



Hemophilia and Thrombosis Center of Nevada

A Non-profit Center

MEMBER 2003

FALL NEWSLETTER NO

Summer Carnival Fun



Clowns, racecars, and carnival games, what do they all have in common? For the July annual pediatric clinic, all three congregated at the Palomino Office. This year, because of the rapid expansion of our clinic, an entire day of clinic was held. While this was a little hard on the staff, it was lots of fun for everyone involved.

The planning of this years pediatric clinic was in the hands of two experts, Mary Bobier and Cheryl Lawrence, both active members of HART's special events committee. Everything was a carnival theme. The entry of the office and each examination room was covered with animal print helium balloons. There was a ring toss game, dart game, and prizes were awarded to the winners. These included stuffed animals, hats, and small toys. Everyone got an animal visor to wear to keep the sun out of their eyes as they were ogling the wonderful race cars parked in the parking lot. This year as a treat, the

class cars were available for everyone to get a close up and personal view. The racers included Cindy Clark with a super late model car, Jimmy Parker Jr. an Dustin Ash in Legend cars. What a wonderful motivation for everyone.

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Happenings in Politics

by Ken Cox

Funding for your area

One of the first missions of HART was to become politically active in order to improve funding available from the state for persons with bleeding disorders living in Nevada. Many states for years have added to the federal funds that are available to assist in patient care funding for hemophilia treatment centers. Nevada has never participated.

As the population of Nevada continues to grow, so too do the number of affected persons living in the state. It is important that we make our voices heard to draw attention to our needs and how they differ than other medical disorders. For this purpose, HART has designed a letter that may help if you take the time to send this to your representatives in Carson City.

Enclosed in this newsletter is a sample of this letter with a list of the representatives for your area. Help our community by helping to be heard by the politicians you elect each November.

Motorcycle Mania

**SAVE THE DATE
JANUARY 18**

This years annual Winter Event will be spectacular. Just when you think you've seen and done it all, it just gets better. That's why this year, the winter party will be held at the Harley Davidson Café on Las Vegas Blvd. So, get out your leather jackets and come join us for all the fun.

Dinner will be served and a special event will thrill all. Because space will be limited RSVP is mandatory. Invitations will be forthcoming and also notice will be posted on the web site on the calendar pages.

Don't miss all the fun. Plan to come join us.

Summer Carnival

Cont. from Page 1

A deli lunch was served with plenty of cold drinks complements of Lynn Barker from Wyeth Pharmaceuticals. Channel 3 attended and several of our children were interviewed for the evening news, including the Zuk girls.

Mr. and Mrs. Majic were once again in attendance entertaining everyone while they waited to see the treatment team.

Thanks to the Las Vegas Speedway, Mr. and Mrs. Majic, Mary Bobier, Dave White, Donald Valentine, Lorelee Jelenfy, and Cheryl Lawrence.



Questions and Answers: How to Manage an Injury

My son is very active both at school and at home. He suffers from mild hemophilia and so I am always concerned when he comes home with bangs and bruises. I would like to lock him in a closet until he turns 20 so that he will be safe, but know that he needs to experience a normal childhood. How should I respond to these injuries?

The most important thing in your son's life is that he grow up as normal as possible. That means all of life's little bumps and bangs. Granted that with his underlying bleeding disorder, these bumps and bangs take much more out of you since you always worry that the damage will be serious.

First, I would recommend that your son's teachers and the school nurse are well versed in the care of persons with bleeding disorders so that they can intervene immediately and decide if additional treatment is needed. Often the treatment center team will make a trip to the school to help discuss the child's disorder so that everyone is comfortable with "life's emergencies". If your son uses DDAVP, make sure that a bottle is available at the school. If he uses factor, it is important that the school contact you if there is an injury so that he may be infused promptly.

At the first sign of any injury, even before there is a mark on the skin, always apply pressure and ice to the area. This constricts the blood vessels and decreases the immediate bleeding. This may be all that is necessary. Make sure you have a dialogue with your son so he can notify you of any injuries that occur during the day so that you may monitor them. Rest may be needed for joint bleeding. Remember that head injuries always require immediate treatment. Bleeding into a joint always results in pain and decreased movement, whereas soft tissue injury results in swelling and pain in the area. Bruises without swelling or pain often don't require any treatment at all. In time, your son will learn which injuries require treatment and which do not and so you can both rest easier.

Update on HART

Meeting Minutes from Sept. 16

Patient assistance application forms are available in the office and on the web site. Some funding is available. Thus far one inquiry from out of the area regarding funding has been made. No funds have been dispersed.

A durable medical equipment stock pile is being collected. A form for borrowing of equipment will soon be available. This will allow the borrowing of medical apparatus such as crutches, wheelchairs for those in need on a temporary basis. Anyone with donations, please contact the treatment center office.

A new project from the education group will be to participate in teacher in-service programs within Nevada. This will increase the awareness of bleeding disorders within the community and also improve the care of affected children in Nevada schools.

The planning of the winter event was discussed. Additional information will be forthcoming once plans are confirmed.

A new committee was started whose goal it is to offer scholarships for HTCN patients. Additional funding for this program will be sought through community fund raising projects. Details regarding the scholarships will be discussed at the subcommittee meeting planned in the near future. Anyone wishing to participate in this committee should contact the treatment center office.

The HART board is a full and active board and so new members will only be considered through attrition of current members.

The next meeting will be held in February of 2004.

It's Not Just Home Care Any More

by John Lewis, Corum Hemophilia Services

PART ONE OF TWO PARTS, TO BE CONTINUED IN THE WINTER NEWS-LETTER

Not long ago, frequent visits to the emergency room were the norm for most in the bleeding disorders community. Complications from delayed factor treatment further complicated the daily struggle of managing the disease. For many, quality of life was at the mercy of the next bleed. With the introduction of concentrated clotting factor products in the 1970's came the option of home treatment. Home care provided delivery of clotting factor products directly to a patient's home for self-infusion. Delivery was, and still is today, managed on a regular order and ship cycle by monitoring patients' home inventory levels. This allows patients to travel more and frees them from the constraints of the hospital or emergency room. As a result, much of the stigma of what hemophilia was has been lifted, allowing patients to live more normal lives.

While an innovation during that time, home care today means even more. The depth and breadth of services has only grown since the introduction of basic home delivery services. For many, home care is the light that families see after they learn of their child's diagnosis. Just as Art Stinger, the father of a son with hemophilia and a patient advocate for Coram Hemophilia Services. "When Matt turned 8, we were introduced to home care and it changed our lives dramatically. We had found the final piece of the puzzle of managing the disease."

Learning Home Infusion

Before patients learn to administer infusions on their own, many will go to the local emergency room or doctor's office for treatment as bleeds occur. For many, including Art, this is not a long term proposition. That is why a

A doctor will encourage and train able parents and patients to infuse on their own. While it might seem overwhelming at first, self-infusion becomes second nature for most after the first few attempts. Another option for the apprehensive parent or patient might be visits by a home infusion nurse who can help during a transition period. Parents of newborns or patients with mild conditions may choose this home care option.

Once the family becomes comfortable with the products, supplies and techniques for home infusion, they usually discover that life with a bleeding disorder is less about managing a disease than it is about managing the day to day lifestyle challenges that a chronic disorder can bring.

The Home Care Standard

Today home care is less of an alternative treatment option than it is the standard treatment. For physical, emotional, and financial reasons, approximately 80% of hemophilia patients now treat at home. The National Hemophilia Foundation recommends home infusion as the preferred course of treatment.

In addition to saving time and money, and, in many cases, significantly reducing complications, home care can actually improve the outlook people have about living with a bleeding disorder. This value is recognized in a resolution by the Medical and Scientific Advisory council of NHF. "Home self care is recognized as an important component of comprehensive hemophilia care and increases convenience, self esteem and quality of life for individuals with hemophilia. Home care delivery companies have been instrumental in developing user friendly programs." The emotional benefits build confidence and can greatly reduce stress by eliminating frequent hospital and ER visits. In short, for many patients, home care helps them better enjoy their lives.

Loss of a Loved One—Grieving

By Alice Ashbaugh

Grief is about loss and in one's life time everyone will experience grief and loss whether it be a loved one by death, a divorce, relocation, and many other of life's experiences. People suffering a loss may notice one or more of the following symptoms including emotional changes, feeling out of control, high levels of anxiety, and immune system compromise with frequent colds and viral illnesses. Feelings of hopelessness, guilt and anger may submerge. Sometimes, you may cry for no apparent reason or be unable to focus your thoughts and concentrate. Other symptoms may be loss of appetite or trouble sleeping. You may miss having the support of that loved one when making important decisions in your life.

There is light at the end of the long tunnel called grief. Remember to treat yourself gently and allow your body the time it needs to rest and reenergize. Refrain from taking on any new responsibility right away. It is very important to have a friend who will listen and with whom you feel comfortable enough with to share your deepest thoughts and feelings. Allow the grief and healing process to proceed at full course. Healthy takes time. Know that it's all right to go through these emotional feelings and experience depression. Schedule activities that you enjoy to take your mind off of the loss, if only for a short time. Seek the help of a counselor, clergy, or support group when you need it. Another important aspect of healing is nutrition. Eat balanced meals to try to decrease your intake of junk food. Think healthy and pamper your body.

Keeping a daily journal is very important to put down on paper what you are thinking and feeling. It is also useful to understand yourself more and can be reread later to see how well you have done in the grief process.

Try to get adequate rest and avoid caffeine. Exercise also offers the opportunity to work off frustration and aids in sleep.

To heal from loss may take weeks, months, or even longer. When you love someone you have lost they always have a place in your heart and the memories of that person are kept alive through remembrances of that person and sharing pictures and stories of the time spent together.

Be kind to yourself during this period of time and know that you are not alone. Seek out caring friends to spend time with and talk to them about your loss. Most of all, know that the person is never gone and is as close as your last thought of him.

The grieving process, which seems insurmountable at the start, will result in healing if you follow good advice and allow time for recovery. There is a light at the end of the tunnel and promise of future ahead.

There are several grieving groups in the local area that may be of benefit. They include groups for single individuals, recent divorce, and loss of a loved one from death. In addition, the local hospices offer support services usually at no charge. For additional information or help during this critical time, contact Alice at the treatment center.

Oh My Aching Back

By Jennifer Wells

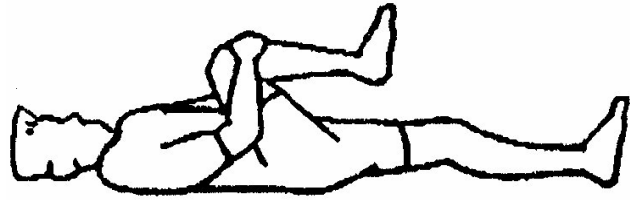
“Oh my aching back” is a complaint heard in doctor’s offices everyday. Did you know approximately 80-85% of all people suffer from back pain at least once in their lifetime? Most incidents of back pain occur between the ages of twenty to fifty but less than three percent will ever require surgery. There are a few things you can do to control your back pain.

First, listen to your body and avoid activities and positions that may increase your back pain such as sitting for too long. If you have to lie down, every couple of hours try to walk ten to twenty minutes and increase your walking times as you can tolerate it. The use of ice can help break up muscle spasms and pain by decreasing swelling and inflammation in an area. It should be used for twenty to thirty minutes every couple of hours. The area should sting, burn, and then become numb.

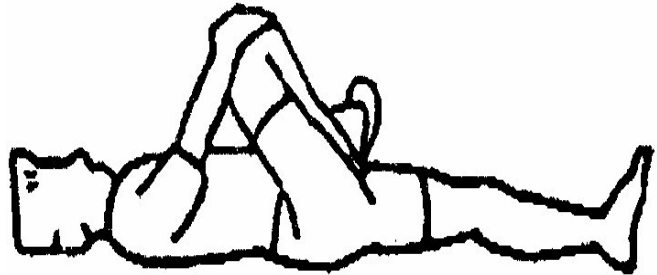
When the pain decreases, attempt some gentle stretches. Stretches should be felt in the front, back, inner thigh of your legs and your buttocks. Stretches should be held for ten to twenty seconds with no bouncing. You should not have any increase in back pain with stretching!

If your back pain continues for more than a few days or you have pain and numbness radiating down your legs, it’s probably a good idea to see your doctor. If you have any loss of bowel or bladder control problems see your doctor immediately.

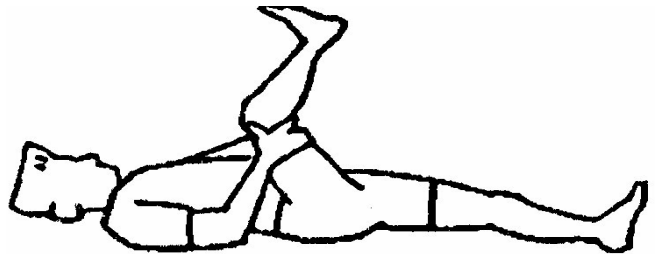
With regular exercise, and careful living managing back pain can be an easy part of your life.



Knee to chest. Grasp knee with both hands and pull towards chest 3-4 times. Hold 15-20 seconds.



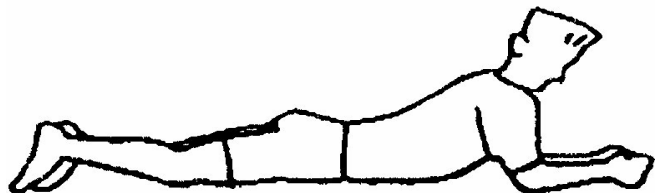
Piriformis Stretch. Outside hand on knee, inside hand on ankle. Pull towards opposite shoulder 3-4 x. Hold 15 sec.



Hamstring Stretch. Grasp hands behind knee. Keep knee straight. Pull towards chest 3-4 x. Hold 15 sec.



Lumbar Rotation. Bend knees. Rotate side to side 20 times



Prone extension/Prone on Elbows. Lie on elbows 1-5 min.

Thanks for Your Donations

The staff of the HTCN is grateful to the following corporations and individuals who have provided support for our special events:

Chef John Guinivere	Las Vegas Mini Gran Prix	Aventis Behring Pharmaceuticals
Gameworks	Las Vegas Motor Speedway	Cheeryl Lawrence
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In N Out Burger	B. Dalton Booksellers	
Rio Hotel and Casino	Gena and Bob Bunim	
	Factor Support Network	
	Gold Coast Hotel and Casino	

Calendar of Events

DECEMBER 6-9	American Society of Hematology Annual Meeting San Diego, CA For information www.hematology.org
JANUARY 8	Comprehensive Hemophilia Clinic
JANUARY 18	Winter event Luncheon Harley Davison Cafe
FEBRUARY 12	Comprehensive Hemophilia Clinic
MARCH 11	Comprehensive Hemophilia Clinic

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The Hemophilia and Thrombosis Center of
Nevada
University Medical Center
Lied Outpatient Building
1524 Shadow Lane
Las Vegas, Nevada



Mailing address:
2020 W. Palomino Lane
Suite 110

Phone: 702-385-2702
Fax: 702-383-6264

www.htcnevada.org



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