MY BLEEDING DISORDER

Hemophilia Federation of America

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MY EMERGENCY NUMBERS

Parent's/Guardian's Name(s):

Parent's/Guardian's Home Phone:

Mom/Guardian Cell:

Mom/Guardian Work:

Dad/Guardian Cell:

Dad/Guardian 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 good15–20 minutes with pressure to slow bleeding. **Tylenol** may be okay for pain.
3. **NEVER** give me any aspirin products, as they are a blood thinner. Ibuprofen and NSAIDs are not recommended.

Hi, my name is: _____
and here is some information you need to know about me.

My Date Of Birth:

Type of Bleeding Disorder(s):

Severity:

This is the brand name of my medicine:

My dose may be based on my weight. This is my current weight:

This is my current dose of my medication:

This is how often I receive my medication:

This is how I give my medication (e.g., port, central line, peripheral infusion):

This is where is my factor/medicine should be kept:

The name and location of my Treatment Center (HTC):

Allergies:

This is where I wear my medical alert tag:

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 Hematology Nurse Practitioner:

BLEEDING DISORDERS 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 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 bleeding disorders, spontaneous joint and muscle bleeding can happen without any known trauma. I may not be able to identify a specific event that caused bleeding.

    1. **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.**
    2. **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.**

- **Ice for 15–20 minutes may slow bleeding while medication takes effect.**

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/them seriously if they say they are not feeling well and consult the school nurse.

2. Protective gear may be necessary for _____ to enjoy physical activities, but he/she/they should be allowed to participate. Please work with us on helping them be as safe and active as possible.

3. It's okay to let my child's classmates know about his/her/their 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/they is still a child with ordinary interests and hopes and dreams. Please help us keep his/her/their 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.

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