

Shoulders, Elbows, Knees and Toes



**A Manual for
Children & Their Families
About Orthopedic Issues
Related to Hemophilia**

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The University of Miami Hemophilia Treatment Center

The University of Miami Hemophilia Treatment Center was begun in 1987. Since then, it has grown from six patients to over 350 children, adolescents and adults who are living with hemophilias, von Willebrand's disease and other coagulation disorders. The center is the only federally-funded HTC in South Florida. Patient and family education is a primary focus for the HTC staff, because the best patient care results from cooperation between the medical and psychosocial personnel and a well informed patient

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Baxter Healthcare Corporation is the principal U.S. operating subsidiary of Baxter International Inc. (NYSE:BAX). Baxter International Inc., through its subsidiaries, assists healthcare professionals and their patients with the treatment of complex medical conditions, including cancer, hemophilia, immune disorders, kidney disease and trauma. The company applies its expertise in medical devices, pharmaceuticals and biotechnology to make a meaningful difference in patients' lives.

-A NOTE TO PARENTS-

Joint bleeds are the "hallmark" of the hemophilic condition. Most persons with severe hemophilia, and many with moderate hemophilia, will experience a few joint bleeds. Learning to recognize the symptoms of an early bleed, seeking prompt medical attention, or learning how to infuse become part of the "routine" of everyday life. Dealing with an occasional bleed, often resulting from trauma, which responds to one or two infusions, becomes but an interruption in day-to-day activities.

However, the development of a target joint can be initially confusing, and often worrisome. Frequent, repetitive bleeds in one joint, unrelated to activity, lack of the expected response to the "normal" factor infusion regimen, subsequent activity restrictions, and the possibility of having to deal with a surgical procedure can be not only frightening, but overwhelming.

Understanding a process makes dealing with the necessary interventions easier. Since it is the child who bears the brunt of the more-frequent infusions, physical therapy, possible temporary interruption in participation in favorite sports and possible surgery, it is imperative that he understands what is happening and why his "routine" is being changed. When children know why things are different, and understand why they need to participate in sometimes difficult treatments, they are more likely to become cooperative partners in their own health care.

It is hoped that this story will serve to help develop that partnership, by providing a simple explanation for a not uncommon, but often difficult, problem.



I have hemophilia.

Having hemophilia means that my body doesn't make enough of a protein that is important to help stop bleeding. The protein I don't make is called factor 8 (or 9). I have trouble making a clot if I get hurt.

It's nobody's fault. I was born that way.



Yo padezco de hemofilia.

Padecer de hemofilia significa que mi cuerpo no produce lo suficiente de una proteína que es importante para detener los sangramientos. La proteína que yo no produzco se llama factor 8 (o 9).

Tengo problemas para que la sangre coagule si me lastimo.

No es culpa de nadie. Yo nací así.

Having hemophilia means that I need to get special injections of the factor right into my blood, through a needle in my vein.

Then I can stop bleeding quickly, like everyone else.

Having hemophilia means that I may need to get the factor before I see my dentist, or if I need an operation - like taking out my tonsils or my appendix- or if I fall and get hurt.



Padecer de hemofilia significa que necesito inyecciones especiales del factor directamente en mi sangre, a través de una aguja en mi vena.

Entonces puedo parar el sangramiento rápidamente, como cualquier otra persona.

Padecer de hemofilia significa que puedo necesitar administrarme el factor antes de ir al dentista o si necesito una operación - como sacarme las amígdalas o mi apéndice - o si me caigo y me lastimo.

Padecer de hemofilia significa que me salen mucho

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