Hemophilia of South Carolina is a proud recipient of the Advocacy & Public Policy Chapter of Excellence Award in recognition of our commitment to advocacy and education initiatives both at the state and local level, aimed at improving the lives of those in the bleeding disorders community.

Preparing Teachers, Administrators, Nurses, and Other School Personnel for my Child's Arrival

This Guide was created to provide you with a guideline of how to ask for, prepare for and present your child's bleeding disorder to his/her teachers. The best advice we can provide you is to create a working environment with your child's school. You are all on the same team with the same goal—provide my child with a great education in the safest environment possible.

Step 1 is to find out your child's teacher or teachers BEFORE school starts so you can set up a good time to conference with teacher(s), nurse and guidance counselor.

Step 2 is to bring copies of paperwork you want to provide the school.

Page 2 is an agenda or guide for the Conference. Make a personal connection with all attendees to you and your child.

School Beginning Conference Notes

- Introductions

  Who is in attendance? If bleeding disorder child is not present, bring a picture.

- Define Hemophilia, Von Willebrand, or Bleeding Disorder
- Medical History of Student

  Surgeries, frequency of bleeding episodes, target areas, preventative treatments

- Expectations of teachers, administration, parents & student
- Formal teacher or caregiver shares their experience with the student
- Present Facts, Put an end to falsehoods
- Questions?
- Thank them for coming
- Sign appropriate paperwork
- Dismiss

Introductions:

Say hello first then let them introduce themselves to you.

Your story should include:

1) Name
2) Occupation, including work hours
3) Marital Status, explaining if the other partner/spouse is in the picture
4) How many children you have & what schools they attend
5) How Hemophilia enter the picture, like if you knew you were a carrier, other family members with it, father had it, bleeding episode discovered it, etc.
6) Let them know your fears and daily struggles

**Provide a picture or have a PowerPoint with student's picture on it

**Example: My name is Cristal Day. I am a Teacher's Assistant at a local elementary school. I only work when the students are in school and have my summers off. I am divorced from Hunter's father. He is not in the picture and knows very little to nothing about Hemophilia. I do have my mom and many other family members that help me so I am not completely alone. I have 2 other children, girls where one is older and one is younger than Hunter. The oldest one attends Clemson University and the youngest one is here at the high school as well. My father was not in the picture growing up. I knew he had a disease but I didn't know what it was until I was 14, one year before he died. I found out that I am a carrier of Hemophilia when I was pregnant with my oldest child. We took precautions during my pregnancy with Hunter but we did not confirm his Hemophilia until he was 9 months old. Hemophilia is a daily struggle and it is very unpredictable. It affects every aspect of our lives but we work together to deal with it and handle each day.

Define Hemophilia, Von Willebrand, Bleeding Disorder:

Pass out a pamphlet, print out or flyer defining Hemophilia, Von Willebrand or bleeding disorder. Go over it. If you have a PowerPoint, then display the definition while discussing it or embed a video defining your child's bleeding disorder. Make it simple, using simple terms.

> *Hemophilia is a life threatening disease where their blood does not clot properly or at all. It is incurable. There are different levels of severity and each case is truly unique.*

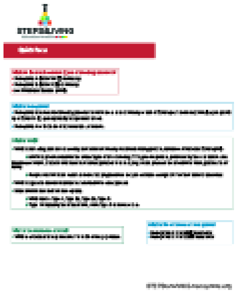
Great 3 minute video on YouTube that explains Hemophilia and its challenges: What Schools Should Know: Having a student with a bleeding disorder

https://www.youtube.com/watch?v=dZOZe-mYOWU&feature=youtu.be

Great pamphlets for general information are:

10 Things Everyone Should Know About Bleeding Disorders

Quick Facts About Bleeding Disorders



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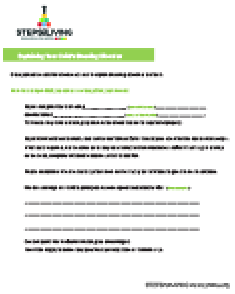
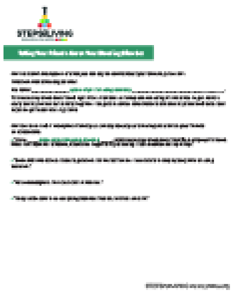
Explaining Your Child's Bleeding Disorder to Others



Telling Your Friends About Your Bleeding Disorder



Basics of Bleeding Disorders

Sample Letter for Day Care/Preschool/Elementary/Middle School

School Tool Kit for People With Bleeding Disorders

Medical History:

Let them know how many surgeries he/she has had. Target bleeding areas. How you treat them whether it's precautionary, preventative or during a bleed. Let them know whether he has 1-2 bleeds a year or 20+. Tell them about other ailments like arthritis. This does not need or have to be long or detailed just enough to let them understand your child better and how they are affected by their bleeding disorder.

Expectations:

This is when you build your educational team. Let them know you are all on his/her team to help your child succeed. This is a team effort that you take very seriously.
Tell them what you expect from them as teachers.

1) Patience and understanding when your child is fine when they enter class but 10 minutes later they are not fine and need the nurse.
2) Fairness and respect that they have a bleeding disorder but they are not defined by it.
3) Protect your child. Call for help or concerns with the nurse or parent. Create a secure classroom. Never send the student alone in the hallway if they suspect injury or bleed. Be proactive!

They can expect from you:

1) Information as to current bleeding issues, concerns.
2) Patience and understanding that your child is not the only child in their class and that they have not dealt with Hemophilia as long as you have so allow them time to adjust.

3) Support. Provide them with information, help, supplies or whatever they need to help your child.
4) Updated and a complete list of emergency contacts. *I always had a list of who to call in what order. Always 4 people on the list. However if I was on a Field Trip or at an appointment, I would send in via email to nurse who to call that day and in what order.

They can expect from administrators (nurses):

1) Protection for your child from other students and from severe weather.
2) Patience and understanding that Hemophilia has many unknowns and situations can arise quickly so preparation is key.
3) Making the school staff knowledgeable about Hemophilia and how it can impact students

They can expect from student:

1) Understanding and information. They will let you know when there is a problem. They will understand you are new to Hemophilia.
2) Truthfulness and accountability. They will be truthful about their issues and not misuse any privileges and will responsible for maintaining their credibility and trust.
3) Shyness or openness depending upon your child about their disease.

Former Teacher/Caregiver:

Bring in someone that has been in their shoes. Sitting in a meeting hearing scary information looking all doe eyed. This helps them understand that what they are feeling is normal and okay and gives them insight onto what to expect from someone who was new to it last year and made it through the year. In person is best but a letter from them works too.

Facts and Fiction:

Fact—Hemophilia effects how blood clots.
Fiction—My child will bleed to death faster than a normal child. They may bleed longer but Hemophilia does not cause the blood to flow faster.
Fact—My child is healthy and has some or no or a lot of restrictions.
Fiction—My child cannot run, jump, play games, participate in PE

***Realize that HIPPA prevents teachers, nurses or administrators to share your child’s information. This comes into effect when there are substitutes and they do not know your child’s condition. I always wrote a letter; negating HIPPA and said to make sure EVERY substitute knows about my child and to send them to the nurse IF there is EVER a problem. The nurse is well informed and will know what to do.