

The National Alliance for Thrombosis and Thrombophilia

NATT

Spring 2007
www.nattinfo.org

2006 represented another banner year in the ongoing battle against blood clots. Our last newsletter summarized NATT's involvement in important events, including the Surgeon General's meeting and the Steering Committee for the Joint Committee for Accreditation of Healthcare Organizations (JCAHO).

In the last quarter of 2006, NATT met with leaders of major pharmaceutical manufacturers, including Bayer, Boehringer-Ingelheim, Eisai, GlaxoSmithKline, and Johnson and Johnson-SCIOS, all of whom continue promising clinical trials in the development of injectable and oral anticoagulants to advance the safety and efficacy of the treatment and prevention of blood clots. NATT showed them the "Faces of Thrombosis and Thrombophilia" to remind them that their research and development is paramount in our effort to prevent and treat debilitating and fatal blood clots while providing blood clot sufferers the highest quality and normality of daily life.

NATT also continued its educational efforts through patient seminars, which provide fundamental information on the sign, symptoms and prevention of blood clots. These seminars reach out directly to health care workers and to patients and their families.

NATT accomplished a lot in 2006, but it's not enough! Too many people are still suffering and dying needlessly because of lack of awareness and insufficient or delayed treatment.

NATT's efforts in 2007 will remain focused to closing the tragic gap in awareness.

We will be upgrading and expanding our advocacy, education and communication efforts on all fronts in order to:

- Expand patient advocacy efforts to increase our effectiveness in educating



Members of NATT's Board of Directors (Seated left to right: Lynn Levitt (CO), Lori Preston (MD), Pat Koppa (MN), Elizabeth Varga (OH); Back row left to right: Ed Stransenback (NY), former Executive Director Joe Webber, Tom Hogan (CT), Stephen Kinsman (QC, Canada) at the patient education seminar at the Boston Quincy Marriott in Massachusetts on Oct. 21, 2006. The seminar attracted almost 80 people from the New England area and as far away as Kentucky and Arkansas who were interested in learning about blood clots, their causes, treatment and diagnosis.

- policy makers in Washington D.C. about changes needed to address the major public health issue of blood clots;
- Establish our first local support group to provide convenient and consistent "on the ground" opportunities for patients and to enhance the quality of their lives through shared experience and knowledge;
- Expand (in number and in geography) our patient education seminars;
- Provide wider distribution of our patient education brochures to doctor's offices, clinics, and hospitals;
- Upgrade the NATT website to enhance and expand its utility as a resource for the public, patients, and healthcare providers. We will continue to provide information related to prevention, diagnosis, and treatment of blood clots;
- Continue to expand the distribution of the NATT Newsletter. It will be a tool to update and teach current supporters of NATT, but will also be used to reach out to new audiences who are not yet aware of the dangers of blood clots;
- Expand working relationships and collaborations with governmental health agencies, professional organizations, and other health advocacy groups to pool resources and develop innovative methods for implementing programs of education and support.

With your continued support, we will be up to the challenge in 2007. We will try to expand awareness about blood clots and clotting disorders, and educating others about the hope a patient organization like NATT can provide. We look forward to working for you, and with you, to save more lives in 2007.

Mark Jablonski, *Exiting President*





Blood Clots in Children and Young Adults

Neil A. Goldenberg, MD and Marilyn J. Manco-Johnson, MD

University of Colorado at Denver and Health Sciences Center

The Children's Hospital, Denver, and Mountain States Regional Hemophilia and Thrombosis Center, Aurora, CO

Deep-vein thrombosis (blood clots in the veins of the body; also called DVT) and pulmonary embolism (blood clots in the lungs; also called PE) can occur at any age. Although blood clots occur more commonly in adults, about 1 in 10,000 children will be affected. The first month of life (especially in premature and other hospitalized infants) and the teenage years appear to be times of greatest risk for young people to develop blood clots.

There are some issues that are unique to young people who develop blood clots. For instance, young people with DVT or PE appear to have single or multiple genetic thrombophilia (excess clotting) traits more frequently than older adults, and this can affect the risk of a future blood clot in both the young patients and their family members.

All people, including children and young adults, may develop a chronic condition

of poor venous blood circulation called the post-thrombotic syndrome (PTS) following a blood clot in the arm or leg. PTS is often diagnosed when swelling and pain in the arm/leg develops with activities or when these symptoms persist over a period of months to years following the diagnosis. In severe cases of PTS, there may be skin breakdown as well as pain in the arm/leg while at rest.

What are the causes of venous thrombosis and pulmonary embolism in children and young adults?

DVT and PE in children and young adults can be caused by poor blood circulation (for example, during times of decreased mobility or vein constriction for a prolonged period), damage to the inner lining of veins (such as when a catheter is placed in a vein, or when certain drugs or toxins are circulating in the blood), and thrombophilia states. In children and young adults, a combination

of these risk factors is often present at the time of DVT or PE. Also, in young people, genetic causes of thrombophilia may be important contributing factors to DVT or PE. Sometimes, however, the cause of DVT or PE in children and young adults remains unclear. Research at some specialty centers in the U.S. is focusing on the discovery of new thrombophilia traits and other risk factors in these patients.

How are venous thrombosis and pulmonary embolism diagnosed in children and young adults?

Signs and symptoms

DVT in young people may occur with a variety of signs and symptoms, depending mainly on the area of the body that is affected and the degree of blockage of the vein(s) involved.

Unfortunately, in some cases of DVT and PE, signs and symptoms can be absent. When DVT or PE are found on scans in a patient who does not have (or does not recall) any signs or symptoms, it may be difficult to determine whether the clot is new or old, and this can affect treatment decisions.

Radiologic imaging tests (scans)

For DVT in an arm or leg, ultrasound or computed tomography (CT) is typically used. In some cases, a dye scan of the veins (venogram) or specialized magnetic resonance imaging (MRI) scan that allows detailed views of the vessels (MR venogram) may be required in order to be sure about the diagnosis. To diagnose clots in the brain, MR venogram or CT venogram is typically used. Suspected PE is confirmed by specialized CT scans or by a nuclear medicine scan called a "V/Q" scan.

Laboratory tests

Another critical step in the evaluation includes laboratory testing for thrombophilia. Thrombophilia testing for blood clotting risk factors can vary across treatment centers.

Continued on page 3

Signs and symptoms of DVT

- Unexplained pain and swelling in an arm or leg, sometimes also with redness of the skin;
- Swelling of the head and neck (can occasionally occur in patients with DVT of the arm or chest veins);
- Unusually severe or persistent headache (when the blood clot occurs in veins that drain the brain circulation);
- Weakness of muscles on one side of the face (when the blood clot occurs in veins that drain the brain circulation);
- Unexplained change in vision (when the blood clot occurs in veins that drain the brain or eye circulation or eye vessels);
- High blood pressure and blood in the urine (when the blood clot occurs in kidney veins).

Signs and symptoms of PE

- Unexplained shortness of breath or difficulty breathing;
- Cough that brings up blood;
- Chest pain that usually is worse when taking a deep breath.

What I think a blood clot looks like:

Rachel, 8 years old.



"Ow, my leg hurts!" The blood clots says, "Haha, I've clogged your blood stream." The thigh (thy) says to the blood, "Come on down!" and the blood says, "I can't!"

Continued from page 2

In addition, because young people who develop DVT or PE often have an underlying illness, other laboratory testing relating to the underlying illness may be performed in order to monitor its course. Patients who have other signs and symptoms that could suggest an underlying rheumatologic condition (a broad category of medical disorders -- including lupus, juvenile rheumatoid arthritis, and others -- in which the body's immune system is overactive) may have specialized testing to evaluate for these disorders.

How are venous thrombosis and pulmonary embolism treated in children and young adults?

In a child or young adult with newly-diagnosed DVT, the standard treatment is anticoagulation (blood thinner therapy). Blood thinners typically used include heparin, low molecular weight heparin and/or warfarin (Coumadin®). The blood-thinning effect of heparin and warfarin treatments are measured by blood tests in order to keep the level of blood thinning in a safe and effective range.

In cases of acute DVT that is large and completely blocks blood flow from an arm or leg, special medicines or techniques to remove or break up the clot (thrombolysis) may be considered early in the initial treatment instead of routine anticoagulation (although later followed by anticoagulation).

How are venous thrombosis and pulmonary embolism treated over the long term in children and young adults?

Long-term management of DVT and PE is focused primarily upon: (1) safely preventing further blood clots; and (2) enabling the child/young adult to function as best as possible in school, work, family, and/or society.

Prevention of further DVT or PE

In an effort to prevent further blood clotting (including the worsening of an existing blood clot and the development of a new DVT or PE), most children and young adults with acute DVT or PE are treated with anticoagulation for at least 3-6 months. Some patients, such as those with certain thrombophilia states and individuals who have had multiple blood clots, may be prescribed anticoagulation over a longer period.

In patients with particular underlying medical conditions, other treatments aimed at improving the underlying disorder may also decrease the risk of further blood clotting. For example, in patients with severe infections, antibiotic treatment is also given, and in patients with rheumatologic conditions, drugs to control the overactive immune system may also be used.

To prevent a first or subsequent DVT or PE, all patients and at-risk family members should also take care to avoid dehydration and smoking, and should adopt a regular aerobic exercise program.

Prevention and treatment of post-thrombotic syndrome (PTS)

Enabling the child/young adult to function as best as possible in school, work, family, and/or society involves prevention and treatment of PTS. Clinical research studies in older adults have shown that daily continuous use of compression stockings on an affected leg or arm for a period of at least 1 year following the diagnosis of DVT can reduce the risk of developing PTS. Based on this knowledge, routine use of compression stockings should also be strongly encouraged for all young patients with DVT.

In children and young adults with DVT, if PTS is severe and does not adequately improve with the use of compression stockings, or if chronic SVC syndrome is present (a syndrome of swelling of the

Continued on page 6

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Beverly Thao's Story



Beverly Thao has had multiple blood clots beginning when she was only 18. The causes of her blood clotting episodes are still undetermined. Beverly lives in Northglenn, CO and is currently a sophomore majoring in Biology at Regis University.

I had just been released from the hospital due to a severe allergic reaction. I was allowed to leave, but with some medication and no signs of blood clots. It had been just two days after I left when I began to get a high fever with swollen lymph nodes on the right side of my neck.

The next morning I woke up to go to school when I felt fatigued and had a temperature of 102°F. After going back to the hospital I was sedated and put on a ventilator, and soon found out that I had two blood clots in the right side of my neck.

According to my family and a friend who saw me, my head swelled up twice its size. Everyone was in disbelief. No one knew that I got a blood clot and did not understand how I got it in the first place.

Doctors put me on a heparin drip to allow the blood clots in my neck to deteriorate and to prevent my blood from clotting further. Due to an immediate need to get medication in my body, doctors put a central line in my groin. Eventually, the central line was removed, but the heparin prevented my incision from healing. Finally, it did begin to heal, but then a blood clot developed around a nerve in my thigh, giving me a horrible pain. The tension this created resulted in me not being able to use my left leg until the nerves built back up.

After a couple of weeks in the hospital I was released again, but the doctors kept a close watch on me. I received Lovenox to stay anticoagulated.

Just a week later, I was rushed back in the hospital because I felt a sharp pain in my mid back when I would breathe in and out. After a CT-scan the doctors once again told me that I had a blood clot, but this time it was at a worse spot. The blood clot that was in my neck had traveled down to my left lung resulting in a pulmonary embolism. The sharp pain I was feeling was the blood clot that had blocked a small airway at the bottom of my left lung, causing a little piece to die with the lack of oxygen. If the blood clot had flowed anywhere else in my lung, it could have been even more severe. After being released once again, I was put on Coumadin® to regulate the coagulation of my blood.

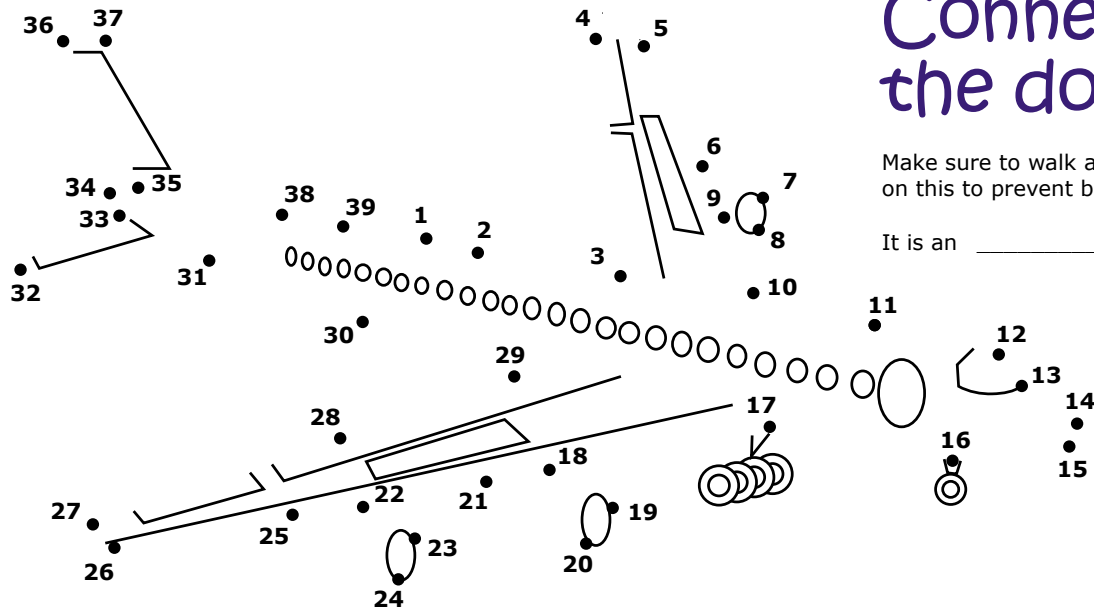
My experience has made me aware of blood clots, their causes and effects. Before this experience, I was unaware what blood clots could do to me and how I could get them. Still, the doctors are not exactly sure where my blood clot formed but they speculate that it originated from the central line the very first time I went in the hospital. After about a year of being on anticoagulants, things have been better and I meet with the doctor often since my medication is watched closely. I now know what things can happen and what signs I should look out for to recognize blood clots.

Word Seek

Find the **RED** words within the Word Seek.

T	A	L	V	I	S	D	R	U	I	P	S
P	V	Z	A	B	D	O	C	T	O	R	N
H	E	A	R	T	M	K	L	E	M	A	W
S	I	N	T	E	A	B	O	J	Q	R	A
V	N	L	E	G	J	C	T	F	P	M	T
T	S	V	R	M	E	D	I	C	I	N	E
D	P	G	I	H	S	Z	N	T	X	G	R
V	A	A	E	K	D	S	T	I	C	K	Y
T	B	I	S	S	P	E	C	I	A	L	N
N	U	R	S	E	L	Z	B	L	O	O	D
P	H	O	C	D	G	A	T	C	U	I	S

The **ARTERIES** carry blood to the lower parts of your body.
 Your **VEINS** carry **BLOOD** from the lower part of your body up to your heart.
 The **HEART** helps pump the blood through your body.
 If you have **STICKY** blood your blood can form a blood clot.
 A blood **CLOT** blocks blood circulation.
DVT stands for Deep Vein Thrombosis.
 Sometimes people who have had a blood clot might have to take **MEDICINE**.
 A **NURSE** and a **DOCTOR** will help you if you get sick.
 Clots often occur in the **LEG** or **ARM**.
 Drink lots of **WATER** to keep your body hydrated!



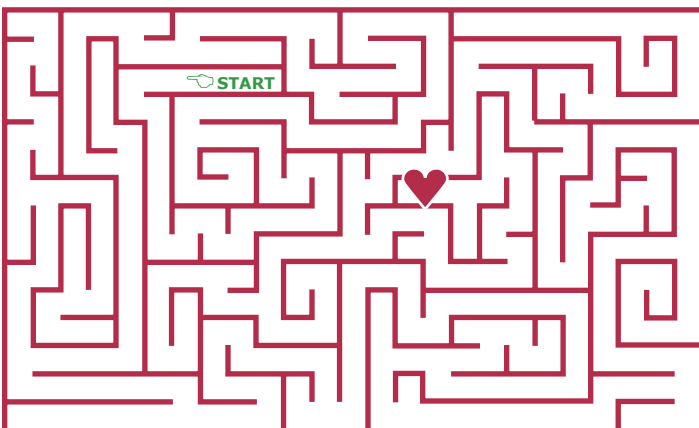
Connect the dots

Make sure to walk around when on this to prevent blood clots!

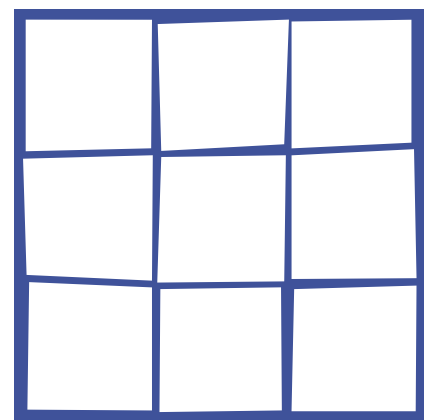
It is an _____ !

Maze

Help the blood find a safe way back to the heart!



Tic-Tac-Toe



☞ LINE ROBILLARD ☞



Line Robillard, founding executive director and spiritual leader of the National Alliance for Thrombosis and Thrombophilia (NATT), died this past October 25 following a courageous battle with cancer.

“Line’s intensity, spirit, and selflessness served as a shining example to all who knew her,” said NATT President Mark Jablonski. “We will remember her for her service and contributions to the patient communities she served and we will honor her by continuing to follow her example.”

Line served as Executive Director of NATT from its founding in August of 2003. Her involvement in the formation of NATT occurred following the gathering in Atlanta, GA of a small group to discuss the development and effects of a patient advocacy thrombosis and thrombophilia organization. Shortly after that meeting, Line volunteered to help a fledgling NATT organization get off the ground.

As our Executive Director, she was instrumental in forming NATT’s governing structure, planning, and coordinating the first series of highly successful patient education seminars. Her years of experience in healthcare provided NATT with the leadership for establishing relationship with industry supporters and other professional organizations.

Line, born in Montreal, Quebec, graduated from McGill University with a degree in Economics and Political Science. She schooled further at La Sorbonne in Paris before working for the European Bureau Chief of The New York Times. She later served for United States Department of State as a political analyst and then as program director at the U.S. National Commission for UNESCO.

From 1981 to 1987, Line was special project consultant for the Royal Commission on the Canadian Economy and to the Canadian Minister of Health and Welfare. Line entered the field of healthcare advocacy when in 1994 she began a 10-year stint as Executive Director of the World Federation of Hemophilia.

Line enjoyed working in her showpiece garden at her country home southeast of Montreal. She adored music and was fascinated by astronomy and exploits in outer and inner space. She’ll be remembered for her great intelligence, her compassion, and for her quiet, but sometimes outrageous, sense of humor. She was without doubt, a Renaissance Woman.

For NATT, she was a spiritual leader who will be missed.

NATT is pleased to announce the recent appointment of Alan P. Brownstein as its new Executive Director.

For over 30 years, Mr. Brownstein has combined his business/strategic planning skills and expertise in public health programs and policy to provide leadership in developing and growing health organizations and shaping health policy/regulation in the U.S. Mr. Brownstein, most recently President and CEO of the National Down Syndrome Society, will begin immediately his work to assist NATT’s efforts and goals.



Blood Clots and Children

Continued from page 3.

head and neck due to blockage of a central vein in the upper body, called the superior vena cava), other options may be available. For example, in some patients, procedures to restore or improve venous drainage may be possible. These procedures (including stenting, venous bypass grafting, and other techniques) are typically evaluated and performed by specialists in interventional radiology or vascular surgery.

Other practical considerations

It is important to work with a knowledgeable team of health care providers, including blood clotting specialists from Hematology, in the care of the child or young adult with DVT or PE. Thorough evaluation of DVT and PE is often challenging, and both short-term and long-term treatment decisions can be difficult. The identification of thrombophilia is an important component of this care, and is best guided by experts in blood clotting. A list of centers specialized in clotting disorders can be found at www.nattinfo.org/provider.htm. ●

SELECTED REFERENCES

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“Laboratory testing for thrombophilia in pediatric patients. On behalf of the Subcommittee for Perinatal and Pediatric Thrombosis of the Scientific and Standardization Committee of the International Society of Thrombosis and Haemostasis (ISTH)”. Manco-Johnson J et al. *Thromb Haemost* 2003;89:204-5.

“Long term outcomes of venous thrombosis in children”. Goldenberg N. *Curr Opin Hematol* 2005;12:370-376.

“How I treat venous thrombosis in children”. Manco-Johnson J. *Blood* 2006;107:21-29.

Editor’s Note: This information, and more, will soon be published in a NATT brochure entitled “Venous Thrombosis and Pulmonary Embolism in Children and Young Adults”. You can request free copies by contacting nattinfo@yahoo.com.

UPDATES FROM THE EDUCATION COMMITTEE

By: Elizabeth Varga, MS, CGC, Committee Chair

It is incredibly exciting to be able to share updates from the Education Committee. Now, more than ever, our committee has made tremendous progress in fulfilling our mission to educate and inform the general public, people affected by thrombosis and thrombophilia, and health care providers. We have improved our capacity to facilitate Education seminars and produce materials as more committee members have stepped up to help with seminar organizing, including Lynn Levitt, Stephen Kinsman, Ed Stransbeck and Tom Hogan who also serve on the NATT Board. Several more volunteer authors and reviewers for education materials were also recruited. We have also been fortunate to have the ongoing support of Jeff Harrison (brochure design and layout) and Marie Walker (web updating).

SEMINARS:

As you can see from the Calendar of Events, the NATT Education Committee has been busy planning Education seminars across the country. We look forward to replicating the success of our Boston and Albuquerque seminars at our upcoming events. These include seminars in:

Minneapolis, MN- April 21st, Sponsored by NATT and the Hemophilia and Thrombosis Center-University of Minnesota Medical Center/Fairview

Pittsburgh, PA- April 28th, Sponsored by NATT and Western Pennsylvania Hospital / Western Pennsylvania Cancer Institute and University of Pittsburgh / Laboratory Institute for Transfusion Medicine.

Salt Lake City, UT- September/October (tentative), Sponsored by NATT and the University of Utah Medical Center and Intermountain Health Care.

Full agendas can be found at www.nattinfo.org/commandevents.

NATT representatives have also been invited to collaborate with other organizations and professional groups to present education sessions. We were grateful to participate in the patient education day at Michigan State University on March 24. We also look forward to a 2.5 hour advocacy session, open to health care providers and the general public, that we are co-sponsoring with the Anticoagulation Forum (a network of health care providers that specialize in anticoagulation therapy

and monitoring). NATT, an organization called ISMAAP, who has advocated for home anticoagulation monitoring, and the Genetic Alliance (who has advocated for improvements in genetic non-discrimination legislation and more) will participate in presentations and panel discussion about awareness and advocacy issues. Other thrombosis/thrombophilia patient groups will be invited to attend. This event will take place from 1:30-4 pm on May 5th at the Chicago Marriott Hotel and we hope to see you there! More information can be found on our website and www.acforum.org.

EDUCATION MATERIALS:

We were fortunate to receive funding from **Talecris Biotherapeutics** to support the printing and distribution of our education brochure "Antithrombin Deficiency: An In-Depth Guide for Patients and Health Care Providers" which was sent to over 6000 health care providers in a March mailing. This, and other education brochures can also be accessed on the NATT website (www.nattinfo.org/brochures). Our newest brochure additions include:

- **Vitamin K and Warfarin**
- **Antiphospholipid Antibody Syndrome**
- **Postthrombotic Syndrome**

Topics to be featured soon include:

- **Venous Thrombosis and Pulmonary Embolism in Children and Young Adults**
- **Stroke in Children and Young Adults**
- **INR and Home Monitoring**

New fact sheets on "The Congenital Thrombophilias", "The Prevention of DVT in Hospitalized Patients", and "Thrombosis in Pregnancy" are now available on the NATT website. These fact sheets were produced by a charity based out of the United Kingdom called Lifeblood: The Thrombosis Charity. NATT and Lifeblood look forward to working together to share resources to help educate and raise awareness.

In the coming months we will be focused on grant writing to fund more seminars for 2007-2008, as well as other education initiatives. We welcome your input regarding what we are doing, and ideas you have for the future.

Make a Difference...
Make a Pledge!
Please Donate Today!

The National Alliance for Thrombosis and Thrombophilia is chartered as a charitable 501c3.

Please send donations to:

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P.O. Box 66018 / Washington, DC 20035-6018

Thank you for your support!

Calendar of Events

What events are happening in your area? Find out about the different thrombosis and thrombophilia related events and activities happening in your community. Also, please check our website for more detail at <http://www.nattinfo.org/commandevents.htm>.

MARCH

DVT Awareness Month (Nationwide Awareness Campaign)

March 24: Patient Education Seminar
Sponsored by Michigan State University.

APRIL

April 13: The New York Chapter of the American College of Surgeons' Annual Meeting
This meeting is intended for members of the health care profession only.

April 21: Patient Education Seminar, Minneapolis, MN

All are welcome to attend. Sponsored by NATT and the Hemophilia and Thrombosis Center-University of Minnesota Medical Center/Fairview.

April 28: Pittsburgh, PA

Sponsored by Western Pennsylvania Hospital/Western Pennsylvania Cancer Institute and University of Pittsburgh/Laboratory Institute for Transfusion Medicine. All are welcome to attend.

MAY

May 3-5: Anticoagulation Forum 9th Annual Conference

To be held at the Chicago Downtown Marriott. Meeting events on May 3-4th are intended for health care providers only. On May 5th from 1:30-4 pm there will be a NATT co-sponsored Advocacy Session open to the public. More information can be found at www.acforum.org.

May 20-24: Cardiovascular Medicine: Review and Update for Practitioner

This CME event is for members of the health care profession only. Information can be found at <http://www.natfonline.org>.

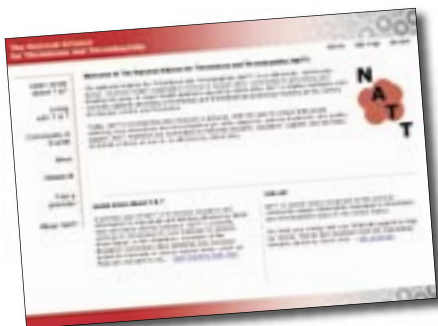
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