

How Do I Get What I Really Need For My Family? Some helpful hints for dealing with insurance

So you had a great pharmacy that provided your child's factor through your good insurance provided at your place of work. Everything was going well (except for the complexities of having a child affected by a bleeding disorder). You were receiving your child's factor at home, on schedule, in the proper amount each month. You also had access to other services that you found valuable. In fact, life seemed pretty good. You were able to go to work, confident that, barring some emergency situation, your child was receiving factor on his/her schedule, as directed by your hemophilia treatment center and your could stay "on the job."

Then.....you get a letter in the mail from your insurance company that you and your family, covered by the group insurance at work, must use a different pharmacy starting on a particular date.

Your emotions might lead you to:

#1: Call your insurance company, lose your temper and get argumentative.

Many very wonderful parents, in their frustration, have done that. Probably not a good idea, however. It usually doesn't get you too far.

#2: Do the same thing to your Human Resources manager at work (or your boss).

Ditto here too. Probably not a good idea.

However, the following actions might be more helpful to you.

#1: Get informed to know what you are talking about.

Many, many articles have been written in hemophilia-related publications in the last two years, dealing with access to care issues....access to all available factor therapies, preferred product

issues, access to home supportive services, access to treatment centers, access to the coagulation laboratories at the HTC's and on and on. So go ahead and get on the NHF website (www.hemophilia.org) and other great sites, as well. Do a search on the internet. You won't believe how much information is out there.

Be an informed consumer. Know your insurance policy, front to back. Know what benefits your insurance company says it will provide to you and your family. And here are a couple of other ideas that we haven't heard much about, but that might help you.

#2: Call your old pharmacy.

Ask them to call your insurance company to see if they can get in the (approved) network.

#3: If you are willing, approach your human resources person at work and try this.

"I just got this letter in the mail telling me that I have to switch to a new pharmacy provider. My son/daughter has very special needs that aren't met by all or any old pharmacy. Consequently, I am asking you to intercede and override the current directive and make my pharmacy (my old pharmacy) eligible to service my son/daughter for just his/her current disease state products (factor)." This style of conversation eliminates the need to disclose your child's specific diagnosis. Of course, if you wish to, you can tell them whatever you like.

So what do you do if none of the above work or you wish to be proactive so you don't get that same type of letter next year? Try this.....

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From the Executive Director

This fall, the DVC welcomed a new board member, Noel A. Fleming, Esquire. Noel is an associate in the law firm of Lundy Zateeny, LLP, Bala Cynwyd, Pennsylvania, a partnership devoted to the legal representation of nonprofit organizations. The firm provides services in the areas of corporate law and governance, charitable trusts, federal, state and local tax matters, fiduciary duties, charitable fund raising and related matters. Prior to joining Lundy Zateeny, LLP, Noel was an associate at Ballard Spahr Andrews and Ingersoll, LLP in Philadelphia where he practiced in the Tax Department and the Public Finance Department.



Noel, a native of Ireland, is a 2003 graduate of Temple University's James E. Beasley School of Law where he was a Beasley Scholar and the recipient of the Benjamin Winderman award for scholastic achievement in Temple University's JD/MBA program. He was the Managing Editor of the Temple Law Review and interned at Temple's Center for Community Nonprofits.

"Although my family is not affected by bleeding disorders, I am proud to be able to provide philanthropic service to the board of directors and to the community of patients affected by hemophilia and Von Willebrand Disease. The Board and the Chapter continue to provide important resources to local families. I am inspired by their mission of service and all that they continue to accomplish for the community. It is a privilege to be a part of such a consumer-focused organization."

Welcome, Noel!! We're glad you are a part of the Delaware Valley Chapter!!

"We Had at the Blast at the Family Camp Weekend!!"

The following letter is from a mom who attended the DVC Family Camp Weekend!!

"We really had a blast at the weekend camp in Pennsylvania in September. Yes, it rained and the cabin was, let's say 'rustic,' but that's to be expected when you camp!! The photos I took are just great!

We met so many nice parents and nurses. The Chapter folks were just great, too. On Saturday, we met a lovely couple. Their son died of AIDS about 15 years ago. They explained how they tried to have a normal family life, even with the challenges they faced with hemophilia and HIV. They kept life positive and upbeat. Listening to the stories from others who also went to camp, made us feel so lucky. We have great care at the HTC, and a great support at home, plus all the Chapter provides to us to help us network together. Well, it was just great!!

My son had lots of first time experiences on the weekend...sleeping on the top of a bunk bed, playing flashlight tag with his new friends, camping in a cabin and taking a shower with a spider. We did archery, canoeing, tennis and met lots and lots of kids and their parents who understand what life is like for us. The food was good, activities many, arts and crafts were fun, the swimming pool was heated and the bonfire was so much fun, complete with smores!!

We left on Sunday, having met lots of new people. We can't wait to see them all again next year!! We wouldn't miss it for anything!! Thank you."

We Gratefully Acknowledge...the pledge of support from the following manufacturers for 2006

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Helixate FS
Humate-P
Stimate
Gammar-P I.V

- November
3 Casino Royale!!
- December
9 Holiday Party!!
- April
14 Fashion Show!!
- May
8 Family Dinner!!



Here's the report out on our early fall events!!!!

Our **DVC Annual Family Camp** was held on the weekend of September 15, 16 and 17, 2006 at Camp Green Lane in Green Lane, PA. Although it rained for part of the weekend, our families came and just had a great time! Our kids participated in "Dream Builders," made possible through the support of Wyeth and they assembled great derby cars and raced 'em too!! Families enjoyed swimming, fishing and boating and just had an all around wonderful weekend. We are hoping for better weather next year. We've already set the date: **September 28, 29 and 30, 2007!!** Mark your calendars for this great weekend that brings families together!!! It doesn't get any better than that!!!! Check out the pictures!!

On Monday, **September 18, 2006**, 124 golfers attended the **DVC Annual Golf Classic!** This year's event, held at the Radnor Valley Country Club, was a complete success!!! Beautiful weather, great food and thousands of dollars were raised to further the mission of the Chapter!!! We are very grateful to ZLB Behring for being the event sponsor again this year and to Rich Dates (from ZLB) who did a great job as event Chair!! Everyone had a great time!!! Our deep appreciation to Rich and his committee and to all of you who supported this important day for our Chapter!! See ya' next year!!!!

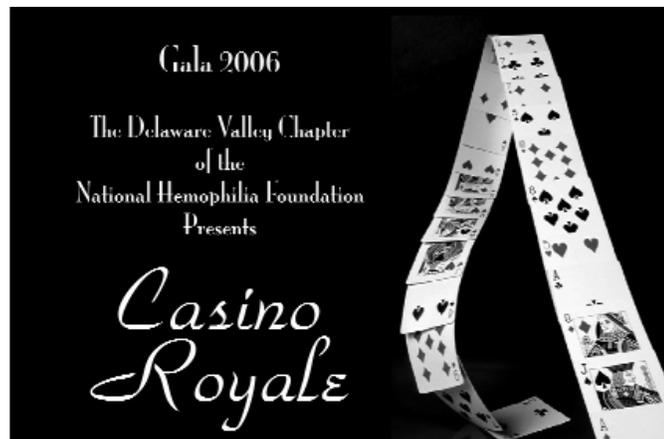
Happy DVC Family Campers!

And here's what's coming up!!!!

NHF's **58TH** ANNUAL MEETING

A report on the **NHF Annual Meeting** in Philadelphia, held in Philadelphia on **October 12, 13 and 14, 2006!!**

A report on **Casino Royale** to be held on **Friday, November 3rd** at the Hilton on City Avenue in Philadelphia. For tickets or more information, call the DVC office 215-885-6500!!



The **DVC Annual Holiday Party** will be held at Jefferson Alumni Hall in Philadelphia on Saturday, **December 9, 2006!!** To register for this great event, call the DVC office!! 215-885-6500!!! This is a fun day for kids of all ages!!!!

William Penn and the Family Tradition of Bleeding to Death

The following working paper was written and sent to the Delaware Valley Chapter by Richard J. Atwood, MA, MPH. Richard resides in Winston-Salem, NC and currently serves on the Board of Hemophilia of North Carolina. Richard worked for 17 years at the Hemophilia Treatment Center at Wake Forest University. Hope our readers enjoy this interesting bit of Philly history!!

There is speculation that the hemophilia gene was in the extended family of William Penn at the time that the colony of Pennsylvania was first settled in 1680. Recreating the family tree and determining those members with bleeding disorders raises more questions than answers in this mystery.

In 1925, Edward C. Davidson and Irvine McQuarrie at the Henry Ford Hospital in Detroit, MI reported on 2 cases of true hemophilia (E.H.T. and R.R.), both members of a single, large, multigenerational, typically hemophilic extended family. The genealogy of the family was traced back to the marriage in 1746 of a Quaker woman named Jasper to Sir William Crispin. This couple bore 3 children including 2 girls and a boy. The elder daughter did not marry; the second daughter bore a bleeder; and the son bled to death from an accidental laceration to the scalp. The family tree was charted over 8 generations and contained 14 individuals who were proven bleeders.

Davidson and McQuarrie reported that R.R., or Case 1, a bleeder in the sixth generation, was a 39 year old, moderately obese, healthy-appearing, American, white male. He was married, had 4 sons, and worked as a superintendent at an automobile factory. R.R. was practically an invalid until 13 years old, and had even spent 3 years of that time in bed, when his tendency for prolonged hemorrhage improved after puberty. In February, 1911, the patient was treated with horse serum for hemorrhage for 3 weeks following the extraction of a tooth, and he subsequently had "joint disease" which incapacitated him for 6 months. R.R. was admitted on August 24, 1921 for pain in the left flank, similar to previous attacks of pain in the left flank accompanied by severe hematuria traced back to an accident in 1914 when he received a severe blow over the left kidney. R.R. had 3 brothers and 3 maternal uncles who were proven bleeders who also experienced an improvement with less prolonged hemorrhage after puberty.

Subsequently in 1937, Carroll LaFleur Birch, MD at the Research and Educational Hospital of the University of Illinois in Chicago, IL reported on 4 cases of hemophilia, including Patient 58 (who had been listed as Case 1 or R.R. by Davidson and McQuarrie). Based on the written records of competent genealogists in 1910, the family was traced back to the eleventh and twelfth centuries in England, though the family tree was charted back only to the marriage of Anne Jasper to Sir William Crispin.



Anne Jasper was the sister to the mother of William Penn (making them maternal aunt and nephew), while Sir William Crispin was one of William Penn's first commissioners of the Province of Pennsylvania. The couple bore only one child, a daughter who married in 1666 in England. The family tree (which differs greatly from the previous one published by Davidson and McQuarrie) was charted over 10 generations and contained 15 hemophiliacs. While the stated family tradition was that the members bled to death in the sixth generation, bleeders were not identified until the seventh generation.

Birch reported that Patient 58, an American hemophilic in the eighth generation, was born in 1882 and died in 1934. His first hemorrhage was a hematoma from knee trauma when 3 years old. He had a history of many severe hemorrhages from his nose, teeth, kidneys, and bowels. When shedding his first teeth, he was kept in bed almost continuously for 3 years due to hemorrhages. His frequent and severe joint hemorrhages incapacitated him for many months. He had to use a cane for 10 years, and crutches for his last two years. Patient 58 died of pneumonia when 52 years old, 15 days

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after appendectomy. Patient 58 had 3 brothers and 3 maternal uncles who were hemophiliacs.

A web search for Sir William Crispin revealed that some sources claimed his wife to be Ann Jasper rather than Rebecca Bradshaw, and that this misinformation has been perpetuated in the literature. William Crispin (1627-1681) married Rebecca Bradshaw (1631-1660) on September 28, 1652 in St Dunstan's, Stepney, Middlesex, England. The couple bore 5 children including 3 sons and 2 daughters. Rebecca Bradshaw's mother, Rachel Penn Bradshaw, and William Penn's father, Admiral Penn, were sister and brother (making Rebecca Bradshaw Crispin and William Penn first cousins). William Crispin was listed as either a Captain or a Rear Admiral in the Royal Navy. The Quaker William Penn became the Proprietary of Pennsylvania in 1680, and on October 25, 1681 he appointed William Crispin as a commissioner of property; unfortunately, William Crispin died at sea near Barbados on the voyage in 1681 to the Province of Pennsylvania.

History becomes a mystery when the documentation is inaccurate, incomplete, or in conflict. Tracing the hemophilia gene in the William Penn extended family is difficult due to discrepancies in names and dates, and also due to missing information. The name of William Crispin's wife has been listed as Ann Jasper, Anne Jasper, and Rebecca Bradshaw. The marriage date of William Crispin has been listed as 1652 and 1746. The number of children the couple bore has been listed

as 1, 3, and 5. William Crispin's wife was identified as a carrier of the hemophilia gene in just one family tree, but not in the other, while only one daughter was labeled a carrier and only one son was labeled a bleeder in just one family tree. The grandmother of the patient R.R., a proven transmitter of hemophilia, was listed in direct line to the Crispin marriage in one family tree, but was listed as marrying into the family in the other family tree. The question remains whether the proven bleeders improved after puberty. The hemophilia gene followed the westward migration of original settlers in Pennsylvania into the Midwest which complicates record locations. The grandmother of the patient R.R. moved with her husband and family from Bucks County, Pennsylvania to Ohio sometime before 1857. The relationship of William Crispin's wife to William Penn was identified as either first cousins through William Penn's father or as aunt and nephew through William Penn's mother. There is the teasing possibility that William Crispin's wife was related to William Penn and that the hemophilia gene was in William Penn's extended family, while more detective work is needed to solve this mystery.

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www.stefanovich.com/Crispin/Capt_William_CRISPIN.html

Pennsylvania Man with Severe Hemophilia "A" and Immune to HIV Featured on the Discovery Health Channel

Bill Jamison, 52, has a reason to celebrate. Jamison was born in 1954 and suffers from severe hemophilia A. Until the early 1990's, Jamison's hemophilia was treated with injections of medications derived from human blood plasma. In the 1980's the medication's Bill used to treat his hemophilia, was contaminated with the virus that causes AIDS. As a result of the contamination of the nation's blood supply, 10,000 people with bleeding disorders were infected with the AIDS virus and approximately 8000 have died, destroying the lives, the hopes and the dreams of a whole generation of innocent people.

Bill's life took a 180 degree turn when he was informed that he was exposed to the HIV virus many times through his medication and it was only a matter of time until he would seroconvert to testing positive for the HIV virus. This would change everything. Married, a father of two and a business owner, his life was about to take an ominous turn, or so he thought.

After the last person known with hemophilia to test positive for HIV, Bill was not sick. How could this be? He had multiple exposures to the virus over years of treatment. Bill

was not positive. This was a great curiosity, not only to Bill but to the medical community as well.

In November of 1997, two days prior to the Thanksgiving holiday, Bill learned why he had never become positive to the HIV virus. By a genetic roll of the dice, a genetic mutation caused his hemophilia and another genetic mutation called a "delta 32, double deleted allele" on the CCR5 gene protected him from the HIV virus. In simple terms, this mutation meant there were no receptors on the gene for the HIV virus to attach itself. Bill is an extremely lucky man.

On August 28, 2006, Bill was one of the individuals featured in the Discovery Health Channel's production of "The Great Plagues." What an incredible story. If you would like to contact Bill directly, his information follows.

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Harrisburg, PA 17112-9438
Phone 717-657-0113, 717-443-3669(cell)
Bjamison8@comcast.net

The following was written to Arnette Hams, RN, Nurse Coordinator of the Lehigh Valley Hospital Hemophilia Program by Priscilla Oren, mother and patient. We receive many wonderful letters, but this was a winner!! Thank you, Priscilla, for acknowledging the wonderful work and dedication of a great, local nurse!! Well-deserved, Arnette!!

“Dear Arnette,

In the more than 22 years of knowing you, I can’t remember how many times I have hugged you, thanked you, and said, “I don’t know what I would do without you”, but I know it hasn’t been enough...so here’s one more time.

These years of having to deal with the uncertainties, perils, joys and sorrows of living with hemophilia have brought many people into my life and the lives of all my family and friends who have supported me. All of these have contributed to my life and well being, but you have given more than any health care provider should be expected to give, therefore, I consider you to be a friend and family member.

You have come to know all of us intimately and have shown respect, offered courage, condolences and true humanitarian love to each of us as we needed it in our own unique ways. You have come to our bedsides, our homes and our hearts as we reached out to you for support, knowledge of hemophilia, HIV-Aids and the many issues of health care necessary to support such a complex disorder.

I know and remember the many times you were more than a nurse. I remember crying over bad news and laughing over good. I remember you listening carefully, and diligently composing your replies. I remember calling you from many states, and in many states. You have always been there, and even when you weren’t, you were.

I have spoken to many others in my family and our hemophilia community who have also expressed these sentiments. And, I intend to use this letter to convey this information to those who may more formally recognize your commitment, devotion, and loving care to all of us who have been fortunate enough to have “Arnette” in our lives.

Thank you once again for making this journey less lonely and frightening. I truly admire, love and respect you.

Sincerely,

Priscilla Oren”

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How Do I Get What I Really Need For My Family? Some helpful hints for dealing with insurance

#1: Approach your human resources person and like above, inform them that your child has specific needs that aren’t met by all or any old pharmacy.

Consequently, ask them to make sure that when they negotiate new insurance contracts, they will include in the available network, pharmacy x, y or z for your son’s current disease specific medications (i.e. factor). Asking to have this pharmacy (x, y or z) included for all drugs might be too much to ask for and therefore you might be unsuccessful. Your request should be just for the factor.

#2: Make sure if you’re changing jobs, that you check with your new employer to be sure that x, y or z pharmacy is or can be included in their network.

In the end, you need to determine what you need and what you want for your family with regard to health benefits. By approaching your employer right up front (before you are boiling over), you may be able to get what you really need, even if you don’t get exactly what you want.

What Do I Need to Know When Traveling on the Airlines...

Some considerations for taking factor with you....

Due to recent restrictions about what a passenger can take on board an airplane, we all need to plan ahead. Right now, the Transportation Security Administration (TSA) has tightened restrictions regarding carry-on items such as medications and that would include factor. These new restrictions absolutely impact whether or not you will board that flight, for a much needed vacation or business meeting, with your little cooler in hand.

Most people agree that patients with bleeding disorders, who use factor replacement therapies, should always travel with their factor and supplies (needles, etc.). If you put your factor and supplies in your checked luggage, temperature variations in the cargo compartment (extreme heat or cold) may affect the integrity of your factor. In addition, if your luggage is lost or delayed in getting to your destination, you've got a real problem. So take it on board, just as before, however, contact your airline, treatment center and check the TSA website www.tsa.gov/travelers/airtravel/prohibited/permitted-prohibited-items.shtm to determine what you need to do BEFORE YOUR TRIP, to insure you and your factor arrive together. In addition, the National Hemophilia Foundation has developed guidelines for traveling with factor. You can access that information on NHFs website: www.hemophilia.org.

Some suggestions:

- 1) Get to the airport very, very early to check in so that you can troubleshoot any problems that may occur at the security checkpoint.
- 2) Talk to your treatment center staff well in advance of your trip. They know what seems to be working for travelers with bleeding disorders. They will help you navigate whatever needs to be done.
- 3) Ask your treatment center for a letter that you will carry on the airplane, describing what you have in your cooler, i.e. the number of vials of factor, the number of vials of the diluent (water) and also that you are carrying syringes and needles, etc. You may need to have the treatment center do another letter at the end of your trip, describing the supplies you are bringing back home with you, as well. This can be faxed to you on the last day of your trip wherever you are. HTC's are doing their very best to accommodate you, so plan in advance,

ask in advance for this help and realize that this is an added task for the treatment center staff.

- 4) Contact your homecare company and ask them if they can overnight directly to your destination, what you estimate you will need during your trip. Of course, if you don't use it all, you could have a problem on your return at the airport if you are carrying it with you. For your return, however, factor can be put into an insulated soft case with a cold pack and then into your luggage. A photocopy of the letter from your HTC identifying the contents should also be put into the insulated bag. As long as you have factor at home, you will be okay, in the event your medicine is confiscated or gets lost with your luggage.

The following letter from Dr. Barbara Konkle, Director, Hemophilia and Thrombosis Program at The University of Pennsylvania, Presbyterian Medical Center was sent to us. Share it with your treatment center if you think it would be helpful.

[DATE]

RE: [Patient name]

To Whom It May Concern:

[Mr./Ms. Patient name] is followed in our comprehensive hemophilia program for moderate Factor ____ deficiency (hemophilia ____). Hemophilia ____ is an inherited bleeding disorder that requires treatment with products to prevent and treat bleeding episodes. Patients are trained to administer therapy to themselves, including the administration of therapies through their veins (intravenously). For this reason, when they travel they need to carry the treatment product, which for [Patient's name] is [Product name]. Specifically, [s/he] is carrying ____ boxes, each containing _____ units of powdered factor concentrate and [syringes prefilled with ____ cc of sterile water/ ____ vials containing ____ cc of sterile water]. [S/He] must also carry needles and other supplies needed for its administration, which may include additional syringes. If [s/he] needs to treat [himself/herself] during the trip, one or all of the vials and syringes may be empty on [his/her] return trip.

Bleeding episodes are frequently associated with pain, and this may require the administration of narcotic pain relievers. [Patient's name] carries with [him/her] [Name of drug] for relief of pain.

Please feel free to contact me or members of my staff if you should have any questions concerning the above.

Sincerely,

[Physician]

[Physician's title – i.e., Director, Attending, or academic rank]

The future is called "perhaps," which is the only possible thing to call the future. And the only important thing is not to allow that to scare you.
Tennessee Williams (1911-1983), American Poet and Playwright



For Your Information

Young Families Get a Chance to Meet at Family Camp Weekend!! "First Step" Makes a Difference.....!!!



Young parents had a chance to get together at our Annual Family Camp Weekend on September 15, 16 and 17!! They shared their personal stories with each other and met the "First Step" team, Sue Stinger, Jill Abrams, RN and Lindsay Pepper, RN. Here's what a few of them had to say!

"It was really great to get together with other parents at Family Camp Weekend. Just to hear that other families are having some difficulty adjusting to this new diagnosis really helped me, more than you will ever know!"

"I liked meeting the "First Step" Chapter team and hearing from other parents at camp. By sharing stories with each other, we know we aren't alone. We're just at the beginning of our walk with our kids. I came away with the feeling that other people know what I am going through and I will be able to find others to talk to by attending Chapter events. That was really good. Thank you."

If you would like to register for a "First Step" conference call on January 17th in the evening, please call the DVC office (215-885-6500). All parents who participate on the call will have the opportunity to hear from other parents of young children or those newly diagnosed with a bleeding disorder. Join other "first steppers" and find out how to step to success!!

For Your Information

Hemophilia Awareness Day in Harrisburg!! Plan to Attend!!

The Delaware Valley and Western Pennsylvania Chapters are moving forward with "Standards of Care" legislation to protect patient access to therapies, treatment centers and home supportive services. As part of our efforts, members of both Chapters will be participating together in a Hemophilia and VWD Awareness Day in Harrisburg in April 2007. We will have buses bringing patients and families from the Philadelphia and Pittsburgh areas to the State Capitol. We will meet with legislators to tell them our

personal stories and ask for their help in securing support for our legislation.

If you haven't attended before, but would be willing to give us a day to support this important effort, give the DVC office a call right away (215-885-6500)!! We'll add you to the list of our faithful legislative volunteers!! We really need your help. We will have more detailed information in the winter newsletter!!

For Your Information

A Local Dad Tells His Story

Many times throughout the year, the DVC is asked to send a representative to speak about hemophilia and related bleeding disorders through the eyes of a parent or patient. Our "stand out" representative is Art Stinger, who presents the story of his own life, raising a child with hemophilia. This summer, as in past years, Art presented "Journey" to the National Youth Leadership Forum on Medicine held at Villanova University.

Each summer, over 1,000 students come to the Philadelphia area to experience the field of medicine. Besides getting a "first hand" look at medical schools, hospitals, research facilities and public health sites, they meet in small group seminars to learn about different diseases and disorders. Here are some of the comments from this year's students about Art's presentation!!

"Art was a great speaker and very touching. He gave a great presenta-

tion and was well informed about bleeding disorders. I liked how he talked about hemophilia from his personal experience. He was passionate, very knowledgeable and he was easy to understand and down to earth!! Amazing presentation!!" Thank you, Art, for always being ready and able to help us "spread the word" about bleeding disorders. We really appreciate it!!