

## Explaining Your Child's Bleeding Disorder

Often parents need a few short sentences to explain bleeding disorders to others.

**Here is a sample that you can use or adapt for your needs:**

My son/daughter has a bleeding \_\_\_\_\_ (your child's name) \_\_\_\_\_  
disorder called \_\_\_\_\_ (name of the disorder) \_\_\_\_\_.

This means my child is missing a protein in the blood that would help it clot properly.

My child will not bleed to death, and he/she won't bleed faster than anyone else if he/she has a cut or scrape. If first aid is required, it is the same as for any other child; but I do want to be notified if he/she gets a bump on the head, complains of a bad headache, or has a bad fall.

Please contact me if he/she has any other more serious injury as I will have to give him/her medication.

We do encourage our child to participate in some sports and activities like: (Give examples)

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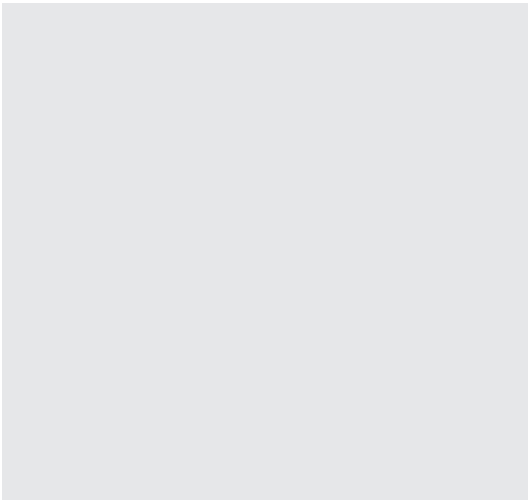
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Contact sports like football or wrestling are discouraged.

I would be happy to answer any questions you may have or that come up.



# 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.**

## Telling Your Friends About Your Bleeding Disorder

***Here is a brief description of what you can say to others about your bleeding disorder:***

I was born with a bleeding disorder.

It is called \_\_\_\_\_ (name of your bleeding disorder) \_\_\_\_\_.

This means my blood doesn't work right. When I fall down or bump into something it hurts a little longer. I bruise easily and my bruises last a really long time. I do get a medicine called factor that makes my blood work better and helps me get better when I get hurt.

***Here are some other examples of what you can say about your bleeding disorder to your friends or classmates:***

- "I have \_\_\_\_\_ (name of your bleeding disorder) \_\_\_\_\_, which means my blood doesn't act like most people's blood. When I cut myself or fall down, it takes me longer to stop bleeding. I take medicine to help it stop."
- "Some kids with diabetes have to get shots. It's like that for me. I need shots to stop my body from bleeding too much."
- "It's not contagious. You can't catch it from me."
- "I may not be able to do everything that other kids do, but I can do a lot."