



## Children and the Emergency Department: A Q&A with Michael Coyne, MD

A trip to an emergency department (ED) can be a daunting experience for parents. The child's safety and well-being are, of course, in the forefront of a parent's mind, and worry, anxiety and fear seem to be there as well. On top of all this, imagine that the doctors at the ED aren't well-informed about the child's condition and actually accuse the parents of abuse. This scenario may seem disturbing, but it is a fact for many parents of children with bleeding disorders. Erroneous knowledge and misunderstanding of the complexity and severity of hemophilia-related problems are commonplace. A child who looks healthy may in fact be suffering from severe internal bleeding. Alternatively, bruising with soft tissue swelling may occur without injury despite heroic parental efforts aimed at safety. Michael Coyne, an emergency physician, who is the assistant director at the Department of Emergency Medicine at the Berkshire Medical

Center in Pittsfield, Massachusetts, and is a member of NIH's Board of Directors, offers some sound advice to parents of a child with a bleeding disorder who need to take their child to the ED.

**HemAware:** What do parents need to bring to an ED if they must rush their child there?

**Dr. Coyne:** There are a few items that are important. The first one is clotting factor and infusion supplies. The second is an ice pack if the child has sustained an injury that requires it, such as a muscle or a joint bleed. Third would be an emergency treatment introductory note from the child's physician. This note would include: an explanation of what hemophilia is and basic management guidelines; the physician's description of the child's type of hemophilia; ▶

BY MICHAEL COFFINO

► the severity of the hemophilia; inhibitor status; a dosage chart that simplifies clotting factor replacement for specific injuries or specific types of bleeds; and the product that is advocated for this patient.

The next items that should be brought are the phone numbers of the child's hematologist, pediatrician and hemophilia treatment center (HTC), if the child is affiliated with one. The parents should also bring their knowledge of hemophilia, confidence in their knowledge and their assertiveness. To this end, NHF's information service, HANDI (800-42-HANDI or [handi@hemophilia.org](mailto:handi@hemophilia.org)) has an emergency treatment packet and in it are some articles about hemophilia emergency care. It's always helpful for parents to bring an article (preferably one from an emergency medicine journal) with them in case they need to bring attention to an issue or underscore a management concern. If parents feel that their child's care is being mismanaged or the triage is being excessively delayed, they can simply reference a section in the article. Bring this to the attention of the triage nurse or physician and clarify to them what your understanding is of the accepted standard of medical care.

I usually advise people to keep a letter from their physician, an emergency medicine article on hemophilia and important phone numbers in a travel pack, along with their factor and infusion supplies. This should accompany families whenever they're traveling. No one ever anticipates an emergency, however, advanced planning may make all the difference when one arrives in the ED.

I would advocate that when possible, parents come supplied with some toys, games or reading material, as often there is some down time in the ED. For the younger children, something to comfort them should be brought, whether it's a favorite blanket or a stuffed animal.

**HemAware:** Is it important to do research on hospitals near where you live to make sure they are prepared for a child with a bleeding disorder?

**DR. COYNE:** First of all, parents of children with hemophilia need to understand quite clearly that hemophilia is a rare disorder and they should never assume that emergency care personnel will always be aware of the appropriate treatment for this dis-



Dr. Michael Coyne

order. Parents and caregivers must accept some of the responsibility in understanding the treatment and care of hemophilia. Physicians in an ED may be very skilled in treating common disorders such as diabetic emergencies, heart attacks and strokes; yet when it comes to something they may only see every five or six years, these doctors may not be on the top of their game. If parents want to help ensure appropriate care and decrease the chance of treatment delays and mishaps, they will need to assume some responsibility.

Parents should, if possible, select an ED where their hematologist and/or pediatrician is on staff. This way, the family will have an accessible advocate and liaison to help them. Secondly, parents should make an appointment to visit the ED staff with an HTC nurse and set up an educational in-service to go over some of the nuances that are important with hemophilia emergency care. Some physicians or nurses may not be familiar with clotting factor or may not understand that treatment needs to be provided urgently. While the child may look fine, he/she might be bleeding internally. Parents can contact the nurse manager of the department or the physician director of the department to set up an appointment.

If parents have an option about choosing from a variety of EDs, they should look at proximity, pediatric experience in the institution and a department that is responsive to working with them (espe-

cially one that is willing to meet with parents beforehand). I would recommend that parents follow their treating physician's advice as far as selecting the department he or she believes is most prepared to deal with their child's emergency when HHC care isn't an option or when the problem can't be handled at home.

**HemAware:** How can a parent avoid problems in the ED concerning allegations of child abuse?

**DR. COYNE:** First of all, I think it's important for parents to appreciate that competent emergency physicians and nurses must forever be alert to the possibility of child abuse in all children. We are responsible for providing children with a safety net. Parents should realize that hemophilia is a rare disorder and caregivers may not be familiar with hemophilia-related problems, including bruising. When a child presents with bruises of different age and in different places, especially impressive ones, the diagnosis of abuse should always be brought into suspicion. Physicians and nurses are trained to look for these types of bruises.

It's very important for parents to educate the staff that bruising can occur often in a child with hemophilia. Parents must inform the staff that their son or daughter has a bleeding disorder that requires clotting factor to help stop the bleeding, and often the child may be covered with bruises that cause him or her to look like an abused child. Parents might mention how hard it is for them to be the recipient of suspicious looks and whispered accusations from other adults who have noticed their bruised child. Bring ammunition in the form of literature as support. Most ED staff will respect information that has appeared in an emergency medicine peer-reviewed journal. Also, it is helpful to reference a note from your child's physician explaining that easy bruising and spontaneous bleeding are not uncommon in children with hemophilia. Parents should bring the physician's phone number and say, "If you have a question, please call my doctor."

**HemAware:** What advice should parents give to physicians who may be unfamiliar with hemophilia when confronted with a young patient for the first time?

**DR. COYNE:** Let them know you realize your child has a rare disorder and that many physicians often have very little expertise in dealing with it. Show them that you have developed some expertise on your own. Don't be afraid to share the knowledge you've amassed. Inform the ED staff that you would like to work with them so that your child has a good outcome. In other words, create a cooperative, team approach. Offer clinicians the literature you have and the phone numbers of consultants (pediatricians and hematologists). Let them know what you think is wrong with your child and what you believe needs to be done. Don't be afraid to speak up, especially in the instances where you feel the physician's judgement may be wrong, or the action they propose may be unnecessary. Explain how you have spent a lot of time reading about hemophilia. Be professional and respectful, but assertive.

I also believe it's useful for parents to understand how an ED functions. A visit beforehand to an ED is a good time to understand the processes: triage, registration and treatment. Some people may fail to understand that emergency departments do not operate like a deli counter: first come, first served. There is a triage process. Emergency personnel must attend to life-threatening emergencies first. A heart attack or stroke victim, or an individual critically injured by a gunshot wound, would take priority over a child suffering from a muscle or joint bleed. All parents want their child to be seen urgently, and it may be very frustrating to wait. Try to understand the triage process, realizing that individuals with hemophilia may be triaged appropriately and inappropriately. A triage nurse might be fooled because your child may appear "well." Additionally, the triage nurse and/or the physician may fail to appreciate the importance of urgent factor replacement.


If the triage is delayed, the care given is inefficient or mishandled, parents shouldn't be afraid to speak up. They should outline the problem, discuss it with their healthcare provider in real time and describe the actions that they think need to be taken. If this approach fails, enlist your resources (article references and calls to your hematologist and pediatrician as consultants). If you just are not getting a response that you are com- ▶

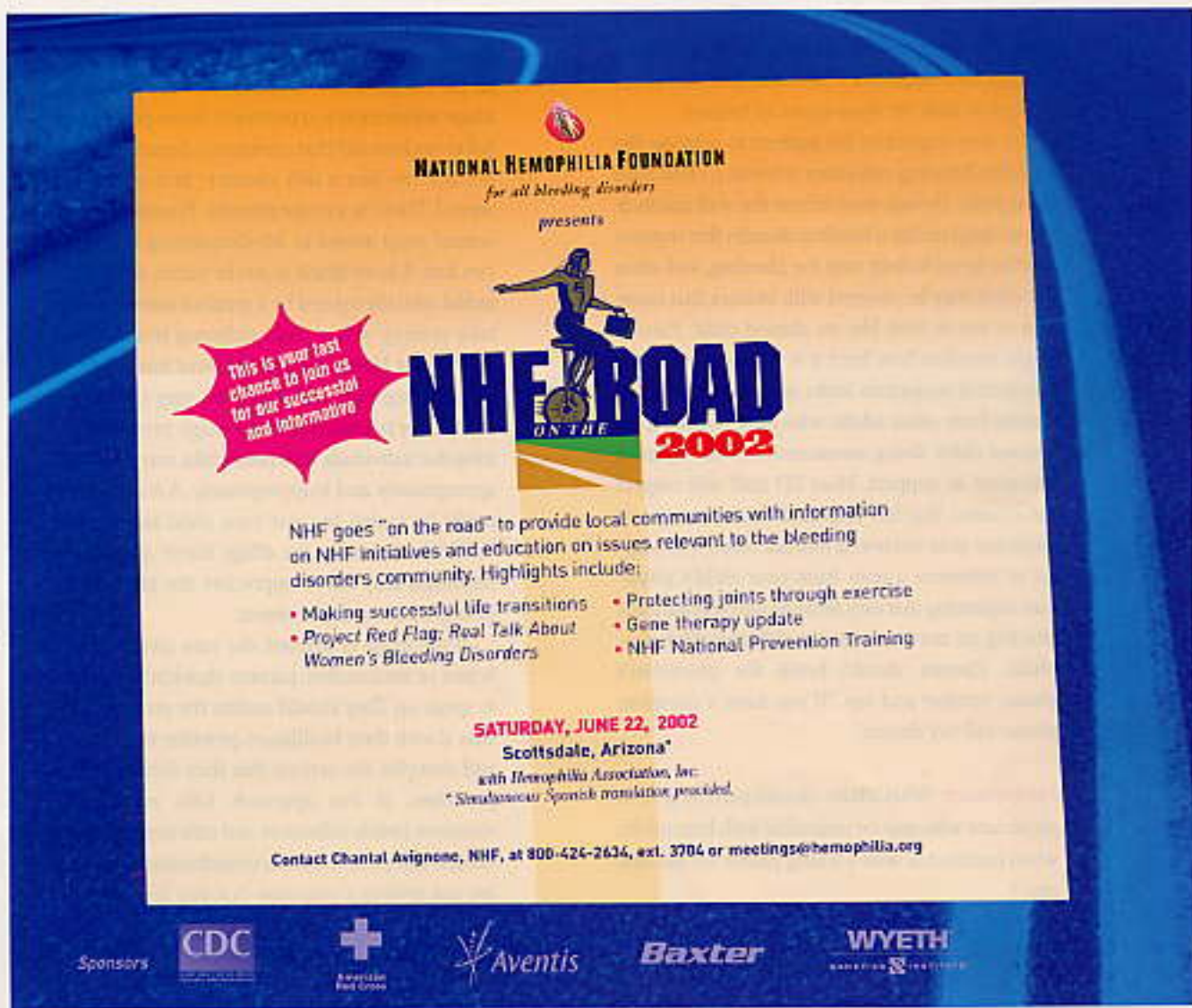
► comfortable with, ask to speak with the charge nurse, the attending physician, the ED nurse manager, the physician director of the ED, the nursing supervisor, the hospital risk manager or the hospital administrator on call. Parents need to go up that list if they're not getting the satisfaction and care they expect

**HemAware:** What are some things parents can do to soothe a child who is nervous about the ED?

**DR. COYNE:** Bring along toys that are age-appropriate, coloring books, crayons and reading material. A blanket or a favorite cuddly animal is also a good idea. Parents should consider taking a trip to the ED with the child beforehand so that they can be somewhat prepared for what's in store. The parents should explain to their child what to expect and tell him/her that there will be some

idle time. I think it is extremely important to remember that if the parent acts fearful, upset and anxious, children will assimilate the same response. Despite what's going on, parents need to maintain their composure, remain calm and utilize their energies productively while trying to reassure their child about the hospital visit. This is always easier said than done. Parents should relate stories about an ED visit when they were young. This will let the child know he/she is not the only one who has experienced an ED.

Afterwards, when the ED visit is over, parents should treat themselves and their child to something special. Celebrate what has been accomplished. Go out for an ice cream and congratulate the child. Feel the relief of putting this episode in the past. Tomorrow, reflect and consider what can be done to make the next visit even smoother. 



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Contact Chantal Avignone, NHF, at 800-424-2634, ext. 3704 or [meetings@hemophilia.org](mailto:meetings@hemophilia.org)

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