



natt

NATIONAL ALLIANCE FOR
THROMBOSIS & THROMBOPHILIA

Letter from the President

Happy spring to all of our readers, families and friends. I hope 2008 will be as exciting and productive for you as it appears it will be for NATT.

The current issue of NATT's newsletter demonstrates the breadth of thrombosis and thrombophilia by focusing exclusively on the many issues affecting women. This is powerful evidence that blood clots, in all their variety, are a significant public health challenge. This means that NATT, along with other government and private organizations, needs to redouble the effort to build awareness, increase research and support those whose needs are significant.

Thanks to the new cooperative agreement with the Centers for Disease Control and Prevention (CDC), NATT is able to take on a much larger share of this responsibility. We are both excited and challenged by this opportunity.

NATT is fortunate to have supportive partners in the pharmaceutical and medical device industries. Their grants and contributions allow NATT to expand its work well beyond the cooperative agreement with CDC. We appreciate the willingness of these companies to see NATT as an effective partner in the joint effort to improve thrombosis care.

As always, I thank the many individuals whose donations to NATT make up an important part of our financial strength. We have recently completed a successful individual donor fundraising drive. This effort will expand in 2008. I also want to thank my fellow board members for

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CDC AWARDS NATT FUNDING TO IMPROVE BLOOD CLOT AWARENESS

Thrombosis Declared Priority by CDC

NATT was awarded two major grants totaling \$1.35 million from the Centers for Disease Control and Prevention (CDC). NATT will use these two grants to "launch a national wake-up call to promote public, patient and healthcare professional awareness of this serious medical condition that each year kills nearly 300,000 Americans," explains NATT President Randy Fenninger.

Fenninger said that "we have a national crisis because few people recognize or understand the symptoms and risk factors of this silent killer. And even equally startling is that not enough of our nation's healthcare professionals have a full understanding of the symptoms and the methods for prevention and treatment of this life-threatening condition."

The first grant will support the Stop the Clot™ Learning Project that will enable NATT in cooperation with CDC, to carry out the following:

- Implement Stop the Clot™ Forums for patients and families
- Initiate Stop the Clot™ support groups
- Create a Clotting Information and Resource Center (CIRC) that will have an interactive Web site and Webinars

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Chapel Hill Stop the Clot™ Forum a Great Success



A Stop the Clot™ Forum took place at the Hilton Hotel in Raleigh Durham Airport on Saturday, March 1, 2008. The Stop the Clot™ Forum focused on Blood Clots and Blood Clotting Disorders: Key Issues in Diagnosis, Treatment and Prevention, and was sponsored in cooperation with The University of North Carolina Thrombosis Program, Duke University Thrombosis and Hemostasis Center, and the National Alliance for Thrombosis and Thrombophilia (NATT). There were almost 200 people in attendance. To find out when a Stop the Clot™ Forum will be in a city near you, visit www.stoptheclot.org!

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Pam Parianna's Story

By Pam Parianna, North St. Paul, Minnesota

It's because of a Good Morning America segment about pain in the back of the leg that I was listening to while getting ready for work that I am able to tell my story. Having similar pain to what they were talking about prompted me to call my physician and I was scheduled for an ultrasound that evening. Little did I know I was going to end up in the hospital with a 1-1/2" blood clot! Due to a bad knee, I have had pain in my right leg for many years. Had I not heard GMA talk about blood clots that morning, I could have gone a long time—or maybe not—without even thinking twice about the new pain, possibly dying of a pulmonary embolism. I sent GMA an e-mail telling them I thought they may have saved my life. They contacted me and asked if I would appear in a follow-up segment to talk about what transpired, hoping to reach out to other viewers suffering from the same kind of pain, thus saving more lives. Of course it was an offer I couldn't refuse. I appeared on their show a week later.

Since that time I have been contacted several times from people I don't even know, wanting to tell me their story. I cannot believe how many people are afflicted with DVT's, yet very little is known about them by the general public, myself included. I guess it was obvious I wanted to learn more, because I was contacted by a member of NATT asking me to participate in the development of a local chapter of the organization in Minnesota. I agreed because I believe I will learn a lot on the subject; but, more importantly hope I can help make a difference to others who are diagnosed with a blood clot for the first time and are as fearful and confused as I was.

I recently had my right knee replaced and am no longer on Coumadin®. I still often wonder, "When will I get another blood clot?" But, with greater exposure and the education NATT is striving to offer, I know I will be more confident and continue to live a worry-free life.

President's Letter

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their contributions to our 2007 campaign and also for the many hours they donate to make NATT the leader in patient education.

All of this activity has Executive Director Alan Brownstein hopping. Almost immediately upon joining NATT he realized that we needed more space. Now that is the kind of problem any organization wants to have! NATT relocated to larger quarters in Tarrytown, NY, as Alan began adding staff to meet the CDC challenges and opportunities. We are very pleased to welcome Mary Ellen McCann as the new Director of Health Learning and Marketing. She brings a strong background in health education that will be essential for NATT to fulfill its mission and obligations to contributors.

The NATT leadership met in March at the new headquarters for its annual planning session. I am pleased to report that the meeting was productive and successful.

NATT's Medical and Scientific Advisory Board (MASAB) had a productive meeting in December in conjunction with the American Society of Hematology's Annual Meeting. The MASAB will be meeting again in June.

MASAB will be working on a number of projects to support NATT's overall mission and to help improve the quality of care for thrombosis and thrombophilia patients nationwide.

It is always exciting to be part of NATT, but this is a particularly energizing time with so many initiatives moving forward. With the continued support of our individual, government and corporate partners, this energy can only increase.

The Venous Disease Coalition (VDC)

An alliance of leading health professional societies and patient advocacy groups united to improve the survival rates and quality of life for individuals with, or at risk for, venous disease.

The Vascular Disease Foundation has organized the Venous Disease Coalition (VDC), a network of professional and public organizations, to help Americans learn the risk factors and warning symptoms of blood clots and their complications.

NATT is one of over 20 members of the VDC that have agreed to help get the message out about blood clots and other venous diseases to increase the early detection, and prompt treatment of these conditions. By joining forces with coalitions like VDC, NATT can reach more Americans with the message about clotting disorders.

For more information visit the VDC's Web site at:
www.VenousDiseaseCoalition.org.

Announcing NATT's New and Improved Website



www.StopTheClot.org

Special thanks to PraeMedica for generously donating this new domain name to NATT so that NATT may continue to increase awareness of thrombosis and thrombophilia. Please visit our new website and take a moment to sign up for our mailing list or to update your contact information.

CDC AWARDS NATT FUNDING

Continued from Page 1.

The second grant will support a Health Professional Education Project that will enable NATT, in cooperation with CDC, to carry out the following:

- **Develop curriculum with accurate clinical content and methods for effective health education teaching**
- **Train-the-Trainer regional workshops for participants from thrombophilia centers and Anticoagulation Forum's member clinics (participants will primarily be nurses, nurse practitioners, physician's assistants and pharmacists.)**
- **Patient/family education**

NATT's Medical and Scientific Advisory Board (MASAB) Chairman Dr. Stephan Moll, of the University of North Carolina – Chapel Hill Thrombophilia Program, stated that the Health Professional Education Project is an essential element in the fight against blood clots. "Improving the content and delivery of health information/education by nurses and other non-physicians," he said, "provides an educational and training aspect to a critical part of a patient's healthcare and wellness." The program, Dr. Moll explained, will be delivered nationally through the utilization of evidence-based teaching methods in small group sessions led by trained faculty. The program's ultimate goal is to prevent secondary conditions in people with clotting disorders by improving their access to knowledgeable healthcare providers.

Minnesota Selected as Pilot Site for Chapter and Stop the Clot™ Learning Project

While NATT will conduct Stop the Clot™ Forums in two to four cities across the county in the year ahead, Minnesota was selected as the "incubator" for developing Stop the Clot™ Forums, Stop the Clot™ Support Groups and a regional chapter infrastructure to ensure that these educational and community-based awareness initiatives are sustained over time. In Minneapolis-St. Paul, NATT will:

- Establish a pilot Minnesota regional chapter
- Establish a chapter–thrombophilia center collaboration model

NATT Executive Director, Alan Brownstein said "the Twin-Cities area was selected for this demonstration project because of the excellent medical facilities in the area, active patient leadership and a community that is supportive of public health efforts." Brownstein said that NATT is looking at the Minnesota pilot as a model of what will be established in other regions nationwide. "We look forward to a high level of collaboration with the Hemophilia and Thrombosis Center at the University of Minnesota Medical Center, Fairview, and other medical leaders, in implementing these programs that will lead to fewer clotting-related deaths."

CDC Identifies Thrombosis as Priority

On January 17, Director of CDC's Division of Blood Disorders, Dr. Roshni Kulkarni, reported that CDC's National Center for Birth Defects and Developmental Disabilities has designated Thrombosis as one of the three top priorities for the Center. NATT President Fenninger said that "assigning thrombosis as a priority is critically important. This, coupled with CDC's grants to NATT, has for the first time placed thrombosis and thrombophilia above the radar as a public health threat."

NATT will collaborate with many organizations in its development of a 12-region training program. Patients will be reached throughout the U.S. network of the 140-federally funded Hemophilia Treatment Centers, the CDC Pilot Thrombophilia Centers and through participants of the Anticoagulation Forum.

For more information regarding the National Alliance for Thrombosis and Thrombophilia and/or their national programs, please contact Alan Brownstein at (914) 220-5040, abrownstein@nattinfo.org, NATT President Randy Fenninger (202) 833-0007 or log on to www.nattinfo.org. NATT is a 501c3 national volunteer community-based organization which welcomes support through involvement and/or donations. Further information can also be obtained from NATT's Medical and Scientific Advisory Board chairman Dr. Stephan Moll, University of North Carolina at Chapel Hill at (919) 966-3311.



The Evolving Story of Pregnancy Outcome, Thromboembolism and Thrombophilia

Michael J. Paidas, M.D.

Associate Professor

Co-Director, Yale Women and

Children's Center for Blood Disorders

Pregnancy and Coagulation (Blood Clotting)

Pregnancy poses unique challenges to the blood clotting equilibrium in humans, probably more than in any other species. In order to orchestrate a healthy and clot free pregnancy, the body must achieve just the right balance between bleeding and clotting. In the beginning of pregnancy, preventing maternal bleeding and loss of the pregnancy is of prime importance. Closer to birth, the body prepares to prevent against the major risk for pregnant women: too much bleeding during childbirth. As part of this preparation, clotting factors increase during pregnancy, and protein S—a factor regulating clot breakdown—decreases. In addition, the effects of the pregnancy hormones, especially progesterone, cause blood vessels to dilate, creating a situation in which the blood pools, particularly in the legs. All of these changes place a pregnant woman at increased risk for thromboembolism (a blood clot).

How common are blood clots during pregnancy?

The risk of developing a blood clot is higher during pregnancy, delivery, and the six week period after birth. The chance of developing a blood clot is about 4-6 times more likely in pregnant women compared to non-pregnant women who are the same age. A blood clot occurs only in about one pregnant woman in 1,000-1,500. Blood clots remain a leading cause of maternal death in all parts of the world, and account for 11% of maternal deaths in the US.

What types of blood clots occur? When in pregnancy is a woman most at risk?

Deep vein thrombosis (DVT), a blood clot that occurs in the deep veins, usually in one leg, accounts for about 75% of all blood clots that happen during or right after pregnancy. An embolism happens when a blood clot in the leg travels to the lungs, and pulmonary embolism (PE) accounts for about 25% of blood clots in pregnancy. PE is typically more acute and more likely to be fatal than DVT.

DVT and PE may occur during pregnancy or up to six weeks after birth. DVT is about three times more likely to occur during pregnancy than after delivery. In fact, about half of the women who develop a DVT during pregnancy experience it around the four month mark or right about the beginning of the second trimester. In contrast, about 60% of PE develops soon after delivery or in the six weeks following it.

Are there certain factors that put women at greater risk to develop a blood clot related to pregnancy?

The most common risk factors for PE in the postpartum period are Cesarean delivery and obesity. Given the steadily increasing use of Cesarean section as a delivery choice (currently done in about 3 out of every 10 women), coupled with the obesity epidemic, the risk of having a blood clot related to pregnancy is rising in the United States. Recently, scholars have highlighted the blood clotting risk associated with maternal obesity and recommended that obesity be managed in an effort to prevent thromboembolism (Duhl A, Paidas MJ et al. Am J Obstet Gynecol 2007).

Inherited thrombophilic conditions may also predispose women to develop blood clots in pregnancy. Understanding of thrombophilias (predisposition to clotting) and their impact on pregnancy continues to advance. As is often the case in medical research, initial small studies tend to magnify the impact of inherited risk factors for clotting, while further research either contradicted the initial findings or showed a weaker risk. For example, a case control study published in the New England Journal of Medicine (Gerhardt, 2000) compared the frequency of common thrombophilic conditions (factor V Leiden, prothrombin gene mutation, antithrombin deficiency and protein C deficiency) in two groups of pregnant women: one group of women who developed blood clots with or after pregnancy, and another group who were clot free. The study found that the pregnant women who developed clots had significantly higher rates of the inherited thrombophilic conditions. In fact, factor V Leiden alone was found in more than 2 out of every 5 women with clots, as compared to fewer than 1 in 10 women who did not have any clots. However, when a large prospective (looking forward in time) study was performed on almost 5,000 women across the United States, the findings were different. This study found that among women with no history of blood clots, having factor V Leiden was not found to be associated with clotting in pregnancy (Dizon Townson D, et al, Obstet Gynecol 2005). Because of these inconsistent results, it is difficult to analyze or conclude what the true risk is of developing a blood clot in pregnancy when a woman has an inherited thrombophilia. At this time, typically quoted risk estimates for thromboembolism in pregnancy consist of 0.2% for heterozygous factor V Leiden and 0.5% for heterozygous prothrombin gene mutation.

Does thrombophilia pose other risks to the pregnancy?

Thrombophilia might predispose a pregnant woman to complications associated with damage to the blood vessels of, or blood clots in, the placenta. A group of obstetrical outcomes, known as “placenta mediated complications” are worth considering. These complications include:

- unexplained fetal loss
- preeclampsia- a condition that is characterized by a sharp rise in blood pressure, protein in the urine and more water retention than usual during pregnancy
- placental abruption, where the placenta separates from the wall of the uterus
- intrauterine fetal growth restriction, where the fetus is smaller than expected

Collectively, these aberrations or complications occur in approximately 8 out of about 100 pregnancies.

In 1999, a case control study in connection with severe pregnancy complications associated with three thrombophilias (factor V Leiden, prothrombin gene mutation, methylene tetrahydrofolate reductase mutation) was published in the *New England Journal of Medicine* (Kupferminc, 1999). Kupferminc and his colleagues found that one of these three forms of thrombophilia was identified in approximately half of total miscarriages, preeclampsia, placental abruption and fetal growth restriction, or failure of the baby to grow in the womb. However, larger studies and analysis of compilations of smaller studies have either not confirmed an association, or found only a weak one. Importantly, it must be noted that to date, a large enough study has not been performed from which to derive any meaningful information. The challenge is to find at least 400-800 women with each pregnancy complication to participate in such a large study to accurately assign actual risk level in what is already a relatively rare group of pregnant women with underlying thrombophilias. Fortunately a large, population-based study is underway in a collaboration between Yale University, the University of Copenhagen and Celera, Inc (see Lekke J. *Semin Perinatol.* 2007 Aug;31(4):219-22). Studies such as this will allow us to better understand the true risks of thrombophilia in pregnancy.

Are women who have thrombophilia managed differently during pregnancy?

Presently, if a pregnant patient has a thrombophilia and has had a blood clot prior to becoming pregnant, anticoagulation (i.e. use of a “blood thinning” medication) is recommended during and after pregnancy. Typically, low molecular weight heparin or heparin is the treatment of choice. In most ‘lower risk’ scenarios, low molecular weight heparin does not require any monitoring of blood levels. However, with higher dosing to achieve greater levels of anticoagulation (therapeutic levels), monitoring of blood levels (factor Xa level) is usually performed, to ensure an adequate level of anticoagulation and prevent bleeding complications with ‘too high’ levels. Low molecular weight heparin is more expensive than heparin. Recently, the unfractionated heparin recall (Baxter) has created shortages in unfractionated heparin, further encouraging the use of low molecular weight heparin.

If a woman does not have an identified thrombophilia, and her prior clotting event occurred because of a temporary risk factor, the risk of a repeat clot in pregnancy is low. In this case, only post-

partum anticoagulation (with low molecular weight heparin, heparin or warfarin) is recommended.

It is less clear whether or not anticoagulation is needed in women who have a thrombophilia without a prior history of a blood clot. Options during pregnancy might include being alert to signs and symptoms of DVT/PE, using prophylactic support hose or compression stockings, treatment with anticoagulants only during the six weeks after pregnancy, or in certain unusual clinical situations, anticoagulation during pregnancy.

Since certain research has shown a relationship between some of the inherited thrombophilias and adverse pregnancy outcomes, several investigators have evaluated whether or not the drug heparin, alone or in combination with aspirin, might be helpful in preventing a poor outcome in subsequent pregnancies. Most of the published studies are retrospective (looking at what happened in the past). Women who have already had a poor outcome in pregnancy are screened for thrombophilia and if they do have thrombophilia, they are treated during subsequent pregnancies to increase the likelihood of an uneventful pregnancy with a safe and term childbirth. In most circumstances, such preventive treatment works. However, only recently have pregnant women with a known thrombophilia and a previous pregnancy that resulted in a poor outcome been followed prospectively in subsequent pregnancies. Fortunately, the live birth rate in this group has ranged from 89-98%, even without treatment (Lindqvist PG & Merlo J. *J Thromb Haemost* 2006), raising questions about the need for any medical intervention.

Several studies are underway to examine the value of treatment of thrombophilia in pregnancy. For example, the Thrombophilia in Pregnancy Prophylaxis Study (TIPPS) is ongoing in several countries, including the United States and Canada (www.healthy-pregnancy.ca). Below is a list of other current trials (Hossain N, Paidas MJ. *Semin. Perinatol* 2007).

Properly designed clinical trials are critical to answer these complicated questions about what constitutes proper management of women with thrombosis and thrombophilia. Such rigorous trials address both safety and efficacy questions and can propose sound treatment recommendations after careful analysis to weigh risks and benefits of a particular treatment. For now, until the trials are complete, each patient needs to have thoughtful discussions with her health care providers to navigate the potential options of screening and treating for thrombophilic conditions to avoid blood clots and maximize the chances of a healthy mother and baby.

Table of Clinical Trials

STUDY	www.controlled-trials.com
TIPPS	Thrombophilia In Pregnancy Prophylaxis Study (ISRCTN87441504)
FRUIT	FRagmin in pregnant women with a history of Uteroplacental Insufficiency and Thrombophilia Study (ISRCTN87325378)
ALIFE	Anticoagulants for Living Fetuses (ISRCTN58496168)
SPIN	Scottish Pregnancy Intervention study (ISRCTN06774126)



Women's Health

Andra James, MD, Duke University

Men may actually have a higher overall risk of thrombosis than women, but women have risks due to pregnancy, birth control and postmenopausal hormone therapy that men do not. These risks are generally attributed to estrogen, a key ingredient in birth control pills, patches, and rings, and in postmenopausal hormone therapy. Estrogen does not cause blood clots, but it does increase the risk by several-fold.

Birth control pills, the leading method of birth control in the United States, increase the chance of developing a blood clot by about three- to four-fold. Most birth control pills contain an estrogen and a progestin (synthetic progesterone). Estrogen and progesterone have many effects on a woman's body. They are the hormones that sustain pregnancy and, when given in the form of birth control pills, imitate, and, therefore, prevent pregnancy. Estrogen also increases the levels of clotting factors and is assumed to be responsible for the increased risk of blood clots during pregnancy. For the average woman taking birth control pills, the absolute risk of a blood clot is still small. Only one in 3000 women per year who are taking birth control pills will develop a blood clot; but for the woman with thrombophilia or a history of thrombosis, the risk becomes substantial. The new patches (such as Ortho Evra) may increase the risk slightly more, since the amount of estrogen absorbed is higher than is absorbed with the pill. There is little information about the risk of blood clots with the birth control ring (NuvaRing®), but, like patches and most birth control pills, they also contain an estrogen and a progestin, and, therefore, probably carry a risk of thrombosis similar to that of birth control pills or patches. Since the risk of a blood clot is reduced by anticoagulation, women who are taking anticoagulants should be allowed to take birth control pills.

Women with thrombophilia or a history of thrombosis who are not taking anticoagulants have fewer choices, but alternative methods are available. One alternative is progestin-only contraceptives. Progestin-only contraceptives include progestin-only birth control pills such as Micronor®, Nor-Q.D.®, and Ovrette®; the levonorgestrel (Mirena®) intrauterine device (IUD); every 3-month injections of medroxyprogesterone acetate (Depo-Provera®); and the new, 3-year implant (Implanon™). While progestin in the higher doses used to treat abnormal vaginal bleeding has been shown to increase the risk of thrombosis five- to six-fold, progestin in the doses used in contraceptives has NOT been shown to increase the risk of deep vein thrombosis or pulmonary embolism.

Women who take anticoagulants are vulnerable to heavy menstrual bleeding and bleeding into the ovary or into the abdomen

at the time of ovulation (mid-cycle release of an egg). Half of women who take anticoagulants experience heavy menstrual bleeding. Heavy menstrual bleeding is not a reason to discontinue anticoagulants, however, since it can be managed.

If a woman is on anticoagulation and experiences heavy menstrual bleeding, the full range of treatments may be tried. This usually consists of an evaluation by a gynecologist to make sure there is no abnormality of the uterus or its lining. If there is an abnormality, surgery may be required. If there is no abnormality, hormonal treatments may be tried. Since birth control pills and the Mirena® IUD reduce heavy periods, one or the other may be prescribed. If a woman plans no more children, she may have the lining of her uterus destroyed by a technique called endometrial ablation or she may even have a hysterectomy. Because anticoagulation should be discontinued at the time of an operation, special planning is required if any surgery is performed.

Ovulation is not normally accompanied by any significant amount of bleeding, but in a woman on anticoagulants, the potential exists for bleeding into the ovary and into the abdomen. Bleeding into the ovary is an infrequently considered complication of anticoagulant therapy. Combined hormonal contraceptives with estrogen and a progestin (pills, patches, and rings) prevent ovulation and effectively prevent bleeding into the ovary and abdomen. This is one reason why women who are taking anticoagulants should be allowed to take birth control pills.

Estrogen, besides being used to prevent pregnancy, is used to treat postmenopausal symptoms. Postmenopausal hormone therapy consists of an estrogen or an estrogen and a progestin (synthetic progesterone). Postmenopausal hormone therapy increases the chance of developing a blood clot by two- to four-fold. For the average woman taking postmenopausal hormone therapy, the absolute risk of a blood clot is still small. Only one in 300 women per year who are taking postmenopausal hormone therapy will develop a blood clot, but the risk is much higher for a woman who has had a blood clot or a woman with thrombophilia.

Postmenopausal hormone therapy with estrogen, or with estrogen and a progestin, increases the risk of breast cancer, stroke, deep vein thrombosis and pulmonary embolism. Postmenopausal symptoms such as hot flashes, sleeplessness, vaginal dryness and bone loss can be managed without estrogen. For women who are not taking anticoagulants, but who have had a blood clot or have thrombophilia, the circumstances that would justify taking postmenopausal hormone therapy are rare or nonexistent.

Jennifer Gray's Story

By Jennifer Gray, Miami, FL

If someone would have told me a year ago that my birth control pills were killing me, I would have laughed. At 25 years old, I was on the top of my game. Professionally, I had just started my dream job six weeks prior as a meteorologist at NBC 6 in Miami. Physically, I was in the best shape of my life, even researching where I was going to race my next 5K. I was excited about my new life and job, and thought I had finally found the challenges I had been looking for in my career. Unfortunately, those challenges were only a drop in the bucket for what was slowly surfacing.

Less than 2 months after moving from Louisiana to Miami, I began to experience fever and body aches. I didn't think too much of it, especially considering the crazy hours and long days I was working. The only issue was it didn't seem like the symptoms were improving. After a run of four different antibiotics, I continued to work during the next few weeks. My doctors kept telling me it was a Urinary Tract Infection (UTI). Then, one Sunday morning, when I could barely stand in front of the camera, I finally went to the ER. I had shortness of breath, severe pain in my lungs, and it was all getting worse. The ER doctors said it was mono, but the chest pains were unbearable. When I asked about the pain, they blamed it on the mono and/or anxiety, but I demanded more tests. Only then did the doctors find pulmonary emboli (PE) in both lungs – the largest measuring 9.9mm. With a pale face, the doctor told me I would have died within hours if I had not been so persistent.

As I lay there alone in a strange new city - I had no idea how this would change my life. My physicians were shocked, especially since I was in incredible shape and wasn't a "candidate." After three days in the hospital and countless blood tests, they found I genetically carry factor V Leiden. I also tested positive for several other anticoagulant antibodies that make me more prone to clotting by 50-fold. The biggest surprise to me was that it was my birth control pills that triggered the clot. I guess I never really knew the potential risks involved with taking birth control pills, and I had only been taking them for a couple of years. A few weeks later, my sister found out she also carries factor V Leiden and was immediately taken off birth control. Since that day, I've spent many hours before and after work in doctors' offices undergoing tests. I've been on Coumadin® ever

since. My doctors at the Cleveland Clinic are still debating whether I should stay on Coumadin® for the rest of my life.

My family and friends quickly became my source of strength and support when I couldn't find any within myself. NBC was my family 1,300 miles away from home. Everyone urged me to take as much time off as I needed, but I refused and returned to work less than two weeks after my hospital release. I tried to hide the magnitude of what happened, because I didn't want to appear "weak" in a business that's so demanding of your strength. Even though I struggled with the denial of something so traumatic happening to me in my prime, I just wanted everything to appear normal.

Five months later, I've developed the strength and courage to face these challenges. I know now that life will never be normal, but it can be managed. I learned to not look at Coumadin® as my enemy, but as my saving grace. I thank God every day for giving me a second chance. I have more energy now than ever before and have even completed my first 5K run since the incident. Needless to say, I'm looking forward to my second run. I now look at my obstacles as opportunities to speak out about PE, especially birth control pills risks.

Statistics show that one out of roughly every 20 people have factor V Leiden, and PE is amongst the three top causes of death in the US. The next person does not have to be you. I often wondered about my purpose in life. How would I be able to change the world, even if it were one person at a time? My mission is now crystal clear - raising awareness about birth control risks and blood disorders, so no one else's daughter, sister, mother or best friend will have to experience what I did. I will continue to challenge my doctors, nurses, and educators when it comes to the risks of taking birth control pills.

My new mission reminds me of an old spiritual song – "If I can help somebody as I travel along; if I can cheer somebody with a word or song; if I can show somebody that she's traveling wrong... then my living will not be in vain."

Remember, my story doesn't have to be yours.

jennifer.gray@nbcuni.com



Mary Ellen McCann, RN MA, joins NATT

Mary Ellen McCann, RN MA joined NATT as Director of Health Learning & Marketing in January.

Mary Ellen will be the program manager for NATT's cooperative agreement with the Centers for Disease Control and Prevention (CDC). She will oversee new programs related to:

- health awareness/education/outreach, directed at patients, families and the general public
- curriculum development and training health professionals to be effective in educating other health care providers to assess and intervene effectively with patients with clotting disorders
- creation and maintenance of the CIRC (Clotting Information and Research Center) internet-based information site

NATT Executive Director Alan Brownstein said, "We are fortunate to have Mary Ellen McCann as part of our team, given all of her knowledge and enthusiasm for our mission. Mary Ellen comes to NATT with a wealth of professional nursing and management experience, expertise in patient learning, and marketing skills well suited to this position."

Mary Ellen implemented the Cardiopulmonary Center of Excellence as the sole Cardiopulmonary Clinical Nurse Specialist

with The Visiting Nurse Service of New York (VNS), where she provided clinical direction to 2,200 nurses.

Mary Ellen has authored professional and patient learning materials that were distributed through print and electronic media as the cardiopulmonary nursing resource at VNS. She developed and implemented an INR@Home initiative at VNS and also developed relationships with external partners including hospitals and third party payers to promote the services provided by VNS to increase its referral base.

Mary Ellen has already met in Atlanta with other recipients of CDC co-operative agreements and presented part of NATT's vision to implement the modules within the agreement. She will be providing staff support to the Curriculum Development Team for the professional education project and is very involved in making the Stop the Clot™ message sustainable. Mary Ellen's email address is mmcann@nattinfo.org.



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