

# Parent Empowerment Newsletter

## Three Stages of Childhood Thinking

BY LAURIE KELLEY

**W**ould you give your child a ten-speed bike before he's physically ready to handle it? Of course not. Similarly, you can't give hemophilia information to your child until he is mentally ready to handle it. How do you know when he's ready? When you can identify and understand his cognitive stage of development.

*You know children are growing up when they start asking questions that have answers.*

— John Plomb

It's been shown, time and again, that regardless of culture, nationality or gender, all children go through cognitive development stages in the same order. *Cognitive* means "thinking." Just as children go through stages of physical growth (like walking at one year), and emotional growth (like the "terrible twos"), thinking also goes through stages of development. When you identify your child's stage of



cognitive development, you can help him progress better and learn more by giving him appropriate tools and experiences, and by asking him appropriate questions.

As you read about these cognitive development stages, you'll see how "thinking tools" can be used by your child with hemophilia to understand many aspects of his disorder. You'll soon see that every thinking tool he uses can relate to hemophilia. Recognizing cognitive stages in your child will help you teach him about his own disorder.

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"Three Stages of Childhood Thinking" has been adapted from the new book *Teach Your Child About Hemophilia*, formerly "My Blood Doesn't Have Muscles!" *How Children Understand Hemophilia*. Free to patients, HTC's and nonprofits, *Teach Your Child About Hemophilia* explores how children understand hemophilia as they mature, including concepts like blood, severity levels, blood clotting, infusions and genetic transmission. It also offers practical tips for answering children's questions about hemophilia. Order your free copy through [www.zlbbehring](http://www.zlbbehring) or [www.kelleycomcom](http://www.kelleycomcom).



Sherrell Portrait Design

**T**he father of a son with hemophilia described to me his pleasure when his five-year-old, watching him dressing, said he wanted to be just like dad when he grew up. Bursting with pride, this father was jolted back to reality when his son concluded, "Yeah, when I grow up I want to be like you: I want to wear a tie." Funny, but not surprising when you know how preschoolers think! In this issue of *PEN*, we offer an overview of the way your child mentally processes his world as he matures from preschooler to teenager. You'll learn to identify the cognitive tools he uses to manipulate incoming information.

This knowledge will help you tailor the information you present to him on any subject, especially hemophilia.

In our cover story, we only skim the surface of how children learn. For more in-depth information about how your child understands hemophilia as he grows, please order my new book *Teach Your Child About Hemophilia*. It's available free to patients, HTC's and nonprofits from ZLB Behring and LA Kelley Communications, Inc. *Teach Your Child About Hemophilia* is based on my older book, "My Blood Doesn't Have Muscles!" *How Children Understand Hemophilia*, which has been out of print for five years. I'm pleased to bring this book back in a form that is easier to read. It also includes a new chapter on how your child understands prophylaxis. Thanks to ZLB Behring for again providing the funding to bring this one-of-a-kind book to the public.

Speaking of understanding hemophilia at an appropriate level, Paul Clement writes a lucid column about the inhibitor therapy called ITT. As a hemophilia organization member, HTC staff member, or parent of a child with inhibitors, please read Inhibitor Insights (page 4) to increase your knowledge about ITT—how and why it can help. We'll continue to focus on inhibitors throughout 2007.

Also in this issue, you'll learn how we operate Project SHARE, our factor donation program (page 5). If you have in-date factor to donate, please contact us to find out if you're eligible to donate, and learn how your factor will be used. So far this year, Project SHARE has shipped over five million units of factor to more than 30 countries, helping scores of patients in impoverished areas who suffer relentlessly from untreated bleeds.

Well, it wouldn't be *PEN* if we didn't mention insurance! In Storm Watch (page 6), I alert everyone to payer cuts in factor reimbursement, and explain how their ripple effect will eventually impact us all. Patient Services, Inc., one of our best programs to help those with insurance premium trouble, has been feeling the pinch of reimbursement cuts. If PSI's funding for its hemophilia patients—derived in part from pharmaceutical and home care companies—drops because of reimbursement cuts, more patients will be left without insurance coverage, and without options. As the storm continues to brew in many states, *PEN* will bring you timely, in-depth coverage.

Stay in touch with LA Kelley Communications at our new blog! HemaBlog™ is posted Monday mornings on our website, [www.kelleycom.com](http://www.kelleycom.com). It's another first in our community, and a great way for me to connect with you regularly. ☺

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## letters

***Hemophilia Treatment Centers: Are They Up to the Challenge?***  
*PEN*, August 2006

**Y**our article was a great portrayal of the history of HTC's and current concerns over their sustainability. We, as the patient community, understand that our link to good health is directly related to the model of care provided through the HTC system. We now have a few generations of healthy patients with bleeding disorders who demonstrate the benefits of that model of care.

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# Adapting to *Chaos*

Shai says, "This medicine keeps me healthy!"

If any woman should understand boys, I think it ought to be me. I'm the sister of two big, hulking guys, and the daughter of a woman who was the only girl in a house of boys. My father taught us "Aussie rules" football, and my mother introduced us to hockey. "Yup," I'd tell any people admiring my kids, "boys are great. They have a simple energy, uncomplicated and wonderful."

One day, I was standing on the playground at my son Shai's school, watching my sweet little man busily rubbing another boy's face into the wood chips. The other kid laughed, flipped over, and started pounding happily on Shai's back. "Oh," I thought fuzzily, "it's a game." That happy energy started looking aggressive, and I began to worry. Seeing my face, the preschool teacher drifted over. "I don't know why they do it," she said, pointing at the boys wrestling in the wood chips, "but for years I've watched boys play those games. It's almost as if they need to."

The combination of this thoughtless energy and hemophilia is alarming. But should it be? When my brother broke his arm riding his bike over the highest ramp he could find, he was "just being a boy." When Shai, who has severe hemophilia, does anything similar, we tell him that he's making an unsafe choice. Is this a difference in parenting style? More likely, hemophilia makes parents redefine that happy-go-lucky behavior as careless and worrisome.

In their book *Raising a Son*, Don and Jeanne Elium point out, "We cannot block the powerful forces of biology, psychology, culture and soul. Nor would we want to, because through them, boys and men feel most alive and inspired."<sup>1</sup> The Eliums feel that we cannot tame our boys; instead, we should embrace their energy and channel it, allowing our sons to flourish by turning boy-style chaos into strength and growth.

It is the great challenge of hemophilia parenting to let our sons make their own mistakes, to let them figure out their limitations. I started by teaching Shai about his hemophilia, helping him understand his body and what it can—and shouldn't—do. He learned the role of factor, knew different kinds of cells in the blood and what they do, and astonished our hemophilia nurse practitioner by drawing a picture of fibrin catching cells in its net to make a clot. But did he truly understand?

One day, our home care nurse called me after a visit to Shai's preschool. Shai's infusions fascinated the other kids, who liked to pull up chairs to sit and watch. Naturally, there were questions, and naturally, Shai loved answering them. That day, another child had asked, "Shai, why do you get medicine? Are you sick?" "Nope," said Shai airily, "This medicine keeps me healthy!" Hearing this story, I glowed. I saw the picture of a child who understood that his diagnosis is not a disability. I saw that he was his own advocate—perfect, perfect, perfect.

But no: I had put my own interpretation on the story, seeing what I wanted to see. Instead, Shai's delighted ener-

gy had taken over even the infusion, making it a happy, sprightly affair instead of a painful chore. He may know what his factor does, and he may be able to recite the definition of hemophilia, but Shai just doesn't have a personal awareness of what it means to have a serious bleed; nor does he have anxiety about what might cause a bleed. Given how much he knows, my son is remarkably ignorant.

Which is why this past Monday, when I spoke to Shai's teachers about his hemophilia, I told them this: We are about to give Shai a gift that he will not appreciate. Because, of course, our gift to him is to pretend that he is ordinary. Almost. To him, his version of normal is just...*normal*. It will be years until he sees his own difference. And not until he's a parent, raising his own children, will he understand what, as his teacher, you have learned: how you have adapted to have him in your class, treating him like any other child, letting him just be a boy. You are helping to give him the childhood that any boy should have, and I thank you for it. ☺

Ziva Mann has an MA in medieval literature from Harvard University. She lives in Cambridge, Massachusetts, with her husband Ezra and sons Shai, age four, who has severe hemophilia A, and Akiva, age one.

Ziva Mann with son Akiva.



<sup>1</sup> Don Elium and Jeanne Elium, *Raising a Son*, 3rd ed. Berkeley, California: Celestial Arts, 2004.



BY PAUL CLEMENT



*Inhibitor Insights* is a *PEN* column sponsored by Novo Nordisk, Inc.

## BANISHING

# *Inhibitors Forever*

**M**anaging bleeds in inhibitor patients is often a challenge. Treatment for low-responding inhibitor patients (<5 Bethesda Units or BU) usually consists of infusions of high doses of the deficient factor. Treatment for high-responding inhibitor patients (>5 BU) usually requires bypassing agents, such as FEIBA® or NovoSeven®. Unfortunately, none of these products works as effectively as regular factor concentrates work in patients without inhibitors. Right now, the ideal inhibitor treatment is to (1) eradicate the inhibitor, or (2) bring it down to very low levels so that standard factor concentrates can be used to treat bleeds. With the inhibitor gone or low enough, standard factor concentrates can be used safely. The benefits? Bleeds stopped more effectively, lower treatment costs, and reduced complications.

So how do you eradicate an inhibitor? There is no standard regimen or “protocol” for eliminating an inhibitor. But all eradication treatments are based on this fact: With the regular infusion of massive doses of factor for weeks to years, the immune system will either tire of producing antibodies or retrain itself to recognize factor as a “normal” body protein, and stop producing inhibitors. The process of retraining the immune system to become *tolerized* to factor is known as Immune Tolerance Therapy (ITT).<sup>1</sup>

Why is there no standard ITT protocol? Although ITT was first used successfully in 1977 in Bonn, Germany, there still is no general consensus on many aspects of ITT. For example, some protocols require two daily doses of factor, others require one dose, and some require one dose every other day. The ideal dosage for ITT is also debated. The Bonn protocol requires 300 IU/kg of factor VIII every day, while the Dutch protocol uses 25 IU/kg of factor VIII every other day. Typical dosages in the US vary from 50 to 100 IU/kg of factor VIII daily. The Malmo protocol also uses immunosuppressive drugs in an attempt to

shorten ITT treatment time and achieve immune tolerance in about a month.<sup>2</sup> But the majority of ITT regimens last one to two years, and in cases showing slow but steady improvement, as long as four and a half years.

Here’s where physicians do agree about ITT:

- The success of ITT is higher when the patient’s inhibitor titer is less than 10 BU. People with an inhibitor titer higher than 10 BU are not considered good candidates for ITT. In these cases, therapy may be delayed until the inhibitor titer drops below 10 BU; or sometimes, the inhibitor may be depleted through filtering the antibody from the blood. (This depletion is short-term, lasting only a day or two.)
- ITT is more successful when the patient’s historic maximum inhibitor titer is low (below 100 BU), and the peak titer while on ITT is below 500 BU.
- ITT seems to work best in young children, and best when implemented soon after the inhibitor is diagnosed.<sup>3</sup>
- ITT is effective 60% to 80% of the time in factor VIII inhibitor patients, and less than 40% of the time in factor IX inhibitor patients.
- ITT with factor IX inhibitors, unlike factor VIII inhibitors, involves a relatively high risk of allergic reaction (anaphylactic shock) and kidney problems, although the kidney problems are often reversible.
- Port infections during ITT decrease the success rate.
- Once started, ITT therapy should not be interrupted.

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<sup>1</sup> Sometimes called Immune Tolerance Induction (ITI). <sup>2</sup> Kasper, Carol K., *Diagnosis and Management Of Inhibitors To Factors VIII and IX: An Introductory Discussion for Physicians*. World Federation of Hemophilia, 2004, #34. [http://www.wfh.org/2/docs/Publications/Inhibitors/TOH-34\\_English\\_Inhibitors.pdf](http://www.wfh.org/2/docs/Publications/Inhibitors/TOH-34_English_Inhibitors.pdf) <sup>3</sup> Some studies have found no correlation between the success of ITT and the time interval between inhibitor detection and start of ITT. Lenk, H.; ITT Study Group, “The German Registry of immune tolerance treatment in hemophilia – 1999 update.” *Haematologica*, 2000 Oct; 85(10 Suppl): 45-7.



It's time to give back.

## How Project SHARE Works

**P**roject SHARE (Supplying Hemophilia Aid and Relief) was officially founded as a humanitarian program in 2002. Since then, SHARE has received more than 20 million units of donated blood-clotting factor, valued at close to \$15 million, and shipped it to developing countries where factor is scarce or unavailable. We've helped hundreds of patients receive surgeries, physiotherapy, life-sustaining infusions and pain relief. Our program is small, but we occupy a vital niche.

Project SHARE's two key functions: (1) gathering donated factor, and (2) identifying patients who need it. Factor is sent from all over the US to the LA Kelley Communications office in Georgetown, Massachusetts. Donors are commonly home care companies with short-dated product that they are unable to sell; patients who switch brands; patients who have completed immune tolerance therapy and are left with excess factor; and, unfortunately, families of patients who have died. At one time, we had to beg for factor; but as word of SHARE has spread, factor has increasingly made its way unsolicited to our office. We are able to use all of the donated factor we receive.

When donated factor arrives at our office, it's immediately unpacked, logged in, and placed in a refrigerator used exclusively for factor storage. A log sheet displays the exact contents of this fridge at all times, and the temperature is checked twice daily. Our record keeping is meticulous and exact. In fact, we received a stamp of approval from the US FDA after a serious-faced officer made a surprise inspection. He left impressed, nodding his head in approval.

This officer was amazed that our small operation helps thousands of people in more than 40 countries. Phone calls, emails, faxes and handwritten letters come from individuals requesting factor for themselves, for a family member, for one of their patients or a clinic, for a camp, or for their society. Most applicants are poor, uneducated, underserved people who hear about SHARE and find a way to communicate with us. We take all requests seriously, and we work hard to obtain complete information, ensuring that each request is thoroughly documented.

For every person who requests factor, we create a permanent file that includes the following information:

- Name, address, contact information, type and severity of person or people with hemophilia, and whether an inhibitor is present.
- Physician's name and contact information, with official signature.
- Applicant's name, address and other contact information.
- Reason for the request, type and amount of factor requested, and level of urgency.
- Whether the patient is a member of the local hemophilia society, if one exists.

If we have never before sent a donation of factor to the country of residence, we require additional information:

- Contact information of the key members in the national hemophilia society.
- Whether the country allows donated factor through customs.
- The factor donation policy of the national hemophilia society.
- Contact information for the medical professional involved in the patient's case who can ensure proper mixing and infusion of factor.
- Report on the adequacy of the facilities to store factor.



Julia Quigley Long, executive director of Project SHARE, makes sure all donated factor concentrates are safely refrigerated.

We distribute factor on a first-come, first-served basis, although life- or limb-threatening emergencies take precedence over all other requests. When a request is approved and ready to be filled, the factor is shipped immediately via FedEx or DHL to a clearly specified location. The recipient returns a Confirmation of Shipment Form as soon as the package is received. To become eligible for another shipment, the recipient must also complete a Treatment Log, which documents factor usage.

In addition to meeting emergency medical needs, we also use SHARE as a tool for long-term, sustainable healthcare development. If a country has no hemophilia society, we ask patients to consider starting a hemophilia patient society, and we guide them through the process. That's exactly how Ghana recently registered its first hemophilia society.

Project SHARE is the largest private factor donation program in the US.

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BY LAURIE KELLEY

## The Current Storm Batters *Insurance Aid Program*

**T**he current insurance storm—caused when payers began targeting factor for cost cutting in 2004—was predicted to impact the way the hemophilia community does business. Cost-cutting measures have already restructured the home health business, causing a reshuffling of ownership and single source contracts for Medicaid patients in some states. But now, nonprofits are feeling the pinch.

One of these is Patient Services, Inc. (PSI), a national nonprofit organization that works to find health insurance solutions for people suffering from bleeding disorders and other expensive chronic conditions. Despite the success of PSI in recent years, helping ever-increasing numbers of patients, the hemophilia and bleeding disorders program within PSI is in danger of being drastically downsized in 2007. Why? Reduced charitable contributions from companies that earn their profits from the hemophilia business. As insurance payers slash costs in the hemophilia community, profits are squeezed. As profits are squeezed, there is less to give to charitable causes like PSI. Every consumer, treatment center, home care company, and manufacturer will eventually feel the ripple effect of this change in the hemophilia business.

PSI was founded by Dana Kuhn, PhD, a person with hemophilia. He has felt firsthand the fear ignited by the danger of losing his insurance. In addition to his own health struggles, Kuhn lost his first wife in 1987 to a chronic condition. As he suddenly found himself with the responsibility of raising two young children, he was forced to accept a COBRA policy that was unaffordable.

“I didn’t know how I was going to afford my COBRA,” recalls Kuhn. “When my wife passed away and we were forced to take COBRA, the premiums jumped 110%. I didn’t know how to make ends meet.”

Kuhn eventually found a new job counseling families of children suffering from cancer and other terminal illnesses at a hospital in Richmond, Virginia. “In one sense, I was fortunate because I then had the affordable insurance

coverage we needed...but it was hard because I worked every day with so many families that were literally forced into bankruptcy because of the cost of treatment for their children. In some cases, families lost everything they had worked for and still lost their child. I vowed I would find a solution. I had to do something.”

For the past 17 years, PSI has implemented programs that provide premium assistance for health insurance policies, Medigap policies and COBRAs, as well as treatment /prescription copayment assistance. PSI also has a medical items program for supplies such as crutches, ice packs, helmets, elbow pads and kneepads. Today, PSI’s bleeding disorders program assists 285 people annually who use \$30 million worth of product (at purchase price). Thousands of other families benefit from PSI programs, for conditions ranging from brain tumors to hepatitis C to Pompe disease.

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PSI board of directors (left to right): Jan Storey; Mitch Mula; Matthew Lawyer, MD, JD; Dana Kuhn, PhD, president; Elaine Martin, chairperson; Gary Cross; John Dutton, JD, secretary; Danielle Stueber, MD.



PSI

## The Magical Preschool Thinker

What makes four- to six-year-olds so endearing and wonderful? It's partly their magical thinking. "Magical" doesn't mean that your child thinks he has special powers or believes in elves, fairies and goblins, although he might. It does mean that your child can't explain causality—why things happen—in a step-by-step, logical manner.

For example, your child observes that if he counts "One, two, three, go!" at each traffic light, the light will eventually change from red to green. If he times his counting carefully, he may say, "Go!" just as the light changes. Of course, his counting doesn't affect the traffic light. But what does he conclude? His counting to three *caused* the light to turn green. To a preschooler, one event causes another event simply because the two events occur in chronological sequence—even if they are completely unrelated.

Do you remember the 1990 blockbuster movie *Home Alone*? In one scene, the young character Kevin shows magical thinking. He is banished to the attic bedroom for the evening as punishment for being underfoot while his family packs for a trip. As he storms off to bed, he turns and yells, "I wish you would all disappear!" The next morning, Kevin awakens to find that he is indeed home alone. His family has unintentionally left for France without him. Kevin doesn't know this. He only knows, *I wished them to be gone*. And his family is gone. His conclusion: *I made my family disappear!*

Preschoolers exhibit other traits in addition to magical thinking. A child uses four other basic "tools" to process incoming information about his world. He uses thinking that is perceptual, egocentric, immediate, and absolute.

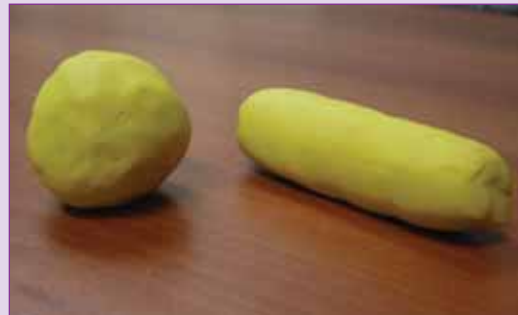
A preschooler's thinking is **perceptual**, or completely dominated by what he sees, hears, feels or smells. Most of what he learns about his world arrives through his senses. Because his thinking is so perceptual, it's almost always externally oriented—outside his body. Indeed, a preschooler's thinking is so ruled by perceptual cues that he relies more on what his senses tell him than on anything else, even when the "facts" stare him right in the face!

Because they are so perceptually and externally oriented, preschoolers generally don't think or process much information about the inside of their bodies. To them, most things concerning their bodies happen outside them. When asked to draw what's inside their bodies, most preschoolers don't know what to draw—except for two organs. These organs are internal, but are well perceived by most preschoolers because they can *feel* them. Can you guess what these organs are?



## Try This

Show your preschooler two equal-sized balls of clay of the same color and shape, and ask which is bigger. He'll probably respond correctly that they are the same size. But roll one, before his eyes, into a long, fat sausage shape. You can even tell him that you didn't remove or add any clay. Ask, "Now which is bigger?" What does he say? Why?



The heart and stomach. Preschoolers can feel both organs. The heart beats very hard and fast while the child runs, and the stomach growls and causes pain when it's empty.

Looks and appearances can be deceiving to preschoolers. For them, "What you see is what you get." Preschoolers make great audiences for magic acts because they swallow the tricks hook, line and sinker. Because preschoolers are so concrete and perceptually oriented, they tend to take words literally. If you happen to tell a preschooler, "Parents have eyes in the backs of their heads," be prepared for a strange look!

While driving in the car at night with your child, you may have heard him exclaim, "The moon is following us around!" This statement is a perfect example of **egocentrism**, another trait that characterizes preschool thinking. Egocentrism doesn't mean that your child is egotistical and selfish. It means that he lacks the ability to see the world from another person's point of view. No matter how much you impress upon him that the moon is not following him, he thinks, "Then why is it there, everywhere I go?" You can't battle his personal experience or viewpoint, even if they result in a magical explanation. He believes that the moon follows him because that is what *he* sees.

A preschooler understands the world from his own shoes—literally! When asked to point to the right hand of a person standing in front of him, he points to the person's left hand. Why? That's the side that *his own* right hand is on. He can't generalize his personal experience, and he can't make general rules about things. Usually, a preschool child can logically understand only what he has experienced or witnessed directly.

Have you ever been on a road trip with your preschooler, and five minutes into the three-hour ride, he asks, "How

## TryThis

Here's an experiment to test for egocentricity. Put a favorite teddy bear or stuffed animal in the corner of the room opposite your child. Ask your child to draw what the teddy bear sees. Does he draw what the teddy bear sees, or what he sees? Why?



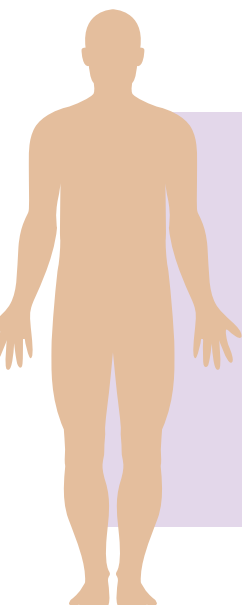
much longer?" Try to explain three hours to a preschooler—or three days, or three years. A preschooler's thinking is **immediate**, in the here and now. He usually can't understand discussions about the past, which for him is short; or the future, which is beyond his immediate experience. To him, three hours equal three days equal three years. Preschoolers may try to get a handle on the intangible concept of time by making it perceptual. My daughter Mary once tried to describe the length of one painfully long school program. She held out her arms to each side, saying, "And it was *this* long!" Mary was trying to make concrete and perceptual something that is by nature abstract. This is why discussing past generations, or death, is difficult for preschoolers. After a favorite pet dies, a child may continue to ask when it will come back. There is no "forever" to a preschooler.

A preschooler also thinks in the absolute, or in extremes. Everything tends to be polarized. People are "good" or "bad," "sick" or "healthy." No in-between, no gray areas, no overlapping. This could be why so many preschoolers are obsessed with superheroes and bad guys!

Did you ever do Venn diagrams in school? (See diagrams, page 11.) They involve seeing relationships among objects and numbers, in order to sort and categorize. Preschoolers don't do Venn diagrams. They don't usually see relationships among objects and ideas. Every idea or object is distinct. Preschoolers, our masters of absolute thinking, place each object into a separate circle. Cheetahs, lions and leopards are not members of the cat family. They are simply cheetahs, lions and leopards. This is why preschoolers usual-

## TryThis

Draw an outline of the human body, leaving the inside empty. Ask your preschooler to draw what he thinks is inside. Prompt him by saying, "What do you think goes here?" and point to the head or abdomen. Date the drawing and save it. Try this again in six months or a year. Notice the difference!





ly can't attach several meanings to one thing; there is one meaning for one thing. I was reminded of this many times as I hurriedly asked my preschoolers to get their "shoes." Although they knew I meant "sneakers," my kids were quick to correct me: "They're sneakers, not shoes."

Discerning relationships among two or more things means being able to identify **the whole and its parts**. A preschooler's absoluteness prevents him from understanding that the whole is a sum of parts. He thinks, "The whole is one thing. These parts are other things." At age five, my son Tommy showed me that five fingers on one hand plus three fingers on the other hand equal eight fingers. "That's great!" I replied. Then I applied some child psychology. "Now, which is bigger, eight or five?" "Five," answered Tommy, pointing to the hand with five wiggling fingers, "because there are more *fingers* standing up on this hand."

You can use this new information about how a preschooler with hemophilia thinks to help him understand his disorder. At this age, avoid mentioning anything abstract—like genes, chromosomes or proteins. When you mention blood, you might not be able to get him to realize that blood has parts, like plasma or red blood cells. He will understand it as "red liquid," which is what he sees. Hemophilia won't be a blood disorder to him, because he is not yet ready to categorize his world into subsets of a whole. Instead, hemophilia will be what happens to him externally ("It's a bruise") or what happens to him alone ("It's when I get a shot"). Factor isn't a missing protein; it's a bottle of medicine that makes him feel better. And he didn't get hemophilia from his mother or from an ancestor—remember, he lives in the here and now. He has hemophilia because he was born with it.

## The Practical, Creative School-Age Thinker

Ages seven through eleven are a time of incredible growth in thinking. The tangible, concrete world still plays a huge role in the way a child thinks, but he is now able to take that concrete world and bring it into his mind. He has learned to manipulate the world, and he achieves very different results in thinking and perception than does the preschooler.

The preschooler and school-age child differ greatly in their ability to internalize the external world. But they are alike in one way: The school-age thinker can manipulate ideas in his mind, but usually only those concepts related to tangible, familiar things and personal experiences. He focuses on his immediate environment and his own experience. Notice how often school-age children use metaphors. While they begin to understand more abstract things—life, death, feelings, faith, the universe—they have trouble explaining them. So school-age children resort to concrete, familiar terms: "I'm as hungry as a bear!" or "Snow is like cold sand," or "Thunder is like the angels bowling in heaven."

The school-age child makes enormous strides in sharpening his thinking tools, especially in one key way. He can see **relationships**. He is no longer thinking magically. He is less perceptual, less egocentric, less immediate and less absolute. If he no longer thinks magically, how does the school-age child think? He can begin to think logically about **causality**—creating steps in sequence. A preschooler might tell you, "Someone went to school and then got the chicken pox," or "My friend played with me and then I got them." But a school-age child will say, "Well, I played with my friend, and he had the chicken pox, and I licked his lollipop and then I got them." The school-age child perceives a step-by-step sequence of events. He can start to figure out logically what happened. And while the school-age child can identify a missing, causal step, it's often a step that is perceptual, such as licking a germ-coated lollipop. He still lives in a concrete world that he inhabits and experiences directly. Yet he is less perceptual than the preschooler. For example, in the experiment with the clay balls, a school-age child



may actually agonize about the answer. He may say, “I *know* that no clay has been added, but it looks bigger!”

He’s tempted, but he’s no longer fooled by what he sees versus what he knows. Recall that the preschooler focuses only on what happens externally. But the school-age child, being less perceptual, is less externally oriented. He can begin to understand what’s happening inside his body. He can name many internal parts of his body, but still tends to describe them in concrete, tangible terms. For example, he

may describe veins as “roads” going through his body, and his heart as a “pump.”

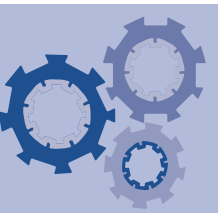
An amazing thinking tool that appears in the school-age group is the ability to take the point of view of another person—to put oneself in another’s shoes. Isn’t this an incredible step? It’s even difficult for adults to do! As your child becomes less egocentric, he can begin to understand what others experience, feel and think. Your child will show empathy, compassion, and greater understanding of the world of others.

Can we prove this? You bet. When a preschooler is shown a teddy bear placed in a far corner of the room, facing him, and is asked to draw what the bear sees, the child draws what *he* sees. But a school-age child, around ages nine to eleven, draws what the teddy bear would see. When you stand in front of a school-age child and ask him to point to your right hand, he points to your right hand.

A single external and perceptual personal experience no longer provides a logical explanation, and no longer limits the school-age child. For example, a preschooler thinks that when it’s daytime here, it’s daytime everywhere in the universe. Forget trying to explain about the earth’s rotation, and why a girl in China is sleeping while he is awake. My daughter Tara persistently asked about this concept at age five. “Why is it nighttime in China now?” she implored. I tried to explain this verbally, but it wasn’t working. I knew she would understand better if I provided a concrete example. So we got a flashlight, two action figures, and a globe. I put one figure on Boston, and the other on China. I told Tara that the flashlight was the sun. We turned off the bedroom light, and she turned the flashlight directly on the Boston action figure. As I started to explain, while turning the globe, her eyes grew wider and she positively beamed. “I get it! I get it!” she exclaimed.

Unlike the preschooler, your school-age child no longer depends on a single personal experience to explain a concept. He is now able to see relationships, and this skill makes his thinking less absolute. He can now serialize, generalize, subdivide, differentiate and combine into new groupings. All these tasks involve the ability to see relationships among objects, people and ideas. Ever notice that children in this age group love to collect things? Sports cards, bottlecaps, paper clips, stamps, sets of toy animals, dolls, rocks. It’s more than play—it’s an attempt to categorize, sort, and make sense of an ever-expanding world of sensory stimuli.

Remember our Venn diagrams? These are fun to do with school-age children. If you ask your child to group members of the cat family together, he’ll probably select pictures of leopards, cheetahs, house cats, lions and jaguars. He can



## Stages of Cognitive Development – a snapshot

### The Preschool Thinker Is...

**Magical:** Unable to explain how things happen in a logical, step-by-step sequence.

**Perceptual:** Dominated by what he sees, hears, feels or smells.

**Egocentric:** Able to see the world only from his point of view.

**Immediate:** Focused only on the present.

**Absolute:** Tends to see everything in extremes, and sees few relationships.

### The School-Age Thinker...

- Explains how things work in a step-by-step, concrete way.
- Can manipulate ideas in his head, but is more comfortable in the perceptual world with which he has direct experience.
- Can begin to understand what others experience, and how others think and feel.
- Can see degrees between extremes; can see relationships; can categorize.
- Understands time concepts of past, present and future.

### The Adolescent Thinker...

- Can think logically, step-by-step.
- Considers hypothetical situations.
- Considers various outcomes.
- Thinks concretely and abstractly.
- Has command over numbers, and understands concepts of time and space.

match pictures of a police officer, construction worker, doctor, teacher and pilot with their correct instruments or vehicles. He begins to understand terms like “aunt” for his father’s sister, and “grandfather” for his mother’s father. He understands classes within classes. This is more than simple sorting. It’s a **concept**. He can make subsets of a whole. He understands a whole and its parts.

Similarly, from direct experience in his world, a school-age child can make generalizations about the greater world. At age five, my son asked me to look at a drawing he had made of a rabbit and an egg. “The rabbit laid an egg,” he told me. “But rabbits don’t lay eggs,” I replied. “They don’t? But chickens do,” he said cautiously. “Right,” I answered. “Birds lay eggs, but animals like dogs, cats, horses and rabbits have babies without shells.”

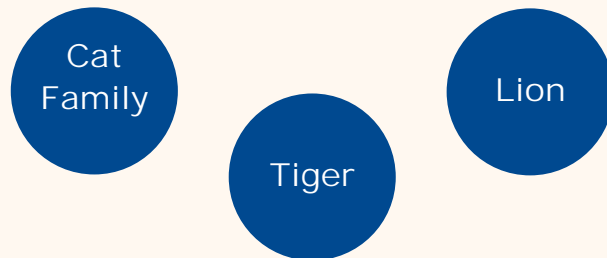
Tommy was attempting to generalize from one thing he knew—birds lay eggs. But his ability to generalize was limited by his experience. If he had grown up on a farm, where the mammal births are within a child’s everyday experience, he might not have made this mistake. The school-age child is logical and can see relationships, but usually only regarding familiar, concrete, existing objects and people. As he learns to tell time and understand past and future, the school-age child’s thinking becomes less immediate. He can understand three minutes versus three hours versus three days. He comprehends “tomorrow” and “next month.” He envisions the day when he will be grown up.

And now, his thinking is less absolute and more relative. He doesn’t view the world in black and white but in shades of gray. Bad guys and good guys aren’t so simple anymore: police officers can become bad if tempted or led astray, and criminals can show kindness and remorse. Someone can be a basically healthy person, but get a cold. You can almost see your child manipulate concepts and turn over ideas in his mind with these new thinking tools!

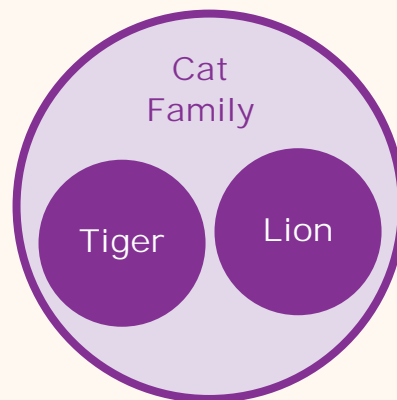
Use this new knowledge to appropriately instruct your school-age child about hemophilia. He is able to understand that hemophilia is a blood disorder because he can now categorize. Blood has parts, and his blood lacks one of the parts.

## How children conceptualize “whole and parts”

*A preschooler cannot discern the whole and its parts.*



*School-age children begin to see relationships. For example, they recognize that parts are subsets of the whole.*



He may not be comfortable yet with abstract concepts like chromosomes. He can understand a simple, step-by-step explanation of blood clotting. Use analogies, like the falling dominoes. He can understand that there are many boys with hemophilia like him. Factor is now the “something missing” from his blood that he can inject. And parents and grandparents figure prominently (as the causal agents) in his understanding of genetics, even though he may not get the genetic



pattern correct, or understand exactly what chromosomes are. More important than the correct answer is *how* he arrives at his answer—through logical, step-by-step thinking.

## The Cool Adolescent Thinker

Adolescents have the mental structure it takes to reach the highest level of thinking. Their mental skills have become complex. They can handle a large load of information that is abstract, not just concrete.

No more magical thinking here. A teen can give a logical, step-by-step recounting of an event, or an explanation of how something works. “A heart attack could be caused by a guy working out in the hot sun, who maybe worked too hard; or maybe he was overweight, or maybe he has a weak heart. Anyway, it closes off part of his blood supply, and the heart kind of starves.” Can you see the amazing pathway of logical thinking? A preschooler might have given a perceptual answer, based solely on what he sees: “A heart attack is when you fall down.” A school-age child would try to fill in what’s missing: “A heart attack is when you fall down because your heart gets weak.” But a teen can give a complex, multilayered answer focusing on internal and external events.

Beyond this, your teen can also consider **hypothetical situations**. He can mentally manipulate all possible combinations of events—if he wants to. “If I apply to this college, I might get accepted. Or I might get rejected. Or I might be

## TryThis

Ask your teen what happens to people when they die. Listen to his explanation. Ask him “Why?” or “What happens then?” Encourage him to think out loud. Don’t judge or lecture him; instead, pretend you are interviewing someone for a newspaper article. Let him do the talking. How concrete or abstract is his answer? What is his thinking style? Does he think silently or out loud? Does he ask you questions in return, to seek further information?



## TryThis

Make a simple family tree on paper. Start with your child, and work your way back through parents, grandparents and great-grandparents. Include branches of aunts, uncles and cousins. Show how everyone is interrelated. Show how one person can be a son, father, cousin and uncle at the same time.



deferred. What are the outcomes of those scenarios? If I get accepted, I can attend, but it will be difficult financially. If I get rejected—Wait, I’d better have a plan in place just in case! I’d better apply to several colleges. If I get deferred, I can line up a job to save some money for a while, and then attend.”

Your teen can perform a mental juggling act with many variables. He is very internalized now, and can be perceptual when he wants to be. He not only understands the various parts of the internal body, but is capable of understanding how all the systems work together: The respiratory system affects the circulatory system, which in turn affects the endocrine system. He can understand microscopic parts of the body, the cells and DNA, and things he may never see. He also knows that in other areas of life, the **abstract**, the unseen, and the completely imperceptible exist. This is why so many teens become interested in religion, destiny, fate,



## How Children's Thinking Develops

Perceptual	→	Abstract
External	→	Internal
Magical	→	Logical
Immature	→	Mature
Absolute	→	Relative
One cause	→	Interrelated causes
Temporary	→	Permanent

spirituality and morality. Your teen now has complete command over numbers, and understands concepts of time and space—but try to get him home at the right hour and you'll swear he can't tell time. The teen can manipulate points of view, and even adopt multiple points of view. Of course, his thinking is still somewhat limited by experience. This is also true for adults. For example, with no direct experience, it's difficult for anyone to truly understand another culture. Still, adults and teens can try.

Teach your teen about the abstract aspects of hemophilia: genes, chromosomes, proteins, inhibitors. He should be able to deftly handle an explanation of the genetic transmission of his hemophilia, and be able to create scenarios of how his

children and grandchildren may inherit hemophilia. He should be able to trace what happens from the moment that factor is infused until its arrival at his injury site, and explain how it helps him heal. He should be able to use medical and scientific terms to describe the steps in blood clotting. Use your understanding of his cognitive level to help him make better decisions about life, including driving safely and protecting himself during sports. Although your teen may not be correct in all his conclusions, remember that he arrives at those conclusions through abstract and logical thought. His capabilities are many!

Just thinking about how children develop cognitively will help you appreciate their amazing capabilities and share in the wondrous journey of childhood. As parents, we can do so much to help our children achieve their highest potential when we can identify each cognitive stage. Teaching children appropriately about hemophilia gives them a sense of competency and self-esteem. Teaching about hemophilia can be fun and can even enrich our relationships. I recall many hours spent with my young ones, using playtime, bath time or driving time as opportunities to ask open-ended questions about hemophilia and to listen actively. Faithfully recording many of these conversations, I have captured their childhood in a journal that they will someday enjoy. Knowing how your child thinks may spark some ideas about what questions to ask him, or what learning tools to provide. How will you respond the next time he asks a question, makes a cute comment, or invites you into his magical world of growth and creativity? Be prepared to go with him. Don't refuse the invitation! ☺

Lauren A. Kelley is the mother of a child with hemophilia. In 1990, she founded LA Kelley Communications, Inc., to provide practical educational materials for families. She has a bachelor's degree in child development, and is the author of ten books on bleeding disorders, including *Raising a Child With Hemophilia* and *A Guide to Living With von Willebrand Disease*. Laurie is the founder and editor-in-chief of *PEN*. She also founded Project SHARE, a humanitarian program that donates millions of dollars worth of blood-clotting medicine annually to impoverished patients in developing countries.



**Do you want to learn how to teach your child about hemophilia using this information?**

Order the new book *Teach Your Child About Hemophilia* from [www.kelleycom.com](http://www.kelleycom.com) today! Free to parents.

PSI funding relies in large part on pharmaceutical and home care company donations. While funding hasn't changed since 2003, insurance premiums have escalated an average of 9% to 14% annually. Over the past three years, this means a cost increase of 27% to 42%. Funding at the 2003 level cannot cover nearly as many patients today. The waiting list for service grows every year.

Without adequate funding for 2007, PSI patients could lose their comprehensive health insurance coverage and face financial hardship. Some may apply for Medicaid, but the process typically takes three to six months. Meanwhile, reimbursements may continue to decrease, single source provider contracts may increase, home care consolidations will continue (shrinking the pool of donors), and companies will suffer financially.

The current storm requires new business strategies for all companies and nonprofits in the hemophilia community. This

year, PSI has made every effort to find new funding by reaching out to hemophilia organizations at the local and national level. PSI has also contacted 340B treatment centers and companies that have not previously donated, but whose constituents depend on PSI services. This year alone, PSI has raised over \$60,000 from 340B treatment centers and some NHF chapters. PSI continues to educate the community on the risks of the current storm, and continues to provide as much assistance as possible. But unless we as a community show our support for programs like PSI, some hemophilia families will be left without a safety net—no premiums, no insurance, no factor, and financially ruined. ☹

To learn how you can support PSI's Premium Assistance and Items programs for the bleeding disorders community, contact Art Wood at 804-366-7741 or Randi Paltrow at 216-521-7770. To learn more about PSI, visit [www.needpsi.org](http://www.needpsi.org).

## Visit our redesigned website and see what we've added!

Easier electronic ordering of books • Archives of past issues of *PEN*  
Laurie's speaking schedule throughout the year • More scholarship listings  
**HemaBlog™** — the community's first dedicated blog!

# LA Kelley Communications

*Experts in Hemophilia Education*



HOME SCHOLARSHIPS HEMABLOG™ FAQ ARCHIVES CONTACT US

### Welcome to LA Kelley!

LA Kelley Communications was founded on the belief that anyone facing hardship, adversity or challenges—when given the right tools—can overcome, triumph, and even grow in character and confidence. Chronic medical disorders like hemophilia can present such challenges. Parents feel overwhelmed because they lack the educational tools needed. Where will they find them?

[Learn more about us >>](#)

### Meet Our Corporate Partners

Know the companies who support our work.



[Find out more >>](#)

### What's New? November



A teen with a passion for writing starts a journal in 1942, the World War II years. What mysterious illness plagues him? Read *Legacy: The Hemophilia of Yesterday*, the personal journal of Ralph Dean Rytting and quite possibly the earliest published personal account of hemophilia in the world.

[To order Legacy >>](#)

### Give to Project SHARE

See how SHARE is saving lives!

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Book the presentation "The Current Storm."

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## Educating, Empowering, Elevating

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NEW

## Newsletter about INHIBITORS

Novo Nordisk is proud to launch *Voices Uninhibited*, a new newsletter dedicated to patients with hemophilia and inhibitors. Each issue will cover treatment, insurance and lifestyle issues.

For more information:  
877-668-6777  
voices@novonordisk.com



## Sports Champs: Kids with Bleeding Disorders

ZLB Behring is pleased to announce a sixth season of its Junior National Championship program, the only national competition in golf and baseball for kids with bleeding disorders. If you're interested in bringing this great family event to your area, contact Janet Reimund at ZLB Behring, 610-878-4061, or Janet.Reimund@zlbbehrg.com.

To learn more, and to view the 2006 winners during the four-city circuit:  
www.zlbbehrg.com  
(select Events and Activities/Junior National Championship)

## Scholarship Winners!

Wyeth Pharmaceuticals awarded \$100,000 to students in the hemophilia community, including sixteen \$5,000 undergraduate scholarships, two \$7,500 graduate scholarships, and two \$2,500 vocational scholarships as part of the Soozie Courter Sharing a Brighter Tomorrow Hemophilia Scholarship Program, now in its ninth year. More than 140 students applied.

Applications for the 2007-2008 academic year will be available in the fall.

For more information:  
Wyeth Hemophilia Hotline 888-999-2349  
www.hemophiliavillage.com



## Novo Nordisk Emphasizes INHIBITOR EDUCATION

A new surgery and hemophilia website was launched in September to provide consumers with inhibitor information regarding elective orthopedic surgery. You'll find information on procedures that have been performed on individuals with inhibitors, and hear from people who have had these procedures.

For more information:  
www.surgeryandhemophilia.com

Community Talks is a grassroots educational program that teaches the community about rare bleeding disorders. The presentations are offered to consumers and their families by nationally recognized nurse practitioners and physician's assistants. Community Talks can be scheduled at any local chapter or HTC.

For more information:  
1-877-NOVO-777 or contact your local  
Novo Nordisk representative

## Ready, Padded, Go!



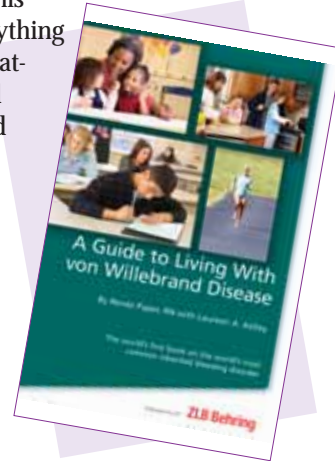
Bruzwear is a new company that makes crawling and exploration clothes for children. Designed by a mother of a child with hemophilia, Bruzwear clothing has machine-washable kneepads. Bruzwear gives children the confidence to crawl, stand, walk, and explore their environment while providing optimum comfort and style. Pants come in sizes 6 months to 4T.

*For more information:*  
Kathryn Ames, 303-522-5101  
kathryn@bruzwear.com  
www.bruzwear.com

## A Guide to Living With von Willebrand Disease New Edition!

The world's only book on the most common inherited bleeding disorder has been reprinted. Written by Renée Paper, RN, who has VWD, with Lauren A. Kelley, this book addresses everything from emotions to treatment to getting good insurance. Sponsored by a grant from ZLB Behring.

*For more information:*  
888-508-6978 or  
www.zlbbehring.com  
800-297-7977 or  
www.kelleycom.com



## Baxter Supports Two NHF Grant Awards for 2006

The National Hemophilia Foundation (NHF) and Baxter Healthcare Corporation awarded each of the following physicians a two-year fellowship through the NHF Clinical Fellowship Program in Bleeding Disorders Research for 2006/2007: Dr. Jordan Shavit, MD, PhD, University of Michigan, Ann Arbor; and Dr. Michael

Callaghan, MD, Children's Hospital of Michigan. Baxter supports these fellowships with the goal of achieving advancement in research.

*For more information:*  
Stephanie Walker, Porter Novelli, 312-856-8816  
stefanie.walker@porternovelli.com

# homecare

## HHS Enhances FactorCare®

Hemophilia Health Services® (HHS), a division of Accre Health Group, Inc., offers FactorCare®, a service designed for its clients, clinicians and payer partners. Components include *Living with Hemophilia*, an age-specific series of booklets covering health, social and psychological issues.



*For more information:* HHS's Hemophilia Education and Advocacy Library (H.E.A.L.)  
800-289-6501, ext. 5145

For clinicians, HHS is upgrading eFactorCare<sup>SM</sup>, its interactive web-based reporting program, to allow clinicians to review reports in PDF and Excel formats. Clinicians can visit this HIPAA compliant site to view their patient-reported therapy management data.

*For more information:* 800-289-6501, ext. 5177

## BioRx Completes Accreditation

BioRx has been awarded accreditation status by the Accreditation Commission for Health Care, Inc. (ACHC), for the services of infusion therapy. BioRx is a national pharmacy and pharmaceutical distributor specializing in highly customized care for a select group of chronic disorders. By attaining accreditation, BioRx has demonstrated its commitment to maintaining a higher level of competency and striving for excellence in its products, services and customer satisfaction.

*For more information:*  
Mark Kestler, Rph, 513-792-7080

## NEW Rebuild Program

Rebuild, the new health and wellness program of specialty pharmacy CoaguLife, features the HydroWorx® 1000 therapeutic pool. The HydroWorx 1000 includes a unique underwater treadmill that allows variable water depth and underwater video monitoring. Rebuild offers patients high-quality strengthening and cardiovascular conditioning, and is indicated for arthritis, target joints, post-bleeding episodes, sprains and strains, and fracture and ligament reconstruction rehabilitation. The program is particularly suited to people experiencing the complications of hemophilia.

*For more information:*  
www.coagulife.com





## 2007 Hemophilia Federation of America Annual Meeting

The 2007 HFA Symposium will be held from Thursday, March 1 through Sunday, March 4, 2007, at the Albuquerque Embassy Suites Hotel in Albuquerque, New Mexico.

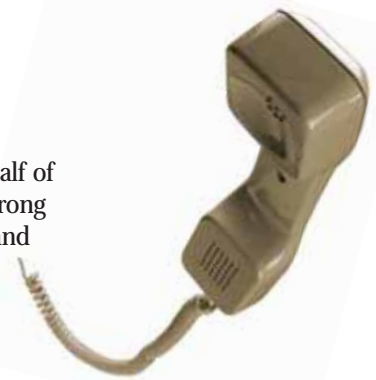
For more information: Embassy Suites, 505-245-7100  
[www.hemophiliafed.org](http://www.hemophiliafed.org)

## FREE Teleconferences!

Inalex Communications offers free 90-minute teleconferences on the third Tuesday of each month, followed by a 60-minute open forum. Participate in an exciting workshop from the comfort of your home. Sessions are led by noted specialists in marriage, relationships

and parenting. Topics in the second half of 2006 include facing anger, building strong relationships, managing stress, goals and parenting skills.

For more information: 866-802-0304  
[www.inalex.com](http://www.inalex.com)

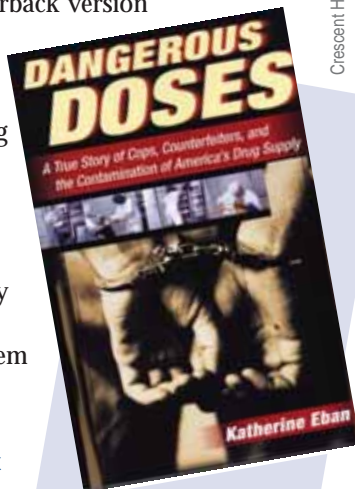


## Read This!

### Laurie Kelley strongly endorses the book *Dangerous Doses*

Laurie Kelley, president of LA Kelley Communications, Inc., recommends that all healthcare consumers and providers read the updated, paperback version of *Dangerous Doses: A True Story of Cops, Counterfeiters and the Contamination of America's Drug Supply*. Since this ground-breaking book was published, a corrupt wholesale factor distributor has gone out of business, and the former owners are going to jail. NuFACTOR has a limited supply of complimentary copies of the book; we are pleased to make them available to *PEN* readers on a first-come, first-served basis.

For more information: Sean Hubbert  
[shubbert@nufactor.com](mailto:shubbert@nufactor.com)



Crescent Hemophilia Services



## Swimming Strengthens Joints

On September 10, Crescent Hemophilia Services hosted two Olympic gold medalists in swimming and water polo to coach 16 children with hemophilia on water safety and swimming. Dr. Mauricio Silva from Los Angeles Orthopedic Hospital spoke with parents about hemophilia and how swimming benefits joints. Crescent Hemophilia Services is dedicated to providing people with bleeding disorders every possible tool to enable them to live life to the fullest. This is the first of many exercise workshops that Crescent will be offering across the country.

For more information: [www.crescenthealthcare.com](http://www.crescenthealthcare.com)

In these challenging times, we must work together as a united community to find the best solutions to secure the sustainability of our HTC's, while still protecting patient access to all therapies and options in distribution and supportive services. I can't remember a time when so much was at risk. I suggest a national summit to discuss current and future solutions for these complex problems. It may already be too late.



Ann E. Rogers, MS  
Executive Director

National Hemophilia Foundation  
Delaware Valley Chapter  
New Jersey

**A**wesome economic forces are converging on hemophilia care. Specialty pharmacy "solutions" to rising health costs put HTC's on the chopping block. Comprehensive care for hemophilia is at stake. Insurance payers place similar pressure on home care providers, while the price and overall cost of factor continue to mount. Now is the time for the hemophilia provider community to stand together. We need to survive for the people we serve.

Laurie Kelley and Paul Clement deserve high marks for thorough coverage of these issues.



Robert W. Fox  
President, Hemophilia Alliance

President/CEO  
Mary M. Gooley Hemophilia Center  
Rochester, New York

**P**aul Clement did a good job. He reflects my pessimism about HTC's. It's ironic that the one mentioned by name, at Orthopaedic Hospital, now is a shadow of its former self. California in general is not doing well. The San Diego [HTC] has sagged ever since the Iraq war, when its director was called up into Army reserves. Another director of an HTC has resigned. Another doc-

tor is leaving a children's hospital in Los Angeles to work for a pharmaceutical company, and so on.

The 340B program for us was too little, too late. I am not offended by strong pressure on patients to use an HTC's 340B. The money has to come from somewhere, and patients often don't realize where the money is going and who is profiting. In the late 1970s, before drop-shipment pharmacies, our hospital was making enough money from concentrate sales to cover the HTC and more. It was useful to have a profitable hemophilia program because then the parent institution likes you. [A profitable HTC] helps to offset the anguish the hospital administration feels when "stuck" with an uninsured hospitalized inhibitor patient using millions of dollars worth of product. After the drop-shipment companies were in full swing, we remained in the black for direct costs through the 1980s and 1990s, but there was no surplus, no overhead, no cover for the inhibitor disaster, and no money for a genetic counseling program, for example. At the moment, there is *no* full-time hematologist at the center, no full-time or half-time licensed medical lab tech—and so many other deficiencies, it breaks my heart to list them.

It would be interesting to see an economic analysis of the budget of

some HTC's, and the profitability of drop-shipment companies. Patients often don't know. I was helping Hawaii organize hemophilia care in the 1970s to 1990s. A major home care company swept in, taking over concentrate delivery after the blood bank decided it didn't want to deal with such expensive inventory.

[We are faced with a potential shortage of hematologists] yet some nonprofit CEOs wind up being paid more than twice the maximum doctors have been paid. Doctors start to wonder what kind of fools go into the practice of internal medicine. It's not good to underpay the professional staff of HTC's.

Thanks for continuing to print such relevant articles. Nobody else is doing it, and it's vital.



Carol K. Kasper, MD  
Emerita Professor of Medicine  
University of Southern California  
Orthopaedic Hospital  
Los Angeles, California

"Desperate Measures for Desperate Times" (As I See It, *PEN*, August 2006) was an excellent article. I hope everyone reads it.



Elizabeth Kallberg  
Minnesota



*Inhibitor Insights... continued from page 4*

Along with concerns about medical protocol, there are other things to consider about ITT. It's very expensive, time-consuming, and mentally and physically draining on the patient and family. Yet most families gladly endure the hardships of ITT because, if therapy is successful, quality of life improves immeasurably. And the future holds great promise: If current research proves successful, vaccines may be able to eliminate inhibitors.

Researchers have found that people who have been successfully tolerized to factor still have circulating antibodies to factor in their blood—yet the factor

works normally. It is now known that these people also have antibodies that *inactivate* the anti-factor antibodies. In a clinical trial currently underway at Johns Hopkins Hospital in Maryland, allergy patients are receiving a vaccine that stimulates the immune system to form antibodies against the antibodies that are causing their allergies. So far, the vaccine has successfully eliminated some cases of allergies. Researchers speculate that we may eventually be able to vaccinate to eliminate inhibitors—a godsend to the approximately 1,200 people with inhibitors in the US, and the thousands more around the world. ☺

*A Project SHARE Story... continued from page 5*

We differ from the Canada-based World Federation of Hemophilia because we focus on shipping factor to individuals as well as to clinics and nonprofits. Our partnership with our corporate sponsors—Baxter BioScience, Bayer Corporation, Grifols USA, Hemophilia Health Services, Novo Nordisk and ZLB Behring—represents the first joint

effort between pharmaceutical and home health service companies with the goal of serving the world's poor with hemophilia. Project SHARE's mission is to ensure that no patient is turned away and no obstacle prevents access to treatment. We use factor as a catalyst for permanent change, and we supply hemophilia aid and relief everywhere. ☺

**Correction/Clarification**

In the last Inhibitor Insights, Paul Clement wrote, "NovoSeven may be used in conjunction with aPCCs like FEIBA." Although some physicians use NovoSeven and FEIBA together clinically, in November 2005, NovoSeven® manufacturer Novo Nordisk officially advised physicians *not* to use FEIBA and NovoSeven simultaneously. The current package insert (PI) for NovoSeven, dated August 16, 2006, warns: "Simultaneous use of activated prothrombin complex concentrates or prothrombin complex concentrates should be avoided." The Novo Nordisk website states that people taking FEIBA and NovoSeven at the same time "may be at increased risk for thrombosis [unwanted blood clots that may be harmful]." Download the new PI at [www.us.novoseven.com/pdf/00609\\_novose\\_pi\\_fa.pdf](http://www.us.novoseven.com/pdf/00609_novose_pi_fa.pdf).

In a related issue, some physicians practice "sequential therapy," in which a dose of FEIBA is administered and several hours later, one or more doses of NovoSeven are administered. This is considered an off-label investigational use of NovoSeven, and Novo

Nordisk will not recommend uses for NovoSeven outside of those listed in the PI, which doesn't list sequential use. The National Hemophilia Foundation's Medical and Scientific Advisory Committee (MASAC) wrote in MSAC Recommendation #167, "The mechanism of action is different for these two products [FEIBA and NovoSeven] and may be synergistic; therefore both agents may be required for the same patient." You can find this recommendation at [www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=57&contentid=579](http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=57&contentid=579).

Finally, Mr. Clement wrote, "But for an unlucky few, nothing except NovoSeven seems to work." This statement is true for individuals with factor IX inhibitors who may have severe allergic reactions to factor IX (found in FEIBA), and for individuals with factor VIII inhibitors who do not respond to FEIBA. However, some people do not respond to NovoSeven—for them, only FEIBA works. Inhibitor patients should keep these issues in mind when discussing the best treatment regimen with their HTC physicians.

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