

A DRAPLET OF NEWS

A Newsletter for the Patients, Families and Friends of the Comprehensive Bleeding Disorders Center

January/February 2012

"Compassionate Care for Life"

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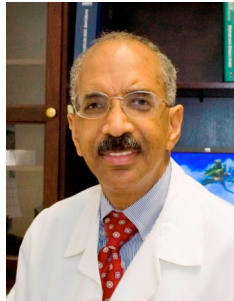
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Dr. Wesly on Excess Blood Clots



The following is an article about excess blood clots by Dr. Osvaldo Wesly, Medical Director at CBDC.

Why does my blood clot all the time?

We at the Comprehensive Bleeding Disorders Center treat patients who have problems with their blood not being able to stop bleeding as it should. These are patients who have problems known as Hemophilia A or Hemophilia B as well as patients with Von Willebrand Disease. What many people may not know, however, is that we as well treat patients who have the opposite problem: Their blood *clots* too much. Patients who have excess amounts of blood clot formation in their blood have a condition known as "*Thrombophilia*." Thrombophilia may be caused by two main kinds of problems: Either problems we inherit or problems which we cause - and which we can control - called "Acquired" causes of excessive blood clotting.

Acquired Causes of Excess Clotting

The problems which we as humans cause - and can therefore control - and which cause the blood to clot excessively are 5 basic problems. These are:

- 1) Sedentary lifestyle
- 2) Excessively overweight status
- 3) Taking birth control pills
- 4) Pregnancy
- 5) Cigarette smoking

People who have any one of the problems or conditions above - which we call "risk factors" - have a higher tendency to develop clots than someone who does not have these risk factors. The good news about the risk factors mentioned above is that since by and large we cause them, we can do something about them. This is in stark contrast to the problems which cause

excessive clotting which we inherit.

Inherited Causes of Excess Clotting

The causes of excessive blood clotting which are caused by factors or conditions which we inherit are many and varied. These range from genes which "turn on" at a certain age to acquired antibodies which our bodies seem to generate at a certain age. Many of the genes which we inherit which cause excess blood clots in our bodies remain "sleeping" in our bodies during our early years of life and then, for some unknown reason, they "wake up" at around the age of 30 or 40 years of age and they start to cause us to have excess amount of blood clots.

Unfortunately, as is typical of many things in medicine, some of these genes have rather difficult names as a "Factor V Leiden" gene or a "Prothrombin Promoter Inhibitor Gene". Others have names which are less difficult to say, but are more complex in their explanations. These are, for example, "Lupus Anticoagulants". Many people will say "wait a minute. I thought we were talking about things that make the blood CLOT too much, why is the blood clotting excessively with something called an ANTICOAGULANT?" and that person would be correct in questioning this. The reason is because this is an old name which has "stuck" with time. The cause of excess clotting which is called a "Lupus Anticoagulant" is neither caused by the disease called Lupus nor is it an "anticoagulant"; however the name has stuck. One other development which is caused by genes which cause excess blood clotting is a possible tendency to cause miscarriages in women who are expecting.

"People who have risk factors have a higher tendency to develop clots than someone who does not have these risk factors."

(WESLY continued on Page 2)

Other Causes of Excess Clotting

Finally, there are other causes for excess clotting which have nothing to do with either acquired or inherited problems; however these are the most difficult for other reasons. These causes for excess clotting are the ones caused by things which may or may not be related to the development of a cancer.

Sometimes patients who experience excessive blood clotting do so because they have developed a cancer. The cancer causes the blood in these patients to clot excessively and the blood clot is the "wake up call" which we receive to tell us to look for a cancer. I have found patients in the past, for example, who have presented with a blood clot in their legs and upon further study we have discovered that they have either a Prostate Cancer or an Ovarian Cancer or Breast Cancer, etc.

Also, sometimes patients present excess blood clotting and they have a blood disorder which is a cancer of the blood - or a condition very similar to one. Patients, for example, who have a condition known as a "Polycythemia Vera" may present as a person with excess clotting when in reality what they have is a disorder which forces them to make too much blood. As a result of this, their blood becomes very thick and thus clots excessively. One of the problems with this disorder has been that over time it is possible for this disorder to develop a "burnt out" bone marrow which becomes little more than a "scar". The good news is that the FDA (Food and Drug Administration) on November 16, 2011 just approved a new drug which, for the first time in years, now has shown excellent response in treating patients who develop a "burnt out" bone marrow following Polycythemia Vera.

In summary, it is important to know that it is possible for someone to have excess clotting problems and for that person to come to the Comprehensive Bleeding Disorder Center to have this checked out. It is important for patients to be seen by physicians with experienced in these areas so that the correct diagnosis can be made and the appropriate treatment started as soon as possible. Even though our name says "Comprehensive Bleeding Disorders Center", it is important for us to let everyone know that we as well treat patients who have the opposite problem - i.e. excess clotting.

Yours,
Dr. Wesly

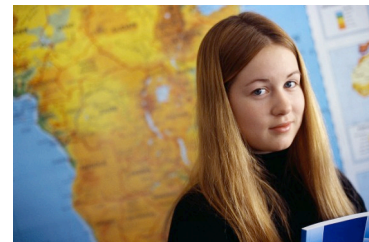
If you or anyone you know has any medical related questions, please call the Comprehensive Bleeding Disorders Center or email us at info@complee.com.

2012 CBDC Scholarship



Our annual CBDC scholarship will be made available to the public for the upcoming new year of 2012.

The Comprehensive Bleeding Disorders Center (CBDC) will be sponsoring two scholarships through the Community Foundation of Central Illinois to assist individuals in gaining and furthering their higher or technical education. Any individual who is diagnosed with a congenital or acquired chronic bleeding disorder and who has attended a hemophilia treatment center's comprehensive clinic annually including this past year of 2011 is eligible. The applicant must have maintained a GPA of 2.5 or above and are enrolled or plan to enroll, as a full or part-time student at an accredited vocational/trade school, technical school, junior college or a four-year college/university. The scholarship award of \$2000 is good for a period of one academic year. The award will be based on the applicant's motivation to accomplish his/her educational and career goals, potential for scholarship, citizenship and leadership. Financial need is only a consideration when other factors weigh equally among applicants. The scholarship will be paid directly to the school of the recipient's choice upon confirmation that the student has enrolled. The scholarship may be used to cover the cost of tuition, books and required fees pertinent to their course of study.



For more information on obtaining a scholarship application, please call us at (309) 688-1345 or Toll Free at 1-(888) 322-8670 and visit us on our website at www.complee.com.

Thank You!



American Red Cross

The CBDC would like to send out a big thank you to all of our volunteer donors who signed up for our sponsored hour during the American Red Cross's 8th Annual 12 Hours of Giving Holiday Blood Drive. This blood drive is held annually right before the holidays to help ensure a stable blood supply during the last week of December when blood collections are typically low. The American Red Cross was able to acquire close to 500 pints of lifesaving blood products during a much needed winter season. It was fun working with the American Red Cross and a breath of fresh air to see the

Nurse's Notes

By: Katy Tinsman, RN, BSN



Q & A with Nurse Katy

When did you first decide you wanted to go into the medical field?

My family is filled with nurses and medics. My Dad was a medic in the Air Force in Germany for 4 years, two of my aunts are nurses, and my grandmother operated the local ambulance service, as well as owning/operating the local medi-coach service for many years. So, from the time I was a little girl, I knew that I wanted to pursue a career in healthcare. It wasn't until my junior year of high school, that I decided that I wanted to become a Registered Nurse.

What is your favorite part about being a nurse?

On the practical side of things, nursing has always provided me with a stable job and steady income, which as most people know, is a huge blessing in economic times like these. Also, whether it is in my clinical skills or my critical thinking skills, I love greeting new challenges and setting goals for myself. On the more emotional side of things, my favorite part of being a nurse is that every day I am greeted with the faces of people that need help, and I am able to leave every day knowing that someone's life was made better because I was there in their time of need. I cannot tell you how many times I have seen someone in the grocery store or at church that recognized me from being their nurse while in the hospital or clinic setting, and thanked me for the care that they received. Little do they know that it is them I should be thanking for giving me the opportunity to grow as a nurse, to develop a love of the nursing profession and develop compassion and empathy for others through hands-on experience.

What is your outlook on the current state of the medical field?

I am amazed with all of the medical advancements that have been made in the fields of genetics, hematology and oncology and I am so pleased to be working in a place where these advancements are put to use every day. I cannot express how blessed we are to live in a place where modern medicine is available. Also, I hope and pray that through the advancements in stem-cell research, we will soon see an end to many of the diseases and conditions that plague many of our loved ones.

Unfortunately, in regards to health insurance, there are many people in the United States without work, and thus without medical insurance to cover their family in their time of need. Due to this, people who need medical attention are less likely to see a doctor for their needs in order to prevent incurring a bill. Over time this leads to physical decline, and by the time the patient is seen by the physician, the patient may be experiencing 2 or 3 other health issues because of the lack of initial treatment. It is because of this issue, that I am even more proud to work for an organization that cares for patients regardless of their ability to pay for such services, and where patient care truly comes first.

If you could sum up your experience as a nurse in one word, what word would that be and why?

Blessed! I would use the word blessed to describe my experience as a nurse because I am given the opportunity to be a part of people's lives at some of the most memorable times in their life; whether it would be the birth of a baby, the diagnosis of a life-threatening disease, the recovery from a life-threatening disease or the death of a loved one. I am blessed because I am a nurse, and I have been given the chance to have a front row seat to the human experience and the hand of God. Due to that opportunity and the experiences that I have had in my nursing career up to this point, I have become the person that I am today.

What is one piece of advice you would give to someone who is interested in becoming a nurse?

Find your calling and run after it wholeheartedly. Regardless of what profession you choose, it is important to discover what makes you happy and find a way to put that happiness into practice every day. If you are able to do that, work will never be work, and you will be rich regardless of the numbers you see on your paycheck.

If you have any questions for Katy Tinsman, Nurse Coordinator, she can be reached by calling CBDC or by email at ktinsman@compbleed.com

The Importance of Medical Jewelry



Medical alert jewelry is recommended for anyone living with a chronic or rare medical condition. Simple medical errors can be avoided if a person wears a description of a medical condition engraved on a Medical ID bracelet or necklace. In most situations emergency teams look for the identification of the person and what conditions they have. A person's health can be immediately recognized by emergency teams and they are able to provide the appropriate care necessary to the person. The wearing of medical jewelry has not only made the identification process easier for first responders, but it has also helped healthcare professionals in determining the best care that could essentially save a person's life. The ID usually includes important information like what medication the person is currently taking. The Medical ID bracelet is a voice under emergency circumstances when a person is not able to speak for themselves. If you are interested in learning more about medical jewelry, please do not hesitate to call us.



Martha's Memo

**By: Martha Wright
MSW, LCSW**

This time of year, it's easy to think that once Christmas is over, we'll be able to relax. However, many people have considerable stress year 'round. Some stress is good and some is bad. Some is self-induced and some is caused by others.

Good stress includes things like planning a wedding, having a baby, getting a promotion—which includes added responsibility—or moving to a new home or community.

Bad stress includes reduced income, loss of a job, loss of insurance, death of a close friend or family member, or chronic/sudden illness necessitating a lifestyle change.

Some stress has both positive and negative components. Patients living with blood disorders need to take precautions that others do not. They need to think ahead in terms of the safety of certain activities and know what to do if they are injured. Parents of young children, especially, face some of these stressors. Managing a blood disorder may be new to them. They constantly monitor the physical safety of their children. The good news is that the parents have considerable control by using medication like factor prophylactically.



If you have questions or concerns regarding medication and the use of prophylaxis, insurance or stress issues, please call our office at 309-688-1345.

Dental Details

By: Ralph Nelson, DDS

There is a major importance placed on the preparation of a patient for oral surgery. There must be open communication between physicians when it comes to what the best steps are when preparing a patient with a bleeding disorder for pre and post oral surgery. First and foremost, the oral surgeon must be made thoroughly aware of the patient's past and current medical history. This includes a whole health history of past bleeding episodes as well as the current medication the patient is taking. Along with this, it is important to understand that the major concern for both the patient and the physician during any surgery is heavy bleeding and how it can be best prevented. Different methods can be used for each patient.



A few precautions that should be taken both before and after surgery include the following:

- Make sure that someone is available in the days leading up to the surgery and the days following the surgery for assistance, which would include driving to and from the surgery.
- Depending on what medications you are currently taking, your oral surgeon and hematologist may recommend different dosing both before and after surgery.
- Any recommendations by the hematologist and oral surgeon should be documented and followed to be sure the step by step process goes as smooth as possible.

A Great Way to Start the Year

An easy, healthy activity we should spend more time practicing is stretching. If muscles are stretched often, we can increase joint range of motion, improve posture and gait, and reduce the frequency and intensity of muscle soreness and strains. All of these benefits will also lead to lower risk of joint and muscle bleeds.

Routinely stretching every day or several times a week is the best way to get results. When you stretch, there should be **no pain**. It should be a relaxing exercise with continuous breathing and a sensation of gentle muscle tension. General guidelines for stretching are as follows:

1. Hold for 10 seconds at a comfortable end range.
2. Breathe while holding. Count out loud if necessary.
3. Never “bounce” at the end range of the stretch.
4. Repeat each stretch 3-5 times.

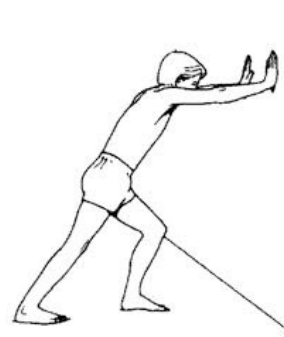
The stretches shown on the right are a great way to begin. The calf stretch **(1)** is a basic stretch you’ve likely done before. It is especially helpful if you get cramps in your calves or “charley horses.” This stretch is also helpful for shin splints and plantar fasciitis. The most important thing is to keep the heel of the back leg, the stretching leg, down. The farther back you put that heel, the more intense the stretch will be.

You can follow with the often forgotten soleus stretch **(2)**. This is the muscle just below the bulk of the calf. Bend the back knee and lower your bottom slightly as though you’re going to sit on that heel.

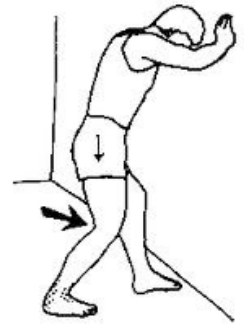
The hamstring stretch **(3)** is very helpful for back pain and muscle cramps in the back of the thigh. The hamstring is a large, bulky muscle which may require more time to stretch and increase range of motion.

Next is the hip flexor stretch **(4)** which is also helpful for back pain. Keep the hips square to the front and keep your torso upright. If you have difficulty kneeling, you can stand on the non-stretching leg and put the stretching knee on a chair.

Finally, the shoulder stretch **(5)** is a great way to open up the chest and stretch the pectoralis muscles. This will be a welcomed stretch to those who sit most of the day and suffer from postural pain in the neck, shoulders, and shoulder blades.



(1) Calf Stretch



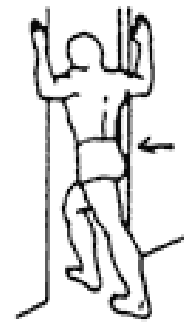
(2) Soleus Stretch



(3) Hamstring Stretch



(4) Hip Flexor Stretch



(5) Shoulder Stretch

Gradually, you will notice less fatigue and more energy. You will be able to stand with better posture and may even feel less pain. Flexible muscles are healthy muscles--and healthy muscles are less prone to bleeds.

This article was contributed by Kate Horst, Physical Therapist at The Institute of Physical Medicine and Rehabilitation.



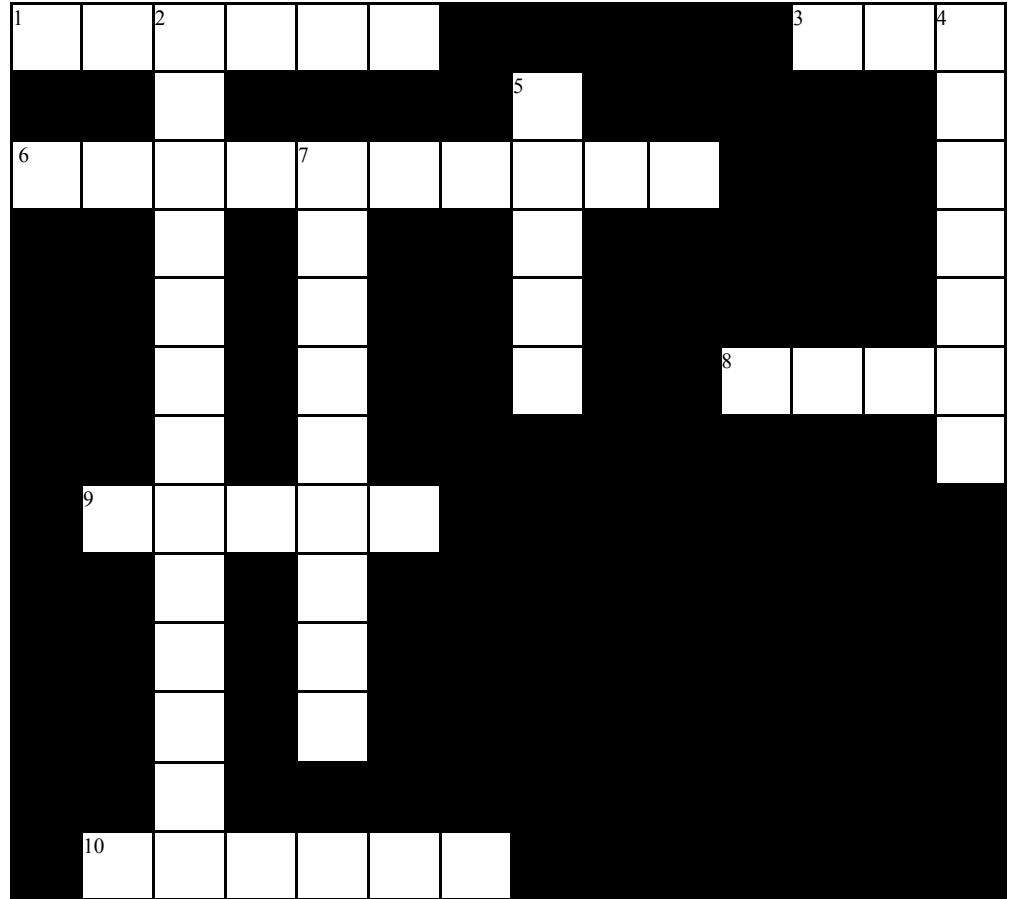
CBDC Kid's Corner



Across	
1.	Clotting _____ is a protein needed for normal clotting.
3.	The most common inherited blood disorder.
6.	Bleeding disorder that affects 1 in 5,000 people.
8.	The word that stands for Rest. Ice. Compression. Elevation.
9.	Dr. _____, Medical Director at CBDC.
10.	City where CBDC was founded.

Down	
2.	_____ Bleeding Disorders Center.
4.	A _____ of News.
5.	Red substance that delivers nutrients and oxygen to your cells.
7.	Sticky blood cells.

Time to test your knowledge with our CBDC crossword puzzle! To see how you did, please check your answers at the bottom of the puzzle.



Across: 1. Factor, 3. vWD, 6. Hemophilia, 8. RICE, 9. Westly, 10. Peoria
Down: 2. Comprehensive, 4. Droplet, 5. Blood, 7. Platelets

DID YOU win an award? Participate in an exciting event? Earn a special recognition at school? We would like to hear from you or your parents so we can feature your accomplishments in our newsletter. If you have any stories or accomplishments to share with us, please email Tom at tjoseph@compbleed.com

ARE YOU in need of an in-service? Education is an important element of the comprehensive care offered by CBDC. One aspect of education is an in-service, which is intended to educate the people responsible for the well being of your child outside of the home. The in-service provides a brief overview of your child's bleeding disorder, followed by instruction on appropriate treatment in the event of a bleed or an injury. Parents should consider an in-service if you or your child are concerned about daycare or school staff and their understanding of Hemophilia, Von Willebrand's Disease or other bleeding disorders. If you are interested in scheduling an in-service, please contact the CBDC.

CBDC at the NHF 2011 Annual Meeting



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

The CBDC staff recently attended the 63rd National Hemophilia Foundation's Annual Meeting that was held in Chicago, Illinois between the dates of November 10th through the 12th. This year over 2,500 people attended which included families, medical providers, researchers, consumers and industry representatives. All of the meeting events and symposiums were held in beautiful downtown Chicago's Hyatt Regency. We met people from all around the United States and other areas around the world. This year's annual meeting consisted of numerous



Cara with Alex Borstein from Family Guy



Cara, Tom and Katy at the Exhibits

presentations and events and was an excellent learning experience as well as a way to connect with others in the community. The conference included guest appearances from Hemophilia advocates like Alex Borstein, who voices Lois Griffin on the animated television series *Family Guy*, and C.J. Wilson, current starting pitcher for the Los Angeles Angels. Every major industry representative was in attendance and the National Hemophilia Foundation was extremely hospitable in welcoming their guests to the events from the Thursday night opening celebration to the Saturday night ending ceremonies. We are already looking forward to next year's meeting in Orlando, Florida on November 8th, 2012.

About CBDC

The Comprehensive Bleeding Disorders Center (CBDC) was incorporated in 1996 as a nonprofit organization, established specifically to serve people with congenital bleeding disorders. Osvaldo H. Wesley, MD, serves as the Medical Director for CBDC. It is the longest standing center of its kind in Illinois outside of Chicago to have received federal grants.

The Center's mission is to provide comprehensive care, outreach and other services to children and adults with blood clotting/bleeding disorders, their families and the communities in which they live. We strive to improve the quality of life for all affected by blood clotting disorders, increase awareness of and access to comprehensive care, and improve understanding and treatment of clotting disorders through state-of-the-art education, research and advocacy.

Comprehensive Bleeding Disorders Center is guided by a volunteer Board of Directors. Since 1998, CBDC staff has provided a wide range of programs and services including blood clotting products, home infusion training, education, and outreach programs for patients and providers.

CBDC Board of Directors:

President Joe Knapp
Treasurer Bill Lawrence
Jeanette Ashley
Stacey Beuster
Don Magiera
Richard O'Connor, M.D.



CBDC Peoria Facility at 4727 N. Sheridan Rd.

After Hours Procedure

The Comprehensive Bleeding Disorders Center is committed to providing excellent care for our patients and their families. Our commitment extends beyond regular business hours to accommodate patients with medical emergencies that arise after hours. **Our telephone hours are Monday-Friday, 8:00 a.m.-5:00 p.m.** If you or your child has an emergency after these hours, please call the answering service and they will page our on-call personnel. You will receive a call from the answering service and will then be connected to either Dr. Wesly or our Nurse Coordinator, Katy Tinsman.

After Hours Physician Answering Service: (309) 688-7490

In the event an emergency arises after hours and you do not have access to the **After Hours** phone number, call our Center for instructions. When our Center is closed, the number to call in an emergency is provided on our voicemail message.



Follow Us on Facebook and Twitter!



Click “Like” on our Facebook page titled “**Comprehensive Bleeding Disorder Center**” to stay up to date on recent news and events going on at the Center along with interesting up-to-the-minute health articles. Be sure to follow and tweet us on our Twitter page titled “**CompBleedPeoria**” as well. You can access both links on our website at www.compbleed.com.

Comprehensive Bleeding Disorders Center
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