**INDIVIDUALIZED HEALTHCARE PLAN**

**Basics of Bleeding Disorders and Care**

**For INSERT YOUR CHILD’s NAME HERE**

**Date:**

\_Child’s Name\_\_\_\_ has a bleeding disorder known as severe/moderate/mild hemophilia A/B, or Factor VIII/IX deficiency/con Willebrand disease (VWD). S/He tends to bleed longer than normal but s/he does not bleed any faster. This is a life-long condition with no cure, but with proper medical care he can have a normal life. A person with a bleeding disorder will not bleed to death from a minor cut. A person with hemophilia/VWD has prolonged bleeding time, because one of the thirteen clotting factors in his/her blood is defective or inactive. As a result, a strong clot does not form and bleeding can continue. Bleeding into internal spaces such as joints, muscles, or organs is the major concern in hemophilia/VWD. These bleeds are usually the result of injury but can happen spontaneously as well.

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| \_Child’s Name\_\_\_\_\_\_\_\_ also has an inhibitor or antibody related to his missing factor VIII/IX. His immune system d  eveloped an antibody to factor VIII/IX. \_Child’s name\_\_\_\_\_\_\_\_\_\_\_ currently takes factor VIII/IX (insert your treatment regimen, i.e. once daily) as part of an immune tolerance regimen to teach his body to accept factor VIII/IX. This makes treatment for some injuries different. For major injuries, including a joint bleed or life threatening bleed, \_\_Child’s Name\_\_\_\_\_\_ may need to use a bypassing agent such as recombinant factor VIIa/NovoSeven and/or activated prothrombin complex-concentrate (aPCC)/FEIBA. At present, for any bleeding episodes, the current treatment is to treat \_\_child’s name\_\_\_\_\_\_ with \_product name\_\_\_\_\_\_\_ and monitor closely. |

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| There are two types of hemophilia. Type A and B. The type depends on the clotting factor that is missing. There are thirteen clotting factors needed in the blood for normal clotting to occur. Type A hemophilia is missing factor VIII and type B is missing factor IX and is also called Christmas disease. \_\_Child’s Name\_\_\_\_\_\_\_\_\_\_ has type \_\_\_\_.    Hemophilia is also given a classification of mild, moderate, or severe depending on the clotting factor level that can be measured in the blood. \_Child’s Name\_\_\_\_\_ is classified as \_mild, moderate or severe\_\_ because s/he has a \_\_\_% level of factor VIII/IX clotting factor. |

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| \_Child’s Name\_\_\_\_\_\_\_\_\_\_ should avoid injury and medications that promote bleeding (ie. Aspirin). Adequate nutrition and good dental hygiene are also important to avoid problems.    Treatment for a small cut is the same as any person. The injured vessel constricts and platelets form a plug. The difference is in the formation of a strong clot. Helped by pressure and bandages, these defenses are usually enough to stop bleeding from a small cut or scrape. More severe bleeding and bleeding into muscles, joints, or internal organs **must be treated** by giving **\_\_factor product name\_\_\_\_\_.** It is important to treat as soon as possible to prevent damage to the joint, muscle, or organ.    For a variety of important reasons, the student’s parents often have chosen to and are trained to administer the factor at home. They are able to start an IV using a butterfly infusion needle, and give the factor necessary for clotting. \_Child’s Name\_\_\_\_ also receives his medication via a med-a-port, a central venous access device which is implanted in his chest. At school if the student should have a need for treatment, his parent/guardian will need to be alerted. The parent will come to school and administer the factor. In some cases, \_Child’s Name\_\_\_\_ can infuse her/himself. The student will probably return to class in 15- 30 minutes, and can resume his normal activities; but strenuous activity should be avoided for about 24 hours. \_\_Child’s Name\_\_’s medication and all necessary ancillary supplies should be kept in the nurses office or clinical area, and the parents should have access to it at all times during the normal school day. Other staff/personnel should have access to these medications at all times and the parents will supply these materials and ensure that they used are within their expiration dates.  \_Child’s Name\_\_\_\_ is able to recognize the first signs of bleeding before any evidence of a bleed is visible. **This is when treatment should be initiated.**  \_Child’s Name\_\_\_ will tell you if s/he is "having a bleed." Some persons with a bleeding disorder have developed a **target joint**, or a chronic site of spontaneous bleeds. \_Child’s Name\_\_\_\_\_\_\_\_\_ has \_#\_target joints:\_Name target joints (i.e. left ankle, right elbow)\_\_\_. Bleeding into the head, neck, or throat should always be treated. These bleeds, due to their location, can be life threatening and medical attention will be needed after treatment with factor. Injury to lower back, groin, hip or abdomen will also probably need further evaluation. The RICE method (Rest, Ice, Compression & Elevation) should be used. For any injury, ice packs should be used while calling the parents for further instruction.  If \_Child’s Name\_\_\_ leaves the school property for field trips, the teacher should travel with the factor and necessary supplies. The parents will provide a bag stocked with these items prior to scheduled field trips. S/He should attend all scheduled field trips.  \_Child’s Name\_\_\_ should not be excluded from normal activities. If s/he is having a bleed, please find ways to include her/him in participating in other manners. Contact sports, including, but not limited to, kickball, lacrosse, floor hockey, and football **are not** appropriate sports for \_Child’s Name\_\_. Close supervision on the playground is a must.  \_Child’s Name\_\_ may be mobility impaired or have limited use of a limb from time to time. S/He may also be in splints or other restricted mobility devices surrounding a bleeding episode. The school will need to be able to accommodate \_Child’s Name\_\_ on crutches or in a wheelchair, if necessary. The school will also need to be accommodating should \_Child’s Name\_\_have limited range of motion in his arms or hands for writing purposes.  It’s plausible that \_Child’s Name\_\_ could miss school due to bleeds or scheduled doctor or clinic visits. The parents will contact the school to inform them of \_Child’s Name\_\_’s absence and a projected date of return to school. The parents will pick-up any make-up work\_Child’s Name\_\_will need to complete. The parents will make all efforts to schedule planned doctor and clinic visits outside of school hours, but hemophilia/VWD can be a very unpredictable disorder and not all absences will be predetermined or avoidable.  As bleeds can be very painful, \_Child’s Name\_\_may be taking pain relievers from time to time. These can have the side effect of drowsiness, nausea and irritability. If \_Child’s Name\_\_ is taking any prescription strength pain relievers, the parents will notify the school.  Because \_Child’s Name\_\_ has a central venous access device, or med-a-port, all fevers must be reported to the parents immediately. The line has to be checked for bacterial infections via a blood culture and if an infection is present, \_Child’s Name\_\_will have to take intravenous antibiotics for a period of time. The parents should be notified immediately if infection is suspected.  \_Child’s Name\_\_wears a Medic-Alert bracelet at all times.  The parents encourage the school to call either the mother or the father if ANY questions arise or if there is ANY injury. The parents will ask questions as to what happened to determine the best course of treatment, but are not placing blame. It is better to tell the parents immediately of any concerns rather than waiting – waiting could be life-threatening! The parents ask that the school treat \_Child’s Name\_\_normally, don’t label her/him, don’t overprotect her/ him, don’t exclude her/him, don’t overreact and believe \_Child’s Name\_\_ if s/he says something hurts. |

**INDIVIDUALIZED HEALTHCARE PLAN**

**FOR INSERT YOUR CHILD’S NAME HERE**

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| **Problem:** | Bleeding, spontaneously or from injury |
| **Goal:** | To recognize signs and symptoms of bleeding |
| **Action:** | Recognize signs and symptoms, call parents |

1. A forceful blow, especially, any blow to the head neck or throat
2. \_Child’s Name\_\_states he is having a bleed. This may be a feeling s/he experiences, bubbling or tingling feeling in joint or pain in muscle.
3. Blueness or a change in skin color.
4. A feeling of warmth in his joint. Pain, swelling or limited movement are late signs of bleeding into the joint**.**
5. A minor cut or bruise rarely needs to be treated with factor
6. Limited use of a limb. Limping, dragging, hanging of limb.
7. Call parent at \_\_insert cell phone number\_\_\_\_\_\_\_ immediately.

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| **Problem**: | Bleeding, spontaneously or from injury |
| **Goal**: | Initiate early treatment. |
| **Action:** | Follow appropriate action as outlined below, call parents |

1. **Apply firm pressure and ice to the site**
   1. Have \_Child’s Name\_\_rest with the injured limb elevated.
   2. Call parent at \_insert cell phone number\_\_ immediately.
2. **Small cut or scrape**
   1. Cleanse the area with soap and water. Apply firm pressure.
   2. Apply a clean bandage. This first bandage should be snug for pressure on the site.
   3. Observe for 20 minutes. If the bruise has a lump or the bleeding continues call his/her parent.
3. **Nose bleeds** 
   1. Tilt head slightly back and have her/him sit down.
   2. Apply firm pressure by pressing the sides of the nose together. It may take between 5 to 20 minutes of uninterrupted pressure to stop the bleed.
   3. If bleeding continues longer than 20 minutes call his parent.
4. **Urine that is bright red or cola colored** should be treated as a bleed into the kidney or bladder. Alert his/her parent. Note any injury. If \_Child’s Name\_\_ is able to drink, have him/her drink fluids to help flush the urinary system, and to help prevent clots which could damage the kidney. (8 oz. of liquid every hour)
5. **Coughing up or vomiting fresh or dark brown material** (appears like coffee grounds), stomach pain with weakness or paleness, treat as a bleed and call his parent.
6. **Any** **injury to or near the eye**, pain around the eye, or any change in vision: treat as a bleed and call his/her parent.
7. **Any injury to the head**, headache, if s/he becomes sensitive to touch, a change in personality, change in the level of consciousness, change in speech, unequal pupils, forceful vomiting, stiff neck, change in motor ability or sensations, seizure: treat as a bleed and call his/her parent.
8. For **bleeding into the throat, tongue, or mouth** call his/her parent.
9. Stay with student until parent/guardian arrives.

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| **Parent Name**:  (please print) | **Parent**  **Signature** | **Date:** |
| **School Nurse Name:**  (please print) | **School Nurse**  **Signature** | **Date:** |

**INDIVIDUALIZED HEALTHCARE PLAN**

**FOR INSERT YOUR CHILD’S NAME HERE**

**Problem:**

**Goal:**

**Action:**

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| **Parent Name**:  (please print) | **Parent**  **Signature** | **Date:** |
| **School Nurse Name:**  (please print) | **School Nurse**  **Signature** | **Date:** |