SPECIFIC TO YOUR CHILD AND AS ACCURATE AND HELPFUL AS POSSIBLE.