

# My Story

by Cheryl Lawrence



SPRING NEWSLETTER MAY 2003

# Hemophilia and Thrombosis Center of Nevada

A Non-profit Center

It was the name *von Willebrand's disease* that scared me more than anything at first. It sounded like it was so serious. In reality though, for me, it means nothing. It's just a new word which has been added to my vocabulary. Looking back, the first time that I ever had a problem was when I was 7 years old. I was playing "hide and seek" in the house with my two older brothers and I fell and hit my head on the landing. They tried everything but could not get my forehead to stop bleeding. My mom and sister rushed me to the emergency room where I was awarded one blue stitch for my war wound. At that time, they had no idea that I had a bleeding disorder to explain why my cut just kept bleeding and bleeding.

I was not diagnosed until late in my teen age years. After freshly being diagnosed with von Willebrand's disease all of these new technical words entered my vocabulary, such as platelets, coagulation, clotting, and so many more. To my relief, when I left the doctor's office I was well armed with ammunition to better equip myself and my family to understand what von Willebrand's disease is and how to cope with the diagnosis on a daily basis. I had a few questions such as, will I pass this on to my children, what is a bleeding disorder, and how will it be treated.

My life today has not changed much since before my diagnosis except that now if I cut my finger I realize that I have to use Stimate and/or Amicar in order to control the bleeding. Also, I now know that it is important to share your diagnosis with your health care providers, especially before dental procedures

Or surgery.

For me, this was resolved by using medications of Amicar and Stimate. I keep this at my house and I also keep some at work just in case I fall off the ladder again.

All and all I still do the things that I like to do, ride bikes, play sports, and be a productive adult.

I Am now more aware if I fall or bump my elbow what it is that I need to do. I am also reassured that if I have any questions that I can't find the answer to, Liz, Dr. Shopnick, or any of the staff at the treatment center will help me find the answer or tell me where to look in order to find it.

**Cheryl is an active member of HART's working group on special events and pediatric clinics. She plans to enter culinary school at the Sorbonne this summer.**

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# Are You Aware? By Mary Bobier

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## *Are You Aware?*

On Friday, May 16, 2003, the Assembly panel recommended that Nevadans vote next year on two ballot plans for restructuring the state's medical malpractice insurance laws. The question which receives the most votes will become law. "Keep our Doctors in Nevada" and "Keep Quality medical Care in Nevada", these two questions on the ballot next year will give voters two widely different approaches for helping doctors dealing with the soaring cost of malpractice insurance policies.

## *What Do They Mean?*

The first, from the Assembly panel, asks voters to allow the current law passed in last year's special assembly, time to work.

The second, sought by an initiative petition backed by the state's doctors, seeks to bring further restrictions to the amount of money that juries can award for pain and suffering. The one main exception in the Assembly panel's action is that the new question will not simply be an up or down on AB1.

The amendment approved so far offers a new cap on jury awards of \$500,000 in non economic cases for non-wage earning seniors, housewives, and children only. As of today, the bill seats in the senate judiciary. No action has been taken as of April 2, 2003.

We need to go to the <http://www.leg.state.nv.us> and look up your State Senator and State

Assembly person. Ask them what they are going to do about, *IP1 makes various changes relating to certain actions against providers of health care.* The bill can die before June 2, 2003.

Source:

The Sun, May 16, 2003

The Review Journal, May 16, 2003

The Nevada State Legislative Home Page

The Nevada State Legislature Session began on February 3 and ends on June 2.

Log onto their web site to review a list of upcoming meetings. It is possible to log on to many of these meetings to view the proceedings as they occur. This allows active participation in your government. Current sessions information is also available and updated regularly.

If there is a bill of interest, sign up for the online bill tracker that will keep you updated regularly regarding its status. Also of interest is the Nevada State Home Page which can be reached at [www.nv.gov](http://www.nv.gov)

**Mary Bobier has been active in local politics for many years with a strong history of working in government. She is an active member of HART.**

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## Welcome Brianna Browne

This summer when you call the treatment center, you are likely to hear a new but yet familiar voice. Brianna has been part of the HTCN family for many years now, diagnosed with von Willebrand's disease during adolescence. She just graduated from Coronado High School and will be spending the summer working as an intern at the treatment center office.

Brianna plans on attending CCSN in the fall with plans to transfer to the University of Nevada Las Vegas. She has been awarded the Millennium Scholarship which is what keeps her in Nevada. This summer she will be working her usual job as a

Receptionist in a hair salon, and also working mornings helping out in the treatment center office. Since summer is such a busy time for the treatment center with the pediatric clinics and also the summer event, help with the planning of these projects is greatly appreciated and helps to free up the treatment center staff to concentrate on helping with medical issues.

Brianna will be available to help at the pediatric clinics so you can see her there with the race car drivers and special events. She'll also be at the office Monday through Friday from 8 am until noon.

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## Come Have fun at the HTCN Circus and Carnival

Yep, it's that time again.

Time for the Annual Summer Pediatric Clinic

Tuesday, July 8

Come join Dr. Shopnick and the HTCN staff at our very own circus. We will have the Race Cars and drivers from the Las Vegas Motor Speedway. But this year, in addition to the race car drivers, Mr. Magic will be there performing exciting tricks. In addition, this year, there will be a circus theme complete with circus games and prizes for all.

Lunch will be available for all who attend courtesy of

Lynn Barker of Wyeth Pharmaceuticals.

Everyone is encouraged to come dressed as your favorite circus clown and be ready for lots of fun.

A day at the doctor's office, count me in.

If you haven't yet scheduled your appointment for pediatric clinic, please call Liz at the treatment center office. We have extended the clinic hours on that day to accommodate everyone needing an appointment.

Don't miss the next newsletter for a full description and pictures of the day.



## Report from HART



Hemophilia Awareness Research and Treatment, HART's committee on Patient Assistance has been hard at work. One of the early goals of HART was to help those in the community in need. Initially it was thought that these needs would be to cover emergency medical care not covered by insurance, cost of medications, and later transportation and babysitting for emergencies. Because insurance coverage keeps paying for less and less, copays for office visits, durable medical equipment, and medication costs have gone up astronomically. Sometimes, this makes it impossible for those in need to receive much needed care. This is the role of the Patient Assistance Program of HART.

The goal of the patient assistance program sponsored by HART is to provide for uncovered medical and social expenses of affected persons and their dependants. Priority will be given to those individuals with financial need with extenuating circumstances who would otherwise not be able to receive needed services.

The program will formally be unveiled at the end of the summer. Application forms for those in need will be available on line and also through the treatment center office. An application form is mandatory for any assistance to be considered. Initially covered expenses will include temporary child care coverage for a maximum of five days for major medical issues for dependants of affected persons. Also included will be co pays for medication including Stimate, Amicar and factor concentrate. Transportation may be covered at a later time to include transportation to and from doctor appointments and to southern Nevada for those in other areas of the catchment referral base.

Initially the program will be available

Only to active patients (seen within one year) of the HTCEN including the entire catchment area. This may be expanded in the future depending upon funding.

### *DURABLE MEDICAL EQUIPMENT*

Many individuals have needs other than financial. This includes the need for crutches, wheel chairs, commodes, and walkers. Sometimes the need is short term following an accident or surgery. Additional items of need include syringes, needles, and bandages. To accommodate these needs of the HTCEN family, a rotating supply will be available on loan to those needing this equipment. In order to ensure that this program is successful, donations of durable medical equipment. In order to ensure that this program is successful, donations of durable medical equipment is needed.

If you have any medical equipment that you are no longer using please contact the HTCEN office so that we may help you to donate this to the HART durable Medical Equipment Exchange. A list of items available for loan will be made available with each newsletter.

If you have need of an item of medical equipment, there will be a short application form available both on line and also through the HTCEN office. Financial need is NOT necessary to take advantage of this loan program. Any individual in need of a piece of equipment and an active patient will be able to use the equipment as long as needed.

Look for more wonderful projects from HART. Anyone interested in becoming a member of HART, please contact the office.

# When It Counts

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In March, in the middle of a sound sleep, about 11:30 at night, I received a panic call from the wife of one of our patients with von Willebrand's disease. Her husband, the very active father of two young boys, was taking some time out for R and R, and had played a wicked and very competitive game of basketball with some friends that afternoon. He collided with another grown man and both had come off the court a little sore. Jeff, had injured his left shin. Thinking nothing of it, just a little sore, he showered, got dressed, and went to work.

Several hours into his shift, he continued to note progressive swelling in his calf with pain. He was finally convinced by his coworkers to go to a quick care to make sure he had not broken anything.

At the quick care, he appropriately told the triage nurse and the doctor on duty about his bleeding disorder. Both reassured him that nothing further needed to be done and after assuring him that the x-ray didn't demonstrate any fracture, they sent him home to follow up with his doctor on Monday.

While still in the parking lot, now several hours after the initial injury, he spoke to his wife and described the incident. She called me immediately, having educated herself on the treatment of vW disease. She said it didn't sound right that no one had recommended any medication and what should she do. Jeff was still in his car in the parking lot of the quick care when I reached him on his cell phone. He figured it would just improve in time and maybe he'd go home and take some Amicar. His leg was quite swollen and tense around the injury and while having downplayed it, I knew he was in considerable pain. He told me that his leg felt a little numb because of the pressure. It didn't sound good, even over

the phone in the middle of the night. So I sent him to the closest emergency room and asked him to bring his HTC card with him and to tell them that he had a bleeding disorder and insist that they call me when he arrived.

Two hours later, after the surgery to reduce the compartment syndrome that had threatened his leg, he was stable, receiving factor concentrate, with the bleeding controlled. A compartment syndrome occurs when swelling continues without relieving the pressure, the nerves and muscles will die as the pressure decreases the blood flow to the area. The consequence is that left untreated, Jeff would have lost his leg. Had his wife not acted immediately and they waited until the morning, it would have been too late.

Jeff has finished his physical therapy and is almost perfect, at least according to his wife, but this was a hard lesson to learn.

First, treatment after an injury should be immediate before bleeding and swelling occurs. Ice the area, elevate it, apply pressure, and if you have Stimate or factor at home, use it.

Second, never trust that a doctor or nurse not familiar with bleeding disorders will understand the gravity of the situation. Never trust them to call your doctor. Get on the phone and call us as soon as you can. You'll never get yelled at for waking one of us out of a deep sleep for a true emergency.

Prompt treatment and good judgment will avoid long term complications. Our patients usually know more about their disorder than most medical personnel including physician. Lastly, always carry your HTC card with you for emergency.



**Congratulations Clayton Shrager**  
**On graduation from the**  
**UNLV Preschool Program**  
**May 13**

## **Summer Event** **Reminder**

Space is filling up fast for the upcoming summer event at Texas Station scheduled for June 26. Following dinner, the first run movie the Hulk, made famous in early comic books and later by Bill Bixby's starring role in the long running television show, will be shown.

At intermission, join the HTCN family for fresh made cotton candy and door prizes. It is sure to be a wonderful evening for everyone.

RSVP is mandatory because the theater only holds a certain number of persons, and will be on a first come basis. Call or e mail Liz to hold your place

## **International Society of Thrombosis** **and Hemostasis Meeting**

The XIX Congress of the International Society on thrombosis and Haemostasis will convene July 12 through 18 in Birmingham, UK. This year's meeting is organized by the Congress President Dr. Ian Peake from the Royal Hallamshire Hospital. This premier meeting is held every two years and represents one of the most important meetings to discuss new developments in bleeding and clotting disorders.

The meeting is preceded by the SSC Scientific Subcommittee Sessions that comprise groups of scientists to discuss particular topics in thrombosis and hemostasis such as particular factor abnormalities, lupus anticoagulant, platelet disorders, von Willebrand's factor and vascular biology.

A poster session and presentations of ongoing research projects occurring throughout the world allows a glimpse into how other areas of the world treat different clotting and bleeding disorders and future treatment options.

this year's plenary lectures will include Dr. Ruggeri discussing von Willebrand factor and platelet interactions, Dr. Mannucci discussing treatment options for hemophilia, and Dr. Rosendaal discussing genetic and environmental risk factor for thrombosis.

The meeting is open to anyone. Future meetings are planned for Sydney, Australia, and Boston, MA. For more information log onto [www.isth.org](http://www.isth.org)

## THANKS

### Congratulations

**Eddie Garcia** came into the world in early March weighing 4 pounds 16 inches long.

Congratulations to **Anabel Ponce** on a beautiful baby boy.

**Brianna Browne** on graduation from Coronado High School  
June 10, 2003

**Barb Lambert's** son on graduating from Arroyo Grande High School in California. Barb is doing great in northern California teaching the gastroenterologist she works for all about bleeding disorders.

Congratulations on a baby girl to **Robin Smerdel**

**Clayton Shrager** on graduation from UNLV Preschool program May 13. At age 5, he looked terrific in his maroon cap and gown. In August, he joins his brother Zach at Estes McDoniel school where Clay's grandmother teaches third grade.

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

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Cheryl Lawrence

Ken Cox

Robert Gonzalez with Amgen

Travis Potter and family with Empire  
of Chivalry and Steel

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