

## INSPIRATION

*Many of you have written in, or told us in person at the education seminars how grateful you are for NATT—grateful to have a competent source of information and to have a forum to express your needs, your frustrations, and your hopes. Your feedback validates for us that we are beginning to meet the unmet need that initiated NATT's founding over two years ago.*

*You provide more than just validation though—you provide INSPIRATION. Your individual stories of perseverance and patience and tenacity in the face of the anxiety and physical and emotional pain that often accompanies thrombosis and thrombophilia are a consistent source of inspiration and motivation. And, to top it all off, at the end of your stories, you almost always have just one simple request: How can I help?*

*As we begin to look to 2006, we expect the opportunities for you to contribute your time and talent to abound. Communications, grant writing, fundraising, web development—let us know where your talents and interest are. I, the NATT Board of Directors, and our growing group of dedicated volunteers look forward to working for you and with you to achieve NATT's mission.*

**T**his past spring we identified our top priorities in 2005. I am happy to tell you that we made excellent progress. Each bit of progress makes us better and moves us further in satisfying our mission to *prevent thrombosis, and ensure that all persons suffering from thrombosis and/or thrombophilia receive early diagnosis, optimal treatment and quality support.*

The priorities and progress are as follows:

### **Develop patient education seminars**

We were fortunate to support two education seminars this year in Pittsburgh with the gracious and enthusiastic support of Dr. Margaret Kennedy, Associate Director Hemostasis Thrombosis Laboratory of Western Pennsylvania Hospital and in Chicago at the invitation of the Hemophilia and Thrombosis Research Society.

### **Produce a regular newsletter**

Thank you for your gracious support and feedback on the first edition of this newsletter this past spring. Many thanks as well to the hard working and growing number of volunteers on the NATT Communications Committee who are responsible for producing the newsletter. We look to the newsletter to be an important periodic communication and education tool to stay connected with you.

### **Create educational materials**

A stellar effort from the NATT Medical and Scientific Advisory Board (MASAB) and the Education Committee for producing educational brochures on Family Testing and ATIII deficiency as well as compiling the "Learn More about T&T" page of [www.nattinfo.org](http://www.nattinfo.org). See page 6.

### **Continue advocacy efforts**

NATT's Advocacy committee was successful in introducing language in the Senate Committee report on the Department of Health and Human Services (HHS) highlighting the priority of thrombosis

as an important health concern deserving greater research and attention. Additionally, NATT is exploring the opportunity to collaborate on advocacy with the National Hemophilia Foundation to promote the security and expansion of treatment centers for thrombosis and hemophilia.

### **Defining standards of care for thrombosis and identify research priorities**

NATT was successful in placing a representative on the National Quality Forum/JCAHO project to develop national standard of care for treatment of DVT. This project will affect the DVT treatment protocols of every accredited healthcare facility in the U. S. Additionally, our MASAB met with the National Heart, Lung, and Blood Institute to create a dialog and working partnership to determine the future research priorities for thrombosis and thrombophilia.

### **Secure regular funding**

The accomplishments above would not have been possible without the donations of our individual and corporate supporters. We did not, however, accomplish as much as we needed to. So many who could be helped are not being reached because of the shortfall of funding for NATT. With your continued assistance and generosity and the development of new sources of funding, we will endeavor to change this in 2006.

With 2005 as a basis, I can only be optimistic about NATT's potential to continue to increase its service to the thrombosis and thrombophilia community. The same overarching priorities that guided us in 2005 are guiding our planning for 2006. With your continued support and enthusiasm, I am certain we will be able to do more, do it better, and reach further in serving the broad thrombosis and thrombophilia community that needs our help.

Best regards,  
Mark Jablonski, *President*





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# Update from NATT's Medical and Scientific Advisory Board (MASAB)

*Dr. Stephan Moll, MASAB Chair*

## MISSION

NATT has established a Medical and Scientific Advisory Board (MASAB) to provide advice and support to the NATT Board of Directors in its actions on all medical and scientific matters.

## STRUCTURE

MASAB presently consists of 9 members and is expanding, to eventually include medical specialists with different clinical and research backgrounds, to be able to support the NATT mission. Present make-up:

- Stephan Moll, MD, University of North Carolina, Chapel Hill, NC; hematologist (MASAB chairman);
- Jack Ansell, MD, Boston University, Boston, MA; hematologist;
- Kenneth Bauer, MD, Harvard Medical School, Boston, MA; hematologist;
- Bruce Evatt, MD, formerly Center for Disease Control, Atlanta, GA; hematologist;
- John Heit, MD, Mayo Clinic, Rochester, MN; cardiologist;
- Edward Libby, MD, University of New Mexico, Albuquerque, NM; internist;
- Marilyn Manco-Johnson, MD, University of Colorado, Aurora and Denver, CO; pediatric hematologist;
- Kenneth Mann, MD, University of Vermont, Burlington, VT; biochemist, clotting researcher;
- Elizabeth Varga, Ohio State University, Columbus, OH; genetic counselor.

## RESPONSIBILITIES

- Assist in collecting and presenting accurate information on prevalence, morbidity and mortality on thrombosis and thrombophilia;
- Define research needs and questions and help to advocate for more research resources;
- Help in identifying, writing or editing public education material;
- Provide resources to answer patient questions on NATT's webpage;
- Give medical presentations during patient education seminars;
- Write recommendations on treatment issues;
- Promote standards of care and treatment guidelines;
- Assist in identifying care delivery and health policy issues and advise on their solution;
- Create a network of thrombosis providers;
- Help with fund development and advocacy efforts;
- Work with relevant professional organizations who share NATT's objectives.

## PROGRESS

Until now, MASAB has had two in-person meetings: (1) in San Diego, CA, in December 2004, associated with the annual American Society of Hematology meeting, and (2) in Atlanta, GA, in January 2005, associated with a meeting of US Thrombophilia Pilot Sites with the CDC. NATT's MASAB has:

- discussed and drafted statements on mission, responsibilities and policies under which MASAB will function;
- established a research subcommittee (chaired by Dr. Kenneth Bauer) to define the most pressing research needs, which are to be discussed with the National Institute of Health (NIH) to explore funding;
- provided volunteer speakers at the NATT-organized patient education seminars in Denver, CO, Charlotte, NC, and Detroit, MI, and the NATT-supported seminar in Pittsburgh, PA;
- reviewed and approved the first 2 NATT education brochures ([www.nattinfo.org/brochures.htm](http://www.nattinfo.org/brochures.htm)) - "Family Testing For Clotting Disorders" and "Treatment of Thrombosis".

*Continued on page 4.*

# My journey with Kyle

When my son, Kyle Posluszny, was 17 years old he developed a massive blood clot in his left leg. Doctors had no idea what caused this; and after being released on blood thinners, we were told “this was your one blood clot that your given.” Recovery took a while, but we survived and moved on.

When Kyle turned 18 and was preparing to go to college, he began having headaches – at the same time of the year he always does – and the usual “cure” was allergy medicine. After about a week of “did you take your medicine” and “my head still hurts,” he agreed to go to the university hospital to be evaluated.

As we were in route to the university hospital, Kyle started getting real frustrated and almost confused ...I knew something wasn't right. He tried to relax and kept asking me “where are you taking me?” He had no idea what was going on or where we were going. Neither did I.

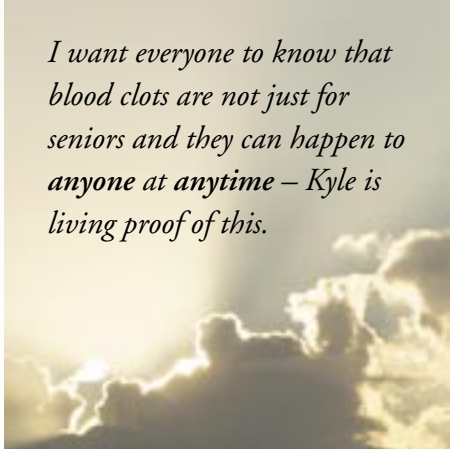
Upon arrival at the hospital, they immediately took Kyle in the back. After numerous doctors came in, it was evident that Kyle was losing some sort of “being” and they recommended a CT scan of his brain. Within 5 minutes, I saw doctors running down the hall towards me with Kyle on the gurney. I was thrown a file, told to follow them and we were rushed into the MRI unit. Kyle was having a stroke.

After being in the MRI machine for an hour, it was confirmed that Kyle had a massive blood clot in his head (*sinus vein thrombosis, leading to severe swelling of the brain. Medical Editor*) The tech said he “never saw anything like it.” We were admitted into the critical care intensive care unit and my world just stopped.

After a few days, the swelling of the brain hadn't subsided and Kyle was slowly slipping into a coma. He was curled up, couldn't talk or even blink his eyes. The doctors said his stroke was equivalent to an 80 year old man. Why?

When digging deeper and looking into Kyle's massive hospital file, it was determined that his blood needed to be evaluated by one of the specialized academic thrombosis university hospitals in the U.S. His doctor made the arrangements and the results were astounding.

Kyle had an elevated homocysteine level to 79 (normal would have been 14 or under). The homocysteine level in your body is normally not checked until you get into your senior years....not a need for an 18 year old for sure! We were able to trace this elevated level back into Kyle's medical history. Kyle was born with his intestines on the outside of his body - therefore



*I want everyone to know that blood clots are not just for seniors and they can happen to anyone at anytime – Kyle is living proof of this.*

having him lack vitamin B-12 and folic acid. Having a lack of those two vitamins will increase a homosysteine level in your body...bingo....blood clot!

Now we found out why, but Kyle was pretty much slipping into a deeper coma and his doctor told me to “be prepared” and “there wasn't much more they could do”. If they opened him up, they would lose him. If they let him go, he would probably just slip away from us and die. I couldn't accept this.

As I stood over Kyle and his curled up, unresponsive body, I began to cry. I remember watching my tears pool up on his shoulder and roll down his side. I was numb, crying and telling him to hang in

there – he wasn't going to leave me now. We were a team. I KNEW he could hear me.

Just before 5:00 a.m., I heard the word “Chili” and thought that someone else had spoken. Then we heard it again, “Chili” I jumped up, ran to Kyle and asked if he was cold and needed a blanket. Out of nowhere, he rolled over, stretched his arms, rubbed his eyes and even shook his head and stared at me in a complete daze. In a slurred, slow, speech, he said “No! I want Wendy's Chili”.....go figure, the kid was hungry!

Doctors piled into our room, I was stunned, and Kyle was hungry! As he slowly recovered, Kyle was moved into a different room and it was determined what path we were going to take. Kyle survived again, defeated the odds and later told me that he felt something wet on his shoulder (my tears) and could hear me saying something to him...did he wake up because of this?

Kyle turned 20 this past May and August 17th marked our 2 year anniversary since his massive stroke. He currently takes a Folic Acid vitamin daily and goes for once-a-month B-12 shots. Every 6 months he has blood work done and it includes checking the homocysteine level. At our last visit, we were told that all is good and not to come back for one full year!

My thanks to NATT for bringing Thrombosis and Thrombophilia to light. I want everyone to know that blood clots are not just for seniors and they can happen to anyone at anytime – Kyle is living proof of this. I encourage anyone that has had the unfortunate experience of a blood clot or knows of someone that does, to get involved with NATT...there is power in numbers and together we can educate and help those who need it most....before it is too late.

Laura Zain,  
Mother of Kyle Posluszny  
Livonia, Michigan



# Jessica Earley's Story

Today was a cool, brisk November day, and I decided to go visit Jessies' Garden. I climbed from my car and walked the short distance to the spot where our journey ended two and a half years ago. We brought her here to her final resting-place while the bagpipes she loved played Amazing Grace. I look at her picture on her marker - the shining dark hair - the dark eyes that could look at you as if she were looking clear to your soul.

Her name was Jessica, but she was also Jess, Jessyroo, Miss Jess just to name a few. It all depended on who was addressing her, to me - she was Jessie. She was more than beautiful - she was striking - with a smile that could turn the grayest sky blue. Jessie never thought she was beautiful. She worried as most young girls do when her face - mainly her cheeks - would break out. She was on the color guard at her high school and later at Appalachian State University. She wanted to look her best and she and her mother tried everything but nothing seemed to help. In 2000, she had a physical and her gynecologist recommended she try an oral contraceptive - explaining that they had the side effect of clearing your complexion. Due to her busy college schedule, Jessie would sometimes forget to take her pills so she was told about the patch you applied only once a week and tried it.

Jessie became ill in the early months of 2003. Her body - strong and athletic - began to weaken. She suffered extreme bouts of nausea and vomiting. Her stomach began to swell. Through this horrible ordeal, at time being so sick she could hardly hold her head up, her goal was to complete her junior year at college. She managed to do so returning home on a Tuesday only to spend a miserable night of pain. The following day she was admitted to a local hospital and the following Friday airlifted to a university hospital. (*Diagnoses: Hepatic, portal, mesenteric and partial inferior vena cava thromboses. Medical Editor*)



Left to right: Jessica and Allison

My daughter Allison and I drove to visit Jessica on May 21, 2003 not knowing what to expect, but praying we would find her doing better. What we did not know was that the worst of Jessies' fight was already over. Her Mother, Kathy, told us about the screen they placed to keep the blood clots from moving to her lung, the port a cath they placed in her side, the pain she suffered as the clots moved through her body. She had been placed in a

coma to keep her from suffering what was explained as excruciating pain if she were allowed to awaken.

The reason behind this nightmare - the culprit that had attached itself to her - was a genetic blood disorder (*Heterozygous factor V Leiden. Medical Editor*) that combined with oral contraceptives caused her blood to clot.

This beautiful young lady, this child that I watched grow up - who gave so much - who was loved by so many, was allowed to believe that

because she had no medical problems, that she did not smoke, that she appeared healthy and had no history of blood clots, would have no problems taking oral contraceptives.

I look at her picture on her marker now and I think how ironic and tragic it is that she had a beautiful complexion - when she died. As I stand and look at her marker, at her grave that we call Jessies' Garden because it is easier for us to say, as I think of her Mother who buried her only child - the joy and sunshine of her life - I realize that I was wrong. This is not where our journey ended - this is where our journey begins.

Those of us who loved Jessie, who still love her and always will - have made a vow to her to keep this from happening to someone else's child. This is Jessica's story - and this is only the beginning!!!

*Terry Peterson. Stanley, NC, close friend to Jessica and Kathy Earley.*

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## MASAB *Continued from page 2.*

### GOALS

- expand its membership to include various specialties, such as obstetrics-gynecology, emergency medicine, neurology, family and general medicine, pharmacy, nursing, and others;
- assist in writing and reviewing further NATT education brochures;
- define the most pressing research needs and sponsor an expert meeting together with the NIH;
- discuss the creation of an editorial board for a Q/A education section for the NATT website;
- provide support for further patient education seminars.

# Air Travel and DVT:

## *Researchers present the latest findings at international forum*

By: Cynthia A. Kos, NATT Volunteer

In a high-paced society, even two-hour flights can seem “long-haul.” This year, researchers flew for as much as 12 hours to attend the XXth Congress of the International Society of Thrombosis Hemostasis (ISTH) held August 6-12, 2005 in Sydney, Australia. It is perhaps fitting that of the multitudes of studies presented, several concerned the association of air travel as a risk factor for deep venous thrombosis (DVT).

Symington and Stack, who reported an apparent increase in DVT in air travelers compared to non-travelers, first described “Economy Class Syndrome” or “Traveler’s Thrombosis” in 1977. The incidence was attributed to cramped seating in the coach cabin. Prolonged periods of inactivity caused by space limitations may slow circulation and produce edema (leg swelling). In addition, bent knees compress the popliteal vein (the deep vein behind the knee), creating a potential site for clot formation over time. Low oxygen, low humidity (dry air), and low cabin pressure at high elevations have a dehydrating effect that concentrate the blood, making it sluggish. This effect is worsened when passengers consume alcohol, or do not adequately replenish fluids lost by dehydration. The body’s natural clot busters typically counter the tendency to clot in these situations; however, in the presence of known hypercoagulable risk factors such as the Factor V Leiden and the Prothrombin G20210 mutations (as well as obesity, smoking, and oral contraceptives) the risk of DVT could be further increased. At this year’s ISTH meeting, several studies attempted to scientifically document a passenger’s general tendency to clot after air travel.

Studies from Ospedale La Carità and University Hospital of Berne (Switzerland) found that changes in clotting enzymes during long periods (6 hours) of sitting increase levels of certain anticoagulants (Tissue Factor Pathway Inhibitor and Antithrombin). This physiologic response resulted in several other adjustments to the clotting cascade that ultimately balanced the effect by increasing Factor V and VIII

levels. Thus, the net effect of immobility itself did not necessarily increase a clotting tendency.

Another group led by Anja Schreijer at Academic Medical Center and Leiden University Medical Center (Netherlands) investigated the issue further by comparing thrombin levels in air travelers versus immobile non-flying individuals who watched movies for 8 hours. Thrombin is the product of preliminary reactions in the clotting cascade and activates fibrinogen to form fibrin (the meshwork of a clot). They



At this year’s ISTH meeting, several studies attempted to scientifically document a passenger’s general tendency to clot after air travel.

found a 223% rise in levels due to traveling compared to 46% rise due to immobility. This suggests that a mechanism other than immobility caused the travelers to be at an increased thrombotic risk.

The Dutch research group also headed the WRIGHT Study, which retrospectively surveyed the occurrence of DVT amongst employees of three international companies for four weeks and after a flight of at least four hours. Compared to non-traveling employees, the frequent flyers were found to be 3.65 times more likely to develop a DVT. The risk of developing a clot on a flight was found to be 1 in 5944 flights.

If more than one flight was taken in the four-week window, the risk of clotting was slightly elevated.

AirHealth.org, a non-profit organization dedicated solely to the topic of travel-associated thrombosis, reports that 3-5% of air travelers will develop clots. Despite continued research, case reports, and a physiological basis for increased risk, not all experts agree that air travel is a direct cause of thrombosis due to a lack of large-scale population studies. Such studies are difficult to evaluate, in that the extended period between flight time and presentation of DVT or PE symptoms induces variability.

In the absence of large-scale studies, some airlines feel there is no scientific basis to warrant thrombosis prevention on flights. Ironically, most airline inflight magazines include extensive instructions on how to avoid DVT during flight. However, the apparent increase in risk has prompted some afflicted travelers to cite the Warsaw Convention of 1929, which holds airlines liable for damages when passengers are injured by an accident, as grounds to file negligence claims against the carriers. The debate is whether a blood clot is a preventable event, or an individualized reaction to normal flight operations. The first cases presented in United States district courts began in Texas (Reynolds vs. American Airlines, 2002) and California (Miller and Wylie vs. Continental Airlines, 2003). Since then, hundreds of cases have been filed domestically and internationally. To date, inconclusive medical evidence has resulted in most airlines to disclaim responsibility. Such attention in both the medical and legal arenas emphasizes the importance of the latest medical studies, as they continue to investigate a cause-and-effect relationship between long-haul air travel and thrombosis.

Until it is clarified whether airline travel is or is not a risk factor for thrombosis it appears appropriate for travelers to engage in some DVT prophylaxis exercises, be well hydrated, and avoid alcoholic beverages during flights.

## UPDATES *from the* EDUCATION COMMITTEE

Greetings from the Education Committee! We are excited to share our achievements from 2005. Some of the highlights include:

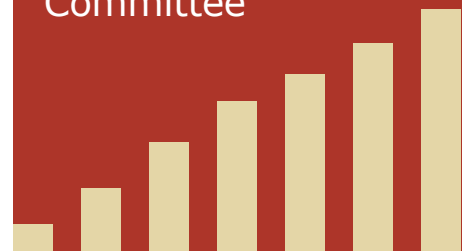
- **The addition of a “Resources for Health Care Providers” section on the NATT website (<http://www.nattinfo.org/learn-resources.htm>).** In this area, health care providers can find downloadable, peer-reviewed, patient information that can be used as hand-out material in clinic. The topics are:
  - Factor V Leiden
  - Prothrombin G20210A (the factor II mutation)
  - Antiphospholipid antibodies
  - Homocysteine and MTHFR: Relation to Thrombosis and Coronary Artery Disease
  - Prevention and Treatment of Blood Clots
  - Pulmonary embolism (PE) and Deep-Vein Thrombosis
- **Attendance at the Anticoagulation Forum meeting in May 2005.** The Anticoagulation Forum meeting takes place every other year and attracts health care providers from around the country who are seeking education on anticoagulation (blood-thinning) therapy, and other thrombosis and thrombophilia topics. Through participation in this forum, NATT increased awareness of the educational needs of our constituents—and interacted directly with the providers who may be able to help support our mission.
- **Presentation at the Anticoagulation Forum meeting.** Work from the NATT Education Committee was also used to create two scientific posters which were accepted for presentation at the meeting. The first, entitled: “Availability of Educational Materials for Patients and Families with Thrombosis and Thrombophilia—A Review of Printed and Web-Based Literature” discussed the Education Committee’s review and compilation of materials for the NATT website, and the identification of “gaps” in the available information for patients. We presented your feedback from NATT conferences in the second poster, entitled: “Education Needs of Patients and Families with Thrombosis and Thrombophilia: Results from Two Patient Education Seminars.”

Now we are beginning to think about our next **NATT Seminar**, likely to be held in **Rochester, Minnesota in April, 2006**. Our Committee also hopes to expand and improve the website, by adding new educational content, and possibly a **chat/message board** feature. We hope to develop, and make accessible, an extensive **resource library** for consumers and health care providers. Lastly, we hope to create a **Speaker’s Bureau**, comprised of health care providers and individuals affected by blood clots and clotting disorders. Our biggest limitation in moving forward with these items is a lack of human and financial resources. **We desperately need volunteers to help!** Therefore, we have created short descriptions of open volunteer positions for our committee. If you would like to become involved, please review the positions on our website and contact Lynn Levitt at [nattinfo@yahoo.com](mailto:nattinfo@yahoo.com) to learn more.

We hope to hear from you soon!

Elizabeth Varga, M.S.  
Chair-NATT Education Committee

## Report from the Income Development Committee



As rich in passion and energy as we are becoming with an increase in the number of NATT volunteers, it still takes dollars to fund the programs necessary to reach out to you and others through educational programs, literature, and the NATT website. More needs to be done and NATT’s Income Development Committee is well into its planning for 2006 to help make this happen. One of the features of our fundraising focus in 2006 will be on promoting efforts of local fundraisers like Karen Kirchoff (see page 7) who raised over \$1,000 through pledges for her run in the Virginia Beach Rock & Roll Half Marathon. If you have an idea (and the energy and time) to coordinate local fundraising activities, please contact us.

**Our goal is to raise  
\$350,000 in 2006**

Our other efforts will focus on cultivating a broader base of individual donors who are passionate for our cause, reinforcing existing and creating new relationships with government and industry funding sources, and seeking private foundations sympathetic to our mission. I want to thank all of our PIONEER donors who helped us raise over \$50,000 through March 2005. Our goal is to raise \$350,000 in 2006—a lofty, but necessary, goal to meet the critical needs of the thrombosis and thrombophilia community.

In addition to your ideas, we would also welcome the priceless gift of your talent. If you have specific experience in development/fundraising and want to contribute your expertise to our effort, please contact Lynn Levitt at [nattinfo@yahoo.com](mailto:nattinfo@yahoo.com) for more information on opportunities to help.



# Karen Kirchhoff's Story

In July of 2004, I was diagnosed with a DVT in my left leg. I had experienced swelling and pain in my left calf, ankle and foot, in addition to fatigue. Until I was diagnosed however, I didn't have the faintest idea what was wrong with me! My mother had experienced two PE's years ago. I made no connection to her experience in my mind, because my symptoms were not similar. At the time, I was training for the Falmouth Road race on Cape Cod – a popular seven mile race. I only made a doctors appointment because I was having trouble getting my swollen foot into my running shoe! I was lucky to be under the care of a very competent doctor who immediately recognized that I might have a blood clot and sent me straight to the hospital.

Aside from the physical pain of the experience, I found it had a tremendous emotional effect on me that I could not have anticipated! It was very difficult for me to accept the fact that my body was not doing what it was supposed to do! Here I was doing everything to keep up my end of 'the deal': running, eating right, not smoking, etc. My body was not cooperating! I felt disappointed, frightened, and extremely vulnerable. My thoughts drifted back to when I was a child, seeing my mother hospitalized twice with PE's. It was a traumatic experience, and I was afraid this was my fate as well. My fears only increased as I spoke to my mother after my diagnosis, trying to gain some insight and information. Her doctors had never determined what caused her multiple PE's. I was also told that I should prepare my self for the possibility that they may never know what caused my blood clot.

Months went by, and I gradually became accustomed to taking Coumadin and getting my regular blood tests. But I still felt very alone in the whole experience. It was only when I began to attend a monthly support group for people who had suffered from thrombosis/thrombophilia that I found some help coping with my condition. The group was started by Dr. Goldhaber at the Brigham & Women's Hospital in Boston, Massachusetts. I finally realized I was not alone! As I listened to people's stories, I was moved and inspired by their strength, insight, sense of humor and perspective. I credit the support group for helping me get out of my rut. Up until that point, I had for the most part abandoned my running. I was now inspired to pick it up again, and raise it to a new level! On New Years day, 2005, I sat with some friends and we discussed our goals for the new year. I wanted to run at least one half-

marathon, and possibly a full marathon, depending on how my body held up.

In a matter of a month, I found a running partner and picked my goal: the Virginia Beach Rock & Roll Half Marathon on September 4th, 2005. In the world of running, many people run for a cause. There are numerous training groups organized by various worthwhile charities. Training for a half or full marathon takes dedication and persistence (not to mention lots of aches, pains and early mornings!), so I wanted to raise money for a cause that had real relevance to my life. This is what brought me to NATT. I first became aware of NATT

through the support group at the hospital. I went to the website, sent out an email explaining my idea, and within a week I had a plan!

So I drafted a brief one page letter explaining my experience with DVT, how it effected me, and what I was doing about it. I enlisted the help of my sister-in-law who spent many years working for both profit and non-profit organizations as a fundraiser. Her advice to me was simple: people want to hear *your story*.



*Karen Kirchhoff, NATT volunteer and Heidi Merlini.*

I emailed my letter to all my friends, family, and co-workers. Additionally, with the help of a friend, I baked and packaged 50 'pairs' of foot shaped cookies in cellophane bags. I gave them to my friends, along with several copies of my fundraising letter, and they kindly brought them to their office break rooms, with an envelope to put donations in exchange for the cookies. The positive response and support was overwhelming! I managed to raise approximately \$1200 at the time I am writing this, and I'm still getting checks in the mail!

There are hundreds of organizations out there competing for donations, so what makes yours different? YOU. Your story is unique. You will be surprised at people's generosity and willingness to give when you tell them your story. It's really as simple as that.

As I ran the final miles of the half-marathon on that warm Sunday morning, I had many thoughts in my mind. By completing this race, I had regained confidence in my athletic ability, and restored faith in my body's ability to perform. Maybe more importantly, I had raised awareness about DVT and PE, and raised funds for a wonderful, community based organization. I would like to thank everyone at NATT for their encouragement and support. I couldn't have done it with out you!

## Make a Difference... Make a Pledge!

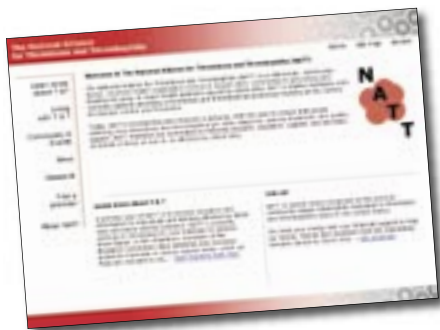
Your donations fund the programs and activities that make a difference in the lives of T&T patients:

**\$20,000** can fund an educational seminar for 300 patients, healthcare providers and family members

**\$5,000** can fund the production, printing, and mailing of this newsletter or a patient educational brochure

**\$3,000** can help fund NATT's outreach to professional medical societies whose members need to be educated to recognize and treat T&T patients

**\$2,000** can fund the development and hosting of the NATTInfo.org website for a year



View our website:

[www.nattinfo.org](http://www.nattinfo.org)

## Calendar of Events

What events are happening in your area? Find out about the different thrombosis and thrombophilia related events and activities, when they're happening in your community, and how you can participate. Also, please check our website for current events happening in your area at [www.nattinfo.org](http://www.nattinfo.org).

### December 2005

**The American Society of Hematology  
47th Annual Meeting and Exposition**  
December 10-13th  
Georgia World Congress Center  
Atlanta, Georgia  
More information can be found at  
[www.hematology.org](http://www.hematology.org)  
For health-care providers only.

### March 2006

**DVT Awareness Month**  
Nationwide public awareness campaign  
sponsored by The Coalition to Prevent DVT  
([www.preventdvt.org](http://www.preventdvt.org))

**Public Education Seminar on Blood Clots**  
March 4th  
Chapel Hill, North Carolina  
For program and directions, see  
[www.nattinfo.org/chapelhill\\_agenda.doc](http://www.nattinfo.org/chapelhill_agenda.doc).

### April 2006

**2nd Annual Hemophilia and  
Thrombosis Research Society (HTRS)  
Symposium**  
April 20-21st  
Northwestern Memorial Hospital,  
Chicago, Illinois  
For information, contact:  
[karen.lombardo@bcw.edu](mailto:karen.lombardo@bcw.edu)  
For health-care providers only.

### May 2006

**Dr. Margaret Kennedy's  
"Blood in Motion" seminar**  
May 13th  
Pittsburgh, Pennsylvania  
For health care providers only.

## NATT Donations

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

Please send donations to:

**The National Alliance for Thrombosis and Thrombophilia**  
P.O. Box 66018  
Washington, DC 20035-6018

*Thank you for your support!*

AWARENESS • PREVENTION • TREATMENT • SUPPORT



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