



Thrombosis News

Hemophilia and Thrombosis Center of Nevada

A Non Profit Center

First Attempt



There are so many advocacy organizations, it seems that whatever illness you may have, there is a group waiting around the corner with information to help you understand what you can expect from your medical condition. There is the National Hemophilia Foundation, American Hemochromatosis Foundation, Leukemia and Lymphoma Society, American Heart Association....I could go on and on. Some disorders are so obscure that there are only several thousand affected persons worldwide. But they still manage to have an advocacy group with information and resources.

So what happened to all of those people that suffer from clotting disorders, or thrombosis? There certainly are a lot of us. Some experts conservatively estimate that one of every one thousand individuals have a blood clot in their life time. We know that this does not include those that have blood clots in their brain (a stroke), in their heart (a myocardial infarction), or in their intestines. So, this number is probably an underestimate.

So, where is the foundation for those who suffer from blood clots, or even recurrent blood clots with predisposing conditions that make them prone to blood clots? I've never found one, so this is the first attempt to offer advice, educational resources, and support to those that suffer from thrombotic disorders. This is a very large and mixed group that includes many different clinical spectrums. But, the one thing that is in common is that most of us

have been placed on some type of blood thinning medications. While these medications have the potential to save our lives, they must be respected. If used recklessly without proper monitoring, they may result in significant problems.

There is information available regarding these disorders and the use of these medications. However there does not seem to be one specific place for them to be easily found. So, our hope in providing this newsletter is to make these resources available to the community, increase awareness of these disorders, improve the outcome of affected persons, promote research in this area, and serve as a support system for those that are affected and their families.

These few goals are the immediate ones. I was always taught to think BIG. OK, grandiose may be more appropriate. So, let's get the entire wish list out and see where it leads. In the future it would be wonderful to form a separate non profit foundation dedicated to clotting disorders to assist those that are affected just like all of the other foundations serving less common disorders. In order to achieve this, one small team in Las Vegas, no matter how big they gamble, can't succeed. So, if you support these goals, please assist by sending submissions for future newsletters and sending suggestions for improving the resources available to all of us.

Together we can realize our goals.

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

Cont. on Page 3

New Risk Factors for Thrombosis

The science of thrombosis is expanding on a daily basis. Fifteen years ago we were only able to identify an abnormality in the blood of 6% of persons with recurrent blood clots. With newer technology and improved clinical trials, we have expanded this to around 50% with new identified abnormalities identified regularly.

The most recent revisited abnormalities are those of clotting factors. For years it has been supposed that high levels of some clotting factors may result in the increased risk of blood clots. Factor VIII and Factor IX which are low in patients with hemophilia, when in high levels may pose a risk for the development of blood clots. Further testing to evaluate the strength of this risk factor is ongoing. This will help us to identify the risk involved with

high levels of these clotting elements and therefore determine whether long term treatment with blood thinners is indicated.

Whenever long term therapy with blood thinners is considered, the risk of bleeding while on blood thinners must be weighed with the risk the patient has of the development of blood clots. This is how we determine the risk benefit ratio and whether treatment should be prescribed.

There are many identified risk factors for blood clots. Who should be evaluated is still under question. With continued research in this field these questions are soon to be answered.

Medical Malpractice *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??

Blood thinners and surgery don't usually mix well. The blood thinners increase the risk of bleeding complications postoperatively, and also make our surgeons question whether we really need to have the surgery, and whether they really want to be the one to do it. Our approach is that if you need to have the surgery, we will find a way. We have been very successful in this regard. The most important step is planning. This includes speaking to whomever is responsible for managing your blood thinners, making sure that they are in contact with the surgeon, and in cases where expensive medication may be required, in contact with the insurance company.

The first question that needs to be answered is, is this an elective surgery or one that I must have. While many individuals on blood thinners have elective cosmetic surgeries, one must think hard to decide whether the risk of bleeding or clotting is worth the procedure in question.

The second question is, why am I on blood thinners in the first place. Am I prone to develop blood clots and if so, how high is my risk of another blood clot if the blood thinners are stopped for any period of time? Depending upon why you are on blood thinners and whether or not an identifiable abnormality has been found in your system will help to determine the risk you may be in. There is some suggestion that within the first month after a new blood clot is experienced, the risk of additional clots may be high. This risk may decrease following the first thirty days. So, if the surgery can be postponed to this time, your medication may be stopped for several days without as high a risk of recurrent blood clots.

If, however, you have had recurrent blood clots, a recent blood clot, or an identifiable risk such as anticardiolipin antibody syndrome or

inheritance of factor V Leiden from both parents, stopping the medication for even a few days may pose a risk.

If the risk of stopping the blood thinners is acceptable, then recommendations are that the blood thinners be stopped for three days before the planned procedure. This allows the INR to decrease to near normal but not be at normal for more than around a 72 hour period. The likelihood of a blood clot developing in this short period of time is low. The anticoagulation therapy must then be restarted after the surgery and should become therapeutic within several days.

If the risk of stopping the blood thinners is not acceptable, then bridge therapy is indicated. This is a way to keep you safe from developing a blood clot in this critical period around the surgery while enabling the surgeon to "turn off" the blood thinners for the surgery. The warfarin is stopped three days prior to the procedure and heparin is initiated. The newer low molecular weight heparins may be easily self administered at home. The last dosage is administered 24 hours before the planned procedure so that it is out of your system before any surgery occurs. It is then restarted as soon as the surgeon feels comfortable, usually the evening of surgery or the next day, along with warfarin. The heparin is continued until the INR is in range and then discontinued. Using this approach we have not found an increased incidence of postoperative bleeding and have been able to proceed with surgery in very high risk patients without adverse consequence.

Those on antiplatelet agents, such as Aspirin, Cilostazol (Pletal), or Clopidogrel (Plavix) must also discontinue these medications prior to the procedure. These medications last in the system for days and therefore they must be discontinued days before the planned procedure.

The most important factor after surgery is to move around as early as positive as bed rest increases the risk for blood clots.

Anticardiolipin Antibody Database

Several months ago, we decided to review all of the patients that we have cared for with the anticardiolipin antibody syndrome. This is a relatively rare disorder and therefore much of the medical literature consists of small groups of patients whose information has been reviewed after the fact and reported upon. There are few studies in this group of patients and many unknowns that persist. We realized that we have seen a large number of patients with this disorder and many of them seem to note the same symptoms that had not been previously reported. Some of these symptoms at first seemed unusual and likely not related to the disorder. We heard about sharp pains in the side of the head that occur with stress or excitement, fuzzy feelings where you could not concentrate that came in waves days at a time, sausage feeling to the legs despite nothing obvious on examination, unusual symptoms with the exception that we heard them over and over again from many different individuals, enough times that we began to believe there was more to this disorder than what is recorded in the medical literature. So, we decided that the best way to identify trends was to begin an anticardiolipin antibody database.

Patients who logged onto our web site, and were not our patients were asked to answer a number of questions regarding their health history, as were those patients that are followed in our clinic. This data will be analyzed for trends that may help to identify additional symptoms present in the ACA syndrome and also help us to target new therapies and diagnostic modalities in this population.

The response has been overwhelming. We have received responses from all over the world and the responses so far are very interesting. Many individuals seemed pleased to have found a friendly interested site and requested a chat group or support group.

Long Term Low Intensity Warfarin

In the April 10, 2003 New England Journal of Medicine (vol 348, no 15), Ridker et al from the Brigham and Women's Hospital and Harvard Medical School evaluated continued low dose therapy with warfarin after patients had completed their initial course of warfarin of three to six months following a deep venous thrombosis (DVT). The study was terminated early by the safety monitors because of a 64% decrease in the risk of recurrent blood clots in those patients receiving long term warfarin.

Almost one third of patients have a recurrence of DVT within eight years after the initial event. Recurrences of DVT in the legs involve the opposite leg in almost half of cases, therefore underscoring the critical role of a systemic hypercoagulability. An effort to prevent recurrent thrombosis with continued treatment with warfarin has been complicated by bleeding complications encountered with the use of warfarin to maintain an INR of 2.0-3.0. This study evaluates the use of low dose warfarin.

508 patients were randomized to either a placebo or low dose warfarin to maintain an INR of 1.5-2.0. Patients included for analysis were those that developed a blood clot not related to trauma, surgery, pregnancy, cancer, or history of major bleeding. Patients receiving other blood thinners including dipyridamole, ticlopidine, clopidogrel, heparin, and aspirin (325 mg) were excluded from participation.

The limitation to long term anticoagulation therapy is bleeding complications. In this study, there was no significant increase in the rate of major bleeding complications in patients receiving low dose warfarin.

This study is expected to change the way in which persons with a DVT are treated. Instead of discontinuing therapy after three to six months of warfarin, long term warfarin to maintain a lower INR of 1.5-2.0 following early treatment of three to six months to maintain an INR of 2.0-3.0 may be safer.

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 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 factors for thrombosis.

The meeting is open to anyone. Future meetings are planned for Sydney, Australia, and Boston, MA

For more information log on to www.isth.org

Novoseven to reverse warfarin

It is sometimes necessary to reverse the effects of warfarin. For instance, an emergency surgery is needed without time to wait for the level to return to normal solely by withholding the drug, or for bleeding complications that occur such as oral bleeding, uncontrolled nose bleeds, or bleeding from the stomach or intestine. In this situation, Vitamin K is usually administered. However this takes at best 8 to 12 hours to work when given by vein. So, for emergency situations, plasma is usually administered.

While the blood supply is safer than it has ever been, following the AIDS epidemic, and the hepatitis epidemic, and the concern over mad cow disease and West Nile Virus, any blood product may carry an unknown risk of infection and should only be administered if absolutely necessary. At the American Society of Hematology meeting several years ago, we reported our experience reversing warfarin with a recombinantly prepared factor VII product used for hemophili-

acs. In the current edition of *Annals of Internal Medicine*, Kessler et al report on their experience using this medication to reverse the effects of warfarin. They describe the successful use of recombinant factor VIIa concentrate in 13 adults receiving warfarin who required rapid reversal of a critically prolonged INR and excessive anticoagulation. Doses of 15—90 mcg/kg were administered. In all patients, the INR was immediately reduced after a single infusion. No adverse bleeding occurred in any persons during or after surgery. In several patients who had recurrent thrombotic events or heparin induced thrombocytopenia, the risk for bleeding was reduced without complete reversal of anticoagulation effects.

Additional prospective studies will help determine the true role of this medication in patients on chronic anticoagulation therapy.

**SPRING NEWSLETTER
MAY 2003**

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



Mailing address:

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

www.htcnevada.org



**COMPREHENSIVE CARE FOR TREATMENT OF
BLEEDING AND CLOTTING DISORDERS**

**A NON PROFIT CORPORATION.
TO VOLUNTEER OR FOR CONTRIBUTIONS CALL 383-6267**