



# Hemophilia and Thrombosis Center of Nevada

A Non-profit Center

## Down on the Ranch



The wild west is known for cowboys and indians. So on a warm summer day, cowboy hats, bar-b-que steaks and the ultimate “shoot ‘em up” at the HTCN Corral were just a few of the wonderful activities we were all treated to at the recent summer event of the Hemophilia and Thrombosis Center of Nevada. On August 11, decked out in cowboy garb, with a few indians in the bunch, the HTCN family sat down to a wonderful grub at red checkered tablecloths at the lodge on top of the mountain at Mt. Charleston. The outside area, with its wonderful cool breezes was redecorated with bales of hay for the summer event. Even the wait persons dressed up in cowboy gear. However, they were not allowed to win the best costume contest. That was reserved for the two adorable matching cowboys, the Martin boys.

While waiting for the wonderful luncheon, we listened to karaoke, both good and bad. After supper, the scavenger hunt was a real challenge. This time instead of just finding things in order to win, participants had to coax adults to draw pictures, and perform stunts.

The highlight of the day for many of the children, both big and small *cont. on Page 3*

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*Production: Thanks to Elizabeth White, Administrative Assistant*

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# **Report from HART**

## **Hemophilia Awareness Research and Treatment**

### **Advisory Board to the HTCN**

The quarterly meeting of the advisory board was held October 15. If this working meeting is any glimpse of what is to come, this group is destined to improve the awareness and daily lives of those affected with bleeding disorders. Composed of an exceptional, versatile group of thirteen diverse individuals, the melding of ideas is exciting and sure to produce great things.

Partnering for the ultimate goal of funding a building for a larger home of the HTCN is becoming a reality. While this seems like an extraordinary feat to accomplish, with each meeting, we grow one step closer to this goal.

The Childcare Committee has made much progress. Several programs with available grant funding have been identified. In addition, HART has begun paving the way for partnering with several established community organizations to assist with respite care. This needed service provides a break for parents with ill children. Utilizing established programs will allow us to achieve our goals quicker without waiting for grant funding to be realized.

Plans for increasing the awareness of bleeding disorders and the care of children who are affected are under way. Once day care providers with an interest in providing these services to our population are identified, training can begin. If we educate child care providers about bleeding disorders, they will be less fearful of caring for our children and this will increase the number of day care organizations that provide safe care for our children.

The Patient Assistance Committee has designed initial guidelines for providing assistance to those in need of financial support after all other avenues have been exhausted. These guidelines will be further refined before the next

meeting when the completed application form will be unveiled so that the program can begin.

The committee members have already begun to arrange for vouchers for medication and durable medical equipment. This will streamline the process and ensure that funds are applied for those most needed services. An equipment exchange will round out this program. This will eliminate the need for costly appliances by allowing sharing by affected persons.

A new concern regarding the availability of life insurance for persons with bleeding disorders will be taken on by this board in the near future.

Lastly, educating the community about bleeding disorders and ultimately involving those in political office is a goal of this determined group. A new brochure has been designed and will soon be available. In addition, a template letter has been written identifying the needs of persons with bleeding disorders and the significant out of pocket cost that affects their care. This letter which we will encourage each individual to send to their local representatives asking for affordable medication and less costly co pays will help to bring the attention of these concerns to our elected officials. At your next medical appointment, ask for a copy of this letter so that you too may help in this important effort.

Join HART for the annual tree decoration at Opportunity Village on November 9 as we can use your help.

Anyone interested in participating in HART is welcome. Please contact Liz at the treatment office.

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## Down on the Ranch

*continued from Page 1*

was the shoot out at the HTCN corral. For those who forgot their ammunition at home, squirt guns were available, leaving no one safe. As everyone entered the party, they were given bandanas of three different colors. These determined which team you were on and ultimately how wet you would get. A prize was awarded for the wettest individual, but it was pretty difficult to award this as everyone was pretty wet. Not that anyone minded being cooled off, except for Dr. Shopnick who was double teamed by Mr. Inghram and Liz's husband and ended up almost winning the contest.

Door prizes were awarded and included dinner for two, show tickets, a cookie bouquet, tickets to wet and wild, and gameworks. Many lucky winners will have more fun using their

prize winnings.

Overall everyone had a wonderful time and young and old left with smiles from ear to ear. Thank you to Cheryl Lawrence for her assistance in planning the party and all those listed at the end of this newsletter that supplied door prizes.



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## Questions and Answers

*What is involved in enrolling in a research study? I am afraid that I will be experimented on.*

If you are lucky enough to be asked to participate in a clinical research study, there are several things to consider. First, are you being offered an opportunity to use a new medication before it is released to the public. If so, this medication may be more beneficial in some ways to other medications currently available. Every new medication approved by the FDA must first undergo strict research studies to identify if the medication is safe and effective and how it compares to regularly available treatment options. These studies are rigorously tested on animals first and often on critically ill patients before being offered in Phase II or III studies to determine their efficacy. However, since new medications have little track record, they must be monitored more closely than routinely used medications to ensure patient safety. This is a highly monitored area of research. Detailed information is reviewed by experts in the field at each step. In addition, often times there are independent reviewers that evaluate the information to make

certain it has been collected accurately. All information regarding the medication and regular updates of all patients using the new medication are reviewed by the institution's Investigational Review Board. This is an added local safeguard to make certain that those enrolled in the study are safe. If there are any questions, the study may be terminated. Besides the opportunity to receive a new treatment that would not otherwise be available, the cost of all medical treatment and medication is covered by the research. Therefore, if a medication that is regularly available is to be tested for a different indication, often times, you may be able to receive the same medication you would normally be prescribed at no cost, in return for your participation.

Before anyone begins a study, there is a consent that lists every possible problem that may occur. These are usually very complete and should be reviewed with the research nurse or doctor. You should be given the opportunity to ask questions, and if you decide you don't want to participate in the study, your doctor should continue to provide you with excellent care.

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# Eating Healthy, What That Really Means

## Part I—Carbohydrates

By Dr. Jonathan Wechsler

We are a growing community. 30% of the adult population has grown to obese proportions, and 20% of teenagers have reached a weight that is defined as obese. We see food every where. Our appetites have been as super sized as our portions. We can turn to the food channel 24 hours a day to feed our obsession with calories and fat. Physical activity has reached an all time low. Now for the bad news, the government published statistics showing that type II diabetes is an end result of eating the wrong things and failure to exercise. We definitely need a good meal to digest this bad news.

So what's a hungry person to do? Eat less calories? Eat less fat? Eat less carbohydrates? For fifteen years, we have recommended that a low fat diet was the answer to our growing problems. Consequently, body weight has increased dramatically since this diet was promoted. Low fat everything is everywhere. We have been inundated with low fat food, but unfortunately, we have traded one bad habit for a diet so dense in sugar and carbohydrates that our total caloric intake has worsened. A growing body (bad example) of evidence suggests that a diet very limited in carbohydrates, and predominately high in protein (and sometimes fat) is the best answer. This diet, originally developed by the good Dr. Atkins, was laughed out of every scientific session for fifteen years. It turns out that the low fat diet is based upon very weak scientific evidence, and mostly just sounded good. The truth is that as we have followed it, we have just gotten fatter.

Dr. Atkins' diet works, but has to be followed very closely. It is good for routine weight loss. It's particularly good for diabetics. Unfortunately, carbohydrates sneak their way into food in the most subtle ways. For instance, you are at a restaurant and just ordered a steak. No veggies, no potato, and no bread. Whoopee for you. Your steak is sizzling hot off the grill and without tell-

ing you, the chef paints it with his magic sauce. Ooh, tasty. But he also just added 15 grams of sugar. Your diet will now work in reverse! This diet works, but you have to understand the subtle nuances very well for success.

Now let's discuss longevity. Not yours, but the diets. That is the likelihood of following any diet for long term success. The national institutes of health reviewed diet in women. What was found was that the only diets with good long term adherence were those low in fat, low calorie and portion controlled. Fad or radical diets may work in the short term, but usually fail over time. Old habits are hard to break. This is so true for diet, and frequently predicts our eating habits with time.

So what's the moral? If we are very motivated to understand, and follow the Atkins diet, we can lose weight. If we are realistic, and face our culinary demons, some of us should follow the old school and eat the low fat diet. However, a dozen snackwells may be fat free, but they are loaded with calories. The best consumer is an educated one. Learn to read the labels and don't trust names like low fat or low sugar without checking out the ingredients.

Next month we will examine the role of exercise, diet supplements and weight loss drugs (prescription and non prescription).

Good luck and happy trails.

*Dr. Wechsler is a board certified internist practicing in Henderson, Nevada. He lectures extensively to physician groups on diet control and is faculty at several medical schools. He may be reached at 990-7035.*

# Hereditary Hemorrhagic Telangiectasia (Osler Weber Rendu Syndrome)

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While most people have heard of hemophilia, and some have heard of von Willebrand's disease, few have heard of Hereditary Hemorrhagic Telangiectasia or HHT. This disorder is much less common than hemophilia occurring in 1 in 50,000 persons and inherited by both men and women. In this disorder, patients develop new blood vessel growth, termed telangiectasias. These may occur in any organ, the stomach, lungs, nose, and/or skin. When they occur on the skin, they look like birth marks, however if they increase in size, they may burst open with resultant bleeding. When they occur in the brain or lung, they pose serious dangers. Often they occur in the nose, mouth, or stomach area and result in nose bleeds or bleeding into the stool. This becomes problematic and often results in severe anemia.

While there is no cure for this disorder and little treatment, centers of excellence are being developed to further research in this area. The closest center to us is Salt Lake City, which has a long heritage of world class hematologists. There is also an international foundation with the web site [www.HHT.org](http://www.HHT.org) and an annual meeting is held.

We have several affected families who are cared for at our center. Recently, one affected person was treated with a new pulsed light therapy for a particularly bothersome telangiectasia on his cheek. This area often swelled, became painful, and bled. Following treatment, there has been almost complete resolution with no new development of any problem. Hopefully, new treatments will continue to be developed to help improve the lives of those affected.

Before  
treatment



After  
treatment



*Services performed by the  
Aesthetic  
Center of  
Medicine*

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## Save the date

For Ladies and Lords, the festival begins January 12  
at 12:30.

Mt Charleston Lodge is the setting for merriment and  
libations.

Invitations forthcoming.

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# The Fire at Camp Firefly

By Zachary Schrager

Well, the story begins when I came to Camp Firefly. I was a day late because I was on vacation. I went to breakfast with my cabin. After breakfast everybody went back to their cabins. We went to our first activity. Mine was archery. My other two were general sports and arts and crafts. Once we were done with all three activities we had a water war. After that we had a “pick your pleasure” activity. Mine was Arts and Crafts. I made lanyards.



The next day we did all three activities again. During snack time I overheard the counselors say we were going to be evacuated because the fires were only one and one half miles away. Many emotions swept over me. The counselors took us to our cabins. We grabbed our stuff and rushed into their cars. We drove to a big park in San Diego until a bus

arrived. My mom was still in Los Angeles so she picked me up.

Most of us were disappointed because camp was cut short.

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## Firemen, Firemen Everywhere

The August pediatric clinic was painted red. Red because we were joined by members of the fire department. Not only were there fire men, but a fire engine was parked in the HTCN parking lot and everyone attending had the opportunity to dress up and see the fire truck close up. What a thrill for everyone.

The children were given fire hats to take home and squirt guns in case of fire. Lunch was served and goody bags were given to everyone attending

complements of Corum Home Health Care.

Just in case, that was not enough to keep anyone busy while they waited for the blood to be drawn or to see the treatment center team, Mr. And Mrs. Majik entertained everyone in the lobby, performing feats of magic and receiving Oohs and Aahs.

What fun for a day at the doctor.



# Pictures from Camp

# THANKS

## Complements of the Davis family



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

- Suncoast Hotel and Casino
- Winifred Johnson
- In N Out Burger
- Wet and Wild
- Rio Hotel
- Novo Nordisk Pharmaceuticals
- Corum Healthcare
- Bayer Pharmaceuticals
- Cookies By Design
- Dillards
- Gameworks
- Fiesta Hotel and Casino
- Amazing Gift Baskets
- Las Vegas Motor Speedway
- Toys R Us
- Cheryl Lawrence
- Gold Coast Hotel and Casino
- Raley's Supermarket
- The Basket Hound
- Ken Cox
- Debra Huntington
- Mr. And Mrs. Nicholas Kuthy
- Aventis Pharmaceuticals
- Wyeth Pharmaceuticals
- Caremark HomeCare

The HTCN is currently in need of donations for the holiday parties. In addition, HART is forming an emergency financial aid program for those in need. If you wish to donate to this fund, please contact the treatment center.

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COMPREHENSIVE CARE FOR TREATMENT OF BLEEDING AND CLOT-

**Medical Director: Dr. Rinah Shopnick**  
**Nurse Coordinator: Myra Davis-Alston, RN**  
**Administrative Assistant: Elizabeth White**  
**Laboratory Supervisor: Angel Moore**  
**Social Services: Alice Ashbaugh, MSW**  
**Physical Therapy: Jenny Wells**  
**Orthopedics: Dr. Robert Tait**  
**Dentist: Dr. Sundquist**

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