

**SAMPLE LETTER – RECOMMENDED FOR:
DAY CARE CENTER/PRESCHOOL/
ELEMENTARY SCHOOL/MIDDLE SCHOOL**

This is a sample letter. Please work with your Hemophilia Treatment Center (HTC) and, where appropriate, your local school district to create a letter that works best for your child.

____ Name of Parent____
____ Street____
City, State, Zip Code
(***) ***-**** (cell)
(***) ***-**** (home)

DATE

To: Principal of _____
Nurse
Office Staff
Teachers
Guidance Counselor
Special Education Coordinator

My son/daughter, _____, has a bleeding disorder called _____. There are many different types of bleeding disorders. He has _____.

About 20,000 Americans are affected by hemophilia. A person with hemophilia has either an inactive or inadequate supply of one of the 13 factors needed for blood to clot normally. People with hemophilia bleed longer because their blood has difficulty developing a firm clot. **They will not bleed to death, nor will they bleed faster than anyone else.**

Small cuts and scrapes are not a problem since they usually stop bleeding on their own from exposure to oxygen. First aid is the same for _____ as it is for other children. If _____ has a more serious injury, he may need an infusion of factor concentrate. I am able to infuse him if necessary, and we have a private nurse that comes to our house to give him his infusions if I am not available.

Typical bleeds for _____ are in his muscles or joints. Some signs of a bleed that you might notice are limping, non-use of an arm or leg, swelling, or any unusual complaints. Some of the unusual complaints _____ gives are that his leg or foot "hurts" or that he cannot bend a joint. _____ has a tendency to have ankle bleeds. Most of the time he can tell the difference between a bleed and another type of discomfort or pain.

However, try to put the number of bleeds he has had in the past year in perspective. _____ is seen at _____ Hospital twice a year. Each time, his dose is recalibrated and adjusted for his growth over 6 months. I always know when it is time for him to see the people at _____ Hospital because he has an ankle or knee bleed. In the past year he has had _____. Most of the time we have no idea what has caused the bleed. Usually, they are a result of regular activity and too small a dose of factor in his blood. _____ will occasionally have nose bleeds at the end of a

cold or during allergy season. They look very serious. His nose will pour blood. The treatment for such a bleed is exactly the same as it would be for everyone else—head held forward, pressure on the nose, and a cool compress or ice on the back of the neck. Other bleeds that are serious, but luckily rare, are bleeds in the head, throat, or abdomen.

_____ will also get minor bleeds from time to time in the form of bumps and bruises. They will appear along his forearms, elbow, knees, shins, hip bones, ribs, and shoulders—anywhere there is a bone close to the skin. We do not infuse him for those bumps and bruises.

Please do not send _____ to the nurse for small bumps. If you are unsure, ask him if he needs to see the nurse or get an ice pack. However, if _____ hits his head so hard you see it bounce, he loses consciousness, he cries excessively, or he later changes his demeanor, **please call me or his nurse immediately.**

If you are ever uncertain about whether or not to get in touch with me about _____, please call. I do not mind being interrupted. I know that many situations with hemophilia are unclear. If _____ needs an infusion of factor, I'll want to provide it for him as soon as possible. Some of the people in the school building are very familiar with his treatment and can also provide a reassuring word if needed when a question arises.

No one, including teachers, other children, or other personnel will be blamed if he bleeds at school. I expect him to be treated as the other children are treated. He can participate in all activities. Other children do not need to be cautioned to treat _____ with special care. Occasionally he will be absent due to an ankle or knee bleed or will be told by me if he should not run on the playground, etc. Approximately _____ days a year he uses crutches to keep his weight off of an ankle bleed. I will also let you know if he should not run on a particular day.

If _____ must be taken to the hospital, for any of the above situations or a situation in which you would take any other child, please call 911 and have him transported to _____. Please also contact me and the _____ Hospital to inform them of his imminent arrival.

My phone numbers are at the top of this letter.

In case I cannot be reached, please call _____ at (***) ***-**** (work) or (***) ***-**** (cell). He/she is the best emergency contact for _____ in terms of notifying a responsible adult.

_____ Hospital Hematologist: _____ – (***) ***-****

_____ Hospital Hematology nurse: _____ – (***) ***-****

Thank you very much. I am looking forward to a good year for _____.

Sincerely,

_____ 's Mom