

I Can Do It Myself!



**A Manual for Children
& Their Families about
Gaining Independence
Through Self-Infusion**

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~A NOTE TO PARENTS~

By the time a child with hemophilia reaches the age of nine or 10, the concept of self-infusion is introduced. The ultimate goal is to have the hemophiliac become as self-sufficient as possible as it pertains to his medical needs. Treatment centers, home care companies, and hemophilia summer camps and retreats stress the need for self-infusion, offering classes and positive reinforcement for participation and completion. The benefits are obvious – prompt treatment, less joint damage, fewer long- and short-term complications and, equally important, independence from Mom and Dad – the hallmark of adolescence.

However when the time comes to learn self-infusion, there may be reluctance on the parts of both parent and son, although one can only speculate on the reasons. For example, parents may feel responsible and guilty. Mothers, in particular, may feel that their efforts have protected their sons, so why stop? Additionally, carrier mothers might feel particularly guilty about passing on the hemophilia gene to their son, and continuing to infuse him might allow her to feel as if she is staying connected and “making amends” for her genetic heritage. Perhaps the son prefers not having to deal with the factor issue, or he might just be scared of sticking himself.

Whatever the reasons for hesitation, once self-infusion is mastered, the pride in self, and the recognition of this major step toward adulthood is significant. Self-infusion is definitely one of the ways in which having hemophilia becomes merely a part of, but not the defining part, of a young man’s life.



I like to watch TV, play video games and eat peanut butter and jelly sandwiches. I like to tease my sister, listen to my mother read stories, and help my dad fix things around the house. I have a pet rat, a bulldog puppy and two goldfish named Whiskers and Sam. I

have a red bicycle, a blue backpack and my own i-Pod®. I have an older sister, a baby brother and a whole lot of aunts, uncles and cousins. I have my Mom, my Dad, and two grandmas and grandpas.

I also have hemophilia.



Me gusta ver televisión, jugar juegos de video y comer sándwiches de mantequilla de maní y jalea. Me gusta fastidiar a mi hermana, oír los cuentos que lee mi mamá y ayudar a mi padre a arreglar las cosas de la casa. Tengo una rata domesticada, un perrito bulldog y dos pececitos de colores llamados Whiskers y Sam. Tengo una bicicleta roja, una mochila azul y mi propio i-Pod®. Tengo una hermana mayor, un hermanito y muchas tías, tíos y primos. Tengo a mi papá y a mi mamá y a dos abuelitas y abuelitos.

También tengo hemofilia.



Hemophilia sounds scary, but it really isn't. I was born with it. Most people who have it have a brother or a cousin or a grandpa who has it, too. But some people are like me – the only one in the family!

My mom says that having hemophilia is just one small part of who I am. It's like having curly hair or blue eyes, or being good at math. Except, sometimes, having hemophilia is not easy.



La palabra “hemofilia” da miedo, pero en verdad no debe asustar. Yo la tengo desde que nació. La mayoría de las personas con hemofilia, saben que un hermano, o un primo, o un abuelito, también la tienen. Pero algunos son como yo: ¡el único de la familia que la tiene!

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