



THE FIRST STEPS

NEWS OF A CHILD'S DIAGNOSIS MADE EASIER BY PREPARATION AND REACHING OUT

Corey Adamkin seemed the perfect newborn baby boy—a mother’s delight at 9 pounds, 10 ounces. The feelings of joy and delight then turned to shock.

Corey’s mother, Deborah, was ready to leave the hospital with her new bundle, when she realized Corey felt heavier than usual. When she started to change his diaper, she found it filled with blood.

“I remember screaming to the nurses that there was something wrong with my baby,” Adamkin says. “Then they came and took him away.”

The diagnosis was a surprise to the Adamkin clan. Corey was the first known case of hemophilia in the family. Today, he is 11 years old and living with severe hemophilia A.

When Julie Doar-Sinkfield’s son, Hunter Plaines, was born a decade ago she believed everything went OK in the hospital—until a day later when Hunter was in neonatal intensive care, bleeding severely.

Doar-Sinkfield, who lives with her husband and son in Washington, DC, knew the family’s women had a history of heavy bleeding, but had little knowledge of hemophilia. It turned out that she was an asymptomatic carrier for hemophilia A.

By Lisette Hilton

A ROLLERCOASTER OF EMOTIONS

Like other parents who find out their child has a bleeding disorder, both Adamkin and Doar-Sinkfield experienced a rollercoaster of emotions. Feelings of shock, disbelief and denial are all common when parents first hear of their child's diagnosis.

"It went from the shock of, 'Oh my God! My child almost died and I don't know what this is,' to 'Oh my God! They're going to send this baby home with me?'" Doar-Sinkfield remembers.

Shock is most common among parents with no known history of bleeding disorders, according to Elizabeth Fung, LCSW, PhD, senior social worker at the Hemophilia and Thrombophilia Comprehensive Clinic at Children's Memorial Hospital in Chicago. About 30% of people born with hemophilia have no family history.

"Most of the parents think this is leukemia or a horrible blood disorder and don't know what to expect, so it adds to their uneasy feelings," Fung says.

Oftentimes, the initial emotions of shock are soon followed by denial. Before parents are faced with their child's first bleed, or first infusion treatment, denying that their child has a condition that requires extra care is a temporary solace.

"I spent a lot of time believing Hunter was not going to bleed," Doar-Sinkfield says. "There's nothing like that first bleed or that first regimen of factor replacement. And I don't know that there's anything you can do to be prepared for it."

Like many, Doar-Sinkfield was afraid that Hunter's condition would stop him from being an active child or inhibit him from doing what he wanted as he grew older.

"But that fear was unfounded," Doar-Sinkfield recalls.

"Particularly at this point in hemophilia treatment. There are things he probably shouldn't do, like tackle football, but in life, everyone has something he or she shouldn't do based on your general strengths and weaknesses."

KNOWLEDGE BRINGS COMFORT

While the news of a child's bleeding disorder can stir up feelings of shock and fear, becoming knowledgeable about the disease can help new parents come to terms with the diagnosis.

Danna Merritt, MSW, social worker for the Children's Hospital of Michigan Hemostasis and Thrombosis Center in Detroit, recommends that new parents try to "normalize" their child's bleeding disorder as much as they can—and as quickly as they can—by making any treatment routine a normal part of the family's day.

"This comes easy once you are knowledgeable about the condition," Merritt says.

Doar-Sinkfield adds that becoming aware of the wealth of support available to new parents is another important step.

"I think the best thing that families can do is get involved with their local chapter of the National Hemophilia Foundation [NHF], or with the national organization so they can meet other children who are just like their kids and are doing just fine," she says.

Doar-Sinkfield participated in a session during NHF's 2004 annual conference that was organized for families of newly diagnosed children. She made it a point to show the reality of hemophilia in a slideshow of her son's life—sharing pictures of the black eye Hunter had for eight months, as well as myriad other bumps and bruises. She also showed his many recoveries. Through it all, she says, Hunter was smiling.

COREY'S HEMOPHILIA DIAGNOSIS SURPRISED HIS MOTHER DEBORAH, BUT THEY NOW ARE DOING FINE.



In addition to its annual conference, NHF offers parents a wealth of resources about many bleeding disorders through its information service—known as HANDI. HANDI staff is available to answer parents' questions, conduct library searches and put parents in touch with other resources as needed. Free information packets that answer the most commonly asked questions can also be requested by calling (800) 42-HANDI.

Learning from parents who know firsthand what it's like to be in the same situation can also bring comfort to new parents. For example, NHF's First Step program encourages family-to-family support by linking new parents with mentoring parents. The program is one model of new parent/family education in which NHF chapters and associations, hemophilia treatment centers (HTCs), parents and guardians all work together to provide education and support for families.

First Step can offer a chance to become more educated about bleeding disorders and to meet other new parents and families experiencing similar "firsts" in their child's life with a bleeding disorder. For more experienced parents with older children, First Step can offer an opportunity to serve as a mentoring parent who can assist new families in navigating their way through the information the early stage events and questions.

Laurie Kelley, whose son was born with hemophilia 17 years ago, founded Boston-based LA Kelley Communica-

tions, Inc., and also aims to connect new parents with the bleeding disorders community.

"Our books are a way to put them in touch with what other parents have gone through," Kelley says. Families can request free materials on the company's Web site at www.kelleycom.com. Most publications are written by parents of children with bleeding disorders.

However, what may be the most important place for newly diagnosed families to turn is the nearest HTC. Today, there are some 140 HTCs in the US, and also a network of HTCs in many countries worldwide. These centers serve people with bleeding disorders in many ways, such as:

- Diagnosing and treating the disease
- Providing a healthcare team that includes hematologists (doctors who specialize in bleeding disorders), nurses, social workers, dentists and physical therapists
- Offering information about factor replacement products for treatment, as well as access to those products
- Educating patients, parents and family members about living with a bleeding disorder

The Centers for Disease Control and Prevention (CDC) and the NHF recommend that everyone with a bleeding disorder visit their HTC at least once a year for a complete exam. What's more, the CDC has shown that patients who get their care at an HTC have a 40% lower hospitalization

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NEW CLOTHING LINE GIVES TODDLERS AN EXTRA BUFFER

Angela White and her husband Gill Baxter took all the precautions they knew to protect their son, Elijah, from bumps and bruises.

But their efforts became more difficult when Elijah, who has severe hemophilia, began the active crawling and climbing that comes with the toddler stage.

"We were having a real problem with tissue bleeding. Elijah was starting to become very active and developed tissue bleeds, which is completely normal for a baby with a severe bleeding disorder," White says. "We tried knee pads, ace bandages, extra cotton in the clothing but none of these worked."

Elijah was about 10 months old and learning to stand when he fell and landed on his buttocks. The severe tissue bleed that resulted had the family going to the hospital for five days. Not long after, he fell again, on the same spot, starting another round of hospital trips.

Desperate and frustrated, White realized that she couldn't prevent Elijah from trying to stand and walk, but she could improve the cushioning between him and the floor *when*

he fell. So, she sewed some of the foam from under the carpet into an extra diaper that Elijah wore.

Elijah's next bleed healed much faster than the first, and it sparked another light bulb in White. And Bruisey Bee—a padded clothing line for infants and toddlers with bleeding disorders—was born.

Launched this year, Bruisey Bee is the first clothing line dedicated, designed and tested to alleviate and help prevent deep-tissue bleeding—with padding in the shins, knees and buttocks. The line includes an assortment of overalls, denim pants and shirts that can be machine-washed and dried.

"For us, the real joy is the feeling that we can do something to help Elijah and other children like him," White says.

Bruisey Bee can be purchased by phone at (707) 823-1482 or online at www.bruiseybee.com.

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rate from bleeding complications than those who do not visit HTC.

Parents can find their closest HTC by using NHF's HTC directory at www.hemophilia.org.

REMEMBER THAT YOU'RE NOT ALONE

Since learning more about bleeding disorders is an ongoing process, newly diagnosed families should know that the bleeding disorders community offers social support that is invaluable for living with a chronic illness.

Besides First Step, parents can look to their HTC for news about available support groups that can provide new families with a much-needed social connection.

Merritt further recommends that parents try to attend upcoming NHF meetings, including the annual meeting that is held each fall.

"Parents should make a real effort to get to those events and spend time with a lot of other families," Merritt says. "The thing that is nice about the national and local meetings is that there is always a special program for kids, siblings included, which allows them to learn about their brothers' and sisters' conditions from other kids."

EFFECTS ON THE FAMILY

Coping with a child who needs extra care and attention can put added stress on any family. From emotional pain to financial burden and even daily time demands—it all can weigh heavily on each family member. During counseling sessions Merritt focuses especially on the parents because "when the parents are OK, then all the kids will be OK."

"When the parents are feeling secure and knowledge-

able as possible, when they're dealing with their feelings and really making connections with people and becoming stronger and more empowered, it filters out to the children," Merritt says.

But, siblings who do not have a bleeding disorder may have a difficult time adjusting and may prove to be yet another stumbling block in the family's progress.

Fung, with the Children's Memorial Hospital in Chicago, has studied the behavior patterns of siblings of children with bleeding disorders, and says that while most siblings know as toddlers that there is something different about their brother or sister with hemophilia, they are not able to distinguish themselves as *not* having the condition until ages eight or nine years.

"If you look at the developmental stages, I think it's a pretty sophisticated understanding that your sibling has a blood problem or some kind of disorder and that you do not have it," Fung says.

Siblings without a bleeding disorder often feel resentment and believe their parents give more attention to the sibling who does, she says. They usually show their resentment by acting out, rather than verbalizing, Fung adds. Some will pretend to be sick or try to get sick in order to get attention.

"I think it's extremely difficult for parents, especially in the beginning when they, themselves, are overwhelmed by this diagnosis," Fung says. "A lot of times they are so overwhelmed and depleted, they don't have the energy to nurture the siblings."

Fung suggests that when parents feel they have a little more energy—when things calm down some—they

should make a strong effort to show and tell their other children how they've felt all along, how much they love them and that they love them equally—not less. She says it's crucial for parents to include the siblings in the issues that surround the bleeding disorder.

Merritt agrees. "Don't keep secrets. Tell them what's going on." "If you're treating the child, don't make their siblings go in the other room. Keep them in the room with you and have them help by holding the bandages or other supplies."

When it comes to caring for the child with the bleeding disorder, another concern is that parents fear the siblings will be too rough when they play or fight—as siblings often do.

Merritt says teaching all the children in the family to play safely is the best solution. Parents should get down on their hands and knees and show them how to play.

"You should actually demonstrate how you can still roll around on the floor without hurting one another," Merritt says.

She adds that simple household rules should be set and followed: don't hurt yourself, don't hurt your surroundings and don't hurt others.

Merritt says the rules should be the same for everyone. It breeds resentment when parents single out siblings and say they're not allowed to hit their brother or sister with the bleeding disorder.

WHEN THE DUST SETTLES

Parents who have been through the baby, toddler and teenage stages will say that while hemophilia is an added burden, normalcy *is* possible. Despite the challenges and initial fear, many say they are grateful their child has such a manageable disease.

Doar-Sinkfield put Hunter into daycare when he was seven months old and resumed her teaching career. She has since founded a performing arts public charter school where Hunter attends.

She says that if someone told her that her child would have a medical issue but she could pick which one, "Knowing what I know now, this is what I'd pick. Fifteen minutes, three times a week is all it takes to treat my child and keep him healthy. That's all it takes." ●

To Learn More...

- For books on caring for your child with a bleeding disorder, call NHF's resource center at (800) 42-HANDI or by e-mail at handi@hemophilia.org.
- To learn how to participate in First Step or other upcoming NHF meetings, visit www.hemophilia.org.
- For LA Kelley Communications material, visit www.Kelleycom.com.