Facilitation Guide for Parents
Hemophilia at School

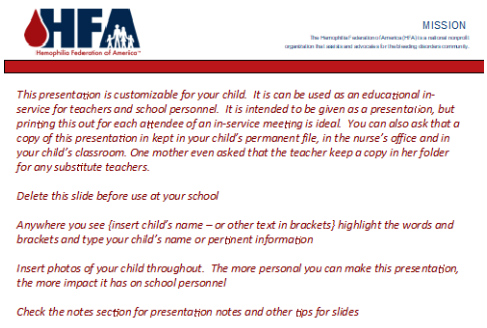
The purpose of this guide is to help you present the information below.

Helpful Tips:

- Read through the facilitation guide beforehand.
- Make your own notes; make it your own!
- When presenting, don't read the slides word for word.
- Practice.
- *Use the comments in italics to encourage group discussion*.

Slide 1 – Introduction

This presentation is customizable for your child. It is can be used as an educational in-service for teachers and school personnel. It is intended to be given as a presentation, but printing this out for each attendee of an in-service meeting is ideal. You can also ask that a copy of this presentation in kept in your child's permanent file, in the nurse's office and in your child's classroom. One mother even asked that the teacher keep a copy in her folder for any substitute teachers.



Delete this slide before use at your school.

Anywhere you see {insert child's name – or other text in brackets} highlight the words and brackets and type your child's name or pertinent information
Insert photos of your child throughout. The more personal you can make this presentation, the more impact it has on school personnel
Check the notes section for presentation notes and other tips for slides.

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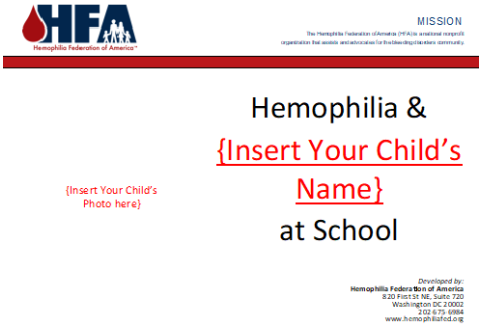
Slide 2 – Introduction

Customize this slide to your child.



Slide 3 – Meet _____

- Age
- List siblings, names, ages, grade or school names
- {Insert Child's Name & LIST DIAGNOSIS} i.e. Has severe Hemophilia A with a history of an inhibitor
- {LIST HOW FACTOR IS GIVEN} i.e. Has a port – venous access to infuse factor
- Developmentally on target

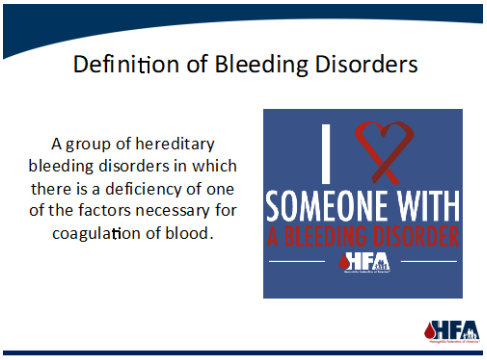
Customize this slide about your child!!! Add photos on the right hand side! May want to mention your child's factor schedule (i.e. "Little Johnny infuses on Monday, Wednesday, Friday and takes ___ units/kilo of factor VIII or IX via IV push. Parents will infuse Little Johnny before school on those mornings.")

Slide 4 – Definition of Bleeding Disorder

A group of hereditary bleeding disorders in which there is a deficiency of one of the factors necessary for coagulation of blood.

Does anyone know someone who's living with a bleeding disorder?

Today we are specifically discussing Hemophilia.



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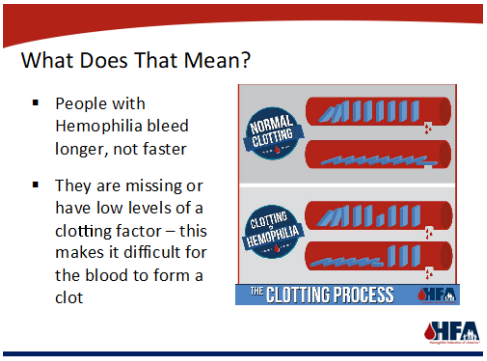
Slide 5 – What does that mean?

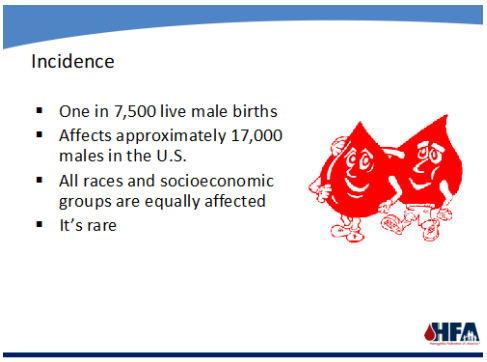


- People with Hemophilia bleed longer, not faster
- They are missing or have low levels of a clotting factor – this makes it difficult for the blood to form a clot

In people without hemophilia (the top picture), all the clotting proteins lined up to work together to form a clot.

In person with hemophilia (the bottom picture), one of the clotting proteins is missing or incomplete. The clotting process begins, but a person with hemophilia is unable to form a stable clot. This doesn't mean they bleed faster – just that they bleed longer.

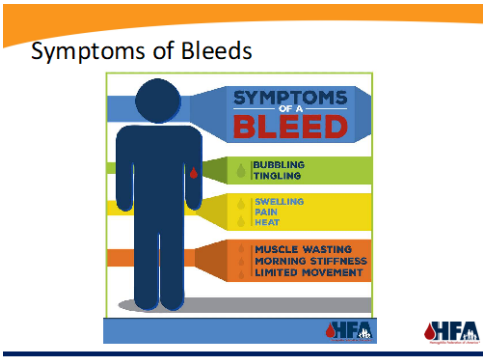
Slide 6 – Incidence



- One in 7,500 live male births
- Affects approximately 17,000 males in the U.S.
- All races and socioeconomic groups are equally affected
- It's rare

Slide 7 – Symptoms of Bleeds

Briefly discuss each and levels…



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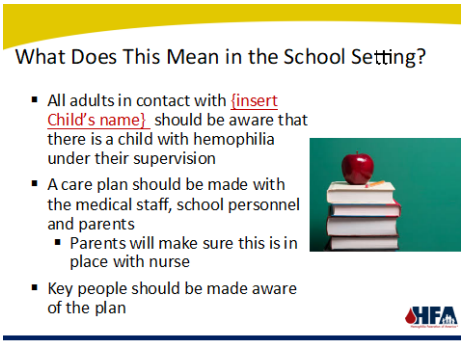
Slide 8 – What does this mean in the school setting?

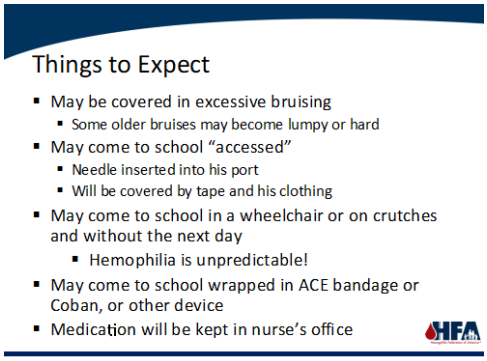
- All adults in contact with {insert Child's name} should be aware that there is a child with hemophilia under their supervision
- A care plan should be made with the medical staff, school personnel and parents
  - Parents will make sure this is in place with nurse
- Key people should be made aware of the plan



Care plan should be created with the school nurse.

Slide 9 – Things to Expect

- May be covered in excessive bruising
  - Some older bruises may become lumpy or hard
- May come to school "accessed"
  - Needle inserted into his port
  - Will be covered by tape and his clothing
- May come to school in a wheelchair or on crutches and without the next day
  - Hemophilia is unpredictable!
- May come to school wrapped in ACE bandage or Coban, or other device
- Medication will be kept in nurse's office



Insert pictures on right hand side (make this two slides if necessary) – maybe of your child in some of these situations – ACE Bandage, with bruises, etc.

It's possible he may missed school due to bleeding episodes. The parents agree to communicate with school to facilitate make up work, etc.

He may also come to school using assistive devices. It's possible he could be in a wheelchair, on crutches, etc.

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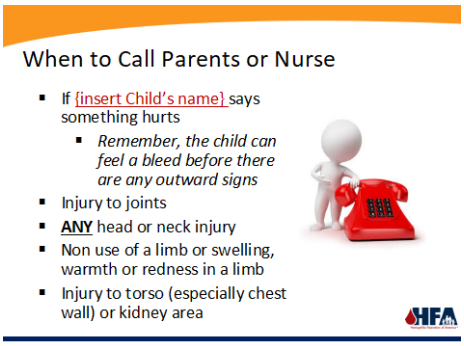
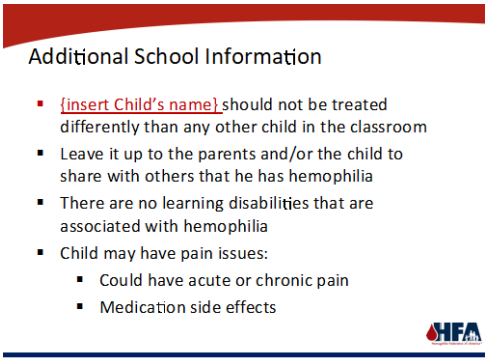
Slide 10 – When to Call Parents or Nurse



- If {insert Child's name} says something hurts
  - *Remember, the child can feel a bleed before there are any outward signs*
- Injury to joints
- **ANY** head or neck injury
- Non use of a limb or swelling, warmth or redness in a limb
- Injury to torso (especially chest wall) or kidney area

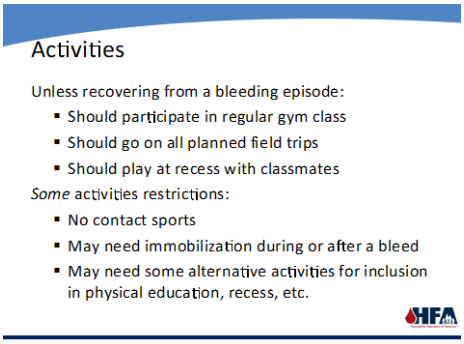
If your child has a port, stress that it's extremely important to call the parents immediately. A fever is a sign of a possible port infection which can be life threatening. Fevers must be thoroughly checked with blood culture to determine the cause of the fever.

Slide 11 – Additional School Information



- {insert Child's name} should not be treated differently than any other child in the classroom
- Leave it up to the parents and/or the child to share with others that he has hemophilia
- There are no learning disabilities that are associated with hemophilia
- Child may have pain issues:
  - Could have acute or chronic pain
  - Medication side effects

Slide 12 - Activities



Unless recovering from a bleeding episode:

- Should participate in regular gym class
- Should go on all planned field trips
- Should play at recess with classmates

Some activities restrictions:

- No contact sports
- May need immobilization during or after a bleed
- May need some alternative activities for inclusion in physical education, recess, etc.

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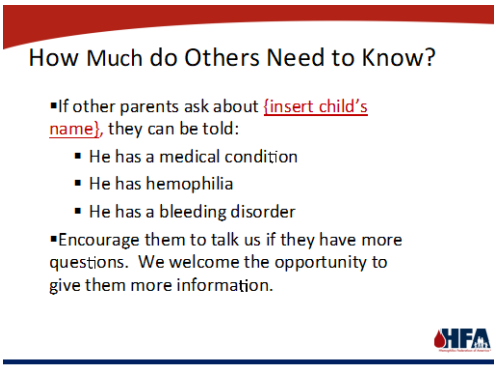
Customize for your child, here are a few other things you can consider adding:

- *Can play along with other kids and do the same activities as others*
- *Pay careful attention at recess & PE*
- *No rough-housing with other kids*
- *Does not have to wear helmet as of now*
- *No jumping off equipment*
    - *Use equipment properly (no going up the slide, don't come head first down slide, no jumping off play-sets, etc.)*

Customize to your comfort level; items listed are only intended as examples from other parents. Prefer that he not be excluded from activities, but intergraded in other manners. For example, he shouldn't play dodgeball, but he can be the "watch" and help spot others who are tagged out.

Slide 13 – How Much do Others Need to Know?

- If other parents ask about {insert child's name}, they can be told:
    - He has a medical condition
    - He has hemophilia
    - He has a bleeding disorder
- Encourage them to talk us if they have more questions. We welcome the opportunity to give them more information.

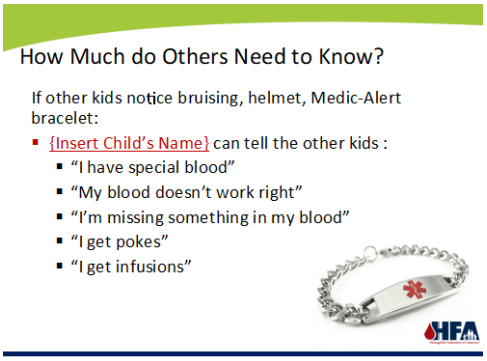


You have to decide what's right for your family in terms of disclosure to persons other than school personnel (other parents and students). If you or your child are not comfortable disclosing to others, you can delete this slide.

Slide 14 – How Much do People Need to Know?

If other kids notice bruising, helmet, Medic-Alert bracelet:

- {Insert Child's Name} can tell the other kids :
    - "I have special blood"
    - "My blood doesn't work right"
    - "I'm missing something in my blood"
    - "I get pokes"
    - "I get infusions"



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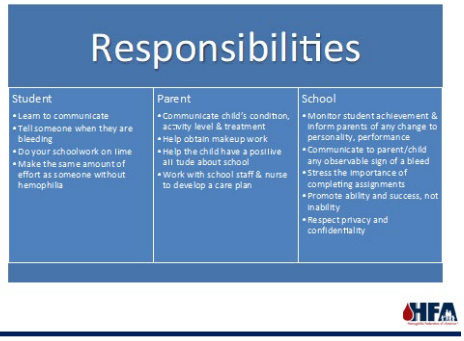
Slide 15 – Responsibilities

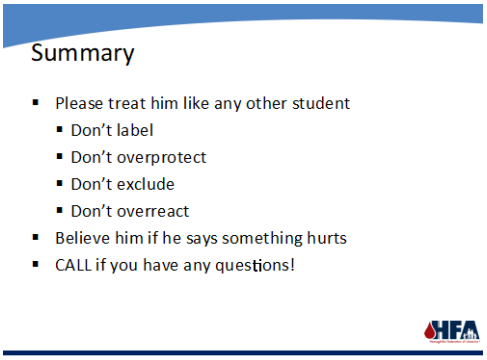


- <u>Student</u>
  - Learn to communicate
  - Tell someone when they are bleeding
  - Do your schoolwork on time
  - Make the same amount of effort as someone without hemophilia

- <u>Parent</u>
  - Communicate child's condition, activity level & treatment
  - Help obtain makeup work
  - Help the child have a positive attitude about school
  - Work with school staff & nurse to develop a care plan

- <u>School</u>
  - Monitor student achievement & inform parents of any change to personality, performance
  - Communicate to parent/child any observable sign of a bleed
  - Stress the importance of completing assignments
  - Promote ability and success, not inability
  - Respect privacy and confidentiality

Slide 16 – Summary



- Please treat him like any other student
  - Don't label
  - Don't overprotect
  - Don't exclude
  - Don't overreact
- Believe him if he says something hurts
- CALL if you have any questions!

All anything else you'd like to summarize.

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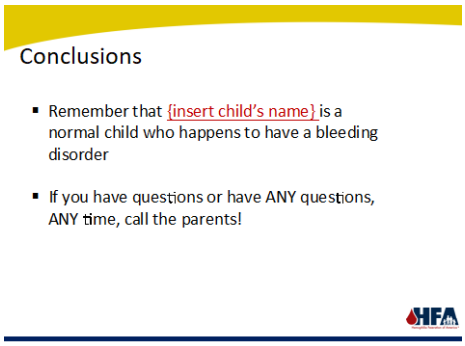
Slide 17 – Conclusions

- Remember that {insert child's name} is a normal child who happens to have a bleeding disorder
- If you have questions or have ANY questions, ANY time, call the parents!



Slide 18– Thank you!

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