



Hemophilia and Thrombosis Center of Nevada

BIG SPLASH AT WET AND WILD



The Black Hole, The Royal Flush, The Lazy River and the Wave Pool were just some of the fun rides that many family and friends of the Hemophilia and Thrombosis Center of Nevada got to play on at the annual summer party at Wet and Wild Water Park. The party, held on Sunday, August 12, was attended by 148 people of all ages including the youngest at one year of age and the oldest at “much older than that”. The hot dry day in August was perfect to spend time in the cool water or sitting around the suntan lagoon.



The private area at the Pepsi Pavilion provided shade along with lots of comfortable seating with a terrific view of the Royal Flush. Lunch was served at noon and drinks were available throughout the park to quench the thirst.

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While some brave souls made it through the Darastuka and the Black Hole, the rest of us lazed around in the Lazy River relaxing with a great view of all the action while keeping cool.

Humate P Study **for Persons with von Willebrand's Disease** **undergoing surgical procedures**

The Hemophilia and Thrombosis Center of Nevada has been asked to participate in a study evaluating the safety and efficacy of Humate-P® in patients undergoing surgical procedures. This study is sponsored by the manufacturer of this concentrate, Aventis Pharmaceuticals and will be conducted at many hemophilia treatment centers throughout the United States.

The primary purpose of this study is to identify the ability of this factor concentrate to normalize the clotting system and prevent bleeding in children and adults who require surgery and have been diagnosed with von Willebrand's disease.

It is expected that approximately 60 patients of all age groups will be enrolled throughout the United States. Because the HTCEN has a large number of patients with von Willebrand's disease, it is expected that several of our patients will be able to participate in this study. This offers several benefits. The first is that the medication, the most costly part of medical care, will be given to the patient free of charge. In addition, very close monitoring with laboratory testing to evaluate the optimal effect of the use of Humate-P® for persons with bleeding disorders will be accomplished.

Myra Davis-Alston, the nurse coordinator at the HTCEN, will be in charge of enrolling and monitoring patients in this study. A study meeting will be held for all participating centers at the Four Seasons Hotel in Las Vegas in late September. Myra will

represent the HTCEN at this meeting. At the Friday night opening session, it is expected that more detailed information will be provided.

Patients who enroll in this study will have baseline laboratory testing done to evaluate the response of the clotting elements after infusion of factor concentrate. This information will be used to dose the factor concentrate for the planned surgery. Patients will receive factor concentrate before surgery and as needed following surgery. Laboratory assessments to evaluate the adequate dosage of medication will be obtained in addition to clinical parameters of bleeding that will be evaluated on a daily basis. All patients will be followed for two weeks after surgery and have one additional blood test four weeks after surgery. The study will end four weeks after the planned surgery.

Since Humate-P® is used for many patients with von Willebrand's disease to achieve adequate blood clotting during surgery, this study does not deviate from usual care. The only difference is the close monitoring with frequent laboratory testing to assess the efficacy of the use of this factor concentrate.

Any patient with von Willebrand's Disease who needs to have surgery of any type that requires the use of factor infusion is eligible to participate. The study will begin this winter. If you are interested in additional information or in participating in this study, please log onto the web site at www.htcnevada.org or call Myra at the treatment center.

What is a PICC

By Myra Davis-Alston, R.N.

A PICC is a type of intravenous device (I.V.) that eliminates the need for repeated “sticks” for lab tests or I.V. therapy. This type of catheter can remain in place for months or longer. Another name for this device is *Peripherally Inserted Central Catheter*.

How are PICC lines used?

These lines may be used to draw blood specimens, or administer medications by vein. To prevent clotting when not in use, PICC lines are connected to a small cap and flushed with normal saline and or a heparin-saline solution as directed by the physician.

Care of the PICC Line

Hands must be washed thoroughly with an antibacterial soap and water before handling the line. The dressing should be changed 24 hours after insertion, then weekly, or whenever the dressing becomes wet or dirty.

Most catheters require flushing at least once a day, and after medication. The PICC line must be flushed with normal saline followed by heparin solution. If you have more than one lumen remember that each lumen must be flushed individually. If you have trouble flushing the catheter, first check to make sure that all clamps are open. If it is still difficult to flush, stop, and contact your nurse or doctor. No smaller than a 10 cc syringe should be used for flushing to minimize excess pressure on the catheter.

Cap changes at least once a week or whenever blood is drawn are recommended to prevent infection.

Dressing changes and the exit site should be cleaned, once a week, or whenever the dressing becomes wet, dirty or the edges rare loose. Most patients have a nurse, or caregiver to help change the dressing. When the old dressing

“Hand washing is the most important step you can take when caring for a PICC line.”

Is removed, the exit site should be inspected for redness, swelling, drainage, or open areas around the catheter.

The dressing should be covered with a plastic wrap before getting into the shower to prevent moisture from getting into the dressing.

Potential Problems

Complications with PICC lines occur infrequently. However, by being aware of specific symptoms and what to do about them, you can minimize serious complications. Let's review some of the problems that you should be aware of, and what should be done.

Infection

General symptoms of infection include fever, chills, swelling at the exit site, foul odor, pain, or warmth to touch. Your doctor or nurse should be notified promptly if you experience these symptoms.

“Being aware of potential problems that can occur with a PICC line will minimize serous complications.”

Break or accidental cut of catheter

The catheter should be clamped between the break (where the fluid is leaking) and your doctor or nurse must be notified immediately.

Bleeding at the insertion site

A small amount of bleeding is normal in the first few hours after the line is put in as noted by a reddish-brown liquid at the exit site. If bleeding occurs after the first 24 hours of insertion, notify your doctor or nurse.

Activities

Strenuous exercise such as contact sports, baseball, basketball, soccer and swimming should be avoided with the arm that has the PICC line. There is a chance that the catheter could come out of place with these activities.

Are you Ready to Apply for Disability?

By Alice Ashbaugh

Many people are unaware that they may be able to receive assistance for medical care and living expenses during periods of time when they are not able to work to earn a paycheck. The county, state, and federal government have several assistance programs designed to help. However, knowing how to begin the process can be confusing. Remember that's what social workers are best at, so if you have any questions about how the system works, or what services you may be eligible to receive, don't forget to ask at your next scheduled annual HTCN appointment.

When a person is diagnosed with a debilitating illness which will result in inability to work for one year, they are eligible to file for Social Security Disability (SSD), Supplemental Income (SSI), or Temporary Assistance to Needy Families (TANF).

In order to obtain an application for any of these programs, it is important to contact the Social Security Hot Line at **1-800-772-1213**. The application materials will be sent to your residence to be completed and returned to the local Social Security Office. For those of you who live in the Las Vegas area, an application may also be obtained at the office on West Sahara.

An application for SSI (Nevada Medicaid) may be obtained at the Nevada State Welfare Office at 620 Belrose Lane, telephone **486-5000**.

After the application is received in the SSA office, expect to be contacted to set up a teleclaim appointment. This involves a telephone call at your home in order to provide additional information. Once the application has been

completed and filed, it takes approximately four to six months for a decision to be rendered. If a young person is filing for SSD and has not worked the requested quarter, there is a possibility that they can be approved for SSD even with a shorter work history. Therefore, if in doubt, filling out an application is definitely the correct way to go.

Don't be dismayed if you receive a letter declining your application. This is not uncommon. In this case, an appeal process will be offered to the applicant. We encourage all of our patients to make at least one appeal.

Once approved for SSD, it takes two years to be medically covered under Medicare. In the two years prior to receiving Medicare, I encourage my clients to apply for a Clark County Medical Card which covers medications filled at University Medical Center and costs of hospital admission.

If a person is approved for Nevada Medicaid, they are covered for doctor visits, hospital admission, medications, and some dental and eye examinations.

The dollar amount you receive for SSD or SSI varies. If you have any question you can call the toll free number at 1-800-772-1213 or the Nevada State Welfare office at 486-5000.

Remember, if you have questions about this process, call either the toll free number or the local office. If you decide to go to the local office, avoid the crowds by arriving first thing in the morning and be patient as you're likely not to be the only one in line.

Wet and Wild, cont

Several patients and their families arrived before the park opened and were among the last to leave at the end of the day. We even had one family travel from Reno to attend the party to meet everyone from down south.

The Hemophilia and Thrombosis Center of Nevada wishes to thank those that helped to make the party such a success including the planning of the event by Barbara Lambert, Chuck

Bobberschmidt from Bayer Pharmaceuticals for providing the food for the event, and Robert Belaski from Nabi Pharmaceuticals for attending and bringing fanny packs for everyone. It is only because of the generous support of the many companies we are able to enjoy the annual parties.

For more pictures of the fun, log onto our web site at www.htcnevada.org



In The News: Youth Spotlight

Excerpts from The Las Vegas Review Journal, June 28

Misty Fortney Brunnmeier

Most 17 year olds don't enter college as a sophomore. But Misty Fortney Brunnmeier of Las Vegas, despite her medical problems, has always been ahead of the class. Brunnmeier skipped fourth and tenth grades. This month, she graduated from Community College High School, earning 44 credits toward a degree at the University of Nevada, Las Vegas and will need less than three years to graduate there.

With her 3.79 grade point average, Brunnmeier qualified for a \$10,000 Millennium Scholarship. She also received a \$1000 scholarship

From the Southern Nevada School Counseling Association for overcoming personal obstacles.

When she was 3, Brunnmeier had open heart surgery and at 12 was diagnosed with von Willebrand's disease.

Currently, she is a spokeswoman for Aventis Behring, a pharmaceutical company. She will travel across the country to speak to students in the hemophiliac community.

"I want to give them a positive outlook, that they shouldn't let anything hinder them," she says. "The quality of life meant more to me than

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Questions and Answers

I have von Willebrand's Disease and just became pregnant. My obstetrician is worried about the delivery and the baby's health. Can you make recommendations regarding the pregnancy, and the delivery?

Most patients with von Willebrand's disease have Type I and respond to DDAVP. We have had lots of healthy babies born to healthy mom's at the treatment center. So, don't worry about the pregnancy or deciding to become pregnant. Having a child is a wonderful experience. The only difference you will face is making sure that both your obstetrician and hematologist have a good working relationship.

During pregnancy, clotting elements in the blood increase. So, even persons with low levels of von Willebrand's factor or Factor VIII will have an increase into a safer range. Therefore, it is important to note that the diagnosis of von Willebrand's

disease is difficult to make until after delivery. After the baby's birth, the clotting levels drop quickly. This drop may sometimes be accompanied by increased vaginal blood loss. Therefore, it is important that during the actual delivery, and for several days following, medication is available just in case bleeding occurs. Some anesthesiologists feel more comfortable using DDAVP before administering spinal anesthesia. Although not always necessary, this is a prudent approach.

The most important thing to remember is to notify the treatment center when you are ready to deliver and to plan your delivery at a hospital where clotting medication is available in case of any problems.

When your child is older, he or she should be tested for von Willebrand's disease as there is a 50% chance of being affected. If a circumcision is planned, this should be postponed until after the baby can be tested.

Thanks to: Jennifer Wells

We're pleased that the HTCN Physical Therapist, Mona Vakil has delivered a beautiful baby boy. However, while we allow her time to recover from delivery and spend time with her new son, we find ourselves without a treatment center Physical Therapist. So, we are thrilled that Jennifer Wells has agreed to fill this void.

Many of you remember Jenny from last spring

When she was the acting exercise therapist at the treatment center. However, she left to pursue other interests in Arizona. She only recently returned to Las Vegas. Her area of expertise is in education and design of exercise programs. Most recently she has worked as the exercise director for Del Webb's Sun City.

Thank you, Jenny, and Welcome Back.

CONGRATULATIONS TO:



**Congratulations
To Mona and Jouen Vakil
On the birth of their first son,
Ishaan Vakil
Born at University Medical
Center
September 9
Weighing 5 lbs, 1 oz. And
17 inches long.
We wish them much health
and happiness**

Misty Brunmeier, cont.

Having a bloody nose.”

Brunmeier has been in the entertainment industry since she was a child. She worked as a child model, and has been an extra in television and film. She would love to become a well-known actress, but plans to get her degree in business management and then pursue a law degree.

“I’ve finally decided that I have to live with it, not live by it.” she says of the disease. “I can do whatever I want.”

**The Hemophilia
and Thrombosis Center of
Nevada expresses it’s deep-
est sympathy for the tragic
loss of life experienced in
the Sept. 11 events involving
the World Trade Towers
and The Pentagon.**

Health Fair

Sun City Summerlin

The Sun City Health Fair, held this fall had an excellent turn out. There were over 1000 people of all ages that attended. The Hemophilia and Thrombosis Center of Nevada was represented with a display table. Barb Lambert, Myra Alston-Davis, and Patricia Marshall were present in addition to Dr. Rinah Shopnick.

Information regarding the diagnosis and management of bleeding disorders was made available. In addition, testing of patient’s INR for those that take a medication called Warfarin, was available, courtesy of the treatment center.

Warfarin (Coumadin) is a medication that thins the blood. It is one of the most commonly used medications used for many disorders including the treatment of blood clots, stroke, irregular heart rate (atrial fibrillation), heart attacks and occasional vascular disorders. The use of this medication makes the person more like one that has hemophilia. Therefore, close monitoring of the blood level, measured as an INR, is needed on a regular basis, usually weekly. The HTCN uses a machine similar to those used for monitoring patients with diabetes who prick their fingers to check their blood sugar level. This makes the monitoring of warfarin much easier for most patients. This was demonstrated by the long lines present at the health fair of patients on warfarin who wanted to have their blood level checked by the HTCN staff.

By supporting the community in health fairs, the HTCN helps to bring attention to disorders of bleeding and clotting that may not be well known to the general public. We hope that community education will improve the diagnosis and management of persons with blood disorders in hopes of improving their lifestyle.

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COMPREHENSIVE CARE FOR TREATMENT OF BLEEDING AND CLOT-

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Laboratory Technician: Angel Moore
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Physical Therapy: Jennifer Wells
Orthopedics: Dr. Robert Tait
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