



National Blood Clot Alliance

Stop The Clot®

IN THIS EDITION: Orthopedics and Blood Clots

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Letter from the President

As president of the National Blood Clot Alliance, I get many inquiries about the world of blood clots and clotting disorders. Among the most common inquiries relate to problems people are having with health insurance. They are not able to afford it or they can't get coverage because their clotting disorder is considered a preexisting condition and they are denied. Even if they have insurance, there may still be limits that affect which drugs are covered.

These are always difficult questions to address. Sometimes I know of a volunteer program that will ensure that the person gets medical care. In some cases, a pharmaceutical firm has a subsidy program to provide medication to people who can't afford to purchase it. Usually, however, there is no adequate answer to the questioner's need. It is frustrating to head a patient advocacy organization and not be able to solve insurance coverage issues.

Those days of frustration may be limited, however, with the enactment of the new health reform law. Although it continues to be a contentious issue in Washington, DC, and many other parts of the country, it may offer great hope to people whose clotting history or life circumstances have forced them outside of the standard health insurance system. Only time will tell if everything works as planned, but a new direction has been set that I hope benefits those who need help, and does not disrupt insurance coverage for people who already have it.

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NBCA has a Strong Presence at the National Conference on Blood Disorders in Public Health

National Blood Clot Alliance, formerly NATT, was strongly represented from beginning to end at the 1st National Conference on Blood Disorders in Public Health: Making the Connection. The conference was hosted by The Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Division of Blood Disorders, in partnership with the Health Resources and Services Administration, the National Heart, Lung, and Blood Institute, and the American Society of Hematology. It was held March 9-11th in Atlanta, GA.

As featured elsewhere in the newsletter, NBCA was given a prime speaking opportunity to announce its name change right before the opening plenary on the morning of the first conference day. This

was followed by an introductory video on blood disorders, where Lynn Levitt, Board member, talked about the impact of her blood clot, and the importance of NBCA.

National Blood Clot Alliance staff, volunteers, Board and MASAB members gave key presentations throughout the 3-day meeting. *Awareness and Gaps in Knowledge of DVT/PE in General Public* was presented by Alan Brownstein, CEO and was prepared in collaboration with Jack Ansell, MASAB Chair. This presentation gave an overview of preliminary data from a survey of patients about their recognition of blood clots, signs and symptoms, and medical terminology. This project was sponsored by Ortho McNeil.

It followed a presentation on *Knowl-*
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Grassroots Fundraising Efforts Gain Momentum

Build on the Grassroots Fundraising Campaign!!! An inspiring development at the National Blood Clot Alliance this year is all of the dedicated people who joined in grassroots fundraising efforts. Whether it was a 5K walk, marathon, baseball game, awareness reception, kick-ball tournament or a personal tribute, the National Blood Clot Alliance sincerely thanks and applauds all of the NATThletes, participants, volunteers, donors and staff who are spreading the Stop The Clot® message and raising funds to promote awareness about blood clots.

The National Blood Clot Alliance's partnership with the leading social fundraising platform, Firstgiving, is raising funds to alert people to the risk of blood clots and clotting disorders. Currently, there are over 60 Firstgiving fundraisers who have raised over \$30,000 in the past few months! A

fundraising page can be set up in about 5 minutes by going to <http://www.firstgiving.com/natt>. It is a perfect site to showcase a personal clotting victory, post photos, and use social media like Facebook to promote the vital mission to prevent blood clots to save lives. Check out a few fundraising tips below to get started on your fundraising efforts today. More tips can be found on www.stoptheclot.org.

National Blood Clot Alliance has staff available to guide you when you join this essential grassroots effort to raise funds. Contact National Blood Clot Alliance by calling 1.877. 4 NO CLOT, e-mail Kristen Holgerson at kholgerson@stoptheclot.org or Judi Elkin at jelkin@stoptheclot.org or visit http://www.stoptheclot.org/events/natt_fund_raiser.html.

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National Blood Clot Alliance Hosts Fundraising Walk to Stop the Clot[®]

by Traci Wilkes Smith



Members of The Association of Black Women Attorneys and The National Blood Clot Alliance stand together for the first annual blood clot and blood disorder awareness walk-a-thon in Prospect Park, Brooklyn N.Y.

On March 20, 2010, one of the more beautiful first days of Spring in many years, more than 40 walkers gathered in Prospect Park, Brooklyn, NY for a 5K walk to spread the word about blood clots in recognition of March DVT Awareness Month. Family, friends, members of the National Blood Clot Alliance and the Association of Black Women Attorneys (ABWA) donned the StopTheClot[®] signature red and white polka dotted T-shirts and wristbands to showcase the organization's key message. Alan Brownstein, CEO, Kristen Holgerson, Director of Development, and Traci Wilkes Smith, Vice President of National Blood Clot Alliance, and Yomi Ajaiyeoba, Community Service Chair of ABWA welcomed the participants, and thanked the top fundraisers for their commitment and dedication to such an important cause.

Traci started the event with an inspiring message to the participants that one vital goal of this walk was to help save at least one life by raising awareness about the risk of blood clots.

Then the walk began! The dedicated walkers navigated the foot and bike traffic going in the reverse direction in the park. The National Blood Clot Alliance banner

was carried front and center and Stop the Clot[®] materials were distributed to the passersby. Joggers and bicyclists were high-fived, and the energy was infectious. Alan Brownstein created the following ditty for walkers to chant and bystanders to hear:

*We do our walk, we do our trot, as we
chant the words: Stop the Clot[®]!
Prospect Park hits the spot, Get the
message, Stop the Clot!
The ABWA team is what we got,
Stop the Clot! Stop the Clot!*

The following week, on March 25, 2010, the team gathered for a celebratory reception at Georgia's Boutique in Soho, NY. Dr. Jacob H Rand, MD FACP Director, Hematology Laboratories, Montefiore Medical Center, gave valuable information about the signs and symptoms of blood clots. Caitlin Augustine, a young, multiple DVT survivor, shared her compelling story. It was a successful evening and another opportunity to deliver the essential Stop the Clot[®] message!

Stop The Clot[®] pins were handed out to top Team ABWA fundraisers to commend their effort that ended up raising almost \$5,000.

NBCA has a Strong Presence

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edge of Deep Vein Thrombosis in the United States that was presented by Sara Critchley, the CDC Project Officer for National Blood Clot Alliance.

Alan Brownstein served as proxy for Randy Fenninger, Board President, in presenting *A Patient Advocacy Response to the Surgeon General's "Call to Action"* (to Prevent Deep Vein Thrombosis and Pulmonary Embolism) that summarized how many of National Blood Clot Alliance activities enact the "Call to Action."

Richard Quattrocchi presented *Use of Online Media to Promote Public Awareness of Blood Clots and Clotting Disorders* to demonstrate the tremendous success of the website redesign and outreach of StopTheClot.org.

There was a team presentation at a "Special Session" on the *Stop the Clot[®] Education Program for Patients with Blood Clots and Clotting Disorders* that was moderated and introduced by Elizabeth Varga. Mary Ellen McCann, Director, Health Learning & Marketing, described program need, planning and implementation, marketing, essential collaboration with volunteers, impact, and lessons learned. Pat Koppa, former and founding Board member, described the success of support groups and Richard Quattrocchi described website growth and outreach.

Elizabeth Varga and Mary Ellen McCann presented posters at the poster session entitled *Stop the Clot[®] Forums: A Successful Model for Patient Education About Thrombosis and Thrombophilia and Needs Assessment for Clotting Care Online Curriculum Design for Nurses, Pharmacists, and Physician's Assistants* respectively. Both posters highlight National Blood Clot Alliance's focus on education of patients and providers about blood clots and clotting disorders.

Alan Brownstein was on the panel of the Closing Plenary entitled *Future Public Health Directions: The Partner Perspective* where he again emphasized the major public health threat of blood clots, and the need for collaborative partnerships.

The presence of National Blood Clot Alliance at this meeting was strong, and it was the most consistent voice for blood clots and clotting disorders. It highlighted the pivotal role of National Blood Clot Alliance in responding to the essential public health service to *inform, educate, and empower people about health issues.*

Letter from the President

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The world of health insurance will not change overnight as many of the most important provisions won't go into effect until 2014. But there are interim actions that could help many of the people who ask the National Blood Clot Alliance for help and guidance on insurance matters.

Although the law is complex, the framework is straightforward.

- First, everyone in the country will have to be insured, beginning in 2014, or pay a penalty.
- Second, employers will have to offer health insurance to employees, or pay a penalty. There are some exceptions to these two mandates, but other mechanisms will be available to help people get insurance coverage in cases where exceptions apply.
- Third, for those people who can't get insurance through their employer, there will be new exchanges, or insurance markets established to allow people to purchase insurance that today is not available to them.
- Fourth, there will be income-based subsidies to make sure that people can actually afford the insurance they need.
- Fifth, no one will be denied insurance because of their health status. For example, a history of blood clots will not be a reason for an insurance company to deny coverage to an individual.
- Finally, public programs like Medicaid will be expanded to cover more people.

Experts estimate that as many as 32 million Americans who currently don't have insurance will be able to get coverage once all of these steps are in place.

While we are waiting for federal, state and local officials to write the rules that will be the framework beginning in 2014, some actions are already being taken that may help many of the people who contact the National Blood Clot Alliance about health insurance problems.

By the end of June 2010, a temporary national high risk pool will provide coverage to adults with preexisting conditions. At the same time, a temporary reinsurance program will assist employers in providing coverage to retirees over age 55 that aren't yet eligible for Medicare. By the end of September, covered dependents will be allowed

to stay on their parents' health policy until age 26. These efforts should expand health insurance coverage to many.

The law also imposes some immediate restrictions on health insurance companies. By the end of this coming September, health plans will be barred from placing lifetime limits on coverage; from rescinding coverage, unless fraud was involved; and from excluding coverage for children who have preexisting conditions.

These changes are important, although not everyone can benefit immediately. Already the media have carried stories about people falling through the cracks because certain provisions of the law don't go into effect for a few more months. Nonetheless, these are major strides to a better situation for many people and their families who are afflicted by blood clots and clotting disorders. It is certainly my hope that the number of people turning to the National Blood Clot Alliance for help with their health insurance will quickly decline and eventually drop to zero.

Increasing health insurance coverage, while tremendously important, still does not solve the medical issues surrounding blood clots and clotting disorders. Many people still don't know about the risk of blood clots or can identify the warning signs. Delayed diagnosis and even misdiagnosis remain all too common in hospitals and doctors' offices. While our knowledge about blood clots is not perfect, much is known about prevention, proper diagnosis and effective treatment. Our challenge is to make sure that the medical establishment uses the tools available to consistently and effectively diagnose and educate patients about blood clots, that the public knows about risk factors and symptoms and that scientists continue to increase our understanding about why blood clots occur and how to deal with them. Health reform answers one important set of questions. The National Blood Clot Alliance, in collaboration with its partners, hopes to find answers to the others.

If you want more information on the health reform legislation, try the federal government website www.healthreform.gov, visit The Henry J. Kaiser Family Foundation website <http://www.kff.org> or this recent article from The Washington Post <http://www.washingtonpost.com/wp-dyn/content/article/2010/04/05/AR2010040504077.html>.

RANDY FENNINGER
President, National Blood Clot Alliance



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Interview with Dr. Richard Friedman of Charleston Orthopedic Associates

A deep vein thrombosis (DVT) is one of the major risks facing patients who undergo hip or knee replacement, or other orthopedic surgery. DVT, a blood clot in the leg, is often preventable. If you undergo hip or knee replacement surgery, ask your doctor what steps you can take to prevent a DVT, since it can be life-threatening if it breaks off and travels to the lungs as a pulmonary embolism (PE) or lung clot.

The National Blood Clot Alliance acknowledges Richard J. Friedman, MD FRCSC for sharing his expertise to answer questions about blood clot prevention after hip or knee replacement surgery.



What factors increase my chances of getting a blood clot after knee or hip replacement surgery?

Any major surgery, including hip or knee replacement, increases your risk of a blood clot, because surgery injures blood vessels. Blood vessel injury causes your body to make clotting factors, which are specialized proteins that form clots. Orthopedic surgery distorts your normal bone and muscle structure for a short time, and you may have difficulty moving around right after hip and knee replacement. All increase your risk of a blood clot. Go to www.StopTheClot.org/stoplight.htm for tools to assess your clotting risk.

What is important to tell my orthopedic surgeon, so that they can better assess my risk for a blood clot?

You should tell your orthopedic surgeon if you ever had a clot, or if anyone in your family has had one, especially your parents or sisters and brothers. If you know you have an inherited condition that increases your risk of clotting, make sure to bring this up. Your orthopedist may refer you to a hematologist, who is an expert in prevention and treatment of blood clots, and will decide how best to treat you, based on your history of clots. The hematologist may order anti-clotting medication (blood thinners) in either injectable or oral form, and advise you and your orthopedist about any additional precautions you may need to take to prevent a blood clot.

What if I don't have a family history of clots - do I need to ask my doctor whether I need blood thinners when I have my hip or knee replaced?

Yes, you should ask your surgeon about what blood thinner you will need to take after your hip or knee replacement, and find out what you have to do to take it safely. Pill form (warfarin) requires regular blood testing called an INR, and injectable forms usually do not require monitoring. In most cases, your surgeon will recommend treatment with a blood thinner to prevent a clot.

At what point do I start taking blood thinners when I have knee or hip surgery?

More than likely, you will start taking blood thinners the day after your hip or knee replacement.

How long will I be on blood thinners?

You will likely be on blood thinners for at least 10-14 days after surgery. If you have a higher risk of a blood clot, your surgeon may recommend continuing the blood thinners for a longer period.

Should I be concerned about taking blood thinners?

These drugs are safe if you take them as your doctor says. Bleeding

is the most worrisome effect. Be on the lookout for very obvious bleeding, but also less obvious signs, such as bruising or black colored bowel movements, for example. For safety, it is better to use an electric razor and a soft toothbrush, and make your home safe from falls. Remove any throw rugs, and have bright lighting to see your way when you walk around.

Should I worry more about bleeding than having a blood clot?

Bleeding from blood thinners is always a concern, but careful dosing and monitoring of your INR (if you are on warfarin) by you and your doctor usually avoids major bleeding episodes. The benefit of taking blood thinners to prevent blood clots far outweighs their risk of bleeding.

What else helps prevent blood clots?

The sooner you can get up and move around after surgery, the better. Walking or moving prevents blood clots. Your surgeon may recommend that you wear a “compression device” or compression stockings that are specially fitted and worn from your feet to your knees. They keep your blood flowing to prevent clots. Compression may be used alone, and is helpful as another clot prevention tool if you are on blood thinners.

Once I am moving around at home, do I still have to worry about a blood clot?

Yes. Most blood clots happen after patients go home. The most common time for a blood clot is around 10 days after knee replacement and 21 days after hip replacement. Be on the lookout for any signs and symptoms of a blood clot, which will likely be avoided if you take your blood thinners, wear your compression stockings, and move around as ordered.

What are the signs and symptoms of a blood clot?

Some swelling in the knee or hip area is normal after replacement surgery, but call your doctor right away if you notice a sudden increase in the amount of swelling or pain in your leg, reddish or bluish skin discoloration, or skin that is warm to the touch. These are signs of a blood clot in your leg, known as a deep vein thrombosis (DVT).

If you feel sudden shortness of breath, chest pain that is sharp and stabbing and worsens with each breath, rapid heart rate, or if you have an unexplained cough with or without blood-streaked mucus, you might have a clot in your lungs, known as a pulmonary embolism (PE). If you have any of these symptoms, **you must get immediate medical attention because a PE can stop your breathing.** See www.stopthecлот.org/learn_more/learn_more.htm to learn more about the signs and symptoms of a blood clot.

What should I do if I think I have a blood clot?

You should seek immediate medical attention if you suspect a blood clot in your leg or lungs. If you have signs of a lung clot, the safest action is to call an ambulance, if prompt service is available in your area, because a PE is a medical emergency that requires immediate care.

What key information should I know about blood clots before having knee or hip surgery?

- Make sure you talk to your surgeon about ordering blood thinners

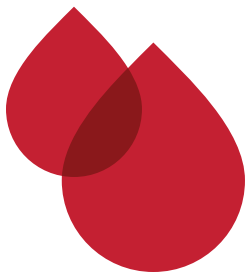
Top Tips Orthopedic Surgery

- **Tell your orthopedic surgeon if you ever had a clot, or if anyone in your family had one, especially your parents, sisters, or brothers. If you know you have a clotting disorder that increases your risk of clotting, bring this up.**
- **Ask your surgeon what blood thinner you will need to take after your hip or knee replacement, and find out what you have to do to take it safely.**
- **Wear your compression stockings every day, and move around as much as you are able and allowed.**
- **Call your doctor right away if you notice an increase in the amount of swelling, pain or tenderness in your leg, reddish or bluish skin discoloration, or skin that is warm to the touch. These are signs of a blood clot in your leg, known as a deep vein thrombosis (DVT).**
- **Get immediate medical attention if you feel sudden shortness of breath, chest pain that is sharp and stabbing and worsens with each breath, rapid heart rate, or if you have an unexplained cough with or without blood-streaked mucus, since you may have a clot in your lungs, known as a pulmonary embolism (PE).**

to prevent blood clots

- Try to be as active as possible after surgery, but follow your orthopedist's instructions about what you can and cannot do
- Seek immediate medical attention if you suspect you have a blood clot

Richard J. Friedman, MD, FRCSC, Charleston Orthopedic Associates, Clinical Professor of Orthopedic Surgery, Medical University of South Carolina-Charleston, Medical Director of Charleston Orthopedic Associates, Adjunct Professor of Bioengineering at Clemson University. He is also Chairman of the Department of Orthopedic Surgery at Roper Hospital in Charleston.



News and Announcements

First Half of 2010

By Tom Hogan and Elizabeth Varga

Several important milestones have occurred in 2010 that contribute to the expansion and outreach of the National Blood Clot Alliance.

NATT HAS A NEW NAME: NATIONAL BLOOD CLOT ALLIANCE

On February 25, 2010, the NATT Board of Directors voted to change its name to the National Blood Clot Alliance. The new name reflects the importance of keeping public health messages as simple as possible.

The new name was officially launched on March 9, 2010. Elizabeth Varga (co-founder and Board member) and Alan Brownstein, CEO announced the name change at the opening plenary of the National Conference on Blood Disorders in Public Health: Making the Connection, sponsored by Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia. Their spoken message was reinforced with a slide that showed a temporary National Blood Clot Alliance logo, with the NATT logo fading into the background to honor NATT's history and legacy. The transition logo was designed by volunteer graphic artist, Jason Vorck, who also designed the new National Blood Clot Alliance logo, which will catalyze re-branding of the new name.

NEW VICE PRESIDENT ELECTED TO LEAD THE NATIONAL BLOOD CLOT ALLIANCE

After 6 years of dedicated leadership as Vice President of NATT since its inception in 2003, Lori Preston, Board member from Baltimore, MD has elected to step down. Lori was instrumental in helping NATT grow from a small patchwork of volunteers to a nationwide, federally-funded non-profit organization, and is relinquishing her post.

Lori and members of her family have Factor V Leiden and some family members have experienced DVT, PE and pregnancy loss. Lori shared these comments with the Board of Directors, "From creating the inaugural newsletter and organizing a Stop The Clot Forum to recruiting new board members and volunteers, it has been a privilege to be a part of our growth. I was in the birthing room when this organization was born and I am proud of our progress. As a patient with Factor V Leiden, my wish was to help create a non-profit to educate others affected by blood clots. This organization is a dream come true. If I helped at least one person, I feel like I made a difference." Lori will continue to be an advocate for National Blood Clot Alliance as she is passionate about its cause.

Traci Wilkes Smith, a Board member and DVT/PE survivor from Brooklyn, NY was elected to replace Lori as Vice President in March of this year. Traci is an agent at Willinger Talent Agency, Inc, where she represents news, sports, and weather anchors, hosts, correspondents, and anchors at networks and local stations in top 30 markets throughout the United States. She obtained her Juris Doctor (JD)

from Rutgers University School of Law. Upon her election, Traci said, "Since joining National Blood Clot Alliance it has been a rewarding experience working with the Board and staff on a cause that is so close to me personally. That I was asked to serve in an expanded role with this organization is exciting, and a true honor." Since taking over the reins, Traci succeeded in hosting her first fundraising event, a 5K walk jointly hosted with the Association of Black Women Attorneys (ABWA), held on Saturday, March 20, 2010.

SOCIAL MEDIA UPDATE

National Blood Clot Alliance launched its first Facebook social networking initiative in February 2010. Within a couple of weeks, the fan base expanded from 10 people to almost 700 from around the nation, as well as Canada and the United Kingdom. National Blood Clot Alliance hopes that its Stop the Clot® Facebook page extends its visibility and new brand, and also provides relevant information about blood clots and clotting disorders.

National Blood Clot Alliance is excited about the opportunity the Facebook page provides for direct interaction with its primary constituents, patients. During March (DVT Awareness Month), several questions were posted on Facebook to encourage dialogue about individual "lived experience" of blood clots. This allows fans to connect and learn from each other, and provides valuable information to leadership of National Blood Clot Alliance about current needs and interests, at least from amongst those inclined to join Facebook. Please consider joining the Stop the Clot® Facebook page, and encourage friends and family members to do the same!

National Blood Clot Alliance also has a presence online on YouTube, where video segments from the Minneapolis Stop the Clot® Forum are accessible. For those who cannot attend a Stop the Clot® Forum in person, this allows access to a video viewing. A video that conveys the importance of anticoagulants with knee and hip replacement surgery (the focus of this newsletter) is on YouTube, and podcasts of the YouTube videos are available to download.

National Blood Clot Alliance YouTube, Podcast, and Facebook websites can be found on www.StopTheClot.org.

NATTHLETE PROGRAM

Another important addition for National Blood Clot Alliance this year is the NATThlete Program. This is a way for patients, families and friends to spread the StopTheClot® message through an individual or team network of athletes. The NATThlete Program recruits runners, walkers, cyclists, and tri-athletes in linking athletic interest and talent to alert participants to the risk of blood clots and clotting disorders, and set up a Firstgiving web page to fundraise, since money is the fuel that drives National Blood Clot Alliance. Read more about becoming a NATThlete on page 8.



LEAH WAJDYK'S STORY

My orthopedic surgeon dubbed me his “airplane” girl, because of an ironic twist of fate (and twist of my knee!). Believe it or not, I tore the anterior cruciate ligament (ACL) in my right knee as I was getting onto an airplane in October 2006. One would think I might be injured throwing a football or playing softball, yet I was merely starting a business trip. My orthopedist and I have shared some good laughs over my unexpected injury. Even though I was nearing age 40, a torn ACL is not an expected part of a routine business trip. I had surgery to repair the tear on January 5, 2007, and I adhered to the prescribed physical therapy (PT) religiously, meaning that I kept my PT appointments, and repeated the exercises at home.

About 3 weeks after my surgery, I noticed I was having a hard time breathing, even when sitting down. This was unusual, and upsetting. Fortunately for me, my mom was at my home when I first noticed my shortness of breath. As soon as I could catch enough breath to talk, I quietly told her, so that my kids would not hear, “Mom, I can’t breathe!” I’ll never forget saying those words, and how frightened I felt. There is nothing more terrifying than struggling for breath. I called my surgeon right away, who told me to call an ambulance immediately. I knew that my mom could get me to the Emergency Room (ER) faster than an ambulance, so I asked her to drive me to the ER. In retrospect, I realize it may have been wiser to go by ambulance. My ER visit was smooth, because my orthopedic surgeon alerted the ER staff that I was coming and that I was very short of breath.

The ER doctor ordered an immediate ultrasound of my leg, and found a blood clot that went from my knee to my groin. The CT scan revealed a lung clot, a pulmonary embolism (PE), so I was immediately started on blood thinners to treat my clots. All of us breathe in and out every moment without even thinking about it, until we can’t catch our breath, which in my case was due to my PE. I learned quickly that breathing is not something I can take for granted.

The blood clot in my leg was more than likely related to my knee injury and surgery, although it formed “under the radar.” I did not have any symptoms from my blood clot, despite its size. A piece of my undetected leg clot broke off and traveled to my lungs, which is why I was so short of breath, my first noticeable symptom. I did

not feel any chest pain, even though it is also a common symptom of a PE.

I was not given any blood thinners after my surgery, but ever since I developed a PE, my orthopedic surgeon has a protocol to give blood thinners to anyone he assesses as “at risk” for a blood clot. He is taking a very proactive approach to prevent DVT (deep vein thrombosis). I took blood thinners for a year and a half after the blood clots in my leg (DVT) and lungs (PE) were diagnosed. I wore compression stockings for a period of time, but stopped doing so, because they were “hot, hot, hot.”

I only learned about complications of DVT and how compression stockings are key to prevention of post-thrombotic syndrome, after I first submitted my story to National Blood Clot Alliance, and I plan to discuss this with my primary care doctor.

I take blood thinners whenever I have a procedure. I recently had an endometrial ablation, and took an injectable low molecular weight heparin (blood thinner) before it. I chose ablation over a hysterectomy, because of the risk of blood clots with surgery.

I now know that a pulmonary embolism is a very serious condition that takes up to about 100,000 lives each year in the US, and needs immediate medical intervention. I was one of the lucky survivors, and was overjoyed to find out six months after mine that I was pregnant. My pregnancy extended the time I was on blood thinners, (again, low molecular weight heparin) that I took throughout the nine months of my pregnancy plus three months afterward. I was tested for clotting disorders by my primary care physician, and none were found. I still do short business flights, about 2 hours each, three times a year. Now I pray whenever I fly, but also do heel toe exercises and circles with my feet to keep my blood flowing, and I do wear my compression stockings on a plane.

Now that I am nearing my mid-forties, I realize that I will have to re-think how I will handle impending menopause, because my history of blood clots makes hormone replacement dangerous. I’ve had a talk with my husband, so that he is aware that even though I am willing to do everything right, such as exercising and making healthy food choices, I may be prone to the unpredictable influence of fluctuating hormone levels on my emotions and mood. I want to

Continued on page 8

Leah Wajdyk's Story *Continued from page 7*

warn him in advance that if I seem upset, my behavior is not targeted at him. My blood clot has changed my life in many ways, and I want to make informed decisions that are best for my health, and work with my doctor to decide together what is best for me.

I feel blessed to be alive, and delighted that I was able to bring my little boy, Zach, into the world to join his two sisters. I am lucky to be here to raise my girls and their brother, who is now 2 years old. On top of the delight of living through a safe post-clot pregnancy that produced our son, I now have a 4 month old "perfect" granddaughter, Jolie. They are so close in age, and it is so much fun to watch them grow up together.

Most of all, I can now breathe freely!

Take Home Messages

- Blood clots can occur even with a "minor" orthopedic injury
- DVTs can happen without symptoms
- It is safer to call an ambulance for transport to the ER in case anything life-threatening happens on the way
- Compression stockings are most effective when worn daily after a blood clot is diagnosed to prevent complications such as post-thrombotic syndrome
- Blood thinners to prevent clots are important with invasive procedures or surgery
- Hormone replacement therapy is riskier in a woman who had a blood clot
- Talking about healthful lifestyle choices is beneficial, both with one's doctor and family
- This orthopedist responded proactively by adding prevention of blood clots to his surgery protocol

Grassroots Fundraising *Continued from page 1*

FUNDRAISING TIPS

Be Creative. A grassroots fundraising event can involve activities that you and your network of friends, family and colleges are passionate about – walking, bowling, wine tasting, pajama parties. Ask us for advice and ideas.

Set a target, and then let everyone know your goal. You'll be amazed at how easy it is to recruit sponsors to support you. Most people are willing to commit time and energy, and they are inspired that you are. Give them the opportunity to show you their support.

Know the facts and be prepared for questions. The NATThlete Program and 5K Walks, in particular, are extremely cost-effective ways of making a charitable contribution. As a volunteer driven organization, National Blood Clot Alliance maximizes every dollar raised to provide an amazing array of services.

The contents of the National Blood Clot Alliance newsletter are for informational purposes only. It is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. National Blood Clot Alliance does not recommend any specific tests, physicians, products, procedures opinions or other information that may be mentioned in the newsletter. Reliance on any information provided by National Blood Clot Alliance is solely at your own risk.

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