

HACA News

October 2003
Volume 19 Issue 5

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Mission Statement

HACA's Vision is to improve the quality of life for persons and their families affected by bleeding disorders.

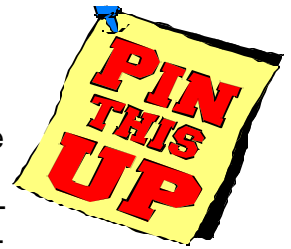
HACA's mission is to:

- ◆ *Educate, support and advocate for persons with bleeding disorders and their families.*
- ◆ *Network with healthcare professionals.*
- ◆ *Increase public awareness.*

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CFC #6022

Combined Federal Campaign

Those of our readers who are Federal workers know that the Combined Federal Campaign (CFC) kicked off September 16th. To support our local chapter, please direct your donation to #6022. Please ask your family, friends, and co-workers to do the same. Thanks to all who have so generously supported the chapter in the past through the CFC. You provide a substantial part of our budget.



United Way Contributions

Although HACA is not listed in the "Agency Services and Contributions Guide", you can direct your donation to HACA by requesting and filling out a "Donor Choice Form"

Follow the six easy steps listed:

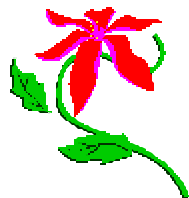
1. Check the box for a specific agency serving people in your community.
2. Fill in Hemophilia Association of the Capital Area as the agency name.
Address: 3251 Old Lee Highway #3, Fairfax VA 22030-1504.
3. Leave the agency ID number blank.
4. Specify the amount of the donation.
5. Fill in your name, address, and employer.
6. Check the box indicating that you would appreciate an acknowledgement.

Thanks to all who have generously supported us in the past through the United Way. Your generosity helps us make a difference.

Other Campaigns

The Hemophilia Association of the Capital Area is listed as #3788 in the Combined Virginia Campaign. This means that anyone who is a state of Virginia employee may designate HACA to receive his/her contribution. HACA also participates in the Montgomery County Combined Campaign and the Prince George's County Campaign. This means that employees of Montgomery and Prince George's counties have an opportunity to support HACA. Please ask your friends, family members, or co-workers to remember HACA when making their pledges.

If you wish to make a donation to HACA through the Fairfax County Combined Charitable Campaign, you will need to request a "Donor Choice" form and follow the procedures outlined in the paragraph about United Way Contributions.



Poinsettia Sale

We have once again begun to think about the Holidays and our annual Poinsettia Sale. Once again, we will be offering 6-inch and 8-inch poinsettias to grace homes, offices, and places of worship. We will be charging \$8 for the 6-inch plant and \$20 for the 8-inch plant. One half of the price represents a tax-deductible donation to HACA.

The deadline for ordering plants will be Thursday, November 20th. Commercial deliveries will be made on December 5^h and sites will be open in Virginia and Maryland for plant pick-up on December 6th. Sales kits will be mailed in October. Please support this venture by inviting your family, friends, co-workers, real estate agent, doctor, etc. to purchase these beautiful plants.

Chapter News continued

Welcome New Board Members

At our annual meeting held on September 13th, several people were elected to HACA's Board of Directors. Those newly elected members include: Mitch Ballweg, an attorney with the U.S. Department of Justice and a person living with hemophilia; Lou Baumgartner, a former comptroller for the Hyatt in Reston who will serve as our treasurer; Cliff Krug Jr., owner of Regency Moving & Storage and father of a child with a bleeding disorder; Dr. Lynda Mulhauser, social worker at Children's Hospital; and Sandi Sanford, a compliance officer at George Mason University with a nursing background.

They join HACA's previously elected board members: Susan Yamamoto, President; Keith Bushey, Vice President; Nina Duggan, Secretary; Sean Kevelighan, Anastasia Lee, Julie LeFevre, and Jack Shoff.

Thanks to Departing Board Members

Each time we elect people to the Board of directors, we must also bid farewell to others who have served the HACA community for at least two years, and in some cases, to those who have served for four years. Accordingly, we extend a huge thank you to the following individuals for their years of dedicated service to HACA: Pam Anderson—when we said farewell to Pam last year, none of us realized that Pam would graciously step back into the role of treasurer when our newly elected treasurer had to resign due to his duties with the war in Iraq; Paul Brayshaw—Paul most recently served as Vice President of the Board. Paul has also been the coordinator of Blood Buddies for the last 4 years and has facilitated small group discussion with our teens at the last two educational seminars; Stephen Kulenguski and Michael Garfield—both men served on the board for the last two years.

Throughout the course of the year, other board members have had to resign for personal rea-

2003 Board of Directors Meetings

General Board Meeting
October 27, 2003
Executive Board Meeting
TBA

General Board meetings begin at 7:00 p.m. and are open to all interested HACA members. Because of security regulations at our meeting place, please notify the HACA office that you will be attending. Directions and site will be shared with you at that time.

sons. These members include: Rick Riccardelli (Treasurer), Amr El-Beshier, and Jim Romano.

We're very grateful to all these individuals for their gifts of time and for all they helped the organization to accomplish.

Educational Seminar Held September 13th

60 people braved the rain to attend and take part in our educational seminar at George Mason University-Fairfax. Special thanks to all our speakers and facilitators for their fine presentations. Thanks, also, to our sponsors for this event: Accredo; AHF, Inc.; American Red Cross, Aventis Behring, Bayer, Baxter, Caremark, Coram, eBioCare, Factor Support Network Pharmacy, HRA, OptCare Plus, NuFactor, and Wyeth. If you are interested in planning next year's seminar, please call the HACA office at 703-352-7641.

Calendar of Events	
October 11	Blood, Sweat & Gears, HACA's Bike-a-thon, Reston YMCA
November 6-9	NHF Annual Meeting is Salt Lake City, Utah
December 6	Pick-up Day for Annual Poinsettia Sale
January	Workshop for Women and Girls with VWD

Participants Needed for a Research Study on Child Distress and Coping when Parents Must Give Injections to their Children

If your child, ages 2-10, experiences great distress when it comes to needle pokes, the following study may be "just what the doctor ordered". Dr. Keith Sliefer of the Kennedy Krieger Institute, Department of Behavioral Psychology, in Baltimore is offering the following study. (Dr. Sliefer is a member of faculty of the Johns Hopkins University School of Medicine.)

We are writing to tell you about a research study being conducted at the Kennedy Krieger Institute, 707 North Broadway, Baltimore MD 21205. The investigators are studying the worries and behavior of children having a medical condition requiring injections to be given by a parent or other family caregiver. Children who are 2 -10 years old and their parents are being invited to participate. Children with diabetes, short stature, bleeding disorders, kidney or heart problems or any medical condition requiring treatment with injections given on a regular basis by a family caregiver can join this study. Participating in this study will not change the medical treatment already being prescribed by your child's doctor.

While there are no certain benefits to you or child from participating in this study, you may learn behavior management strategies that might help your child worry less about the injections and cooperate better when injections are given. Parents also may gain greater confidence and learn to worry less about giving necessary injections to their children. The results of this study may help investigators understand why some children and caregivers adjust better than others do when a parent must give injections. The results also may help investigators learn how to prepare families for the stress involved when parents have to give injections.

There is no cost to you or your health insurance provider for participating in this study.

Children and parents who participate in this study will be observed and videotaped for up to 15 minutes in the clinic during a play activity and when the parent gives an injection on up to 4 visits. Parents will be asked to complete several questionnaires about their child's behavior and emotions. The videotapes and all information collected will

be kept confidential and stored in a secure location under an assigned identification number. Total time for participation will last about 50 minutes on up to 4 visits to the Pediatric Psychology Clinic. Children who participate will receive a gift certificate for each visit and parents will receive a gift certificate at the last session of the family's participation.

If you would like to participate, have questions, or want more information, please call the Project Coordinator, Melissa Beck, Ph.D. at 443-923-2900.

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Leg Length Discrepancy and Target Joints: A Case Study

By Lora C. Joyner, MS, PT, PCS

The role of leg length discrepancy (LLD) both as a biomechanical impediment and a predisposing factor for associated musculoskeletal disorders has been a source of controversy for some time. LLD has been implicated in affecting gait mechanics and economy, standing posture, increased incidence of scoliosis, low back pain and other lower extremity impairments. Authors disagree on the extent to which LLD causes these problems, and what magnitude of LLD is necessary to generate these problems. There is also much controversy on the appropriate treatment and when to institute correction of a LLD.

Limited medical literature exists on the topic of LLD and hemophilia, but within the available articles LLD was described as a long-term result of arthropathy, though there were no recommendations on correction of the discrepancy or the long-term effects on target joints (e.g. the ankle and knee).

The following case study will demonstrate the positive effects of correction of a minor LLD on bleeds and target joints. Correction of the LLD must be done in combination with prophylactic factor therapy and exercise.

“Joe” is a nine-year-old with diagnosis of severe hemophilia A (factor level < 1%). The Pediatric Hematology Department of East Carolina, University School of Medicine in Greenville, North Carolina has followed Joe since infancy. He was diagnosed in April 1995 after his cousin was diagnosed following circumcision. Joe is treated with recombinant factor therapy.

Joe has been followed by a physical therapist since 1995. In August 1996, he began having recurrent bleeds in his left knee and ankle. Leg lengths were measured as equal at that visit. There was a documented LLD at the clinic visit in April 1997 after a significant growth spurt. A shoe lift was recommended at that time, but no other treatment was instituted. In October 1997 Joe continued to present with chronic left knee problems, asymmetrical gait pattern and edema in his left knee. Prophylactic factor therapy was begun for one month as

well as lower extremity strengthening activities in conjunction with the shoe lift. Left knee target joint problems appeared resolved at subsequent follow-up clinic visits that went on until the child was four and a half years old. At that point, Joe was referred for a baseline orthopedic appointment. The orthopedist discontinued use of the shoe lift secondary to “non significant LLD.” Bleeds in Joe’s left knee resumed with additional bleeds in the left ankle. After team consultation, the shoe lift was re-instituted when Joe was five years old. Shoe lifts have been used since that point and no target joint problems have been documented.

The above case study documents the positive outcome on target joints with the use of a shoe lift for even a minor LLD. Appropriate prophylactic therapy and exercise needs to be instituted in conjunction with the shoe lift. Studies need to be done regarding this intervention for treatment of target joints and the prevention of long-term disability.

- from ***Hemaware*** Volume 8, Issue 3

DID YOU KNOW?...

- ◆ In 1907, Coca-Cola was advertised as being “good to the last drop.” The slogan was long forgotten by the time the line was adopted by Maxwell House coffee.
- ◆ The handshake originated in ancient times, out of suspicion, because strangers shook hands to show they were unarmed.
- ◆ Buddy Ebsen was selected to be the Tin Man in *The Wizard of Oz*, but he had to turn down the role because of an allergic reaction to the aluminum dust in his makeup.
- ◆ The state of Tennessee was known as Franklin until 1796.
- ◆ One out of every three cows which are raised for food (beef) in the United States are used by the McDonald’s corporation.

Lost Art of Manners

Revolutionary Common Sense by Kathie Snow

What are manners? Years ago, I read a meaningful definition (and, unfortunately, cannot remember the source) which described manners as “making another person comfortable.” Most of us probably try hard to have good manners, but it seems many of us lose the art of manners when it comes to people with disabilities.

While I was presenting the “History of Disabilities” at Idaho Partners in Policymaking in April, Howard (who is probably in his fifties or sixties) raised his hand and said he wanted to add something about how individuals had been treated and talked about in the past, based on their disability levels.

“I have two brothers,” Howard began. “All the time I was growing up, when my father introduced us, he said my brothers’ names and then he always said, ‘And this is my retarded son, Howard.’ Why did he do that, Kathie? It always made me feel so bad.” Then Howard broke into shoulder-heaving sobs, as the years and years of pain poured out. Several of us comforted him as best we could. Resuming my presentation, I noted that years ago, many people probably believed that it was appropriate to share this information with anyone (including strangers) and perhaps they also thought people with disabilities did not have the cognitive abilities to understand what was being said, so they didn’t think their words would hurt.

Howard’s pain was clear evidence that words—especially the words used by parents and others who profess to care about you—hurt very deeply and the pain is long-lasting. In Howard’s case, the pain was decades old, but on that day, it felt just as raw as it did every single time Howard’s father said, “My son is retarded.” It seems that things would have changed over the past thirty, forty, or fifty years, but...

Week in and week out, I meet parents who talk about their children (regardless of the child’s age) in the same way Howard’s father did! Sometimes the child is present, sometimes not, when parents say things like:

-- My daughter is autistic.
 -- He’s sixteen, but he functions like a 5-year-old.
 -- She doesn’t have much “upstairs.”

Would we share private information about family members who don’t have disabilities? Would we ever say things like:

-- My teenager still sleeps with a night light.
 -- My husband needs to take Viagra.
 -- My wife has a big boil on her behind.

I don’t think so, because most of us have better manners than to share private, personal information that is no one’s business!

How in the world can we, in all good conscience, share private information with others, including talking about people in front of them, as if they’re not there? And talking about them when they are *not* present isn’t much better—that’s a form of gossip, and the person isn’t there to defend himself!

Family members aren’t the only guilty parties, however. Many professionals have lost their manners, as well. After inviting me to present a seminar, some meeting coordinators have “helpfully” warned me, “Some of our ‘consumers’ will be there, and they’re more like children.” Would a coordinator make this announcement during the seminar, when adults with disabilities are in the audience? Don’t think so. If a coordinator feels it’s appropriate to warn me about people with disabilities, why isn’t she also motivated to warn me about others? As in, “Some of the parents and professionals who are coming to the meeting are real duds.” Many educators, especially those in non-inclusive schools, routinely use labels and negative descriptors about their students, both in front of the students and behind their backs. Ditto for many therapists who shamelessly call out, “The Down’s is coming in this afternoon.”

The loss of manners isn’t limited to our words. Our actions speak volumes.

“Janelle” recently introduced me to her 20-year-old daughter, “Micki,” a bright and lovely young lady who happens to have a disability. Micki shook my hand and greeted me. In the course of casual conversation, I asked Micki a couple of questions. She started to reply, but Janelle jumped in and answered! Micki could speak for herself, but her mother got in the way! Why did Janelle do this? Was she afraid I wouldn’t understand her daughter? Was she afraid I would judge Micki by her words or oral abilities? Did she think her daughter is incompetent? Or was she even aware she was doing this? I’m not sure. Janelle probably spoke for her daughter when she was a very young child—like all parents do—and perhaps she hasn’t realized Micki is grown up and can speak for herself. I can’t imagine the frustration Micki must feel—and the anger.

What’s frightening is that parents, professionals, educators, and service providers are supposed to be “on the same side” as the children and adults with disabilities they care about, serve and/or teach. But with friends like these, who needs enemies?

When we exhibit these poor manners, not only are we being downright rude, but we risk causing long-term and severe emotional pain in others. Furthermore, we reinforce the notion (and its accompanying prejudices) that our society has two sets of rules: one for people with and one for people without disabilities. And we wonder why inclusion, dignity and respect for all people continue to be just out of our reach. On a regular basis, our words and actions set people up for exclusion.

How can we do better? First, the person is not her disability, thus, she is not “autistic”—she “has autism.” A disability label simply represents a condition or a characteristic; it does not define a person. A family member of a person who has cancer does not say, “She’s cancerous.” So, why do we say, “He’s disabled [or retarded, autistic, or whatever].”? Saying, “She has cancer,” is more appropriate, as is, “He has a disability.”

Second—and just as important—we need to be careful about sharing information with others. Howard’s father might have shared that his son was “retarded” in order to “explain” his son’s behavior, speech, or something else. But the outcome of his good intention was probably less than desirable: upon hearing “retarded”, people most likely assumed the worst about Howard. (What terrible things we do

to people in our efforts to “do good!”) Once that first impression was formed, there was probably very little Howard could do to change it. The same is true today when we focus on a person’s disability as a “problem”.

There are relatively few times when it’s important to share a person’s disability label with others: in special ed meetings, with medical personnel, and/or with others in the service system.

Many people with disabilities are said to have “challenging behaviors.” Perhaps we would do well to look at our own behavior before judging others. Is it possible these individuals may be reacting or responding to the vicious, verbal assaults they routinely experience when they hear others talking about them? Do we think people don’t hear or understand what we’re saying? How arrogant and uncaring can we be? Shouldn’t we care about how others feel? How would you feel if others talked about you?

Third, we need to demonstrate our good manners by letting people with disabilities speak for themselves and be themselves. They are our equals! We have no right to speak for them, unless they have asked us to do so! To interrupt someone; to “explain” his behavior or actions; or to “apologize” for his drooling, his speech patterns, or anything else is to rob a person of his right to be who he is! How would you feel if your husband interrupted you during a meeting and said to others, “My wife is quite the motor-mouth, isn’t she?”

The lives of people who have been labeled should not be part of the public domain. We have no right to speak for them, to reduce them to medical diagnoses, to share their private information, to talk about them (in front of them or behind their backs) in ways we would never talk about ourselves, and, in the process, strip them of every ounce of dignity. Have they ever given us permission to do any of these things?

Howard gave his permission to share his story. His experiences, as well as the experiences of countless others are continuing lessons that help me stay on top of my manners. I hope they do the same for you.

Know Your Vendor Options

By David Linney

In the August 2003 issue of HACA News ("What You Need to Know about Homecare Factor Product Pricing" May/June 2003), factor product pricing was discussed. In this issue, the importance of knowing your insurance coverage and homecare vendor options and how your insurance coverage and costs may be affected by using one vendor versus another will be looked at.

Background: Insurance coverage for homecare factor products has become a lot more complicated.

How Insurance Plans Cover Factor Products: Insurance plans may cover factor products in different ways. Factor products can be covered through the health plan, drug plan or home infusion service of an insurance plan. Some insurance plans cover factor products in more than one way. (Factor products may also be excluded from coverage.)

Insurance Plan Coverage of Vendors: Insurance plans may cover one or more different vendors (i.e. providers) of homecare factor products. Different vendors include: homecare companies, hemophilia treatment centers, HMOs, drug plans and specialty pharmacies. (Factor products can rarely be obtained at your local pharmacy.)

Insurance Plan Coverage for Factor Products: Factor products may be covered at 100% or at lesser amounts when subject to out-of-pocket costs, co-pays, deductibles and co-insurance. Actual out-of-pocket costs will vary from plan to plan. In addition, there can be a higher level of coverage if you use an in-plan provider versus lesser coverage if you use an out-of-plan provider.

Insurance Limits: Factor products (as a covered service) may or may not be subject to a lifetime limit. It is more common for factor products to be subjected to a lifetime limit. Factor products, on occasion, may be subjected to annual limits. Amounts of limits will vary from insurance plan to insurance plan.

Using One Insurance Coverage Option Versus Another for Factor Products

If your insurance plan provides for more than

one coverage option for factor products and you only know of one, then what you don't know may cost you money. Let's look at three examples.

Example 1: If you get factor product through a health plan (which pays at a rate of less than 100% and has a lifetime limit) and you are not aware of a coverage option through the drug plan, then you may be paying more than you have to.

Many drug plans do not provide coverage for factor product, but some do. If you have a drug plan that does, then you might pay a lot less using the drug plan than the health plan. Many (but not all) drug plans have only a small co-pay for each factor product prescription versus other plans that may have hundreds or even thousands of dollars in yearly out-of-pocket costs (for deductibles and co-insurance).

In addition, since many drug plans have no lifetime limit, you could save on lifetime limit dollars if you have a health plan with a lifetime limit.

Drug plan co-pay: \$25 per prescription with no lifetime limit

Versus

Health plan with \$500 deductible and \$1,000 in co-insurance costs (20% X \$5,000) and a \$1,000,000 lifetime limit

In this example, if you had 12 factor product prescriptions in a year, the cost through the drug plan would be \$300 with no impact on your lifetime limit.

If you were to use the health plan and each prescription cost \$10,000, your cost would be \$1,500 (for the deductible and co-insurance) and \$118,500 would be posted against your lifetime limit (12 prescriptions X \$10,000=\$120,000 minus \$1,500 in out-of-pocket costs=\$118,500).

Example 2: If you get factor product through an out-of-plan vendor and are not aware of a coverage option through an in-plan home infusion service, then you may be paying more than you have to.

Home infusion services are covered under the health plan and typically include coverage for nursing services and may include coverage for factor product. If the insurance plan has one or more in-plan home infusion service providers, which include coverage for factor product, then you could save money. By using an in-plan home infusion provider, you will usually save on out-of-pocket costs, assuming your current vendor is out-of-plan.

In-Plan Coverage
 \$250 Deductible
 90% Coverage/10% Policyholder Liability
 \$500 Co-Insurance Liability Out-of-Pocket Maximum
 \$750 Out-of-Pocket Cost (Deductible & Co-Insurance)
Versus
 Out-of-Plan Coverage
 \$500 Deductible
 70% Coverage/30% Policyholder Liability
 \$1500 Co-Insurance Liability Out-of-Pocket Maximum
 \$2000 Total Out-of-Pocket cost (Deductible & Co-Insurance)

Savings: \$1,250 using in-plan vendor versus out-of-plan vendor.

Example 3: Using an in-plan vendor, however, may not always save you money.

Using an in-plan vendor may save you on out-of-pocket costs, but could cost you more toward your lifetime limit. This can happen if the price per unit for factor product through an in-plan vendor is more than through an out-of-plan vendor (assuming the insurance plan has the same lifetime limit for both in-plan and out-of-plan benefits.) This is another reason to verify the price you pay for factor product.

Use insurance coverage information from Example 2.

If the in-plan vendor charged 20 cents more per unit than the out-of-plan vendor, and the patient used 200,000 units in a year, then

20 cents X 200,000 units=\$40,000 more posted against the lifetime limit using the in-plan vendor than if the out-of-plan vendor was used.

In this example, you could have a dilemma. You would save \$1,250 if you used the in-plan vendor, but have an additional \$40,000 posted against your lifetime limit. If you used the out-of-plan vendor, you would spend an additional \$1,250, but save \$40,000 on your lifetime limit.

How to Verify Different Insurance Coverage Options for Factor Product

To review all your different insurance coverage options for factor product, contact your drug plan and health plan.

Verify if factor products are covered through your drug plan. Check if there is coverage and if the drug plan has any limits. Then verify if and how factor products are covered under your health plan—through general medical benefits *and* home infusion services. Also verify if the health plan has any limits.

To review how your insurance provides benefits for your current vendor, you can:

- Review your Explanation of Benefits (EOB) statements from your insurance. Many insurance plans issue EOBs that detail how factor product claims are paid.
- Call your insurance plan.
- Call your vendor of factor products.

If you need help, contact the nurse case manager for your health plan. You can also contact staff at your hemophilia treatment center. If your HTC is also your vendor, take note of the next paragraph.

Your current vendor can be contacted, but may not be the best neutral party to review other insurance coverage options. This is because other coverage options will likely involve other vendors (i.e. competitors).

Because insurance is complex, it is important for consumers to know their vendor options and insurance coverage. Being better informed may save you a lot of money in out-of-pocket costs and in lifetime limit dollars.

HemAware, July/August 2003

Night Splints: An Option for Treating Chronic Muscle Tightness

By Lora C. Joyner, MS, PT, PCS

People with hemophilia who have severe muscle and joint problems and haven't responded to treatment may find relief by asking their physical therapists to provide night splints. Such splints are different from the more familiar immobilization splints used to treat the effects of acute bleeds. Used for weeks or months, night splints gradually increase the length of a muscle and thereby increase the range of motion of the joint, allowing it to fully extend (straighten out) and fully flex (bend).

Overview of Splinting

A joint is surrounded by a sac-like envelope called the capsule. The capsule's lining, the synovium, contains many blood vessels. Everyday movement causes tiny rips in these blood vessels, or microtears. In a person with severe hemophilia, microtears can begin to bleed. Also, when a person with hemophilia experiences trauma to a joint or muscle, a much larger tear develops, which can lead to a much larger bleed.

In addition to factor replacement, the usual treatment for joint and muscle bleeds is R.I.C.E. (rest, ice, compression, and elevation). Sometimes, if a muscle is especially sore or the range of motion in a joint is especially limited, a second I, for immobilization, is added to the therapy. At times this immobilization is accomplished with a splint that is worn either all day or just at night for one to three days. This is the splinting that many people with hemophilia are familiar with.

Repeated bleeds in the same area can cause a muscle to shorten, which sometimes severely limits a person's range of motion. With recent advances in the treatment of hemophilia, including factor replacement and physical therapy, most people don't develop such problems; however, chronic and severe joint disorders may occur in some individuals, such as those who have inhibitors and those who don't have regular access to treatment.

For these people, prolonged overnight splinting may be needed. Night splints treat muscles that

have become shortened because of an underlying condition such as synovitis (chronic inflammation of the synovium, the lining of the capsule around the joint) or a severe problem called articular contracture, in which the muscles around a joint become highly resistant to stretching. Alice Anderson, clinical team leader of physical therapy at Children's Medical Center of Dallas, explains that chronic muscle tightness due to these conditions is the primary indication that night splints are needed. Anderson finds night splints an option for people who have a very tight muscle that is not responding to standard physical therapy.

Not all physical therapists, though, use night splints to treat articular contracture. "Every center has a different approach," says Sharon Funk, the physical therapy coordinator, Mountain States Regional Hemophilia and Thrombosis Center, University of Colorado Health Science Center in Aurora, Colorado. She believes that patients with contracture need a more aggressive approach than night splints. "It may be serial casting, it may be the use of a clinical apparatus, but I'm not sure how much patients will gain if they've had a long-standing problem using night splints," she claims. Nevertheless, in two review articles published in the March 1999 issue of the medical journal *Haemophilia*, physicians recommend that physical therapy and splinting should be the first line of treatment for articular contracture in people with hemophilia before they resort to surgery.

How Night Splints Work

When stretching a muscle, it is better to apply less pressure for a longer period of time (low-load stretch) than to put heavy pressure on it for a short period of time (high-load stretch). Night splints apply gentle pressure to a muscle. "A low-load stretch may put just two or three pounds of pressure on the joint, so it's a very light pressure" Anderson explains. "When you use [a low-load stretch] over a long period of time (e.g. overnight), you get more effective muscle lengthening." During the day the splint is removed and the patient uses the joint in his

normal activities, building on the newly acquired range of motion.

Three kinds of splints can be used for night splinting: an immobilizer, a static splint or a dynamic splint.

An "off-the-shelf" immobilizer is shaped like a cylinder and is usually made of foam material with metal stays on the side and Velcro straps. It holds the knee, elbow or ankle straight out, in total extension. This type of splint works only if the purpose is to straighten a joint, rather than increase the degree of flexibility. It also requires that the user be able to straighten his leg, elbow or ankle nearly all the way.

A static splint holds the joint in a single position. Splints may be made of plaster, synthetic casting materials, or thermoplastic splinting materials. The material is softened in water and molded to the extremity. Once hardened, the straps are attached for easy usage. This type of splint does not bend or straighten a joint so it has to be modified or replaced as the user gains more range of motion.

A dynamic splint allows a physical therapist to "dial up" the amount of low-load pressure applied to the joint, which can be adjusted as needed. "We're very fearful of pushing too hard on a joint or a muscle in people with hemophilia for fear that our treatment would cause a bleed," Anderson says. Dynamic splints work well, she finds, "because we can apply a very small amount of pressure in order to try and stretch a joint over a long period of time, and it does not seem to irritate most people with hemophilia to the point where they bleed. People wearing a dynamic splint can still bend or straighten their joint and for most people that feels better."

What to Expect from Treatment

Night splinting for people who have inhibitors can take up to six months or a year, Anderson has discovered. When the patient does not have an inhibitor, it can work in six to eight weeks. A study published in *The Journal of Orthopedic and Sports Physical Therapy*, reports on the use of dynamic splinting in the treatment of knee or elbow contracture in five men and eight women, though none of them had hemophilia. The average duration of use was 13 weeks. Another report, presented at a New York State Chapter meeting of the American Physical Therapists Association, concerns research by

multiple therapists into the use of dynamic splints to treat limited range of motion in elbows and knees following immobilization from illness, trauma and/or surgery. The 33 study participants who received dynamic splints needed them for 5 to 12 weeks.

People who use night splints may have some trouble sleeping at first, but most find ways to adjust. Dynamic splints seem to be better tolerated by children than static splints that are easily removed. Mom will put them to bed and then in the morning the splint is on the floor." She suggests that when a young child is given a night splint, a large tube sock may be put over it, to make it difficult for the child to take the splint off.

The Cost

A dynamic splint can cost about \$1,000. The good news is that most insurance companies will pay for all types of splints, although some insurance companies require the patient to rent rather than purchase the splint. Sometimes, a physical therapist will have to educate the third-party payer about what the night splint will accomplish. "Many times, insurers may initially deny coverage of a dynamic splint, and then with more supporting literature say yes," Anderson reports. "Sometimes we really have to jump through hoops to get splinting approved, but I will tell you, I've never been rejected in the end." She points out that night splinting is less expensive and less risky. Splinting can be cost-effective in other ways, by reducing the number of physical therapy sessions required and the duration of the period of rehabilitation.

For More Information

Those who would like to know more about night splints should speak with their physical therapists. Inquiries concerning a particular hemophilia treatment center's philosophy regarding the use of night splints in the treatment of joint contracture or synovitis are also important. In addition, educational material posted on the Internet by two of the manufacturers of dynamic splints is available. Their websites are www.dynasplint.com and www.ultraflexsystems.com.

-from *Hemaware*, Volume 8, Issue 3

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2003 Help for (name of child) with (type and severity of disorder)

What to do if (name of child)	What to do Immediately...	What to do next...
Receives trauma to: Head, Neck, Throat, Groin or Stomach with active bleeding, swelling, significant pain or unconscious	Call 911 – send vials of Factor VIII with ambulance	Contact Mom with “911” in pager or call her if she does not have a pager
Falls a short distance from the jungle gym or leaning in a chair or hit by another child but not on his head, neck, throat, groin or stomach	Check for bleeding, swelling, redness, tenderness at site of impact.	Apply pressure, ice, and First Aid to site. Circle site with pen. Check for changes after 30 minutes. Send note home. If concerned, call mom.
Nose Bleed	Apply pressure to bridge of nose. Cold rag under upper lip.	If bleeding continues for more than 15 min., call mom.
Bites his tongue/looses tooth	Offer ice water/Popsicle	If bleeding continues for more than 15 min., call mom.
Hurts any joint	Check for range of motion, bleeding, swelling, or redness around joint	Apply ice, rest, and elevate for 15 min. Send note home. If no improvement, then call mom.
Hurts his Port	Take his temperature. Check for swelling, redness, bruising, tenderness and page mom.	Call mom.
Superficial cut or scrape	Clean area, apply pressure, and bandage.	If still active bleeding after 30 min., call mom.

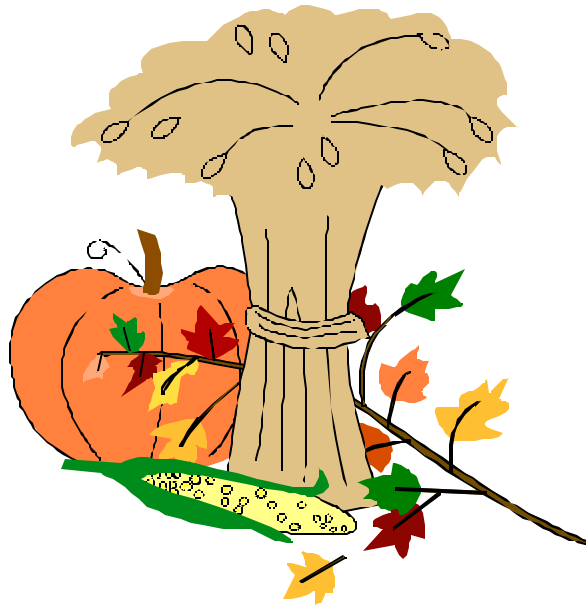
Name	Phone Number
1. Mother	1a.
b. Mobile phone	1b.
c. Home phone	1c.
2. Father	2a.
b. Mobile phone	2b.
c. Work phone	2c.
3. Hematologist on call @ Childrens’	3. 202-884-50000
4. Child’s Pediatrician: (Name)	4.

PLEASE NOTE!!

This is NOT to be taken as Medical Advice.

This form was composed by the parent of a child with hemophilia. The parent shares this form with her child’s school as a means of emergency reference. Each year the parent updates any necessary information, changes the color of paper the form is printed on, and gives this form to the teacher/school.

Any information contained in this form and or any mailing related to the diagnosis or treatment of either hemophilia, hepatitis or HIV-related illness is intended for educational purposes only. HACA does not recommend or discourage any specific medical services or treatments. All questions regarding medical care should be decided by patients in consultation with their physicians or medical providers.



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