





BY PHYLLIS MCINTOSH

Back to School

Make sure everyone learns how to address the needs of your child's condition



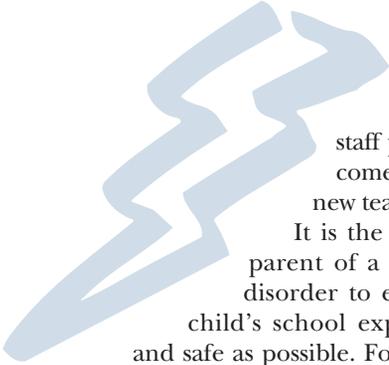
Shari Luckey's son, Jay, has severe hemophilia. When it was time for him to start preschool, there were some anxious moments.

"We were very concerned about him getting injured and not realizing it or not telling the teacher," Luckey says. "So to prepare, we did a lot of education with the staff about what to look for and a lot of practicing with him about what he should do if he felt any pain or discomfort. I even sat in the hallway at school for a few weeks, just in case."

Jay, now 11, has changed schools several times because of family moves; the family now lives in Ann Arbor, Michigan.

"We have been met with fear at every new school and every new teacher situation, although that has lessened as he's gotten older, and teachers can rely on what he tells them," Luckey says. "When we go to a new school, we have a meeting with as many





staff people as we can get to come, and we meet with his new teachers every year.”

It is the responsibility of every parent of a child with a bleeding disorder to ensure that his or her child’s school experience is as normal and safe as possible. For a parent, that means doing your homework *before* your child enrolls in day care, preschool or kindergarten, or moves to a new school. Your local hemophilia organization and hemophilia treatment center (HTC) can help you understand your rights under the law, assemble information packets to educate school personnel about bleeding disorders and arrange a meeting at school to discuss your child’s needs.

While safety is vital, so is your child’s education.

“Parents need to realize that school is an important milestone in socialization and that a good basic education is essential to a successful future and a job that will provide the health insurance she or he will need as an adult,” says Ellen White, hemophilia nurse coordinator at the Children’s Hospital of New Jersey at Newark Beth Israel Medical



Center. “Children need to know that they belong in school, and that having a bleeding disorder does not excuse them from participating in class and doing their homework.”

TACKLING FEARS

While a child may be nervous about starting school, and parents may worry about entrusting their child to the care of others, probably the most anxious of all are school personnel who may have no prior experience with bleeding disorders. Joby Robinson, PhD, child advocacy coordinator at the Children’s

Center for Cancer and Blood Disorders at Palmetto Health Hospital in Columbia, South Carolina, recently surveyed 300 educators throughout the state and found that of 13 chronic health conditions, educators most feared dealing with hemophilia. Furthermore, 83% said they had had little or no training about chronic health conditions, either in college or on the job.

Fear stems from common misconceptions about bleeding disorders, Robinson explains. Many teachers think all bleeds are external and worry that a child with hemophilia could bleed to death from a minor cut or scrape. They may not understand that signs of an internal bleed demand immediate attention and may feel unduly guilty if a child develops a spontaneous bleed. Often, school staff think children with bleeding disorders can’t engage in many normal school activities.

Before they can quell the fears of others, however, parents must first confront their own misgivings about sending their child into a new situation.

“It’s perfectly normal for parents to have concerns and fears, so I think it’s real important to get together with the HTC staff and air those concerns *before* you go to the school,” Robinson says. “The first school meeting can be a little intimidating, so it also helps to practice going over the major points you want to address with the school staff.”

Some HTCs offer workshops to educate parents about their rights and help them practice talking to school personnel. Often, an HTC nurse or other staff members will accompany parents to the school meeting, or arrange an inservice with the school staff. If you are unable to find a nurse, contact your local NHF chapter to put you in touch with an expert who can help.

(continued on page 35)

To Learn More...

Contact NHF’s Information Resource Center at (800) 42-HANDI for these brochures and fact sheets on how to prepare your child for school:

- ▶ “The Child with a Bleeding Disorder: First Aid for School Personnel”
- ▶ “Playing It Safe: Bleeding Disorders, Sports and Exercise”
- ▶ Also check out two PowerPoint presentations on school issues located under the Researchers and Healthcare Providers tab, Nurses Working Group section of NHF’s Web site: www.hemophilia.org.

For more information on how to become an advocate for your child, visit the following Web sites:

- ▶ The Center for Health and Health Care in Schools—www.healthinschools.org
- ▶ American School Health Association www.ashaweb.org
- ▶ Parent Advocacy Coalition for Educational Rights—www.pacer.org
- ▶ National Dissemination Center for Children with Disabilities—www.nichcy.org
- ▶ The Families and Advocates Partnership for Education—www.fape.org
- ▶ U.S. Department of Education—www.ed.gov
- ▶ National Association of School Nurses www.nasn.org

COMMUNICATION 101

Before the school year starts, parents should contact the school nurse, guidance counselor or principal to request a meeting with the staff. Ask to include your child's main classroom teacher, physical education teacher, school nurse and a representative of the administration. (Some private schools and school districts are cutting back on school nurses, so not all schools have a nurse or the nurse may only be available on a limited number of days.) You might also invite the child's teacher from a previous year, suggests Shelley Gerson, immediate past president of the Hemophilia Foundation of Michigan and a former teacher, counselor and camp director.

"It can be really beneficial and reassuring for teachers to hear from other teachers who have had experience with your child," Gerson says.

Middle school or high school children should be encouraged to attend the meeting and speak about their bleeding disorder. Robinson suggests that even young children be present at the beginning of the meeting, perhaps to

“CHILDREN NEED TO KNOW THAT THEY BELONG IN SCHOOL, AND THAT HAVING A BLEEDING DISORDER DOES NOT EXCUSE THEM FROM PARTICIPATING IN CLASS AND DOING THEIR HOMEWORK.”





hand out written information or come in at the end to meet the school staff. If the child is not present, simply showing some pictures to the group can break the ice and help everyone relax, she adds.

At the meeting, distribute brochures or information sheets that explain the basics of bleeding disorders, how to recognize a bleed, emergency contact numbers and how to handle various situations that may arise. For example, make sure the staff know that an injury to the head, neck or abdomen constitutes a real emergency and that they should call 911 right away. School staff also should know the severity of your child's bleeding disorder, special precautions that need to be taken if he or she has an implanted port or an inhibitor, whether your child is on prophylaxis, what medications to avoid, and the sports and physical activities in which he or she can safely participate.

This is a good time for parents to share with school staff the family's emergency and/or disaster plan for their household. At the same time they can obtain information from the school about its evacuation or other contingency

plans if something were to happen on school grounds or nearby. Parents can ask: What is your plan to get together with your child? What does the school do? Give staff several contact numbers of relatives, friends or other guardians who are authorized to pick up your child if you cannot be there.

Work with the nurse and teachers to draft a written individualized healthcare plan (IHP) for your child. (See "Laws That Protect Your Child" on page 38.) Arrange to share this information with anyone else who will have regular contact with your child, such as a bus driver, lunchroom or recess aide, and coach or other extracurricular activity supervisor.

Robinson cautions parents not to assume that the healthcare plan information will be kept on file from year to year. It's a good idea to touch base with the school at the beginning of *each* year, because school personnel change—and so does your child.

Throughout a child's school years, it is important to maintain a positive attitude. Make it clear that you are

there to support the school staff to ensure that your child feels safe and comfortable at school. That means parents should expect to be on call to check out or treat symptoms of a bleed or simply to allay the fears of school staff.

“We tell them if you’re in doubt, just call us and we’ll make the decision,” Luckey says. “Particularly in the younger grades, we’d get a lot of calls from the teacher in the first month of school, but it lessened as they got used to him.”

“I *like* it if they [the school staff] are a little scared,” says April Baird of Clinton, South Carolina, whose son Clayton, 12, has severe hemophilia. “I don’t care if they call me every day.”

It is up to parents to guard against too little or too much caution on the part of schools. “We had an incident in fourth grade where he got hurt and asked if he could go to the health room,” Baird says. “The teacher wouldn’t let him, and by the time he got home he had a big knot on his head. I told him in the future he should just get up and go anyway. I knew they’d be calling me, and I could deal with the situation then.”

On the other hand, Baird says, “Last year we had a nurse who called all the time, and when I got to school she’d tell me she’d feel more comfortable if I’d just take him home. Then I’d have to get more aggressive and let her know that I’ve checked it out, he’s had a shot, and there’s nothing more that can be done, so he needs to stay in school.”

When Tammy McFadden of Rock Hill, South Carolina, went to visit the preschool her son Dentavious, now 11, would attend, she discovered that a staff member had already been assigned to stay with him on the playground.

“I had to let them know that he’s a normal kid and I didn’t want him singled out,” she says. “When I explained what they needed to look for, they scaled back a bit.”

KNOW YOUR RIGHTS

When dealing with schools, it’s important to know that the law is on *your* side. Schools are required to make necessary accommodations to provide every child with a proper education in the least restrictive environment. (See “Laws That Protect Your Child” on page 38 for an explanation of the different laws and written health plans that might apply to your child.)

While some schools may balk at allowing older kids or parents to infuse factor during school hours because of the risk of exposure to needles and medical waste, you do have the right to do so. If you have problems convincing the school staff to allow your child to infuse, you may have to request a hearing. Your child’s hematologist and HTC nurse may need to intervene. You also may need to reassure the school that the child has been trained in self-infusion.

“We always encourage parents to keep a dose of factor at school, stressing that we don’t expect the school nurse to administer it, but so that a parent doesn’t have to go home

(continued on page 38)



LAWS THAT PROTECT YOUR CHILD

Your child's right to an education is protected under two important federal laws. How they are used or deemed necessary can vary by state and school district. In addition, these laws are not always applicable in private school, preschool or daycare settings. You should be able to obtain clarification about what is required by your child's school from your state education department, local school district or school board.

Section 504 of the Rehabilitation Act of 1973 (Public Law 93-112) ensures equal access to an education for a child with a disability that requires some accommodation, whether that disability is visible or hidden. The law specifies that anyone with a physical or mental impairment that substantially limits at least one major life activity—including caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, reading, writing or performing math calculations—is eligible for "reasonable" accommodations.

A written 504 Accommodation Plan (see sample on page 40) is a legal document that lists specific accommodations such as an extra set of books so the child does not have to carry a heavy backpack between school and home; a rolling backpack or top-row locker; modified physical education; early dismissal for class changes; tutoring; and extra time to complete assignments when absent. Federal or state governments do not usually reimburse school districts for providing the accommodations of 504 plans.

The Individuals with Disabilities Act (IDEA) (Public Law 101-476) ensures all children with disabilities a "free appropriate public education" and guarantees special education services designed to meet their unique needs. The law lists a dozen categories of disability; children with hemophilia are covered under the category called "other health impaired." An updated IDEA was reauthorized in July 2005 and became effective when the school year started.

Under IDEA, you have the right to ask the school to provide a written **individual education plan (IEP)**, a legal document that guarantees your child such services as special resource classes in subjects in which he or she has fallen behind; increased time for tests or completion of as-

to get it or that if a child is self-infusing he can do it there without having to miss class," says White, the hemophilia nurse from Children's Hospital of New Jersey at Newark Beth Israel Medical Center. Make sure the school has a refrigerator to store the factor and also discuss where staff will store the syringes.

Another important safeguard is the right to privacy. Ask teachers not to discuss your child's health or health needs casually anywhere at school. It also is up to you and your child—not the school—to decide whether and how to tell classmates about the bleeding disorder. Often, older kids prefer that their peers not know, while younger children may be less inhibited.

In short, when dealing with your child's school, Robinson says, "It is really important that parents come across as team players, that they express appreciation to the school and make it clear that they're there to support their child and the teachers so their child can have the most normal school experience possible. A parent's motto should be 'advocate and educate.'" ●

signments; and small-group standardized testing. The law also provides for related services, such as counseling and psychological testing.

IEPs often are given to students who need special education services due to a learning disability, emotional disturbance, traits of mental retardation or other impairments to a child's ability to learn. An IEP might be appropriate for a child with a bleeding disorder who experienced a brain bleed that affected vision or cognitive ability. The federal government does reimburse a percentage of IEP-related services.

"Typically, you'd only get an IEP if there was some reason they could show failure to learn compared with same-aged peers," says Doreen Rousseau, a school psychologist in northern New York. She has experience writing 504 plans, IEPs and consulting with general education staff about interventions for students struggling academically or behaviorally. "This could require a psycho-educational assessment to determine if a learning difference exists."

In New York, Rousseau says, the new IDEA requires schools to provide academic intervention services (AIS), in which general education staff, in one form or another, give support to the student in need to try to compensate for whatever is causing the learning difficulty.

"It is much more difficult to get an IEP these days than it was prior to this past September," Rousseau says. "There is more emphasis on general education rising to meet the challenges of teaching students that learn differently or have different needs."

Additional Considerations

Another important protection for a child with hemophilia or other bleeding disorders is an **individualized health plan (IHP)**. A number of states now mandate that schools have on file an IHP for a child with a disability, which provides classroom teachers, the school nurse and administrators with specific instructions for meeting the child's healthcare needs.

An IHP can suffice to help meet the student's medical needs; however, once an accommodation is required to meet his or her educational needs, a 504 plan or IEP is called for, says Rousseau, who is also a parent of three children, two of whom have severe bleeding disorders. For example, when taking certain New York state exams or other standardized tests, a student who might require a word processor or other help would not receive it without a 504 or IEP. However, some

(continued on page 41)

SAMPLE 504 ACCOMMODATION PLAN

Name: John Brown*

D/O/B: 01/19/99

Grade: 2nd

School: XX

Date of Meeting: 9/8/05

Date of Review: 9/8/05

1. Describe the nature of the concern: John is a student with a medical diagnosis of Severe Hemophilia A (Factor VIII). Hemophilia is a bleeding disorder that impairs a person's clotting ability, usually affecting tissue, muscles, joints and internal organs. Students with severe hemophilia often are subject to limited motor ability during bleeding episodes, which may result in the need for crutches, wheelchairs, splints or slings. Some severe bleeding episodes may result in bed rest or hospitalization. Bleeding episodes may affect John's attendance and performance in both class and physical education.
2. Describe the basis for determination of disability: Diagnosis of Severe Hemophilia A (Factor VIII).
3. Describe how disability affects a major life area: Bleeding episodes may cause an unusual amount of absences, a need for physical accommodations or adaptive physical education.
4. Describe the reasonable accommodations necessary to provide a free appropriate education (FAE):
 - a) John should be given the opportunity to make up missed work (it is expected that John will make up all missed work).
 - b) John may require adaptations to school environment based on bleeding episodes (crutches, wheelchairs, splints, slings).
 - c) John should be allowed to participate in all regular physical education programs unless indicated otherwise. If John is unable to participate physically, he should be involved by coaching, scorekeeping or as a referee.
 - d) John's grades should not reflect late work or absences due to bleeding episodes, either in the classroom or in physical education classes.
 - e) All rooms should carry rubber gloves and a bleach and water solution.
 - f) Home tutor as needed—due to bleeds that require bed rest.

Participants: (Name and title), Parent, School Psychologist, Principal, Teacher

I have read the accommodation plan and am aware of my due process rights to appeal this plan if I am not satisfied.

Parent Signature

Date

Cc: Psychologist
Building Principal
Classroom Teacher
Guidance Counselor

*fictitious name



schools will grant accommodation for a temporary disability, such as a broken arm or a finger or hand bleed, she notes.

“The IHP can serve as the health plan component of a 504 plan, and for students qualifying for special education it can be incorporated into the Individual Education Plan when the healthcare issues are related to the educational needs of the student,” according to the 2003 position statement of the National Association of School Nurses.

Depending on the school and its policies, children with a health condition that can lead to sporadic, unpredictable absences may also qualify for **homebound instruction**. If you are concerned that your child might miss several days a month because of bleeds, ask the school at the beginning of the year to set up a plan for intermittent homebound instruction, recommends Joby Robinson, PhD, child advocacy coordinator at the Children’s Center for Cancer and Blood Disorders at Palmetto Health Hospital in Columbia, South Carolina.

“Then when the child is absent, you don’t have to waste time on paperwork, which can take weeks, and a teacher can come out immediately to make up time missed,” Robinson explains.

A homebound instruction plan may also be incorporated into a 504 plan or IEP, Rousseau says. For example, the plan may state that if the student is out of school for three days, then he or she gets a tutor, and the school gets 24 hours to make those arrangements.

“The main message is that one recipe isn’t going to work for everybody,” Rousseau says. “It depends on where you live, what your school is, and what your child’s needs are to determine which of these avenues you need to take.”

The question on the minds of parents and school personnel is: How does the disability affect the student’s ability to learn in the classroom? If he has a bleeding disorder and is doing fine in the classroom, the school might say he doesn’t need anything, Rousseau cautions.

“But you can’t plan when a bleed will occur or how it will affect the student, so it is better to plan ahead than to wait for these things to happen,” she says. “We still have kids with inhibitors and internal bleeds. It is a very personal decision, based on your family and child, and your protocol for dealing with a bleed. Do you want to send them to school or keep them home on bed rest until the joint or muscle is better?”

“It is more than what the school perceives the need to be, but how a family functions with disorders as well,” she continues. “There is nothing black and white about it. You need to know what questions to ask and information to share to do what’s right for each student.”