



Hemophilia and Thrombosis Center of Nevada

A Non-profit Center

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WINTER NEWSLETTER F

Medieval Times



On January 12, in the hamlet of Mt. Charleston amid the snowflakes, damsels in distress were saved by knights in shining armor jousting to save their honor, as hot chocolate and a roaring fire warmed the heart. In other words, the HTC� family had a fabulous time at the annual holiday party held up at the lodge. Not only were we blessed with snow this year, but compliments of Liz and her friends and family, we had a medieval wonderland. Being back in time for the afternoon proved to be a great success with over 100 HTC� family members in attendance.



Those in period dress outdid themselves. For instance, the Queen of England herself attended and because we were so pleased, she won the grand prize for the best costume, a weekend for two at the Rio Suites (compliments of the Rio Hotel).



The food as usual was superb with a warm dinner including Prime Rib, Chicken Angelo, Pasta Primavera, and Scalloped potatoes topped off with Chocolate Cake. While the band played, in between sets, knights in armor allowed the children, and adults alike, to try on the armor and see first hand the period tools and weapons used. What a treat! The pictures were great. For a look, check out the web site at www.htcnevada.org.

A treasure hunt turned up gold coins with prizes attached to them, and the door prizes were overly generous. This is thanks to the community support we have garnered and the hard work of HART board member Cheryl Lawrence along with Liz's persistence.

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How will the Medical Malpractice Crisis Affect my health care?

By Dr. Rinah Shopnick

For anyone living in Nevada, West Virginia, Pennsylvania, or Florida, the headlines are more than concerning. The media insists on telling us that there are no doctors left to take care of the sick, hospital emergency rooms are turning patients away only to look for other places to receive their care, and that pregnant women may not have anyone to deliver their babies. While we often take our health for granted, those of us who need expert medical care or have had need of emergency services know how critical this is. Not only is it critical, but timing is of importance. Try telling an accident victim to drive 40 minutes away in order to receive treatment. This only makes complications more frequent. So we all agree, that expert specialized medical care must be available, close by, at all times.

What we don't all agree on, is what to do to ensure that we will continue to receive the current level of care available in Las Vegas. While there is talk of many obstetricians leaving the area, and of surgeons not wanting to see patients who have been in accidents, currently in Las Vegas, there is no difficulty in receiving the same level of medical care that has always been available. So, while many of you may be concerned when you hear the issues on the evening news, keep in mind that these are ominous predictions of what could happen if things don't change soon. **REMEMBER THAT ANYONE THAT NEEDS MEDICAL CARE HAS AND WILL CONTINUE TO RECEIVE IT AT THE PRESENT TIME.** Panic never fixed anything. However, concerned citizens have always been able to change laws and societies expectations. This is what our great nation is based upon. Our democracy allows anyone with an idea to pursue it in a political forum. So, don't just sit there and worry, get active.

What are the real concerns and problems

facing health care in our community and others with similar issues?

First, because doctors are human, mistakes may happen. Also, anytime that anyone even takes an aspirin, there is the chance that something not planned, and not beneficial, may happen to the patient. So, we have a legal system that ensures that injured parties can receive damages to cover expenses that may be incurred from complications. This means that every doctor, just as every automobile owner, every business owner, and every lawyer, must carry insurance coverage in case of unplanned side affects and lawsuits. These insurance companies gamble for a living. They bet that they will collect more money from the doctors then they will have to pay out in legal settlements. What do they do with the money that they collect? They invest it. Well, anyone with a retirement account knows that the stock market has done badly following 9/11. So, these insurance companies have also lost money and this results in them needing to increase their premiums. But, the doctors and hospitals are highly regulated and they cannot increase their fees to cover the increased cost. When those costs increase 50-100%, it is no longer possible for the doctor to pay his staff, rent, and also pay himself a salary. This is especially true in specialties where the insurance premiums may easily run \$60,000 per year. The doctor may need to see 50 patients a day just to pay their staff and cover this additional cost. Just to put the icing on the cake, in the middle of this crisis just as the governor was calling for a special session to legislate relief, the Nevada insurance commissioner decided to approve an insurance increase.

So, what lies ahead and what can you do to prevent this crisis? First, don't panic. It is unlikely that all of your doctors will decide

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Medieval times *continued from Page 1*

A special thanks to Dennis Gomez of Novo Nordisk, the makers of Novoseven, who again out-did himself by offering to pay for the entire winter event. This will allow us to have an even better than planned summer event as the donations will go much farther. Unfortunately, he was on one of his world travels and unable to attend.

We would like to thank those companies that helped to support this event with in kind gift (list on page 7) Please help to support them as they have supported us. A special thank you to Travis Potter and family with the Empire of Chivalry and Steel for an impressive demonstration.



Medical Malpractice *continued from Page 2*

to pick up and move. After all, where will they go? This is a national crisis. Second, make sure you are a registered voter, as your representatives are more likely to listen to your concerns if they think that you may vote against them in the next election. This is your chance to be heard.

While the emphasis is on writing laws that will restrict lawyers ability to collect large sums of money for patients who have any damage occur, this may not be the only or best option available. After all, if you are injured you deserve to be able to pay your bills. You don't deserve to win the lottery, so there are some restrictions that should apply. In addition, the current legal system pays the lawyers based upon how much money they receive in judgement. Few professionals are paid based upon the amount you make, but rather have a fee schedule. Lastly, insurance companies must be responsible for any investments that may have worsened the current situation. Insurance reform is paramount to improving this situation.

So you see, this is not an easy fix. Do those

living in Europe and Canada have it any better because of their socialized medicine? Well, there are plusses and minuses. My husband's family is Canadian. While they receive their health care at "no additional cost", their taxes are very very high. In addition, those that can afford it, come to the United States and pay cash for some of their procedures including open heart bypass surgery, and cataract surgeries. This is because any system that has a fixed amount of money must have a fixed amount of tests and operations that can be done in any given year. If the government can afford to pay for 500 cataract surgeries a year, you may have to wait an extra year if your number is 502.

Every good system has needed tweaking, and progress, and perhaps this is the perfect timing to reevaluate both our legal system and health care system in order to achieve an even better system that will work for all of us.

Please let me know your thoughts and we will publish them on the web.

What do I do if I need to have surgery??

By Liz White

Have you ever tried to call the car repair shop, the dentist, or even your hair dresser the day before you want to have something done? It's usually a disaster.

Calling the treatment center the day before your scheduled surgery doesn't give the treatment center team enough time to get things organized for your surgery, especially if your surgery is at 7:30 am the next day.

Here are a just few of the things that have to happen. Your chart needs to be reviewed to make sure your labs are current and so that we know exactly what medication you will need to prevent bleeding. The hospital pharmacist must be contacted to make sure they have more than enough medication, whether it's DDAVP, Amicar, or factor concentrate. The surgeon's office needs to talk with Dr. Shopnick so she can decide how involved the surgery will be and how much medication will be needed. Sometimes medication will need to be ordered through a home care company so that you can be discharged from the hospital without delay but still not risk bleeding. Lastly, orders must be written and received at the hospital pharmacy and to the doctor doing the surgery so that everything is set up with no room for failure.

By calling with very short notice for scheduled surgeries you place yourself at risk that you may not receive adequate treatment to ensure that there is no adverse bleeding. It's even more upsetting to have to cancel the surgery at the last minute because the hospital could not get the medication you need in time. The more notice we give the hospitals and surgeons to prepare for the surgery, the better off you will be. So PLEASE help us to help you stay safe. Surgeries are uneventful with proper planning. Preparedness is the answer. Call us the minute you and your physician are planning any invasive procedure.

Report From HART



The Advisory Board to the HTCEN, HART, has made an amazing amount of progress in its short existence. The Patient assistance committee is finalizing criteria for assistance. Because of the donations received by the HTCEN in this fiscal year, a new bank account with \$2000 to start will be available in order to begin helping those in need. When the final criteria are formulated, in the next several weeks, we will post this on the web site so that the application process can begin.

The newsletter will be available on line in pdf format and may be e mailed saving money and also allowing it to be more readily available.

The new logo and letterhead will soon be unveiled so that it can be sent out with the new brochures. This will help educate the public about bleeding disorders.

Lastly, the child care committee is busy at work with a difficult task. Letters are going out to day care workers throughout Las Vegas in an effort to identify centers willing to receive additional training to care for children with bleeding disorders.

The hard working HART members deserve a round of applause.

HART is open to any member of the HTCEN community that wants to improve the lives of those affected. For more information check the web site or contact Liz at the treatment center.

Holiday Decorating with HTCN

Each summer the HTCN staff gets together and starts to worry about how we will outdo ourselves to decorate the annual tree at Opportunity Village's Winter Carnival. While this may seem like a small task, coming up with an idea that fits our mission at the treatment center, will withstand the rain and wind the Vegas Valley usually sees in November and December, and isn't impossible to do, is a pretty hard task to do *every* single year. While the decorations at Opportunity Village get better and better with more participants annually, this task becomes monumental. So, this summer we were thrilled to have lots of helpers with great ideas who were willing to climb ladders and help make this year's tree the best ever.

This year, Angel Moore came up with a wonderful idea to use our logo on the tree and incorporate drops of blood. It was Liz's husband, Dave, who thought of the medium of wood and with help from her son Donald, we had wonderful ornaments. Then Cheryl Lawrence, the resident HTCN designer, contributed with her advance planning. She picked up hundreds of wonderful ornaments that matched our color scheme and twinkled in the moonlight. The final outcome is too wonderful for words. Unfortunately, the pictures just don't do it justice.

As if this was not enough, because our tree was in a strategic place visible from all sides, what would complement it, but a train, thanks to Liz's bargain hunting instinct. Now I'm certain that we won't be able to outdo this idea next year.

The entire HTCN team members and their families helped decorate. They did a terrific job.

A special thanks to Angel Moore's



mom, dad, and husband (Lillian, Michael, and Jaques) who spent much of the day up on a ladder helping make sure of the perfect placement of everything that needed to go up on the tree.

Opportunity Village is a wonderful organization with a longstanding reputation in Las Vegas. The holidays are always such a rushed time of year that it is easy to forget the importance of charity and good will towards all. Participating in community events as this helps the community but also allows us to contribute our own charity and good will. The Christmas event is the largest fund raising event that Opportunity Village has. It's our pleasure to continue to support it.

The planning for next year's tree will start as soon as this year's holiday decorations get put away, so don't lose out, come help us in this fun family experience.

Research Trials

The only way that we find cures and better treatments for disorders is to do clinical research. The HTCEN participates in several research studies. (For a complete list log onto www.htcnevada.org)

We are actively seeking individuals who wish to participate in the following research studies.

1. Humate-P for treatment of persons with von Willebrand's disease who need infusion for surgical procedures. Medication and all testing is provided free of charge.
2. Anticardiolipin antibody database
3. Patients with inhibitors who require treatment with factor. A new factor concentrate will soon be available. Medication and all testing will be provided free of charge.

New Brochures

It's finally arrived. The new HTCEN brochures with their glossy pages.

The best part is the wonderful picture on the cover of HTCEN's family (are you in the picture??).

HART, the advisory board of the HTCEN, will soon be distributing these brochures to increase awareness of persons with bleeding disorders.

If you haven't seen one yet, please give Liz a call or e mail and we'll get one to you to admire.

A special thanks to Kevin Anderson whose design expertise and advertising know how was instrumental in making this happen.

Scholarships Available

In the middle of all those applications for college, don't forget that once accepted, the bills will start coming. There are many scholarships available that are set aside for persons with bleeding disorders. We would encourage you to take advantage of them. Listed below are two such available scholarships.

THE ARTHUR B. KANE MEMORIAL SCHOLARSHIP from AVENTIS BEHRING PHARMACEUTICALS. Applications are currently being accepted through March 15, 2003. To qualify to apply, you need to be a member of Aventis Behring choice, and have a bleeding disorder diagnosis. Joining Aventis Behring Choice just takes a phone call. Scholarships are available for students applying to and accepted to or currently enrolled at an accredited 2 or 4 year college, uni-

versity, or vocational/trade school. The amounts vary but can be up to \$25000 over the course of study. This money can be used for books, tuition, and fees.

AMERICAN RED CROSS PLASMA SERVICES HEMOPHILIA EDUCATION FUND. Awards \$5000 one year scholarships to three outstanding students who will be entering college freshmen in 2003 or who are currently enrolled in an accredited 2-4 year college, university, or vocational school. Two scholarships will be granted to students who have hemophilia, and one will be awarded to the child of a parent with hemophilia.

For more information on how to apply, contact the treatment center office.



To see more pictures from the Winter Event, log onto our web site at www.htcnevada.org

The pictures may be downloaded or printed.

Above, the duke and the king and queen take prizes for best costume.

THANKS

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

Gameworks

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Factor Support Network

Gold Coast Hotel and Casino

Aventis Behring Pharmaceuticals

Corum

Factor Support Network Pharmacy

Cheryl Lawrence

Ken Cox

Robert Gonzalez with Amgen

Travis Potter and family with Empire of Chivalry and Steel

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.

Donations of durable medical equipment are needed.

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FEBRUARY 2003

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