



# Hemophilia and Thrombosis Center of Nevada

## Pediatric Clinics



The pediatric clinics are always the most fun for all of the HTCN Staff. While it is difficult enough for adults to go to the doctor, imagine how children feel. So, we at the HTCN have tried very hard to make the annual visit for children as pleasant and fun as can be. The result is a wonderful carnival for everyone.

This year, because our numbers are growing so rapidly, we decided it was time to have two pediatric clinics. At the first clinic, we were treated to up close NASCAR race cars and their race car drivers. Everyone had a chance to take their picture in the drivers seat of a real live race car. As if spending an afternoon with a race car driver wasn't enough, everyone attending received race hats and shirts and admission tickets for the Saturday night races.

While racers were outside, inside was Mr. and Mrs. Majik entertaining everyone while they ate lunch waiting for their appointment. Special thanks to

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Kathy Mayberry for providing lunch.

NASCAR racers and their staff are special people that helped make this a wonderful day for all.

We will paint the town red at the August clinic where the fire department is expected to join us in their truck, and again Mr. and Mrs. Majik have agreed to entertain.



# Report from Training in Indianapolis

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By Barb Lambert

On March 21 and 22, I attended the Advanced Hemophilia Program sponsored by Baxter Pharmaceuticals and the Indiana Hemophilia Treatment Center in Indianapolis. Baxter makes it possible for continued training of hemophilia personnel through sponsoring this grant at Dr. Shapiro's well recognized treatment center. They hold both a beginners and advanced session, and I was lucky to be chosen to attend the advanced seminar. I had a great time and learned a lot that will help the treatment center care for our patients better.

We were picked up at the airport, however, the driver first dropped us off at the wrong hotel. We were thrilled when we finally arrived at the correct hotel, a very nice Embassy Suites.

Our first day of meetings was very busy. We first heard a talk on pain management given by Dr. Anne Greist. Dr. Amy Shapiro then discussed platelet function disorders. I have much new found respect for platelets. I had no idea this little thing could do so many important jobs in the body. Dr. Shapiro reviewed the most used test for identifying platelet disorders, the platelet aggregation study. I was happy to learn this, as this new test is now available locally in Las Vegas. Dr. Shapiro also discussed many medications that can inhibit the platelet function and result in bleeding abnormalities.

The following day, we covered prophylaxis. This talk was given by the nurse practitioner Jennifer Maahs. She was an excellent speaker with much experience in this area. Questions include at what age should prophylaxis be started in order to prevent joint disease, and what is the best dose?

After this, we discussed the management of inhibitors. We discussed several case

histories of patients seen at the various treatment centers. One important issue in the treatment of patients with inhibitors is the cost of immune tolerance therapy and access to this treatment with insurance companies. They covered the treatment of both Hemophilia A and B with inhibitors. This was so useful for us as we have a large population of patients who have inhibitors and it is useful to compare notes as to how different centers handle the same problem.

The next talk was by Allison Stanley. She discussed laboratory testing for hepatitis C and its treatment with Interferon and Ribavirin. To end our second day of talks we heard from the center's research nurse, Sue Hatcher. She reviewed the many research projects that their treatment center is involved in. More importantly, she discussed the need for participation in research trials in order to advance the treatment of our patients. Accurate documentation of patients who are enrolled in treatment protocols is so very important in order to ensure that the data is of high quality. There are also ethical issues that may arise in relation to research trials, and we had an interesting interactive discussion about this issue. Because our treatment center is involved in many research projects, this was a useful talk for me and will help to improve the way in which we manage research trials at the treatment center.

We were treated to a lovely dinner and treated well. Indianapolis has a wonderful well recognized treatment center and a terrific team. It was great to be able to spend some time with them and compare notes.

Thank you to everyone who supports this program.

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## **NHF Congratulates OB/GYN Group on von Willebrands Screening Recom- mendations**

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The National Hemophilia Foundation in their news release dated February 8, congratulated the American College of Obstetricians and Gynecologists (ACOG) for releasing “Von Willebrand’s Disease in Gynecologic Practice”. This committee opinion adopted by the prestigious group of obstetricians and gynecologists recommends screening for adolescents and adult women with heavy bleeding, or menorrhagia.

While this is the first time that ACOG has issued a committee opinion about vWD, representatives in our area, have advocated this for some time and lent support at ACOG meetings. Dr. Warren Volker, assistant professor of gynecology and director of research for the division of gynecology, has been a staunch supporter of testing for bleeding disorders in women presenting with menorrhagia. He lectures on this topic to the community and the residents in the training program at University Medical Center.

According to Dr. Elbert, the chair of NHF’s women with bleeding disorders task force, this publication is another step in helping the millions of women with vWD receive proper diagnosis and treatment.

The December 2001 ACOG committee opinion recommends vWD testing for adolescents presenting with severe menorrhagia as well as adult women with significant menorrhagia without another cause. It also suggests that hysterectomies for excessive menstrual bleeding should not be performed without screening appropriately for bleeding disorders.

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## **Good Luck to Barb Lambert Welcome to Elizabeth White**

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Many of you may have recognized a new voice on the other end of the phone when you call the treatment center. No, that’s not your imagination playing tricks on you, there has been a change recently at the treatment center office. Barb’s husband received a terrific job offer back in their home town of Pismo Beach. Talk about a hard decision. While it was close, Barb chose her biologic family over the HTCN family and moved to the beach side town in early July. Barb misses us terribly and keeps in touch via e mail. Her address remains the same blhtcn@aol.com. She started a new job there with a new doctor who specializes in stomach disorders and lives just minutes from the beach with her two children, her husband, near her entire family and friends that she’s known since childhood.

Welcome, to Elizabeth, who pinch hit with very short notice, and has been a welcome addition to the HTCN family. She was thrown in at the busiest time for the HTCN, before the pediatric clinics and the summer event. Already, she has a wonderful reputation for going above and beyond her job duties to see that everyone is healthy and happy. Elizabeth, or Liz as she prefers to be called, has an extensive medical background working in pediatric offices and cardiovascular offices in Arizona and Nevada. She is a newlywed and lives with her son, Donald, husband, two dogs, and two cats. In her spare time, she is an avid race car fan, volunteers with the boy scouts, and is involved in medieval groups. Please help make her welcome. Her e mail address is ewhtcn@aol.com.

# **HART—Hemophilia Awareness Research and Treatment**

The HTCN Advisory Board has been incredibly busy trying hard to improve the health and well being of persons with bleeding disorders in Nevada. At the same time, they are having a wonderful time and developing new friendships. The first meeting held on April 16 was a get acquainted dinner meeting. Board members include: Debra Dorn, Mary Bobier, Cheryl Lawrence, Michelle Shahar, Kim and Jeff Schrager, Ted and Danielle Marcoccia, Ken Cox, and Angel Moore. This group is very special because it represents many different bleeding disorders including severe and mild hemophilia in adults and children, Type I and III von Willebrand's disease in adults and children, and Hereditary Hemorrhagic Telangiectasia. Because of the diversity of this group, they are able to relate to and identify needs throughout the bleeding disorders community.

At the first meeting, several areas of interest and concern were addressed by the group and immediate areas of concern were identified. Subcommittees were formed to begin developing ideas to pursue in these areas.

1. Child Care subcommittee. Many children with disabilities are unable to find capable child care. This limits their parents opportunity to pursue work and social lives. Designating a group of child care facilities with expertise in caring for children with bleeding disorders, and ultimately funding this will improve the socialization of affected children, and also improve the lifestyles of their families.

2. The Patient Assistance Program will attempt to assist with expenses often present in persons with bleeding disorders not covered by regular insurance.

3. The Education committee was designed to improve the awareness of bleeding disorders in the general community.

Lastly two long term goals were identified

The first included improved lobbying on a state level to assist in payment of healthcare costs not covered by conventional insurance. A 20% copay for factor concentrate is able to bankrupt a median income family. If state funds were available for assistance with medical expenses for pharmaceutical agents not covered by insurance, this would make a major impact in the lives of affected families.

Lastly, because the treatment center has long ago burst out of its seams, evaluating grant funding to build a larger facility, centrally located, is an important long term goal.

The second dinner meeting held on July 30 was exciting. At this meeting everyone brought their ideas to the table and came up with plans that will help us to come closer to realizing our long term goals. At this meeting, Danielle Marcoccia came up with our wonderful new name, HART—Hemophilia Awareness Research and Treatment. The wonderful new logo of a heart with a blood drop inside will soon be visible on brochures, stationary, and the web.

Significant headway to identify several child care facilities in southern Nevada who are interested in developing expertise in caring for children with bleeding disorders has been initiated. Once additional training is complete, we will pursue funding so that it may be afforded by every family. Clear cut guidelines for the patient assistance program are in the works. This new program should be up and running for families in need within the next several months. A new brochure and promotional materials will be available. Lastly, the newsletter will soon be available via e mail and on the internet so that it may be distributed to the many individuals who write to us from around the world. Look for great things to come from HART. If you are interested in joining us in any of these areas, please contact Liz in the treatment center office.

## Riley Forsythe—TV celebrity

Congratulations to Riley Forsythe. First he received national recognition for a drawing he submitted to the Aventis calendar contest. His entry, a picture of himself boating, won a place in the calendar as a featured month. As if this wasn't enough for the six year old Las Vegas boy, because of his notariety, he was featured on a recent segment of the news on kvbc tv.

The news did a special on bleeding disorders and interviewed Riley on the 4:00 show.

His mother, Chelly Forsythe was also interviewed. She said that "He knows that he's different, and he can't play like his friends. He can't do real extreme sports." But, for anyone that knows Riley, that certainly has never kept

him down for a minute. He is an active kid who refuses to let a bleeding disorder slow him down.

While the general public may think that people affected with hemophilia don't lead normal lives, it is important for them to spotlight this disorder. Not only does this bring attention to those with bleeding disorders that are not receiving state of the art medical care, but it also allows the public to become aware that children and adults with bleeding disorders can lead normal lives. Often times, teachers, close friends, and even relatives are unaware that someone has a bleeding disorder unless it is brought to attention.

**Way to Go Riley.**

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## Platelet Aggregation Studies Now Available

American Medical Laboratories—West now offers platelet aggregation studies to evaluate patients who are suspected of having functional platelet disorders. This testing, not previously available in Las Vegas, may aid in the diagnosis of von Willebrand's disease and other platelet disorders that may result in bleeding complications.

Typically platelets are necessary to initiate the clotting to occur. They act like the plug in the dam. If there is a problem with the way that they work, then oozing usually results. There are many acquired conditions that result in abnormalities of platelet function. These include kidney disease, aspirin containing agents, non steroidal anti inflammatory medications, and multiple myeloma just to name a few. There are also several conditions where people are born with platelets that do not function normally. These are usually familial. The only way to test for these disorders is by platelet aggregation testing.

Prior to the availability of this testing in Las Vegas, patients had to travel to California or Arizona to receive testing. Now it is available in our own backyard.

The testing is done by appointment at the Burnham outpatient facility. Most insurances cover the cost of testing. Specimens must be collected after a ten hour fast. For ten days prior to having the test done, the patient must not use aspirin containing products, caffeine, cigarettes, ibuprofen, alcohol, Plavix, or Pletal. These agents may cause false readings on the testing.

The appointment must be ordered by your physician and arrangements for testing will also be make by your provider. Testing is available Monday through Friday from 8 am to 3 pm.

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# Questions

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**I need to have several teeth pulled. Why do I need to use any medication unless there is bleeding after I leave the dentist?**

This is a common question. It makes sense that unless there is bleeding, why should any medication be administered. However, once there is bleeding, it may be difficult for the dentist to stop the bleeding or even be able to see through the bleeding in order to continue with his work.

It is easier to normalize the clotting system of the body with medication before there is any cutting with bleeding. Once tissue is cut, substances are released that are supposed to stimulate clotting to occur. However, if you lack the necessary proteins for clotting to occur, these substances continue to be released in an effort to try to get the body to stop bleeding. This process sets up a cycle that is much easier to treat before hand rather than after the cat has been let out of the barn. While not every procedure results in bleeding it may be difficult to predict when and in whom bleeding will occur. Therefore, we recommend treatment in every person with a bleeding disorder before the bleeding occurs.

In addition, once blood pools in an area, healing is delayed. If you've ever had an injury and not been treated for it, think about how long it took for the area to heal? Usually it takes longer for healing to occur because of the blood that remains in the area due to the uncontrolled bleeding that occurred initially. By treating with factor, amicar, or stimate before bleeding occurs, blood will not pool in the area and healing will be much quicker. It is also unfair to the dentist to expect him to do his work not knowing if he will end up with a "bloody mess". Therefore, most dentists will require clearance from your physician with recommendations prior to proceeding with any dental extractions. This is in the best interest of the patient and promotes good health. Be glad we have excellent medication available.



*For more pictures of the fun at the pediatric clinics, or to download your picture, join us on the web at [www.htcnevada.org](http://www.htcnevada.org).*

*A special thanks to Jennifer Buis who was instrumental in organizing these clinics. It amazes me each year how she is able to pull this off and each year it only gets better.*



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## **CONGRATULATIONS TO:**

**Marti Stimpson for doing what we all wish we could. She set her mind to being healthier and lost 100 pounds through exercise and diet. Way to go**

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**The Kelly Family**

**On the birth of their daughter**

**Maia Grace Kelly**

**A movie star in the making she's so beautiful**

**Born May 23 at UMC**

**10 pound 1 oz**

**20 inches long**

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**High School graduation of Robin Smerdel from Western High School**

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**High School graduation of Josh Buis from Faith Lutheran who will be a star pole vaulter at Baylor where his sister can cheer for him**

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**Ben Mehr on the birth of his granddaughter, Zoe born to Jodi and Michael on June 23 and weighing in at 6 pounds, 10 ounces.**

**What a beautiful baby**



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# Thanks

The Staff of the HTCN are grateful to the following corporations and individuals who have provided support for our special events.

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Mark your calendars for the winter wonderland at Mt. Charleston. This year, the theme will be medieval fairy tales and we already have wonderful prizes waiting, like a weekend at the Rio Suites. So, start thinking about what you will wear and mark

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



Mailing address:  
2020 W. Palomino Lane Suite  
110

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

[www.htcnevada.org](http://www.htcnevada.org)



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