

NHF/DVC THE WINNING SPIRIT

Quarterly Newsletter, National Hemophilia Foundation, Delaware Valley Chapter, Fall 2011 – Volume 18 #4



National Hemophilia Foundation
Delaware Valley Chapter

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PSI

If you need help paying insurance costs, go to our website for more information or call
800-366-7741

www.hemophiliasupport.org/fyi.htm

The Chapter reserves the right to refuse admittance to any person at any event in its sole discretion.

The Delaware Valley Chapter AN INSIDE LOOK

Many times throughout each year, we are asked, "Just exactly what is the Delaware Valley Chapter, how does it raise funds and what does it do with all the money?"

If you are a patient or a medical provider who is active with our Chapter, then you may already know the answers to those questions. But in any event, here's a re-cap!!

We are one of 41 Chapters of the National Hemophilia Foundation (NHF), providing services and programs to more than 2,000 local patients with bleeding disorders in southeastern Pennsylvania and Delaware. Actually, we are one of the three founding NHF Chapters, incorporating more than 60 years ago! There is one other NHF Chapter in Pennsylvania...in Pittsburgh. Each Chapter raises its own funds to service the local community of families affected by bleeding disorders in its jurisdiction. The DVC pays no fees and is not required to share any funds collected with NHF (or the other PA Chapter, for that matter). All money raised at the local level, stays local.

Throughout each week, we receive hundreds of calls...calls for resources from patients, parents, treatment centers, school district employees, other Chapters, local social service agencies and even college students and scientists who are writing papers or doing research! We receive more than 300 emails each week...from around the country and around the world, asking for help. We provide scholarships, health insurance premium assistance, financial help for life needs, publications, advice on where to go for help, how to network insurance problems, Medicaid and Medicare issues, how to find legal help for a problem or even a dentist...you name it, we're here to help!

We provide incredible financial support to local programs as well. We fund Patient Emergency Funds at local hemophilia programs in Pennsylvania and Delaware and work to help with their individual patient needs. We provide the publications and printed materials for hemophilia treatment centers...more than \$35,000 in publications last year alone. We sponsor patients and medical providers for training and education at local, regional, national and international meetings. We sponsor kids to camp each summer and we provide more college scholarships each year than any other Chapter in the country. The Delaware Valley Chapter also supports research in a very generous way.

We sponsor events that give families an opportunity to get important information and have fun with other families who understand the complex issues of dealing with bleeding disorders. We provide Information Sessions throughout the region each year on topics of interest to patients and their families. In fact, serving families is just about the most important thing that we do!

We are active in national legislative issues and not only participate in NHFs Annual Washington Days, but we work closely with the NHF throughout the year and maintain relationships with federal legislators in our area. We communicate routinely with them on different federal issues that affect our patients and families. We participate in legislative forums and hearings to voice the needs of our community.

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National Hemophilia Foundation

DELAWARE VALLEY CHAPTER

222 S. Easton Road, Suite 122
Glenside, PA 19038
Phone (215) 885-6500
Fax (215) 885-6074
E-mail: hemophilia@navpoint.com
Ann Rogers, Executive Director
Kim Bayer, Administrative Assistant
Christine Rowe, Fund Development Coordinator

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Thomas D. Galvin, President
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Jonathan Worthington

Noel A. Fleming, *Esquire Legal Counsel*

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We gratefully acknowledge the pledge of support from the following manufacturers for 2011.

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FROM THE EXECUTIVE DIRECTOR....

In this fall issue, we would like to say goodbye to two people who have retired from the DVC board of directors and introduce two new members for this fall! Board members serve one-year terms, beginning each September.

WE SAY GOODBYE TO.....



Bob Babb

Bob is Owner and President of The Physical Therapy & Wellness Institute. Bob was a great asset to the Chapter during his service on the board. With a background in wellness and rehabilitation, he provided help in improving our service to patients and families. Bob will continue to support and play a key role in leading the Broad Street ReRun each spring as he has done since the first year of this event. We say goodbye to a great person and advocate to our community!



Lynn Lindquist

After many years of service to the DVC, Lynn has retired from the DVC board. In addition to her board responsibilities, Lynn committed many hours of volunteer time to the Chapter through her leadership on the Annual Fall Gala Committee and the Annual Luncheon and Fashion Show Committee. Her contributions were valued by all of us at the Chapter. We wish Lynn much success in her new endeavors and look forward to seeing her at upcoming events.

WE WELCOME.....



Bob Sawyer

Bob is a Project Manager for C. Raymond Davis & Sons, Inc., a construction management firm. Bob, along with his wife (Jennifer) and their daughter (Rachael) have been active members and volunteers of the Delaware Valley Chapter for many, many years. When we asked Bob why he wanted to serve on the board, he said, "Through my affiliation with the Chapter as a volunteer, I have met a number of members who have always impressed me with their generosity, integrity, caring nature and their commitment and service to the community.

Simply put, I like the people involved with the Chapter. I believe that I have business experiences and skills that will be of help to the Chapter, especially in the area of finance." "Bob will be very helpful to the Chapter as a member of the board of directors. With his broad skill set and expertise in business, there are many ways he can contribute to improving our model of service. We are so glad to have him on board." *Tom Galvin, President*



Nanette Germain

Nanette is an Administrative and Marketing Manager for Keller Williams Real Estate. In 2010, The Delaware Valley Chapter was the recipient of the Keller Williams Charity Golf Event proceeds. Nanette was our key contact person at KW throughout the planning. She did a great job and worked closely with Christine Rowe (DVC Development) all along the way. She begins her board service with a big commitment...to Chair the 2012 Annual Fashion Show and Luncheon!

She looks forward to this new leadership role and is already on top of all the preparations!! "We welcome Nanette's service on the board. She is enthusiastic, a proven leader and has many great ideas. We will value her leadership on one of the most successful committees of the Chapter. She is a great addition to the Chapter's leadership and we give her a warm welcome." *Bill Widerman, Vice President*

Winning Spirit Newsletter GOING GREEN!!!

If you would like to receive your quarterly Winning Spirit via email (rather than through the mail), contact the Delaware Valley Chapter (hemophilia@navpoint.com) and let us know. Provide the following information in your email: name, current mailing address, home and cell phones and the email address you would like us to use. You will begin to receive your newsletter via your email. NOTE: IF YOU ARE A PATIENT REGISTERED AT AN AREA HTC, YOU WILL CONTINUE TO RECEIVE A HARD COPY VIA YOUR TREATMENT CENTER.

CHAPTER HAPPENINGS

Here's what's been happening!!

Scholarship Winners Fundraise for the DVC!!

Area college scholarship winners used their own ideas to create different fundraising activities to benefit the Delaware Valley Chapter! Wow! Here's what they did.



Patrick Droney

Performed at the Crocodile Rock in Allentown, PA. He and his sister, Josephine, sold tickets for the event and Patrick's portion of the ticket sales went to the DVC (more than \$1,200)! He was the top billing at the show! They sold tickets to friends, fans and Josephine's Pi Phi sorority sisters at Villanova University. A "rockin' good time" from the Droney team!!



Jake and Seth Scicchitano

Organized a Hawaiian Luau Dance on Friday June 3rd at a local school in Mount Carmel, PA to benefit the DVC. They raised more than \$1,200 and had a blast doing it!! A live DJ, pizza, snow cones, popcorn, prizes and even a raffle!! Thank you to the Scicchitano family and all their friends for supporting the DVC in such a generous way!

Perk-Up Half Marathon, August 28, 2011!

The Perk Up Half Marathon scheduled for Sunday, August 28th was cancelled due to Hurricane Irene this year. The extreme weather situation forced us to cancel the event for the safety of all involved. Although Hurricane Irene might have forced us to cancel our event, we are enthusiastic about coming back bigger and better next year. Stay tuned for more information on the Perk Up 2nd Annual Half Marathon at www.perkuphalfmarathon.com. A special thank you to Mayor Ryan Sloyer and The Upper Perkiomen Valley Chamber of Commerce for their dedication over the last year. We will be back next year STRONG and ready to ROCK Pennsburg like a hurricane!



Speakers Series, Central Pennsylvania

The following Patient Information Events were provided for our families in central Pennsylvania during 2011. All were held in Hershey, PA

March 12, 2011: *Managing Your Insurance As You Move Into Adulthood*
Presented by Michele Monahan, BA

March 19, 2011: *VWD: Women and Bleeding Disorders*
Presented by Judy Kauffman, RN, MS, CPNP

April 2, 2011: *Joint Health and Surgery Outlook*
Presented by Jim Munn, RN, BSN, MS

June 25, 2011: *Understanding Inhibitors*
Presented by Joanna Davis, MD

June 25, 2011: *Aging in Hemophilia*
Presented by Christopher Walsh, MD

2011-2012 Chapter Calendar

Call the DVC office (215-885-6500) for detailed information about the events listed here.

October

1 DVC Walk/Run!
21 Fall Gala!
28 Joint Health!
Plymouth Meeting

November

10-12 NHF Annual Meeting/Chicago!

December

3 Annual Holiday Party!

February

18 Inhibitors & Aging!
Plymouth Meeting
24 VWD: Issues for Women!
Plymouth Meeting
25 Bowling for Fun!

April

14 Fashion Show
27-29 VWD Retreat for Women!

May

8 Annual Family Dinner!
12 Broad Street ReRun!

June

4 Carlino's Golf!

Here's what's coming up!!

The Annual Holiday Party, December 3, 2011!

This annual event will be held on Saturday, December 3, 2011. This event highlights the holiday season and is a favorite for Delaware Valley area families. A gift for each child, Santa Claus and lots of holiday cheer!! Mark the date!! Don't miss this chance to have a little holiday fun!!

Speaker Series

All at the DoubleTree Hotel, Plymouth Meeting, PA

October 28, 2011: *Joint Health and Surgery Outlook* (no childcare available) Presented by Jim Munn, RN, BSN, MS, Comprehensive Center at the University of Michigan Medical Center

February 18, 2011: *Understanding Inhibitors* (childcare available)
Presented by Regina Butler, RN, Children's Hospital of Philadelphia Hemophilia Program

February 18, 2011: *Aging in Hemophilia* (childcare available)
Presented by Patrick Fogarty, MD, Penn Comprehensive Hemophilia and Thrombosis Program, Hospital of the University of Pennsylvania

February 24, 2012: *VWD: Women with Bleeding Disorders* (no childcare available) Presented by Judy Kauffman, RN, MS, CPNP, Kansas City Missouri Regional Hemophilia Center

The Delaware Valley Chapter AN INSIDE LOOK

We have strong relationships at the state level, as well and meet with the Department of Public Welfare, the Insurance Commission, Department of Health and various state agencies and legislative committees regularly. Insurance issues, national healthcare reform, insurance exchanges and access to medicine and care remain some of the biggest concerns for our patients. The DVC sponsors a state advocacy day in Harrisburg in April each year, coordinating visits by families and medical program staff in both the Pennsylvania House of Representatives and Senate.

We are continuing our efforts for *HB 635, The Hemophilia Standards of Care*, which was re-introduced in the Pennsylvania House of Representatives this year. It is now waiting for consideration in the PA House Insurance Committee. We are also working on health insurance exchanges (coming in the future) and access to care and pharmacy issues, including specialty tiers for our members in Pennsylvania and Delaware.

We are proud of what we have accomplished in our most recent fiscal year, including these highlights:

- Provided \$76,000 in educational stipends, including scholarships, camperships and sponsorships to regional and national conferences
- Provided \$61,000+ to help local families deal with short term financial difficulties
- Provided \$60,000 for local and national research support
- Provided \$600,000+ for local patient programs and services
- Provided social and referral support for families, including more than 5,000 one-on-one phone calls
- Provided camp opportunities for children and family social and educational events
- Provided \$40,000 in direct financial support to Hemophilia Treatment Centers in Pennsylvania and Delaware
- Actively engaged in supporting state and federal initiatives to ensure access to care and funding for Hemophilia Treatment Centers
- Implemented the PA Bleeding Disorders Premium Assistance Program to provide health insurance premium support to patients with bleeding disorders in Pennsylvania

And.....we accomplished all of that with an overhead that is the lowest of any health charity in Pennsylvania (8%) and we are very proud of that!

Where Does the DVC Get Funding?

As a 501 © (3) non-profit organization, recognized by the Internal Revenue Service (IRS), the DVC relies on donations to carry out its mission and purpose. We receive donations from a variety of sources, but most of our revenue comes from generous supporters....family members, friends, patients, local treatment centers and other foundations. The Child Development Foundation, the Verizon Foundation and many other local and national foundations support our work. We have a large membership base and we have fundraising events throughout the year that contribute significantly to our financial success.

We receive donations from individuals every week of the year. Some are *in memory or honor of someone* and some are general

donations. In addition, our fall membership drive provides contributions that we can apply to our service delivery.

Corporations vested in hemophilia and von Willebrand Disease (pharmaceutical companies) also support the good work that we do, by supporting events and offering grants through their pharmaceutical foundations for specific purposes (i.e. patient education, advocacy). When we have a good idea for a program and it meets the guidelines for their foundation support, we can apply for a charitable contribution for that specific purpose by writing a grant proposal. Submitting a grant proposal does not mean it will be automatically funded. Most Chapters take advantage of this type of funding. We develop an idea for a program or educational event, construct a grant proposal and then wait to hear if our idea is accepted.

Over the last 12 years, Hemophilia Patient and Program Support, Inc. (HPPS) a separate 501 © (3) non-profit corporation of the DVC, has contributed significantly to our financial stability and has expanded our ability to offer more services and programs. HPPS has helped the Chapter support the seven hemophilia programs in our area as well as our Scholarship and Patient Services Programs. HPPS has provided more than \$600,000 to the DVC since it was incorporated in 1998. The revenue generated from the HPPS Program has also allowed the Chapter to establish an endowment with the Philadelphia Foundation, a reputable organization that represents many worthwhile charities in our area.

The DVC is a partner in and receives funds from Community Health Charities of Pennsylvania (we are one of 27 health related charities in Pennsylvania that qualify for funding through CHC) and we are a member of the United Way Directed Donor Campaigns throughout our counties in Pennsylvania and Delaware. We receive contributions through federated workplace campaigns such as the State and Federal Employees Combined Appeals and the Philadelphia School District and City Employees Campaigns. We have received grants from the National Hemophilia Foundation, the Centers for Disease Control and Prevention (CDC) and the Commonwealth of Pennsylvania for local projects in education, prevention and insurance premium coverage assistance.

The rules that govern our operations are very strict. We are audited twice each year, once by an independent auditor and once each year, we have an audit conducted on-site by the Commonwealth of Pennsylvania, just to make sure that we are doing what we say we do in our mission. We must submit our audit each year to our funding sources and we must re-qualify each year for all United Ways, Community Health Charities and all workplace giving campaigns.

So there you have it! Thanks to the generosity of our many supporters, we have been able to increasingly expand the services and programs of the Chapter over the years. We couldn't do it without you!

To see our most recent Annual Report, visit www.hemophiliasupport.org. To request a copy of our most recent audit, call the DVC office @215-885-6500.

HEALTH UPDATES

HOME SWEET DENTAL HOME REGULAR CARE PREVENTS DENTAL PROBLEMS AND EXPENSES

By Elizabeth Thompson Beckley



Brush and floss. Brush and floss. Making dental hygiene part of your daily routine takes only a few minutes. Add to that a couple of annual visits to your dentist, and your preventive care can pay off in the long haul. Unfortunately, insurance woes that range from having a complicated policy to one that doesn't cover all procedures—or having no

insurance at all—may make it tempting to skip those twice-a-year oral checkups.

Having a bleeding disorder doesn't make you more prone to dental problems. However, avoiding proper preventive care of your teeth and gums can lead to more complicated and costly procedures in the future. You need an aggressive, prevention-oriented program to maintain optimal oral health and minimize the risk of possible complications if dental problems do arise. Certain procedures, such as tooth extractions or other oral surgeries, may require a consultation with your hematologist and dentist to determine what precautions need to be taken prior to your visit.

Planning ahead on both the provider and payment fronts can also pay off. Finding a dental care team you are comfortable with—a dental home—is perhaps the most important place to start. Investigating options for how to pay for that care is also critical.

“You have to have a dental home and be seen on a regular basis to prevent problems from developing,” says Richard Burke, DMD, director of the division of pediatric dentistry at the University of Iowa Hospitals and Clinics in Iowa City. To maintain good dental health, you

have to do your part. A preventive dental program that includes daily teeth cleaning with a toothbrush and toothpaste, flossing, appropriate topical fluoride exposure, as well as a proper diet and professional examinations at regular intervals, is effective in preventing most dental problems, Burke says.

Daily flossing should be part of your routine. Contrary to popular belief, people with bleeding disorders can and should floss. If people are not flossing on a regular basis, their gums are more likely to bleed when they start because of a condition called marginal gingivitis, explains Gayle Gilbaugh, RDH, a dental hygienist who works with Burke. Gingivitis is a type of gum disease that develops when bacteria build up between your teeth and gums, leading to irritation, inflammation and bleeding.

“As the bacteria are removed on a daily basis, the gum tissue will get healthier and the bleeding will lessen,” Gilbaugh says. “It's the old vicious circle—if you don't floss because of the bleeding, it will only get worse. I usually tell folks with a bleeding disorder that their gums may always bleed a little easier than someone without

a bleeding disorder, but the goal is to keep the gingival tissue as healthy as possible.”

Prevention Starts with the First Tooth

The American Academy of Pediatric Dentistry (AAPD) recommends that the parents or caregivers of any child should establish a dental home for an infant by the age of 12 months. Children with a bleeding disorder are no different.

“Our academy [AAPD] recommends these kids get to a dentist by age 1, or six months after emergence of the first tooth,” Burke says. Most “baby” teeth emerge without difficulty, but the dentist will likely offer what Burke calls “anticipatory guidance” to the parents or caregivers. The dentist will discuss dietary issues, including the use of bottles and “sippy” cups, which can cause tooth decay and cavities. Experts agree that a baby's bottle should contain nothing but milk or water. The child should not be sent to bed with a bottle. If a child with a bleeding disorder develops problems associated with tooth decay, treatment is about good management, Burke says.

For most children with a bleeding disorder, exfoliation (the loss of baby teeth) is not a problem. Bleeding can usually be controlled with direct finger-and-gauze pressure maintained for several minutes, Burke says. The direct topical application of hemostatic agents—chemicals that help stop bleeding—may also help.

But there can be exceptions. It is rare that one lost tooth causes severe bleeding and hospitalization, says dental hygienist Karen Ridley, RDH, MS, assistant professor of dental hygiene at the University of Michigan in Ann Arbor, who has worked closely with hemophilia treatment centers (HTCs) for many years. But if it happens again, the dentist might recommend a serial extraction, such as taking out all four molars when they are loose.

The Factor Aspect

Whether you will need extra factor product coverage for a dental procedure will be determined by your hematologist. It is based on the severity of your disease and your history, and the procedure itself, such as extractions or deep scaling. Deep scaling is a deep cleaning that your dentist may recommend to stop gum disease from progressing after the bacteria and inflammation from untreated gingivitis have worked their way down to the foundations of the tooth. For such procedures, factor replacement therapy may be considered, Burke says.

Burke recommends that patients with a bleeding disorder and periodontal disease be placed on a maintenance schedule to avoid progression of the periodontal disease. People with inhibitors usually require treatment in a hospital setting. In addition, people with HIV, those with central venous access



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HOME SWEET DENTAL HOME REGULAR CARE PREVENTS DENTAL PROBLEMS AND EXPENSES *By Elizabeth Thompson Beckley*

devices or those who have had recent joint replacement surgery may need prophylactic antibiotic therapy before undergoing any dental procedures. Factor is not always the only solution. According to Burke, hemostatic agents such as Amicar®, Avitene®, Gel-foam® and Surgicel® can be used to help stop local bleeding.

If you will need factor for a dental procedure, the high costs associated with it make it essential to manage those procedures efficiently, Burke says. When someone has multiple problems on different sides of the mouth, it often makes sense to infuse, anticipating a lengthier stay in the dentist's chair. You may need to infuse both before and after the dental procedure.

"We try to get all the treatment done in one visit if possible," Burke says. This may include the use of nitrous oxide (also known as "laughing gas"), sedation and close coordination with the patient's hematologist. The social worker or financial reimbursement specialist at your HTC may be able to help you plan for the added costs of extra factor needed for dental procedures.

Insurance Concerns

Nicholas Reiser is a computer and electrical engineering technology student from Monroe Township, New Jersey. He works 30 hours a week as an automation technologist at Aurora Multimedia, based in Morganville, New Jersey. Reiser has severe hemophilia A and was one of those rare people who had significant bleeding when he lost his baby teeth.

"It was definitely a big hassle for my parents," Reiser says. He recalls alerting his parents to another lost tooth by walking into the room saying, "Hi, I've got a pile of blood in my hands, and it's not stopping." He adds, "So I had trips to the emergency room instead of visits from the tooth fairy." After switching dentists, Reiser eventually found what he considers his dental home, with a dentist who understood his hemophilia.

"But that was my pediatric dentist," Reiser explains. "Now that I'm 20 and on my own, I can't find another one. I haven't seen a dentist in a year and a half. My health insurance changed, and now I don't have dental care. Do I spend my last dollars going to the HTC to get my checkup or pay out the nose without insurance?"

The insurance dilemma depends on geography—some states have better coverage options than others. Many dental patients with a bleeding disorder depend on Medicaid or some form of subsidized dental care, according to Ridley. In Michigan, few providers accept these forms of payment, however, Ridley says.

Most HTCs and chapters have a referral list of resources in your area. Though rare, some hospital-based dental programs treat patients who have multiple health complications. Another thing to remember is that some dental clinics have sliding-fee scales.

Innovative Solutions

A few years ago, leaders at Hemophilia of Indiana, a chapter of the National Hemophilia Foundation, and the Indiana Hemophilia

and Thrombosis Treatment Center in Indianapolis started considering how they could provide dental care assistance for their bleeding disorders community. By offering financial options to help

people maintain their dental health, they hoped to encourage them to see their dentist more regularly. They anticipated that this, in turn, would help avoid some of the problems and complications of coordinating care for more serious dental work, explains Sally McCarty, [formerly] an insurance and advocacy consultant to Hemophilia of Indiana.

Delta Dental, the largest dental health insurer in the state, was open to a proposal to start a group plan for members of the Indiana Chapter and their families. The first member was enrolled on September 1, 2006; the group now includes 138 policies with 341 individual enrollees. Almost none of them had dental insurance before the launch of this program, McCarty says. "Between the HTC and the chapter, we've got 98% of the people in the state affected by a bleeding disorder," McCarty says. The two dental hygienists who work at the HTC act as case managers. They understand the plan and advise enrollees about how to get the most value out of their benefits, based on what care is needed.

McCarty's advice for other chapters or HTCs that want to start a similar program is to review their state's laws for forming a group for insurance purposes and identify the larger dental providers in the region. "The ones with the largest share of business are probably the most willing to work with you and have the best prices," she says.

Establishing and maintaining a connection with a dental team provides peace of mind, Burke says. After all, you can't always predict when you're going to need dental intervention. When you do, it's comforting to have a dentist who knows you and understands your needs. "The concept of that dental home is so important," Burke says. "Emergencies never happen 9 to 5."

To Learn More...

Read the *HemAware* article "Treat Teeth Right, From the Start" in the July/August 2005 issue (available online through hemophilia.org).

The World Federation of Hemophilia's (WFH's) Dental Committee published Guidelines for Dental Treatment of Patients With Inherited Bleeding Disorders in 2006 (Treatment of Hemophilia Monograph No. 40). The guidelines add to two previous WFH monographs on oral and dental care, prophylaxis and treatment (Treatment of Hemophilia Monographs No. 3 and 27). It is written



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HOME SWEET DENTAL HOME REGULAR CARE PREVENTS DENTAL PROBLEMS AND EXPENSES *By Elizabeth Thompson Beckley*

by dentists for dentists and does not provide specific guidelines regarding doses of factor concentrates.

The American Academy of Pediatric Dentistry's Policy on the Dental Home

Selecting a Dentist

During her almost 30 years working with hemophilia treatment centers (HTCs), Karen Ridley, RDH, MS, says one of the most frequent calls she has received is for a recommendation for a dentist to treat someone with a bleeding disorder.

Some dentists have more experience working with people who have bleeding disorders. "There are few dentists who specialize in hemophilia," says Ridley, assistant professor of dental hygiene at the University of Michigan in Ann Arbor. Some HTCs have a specific group of dentists that they use, but not all are so fortunate. Much depends on geographic circumstances and the supply of dental professionals in a region. "If you have to drag someone to the other end of the state, they're less likely to go," Ridley continues. She encourages families to use a local dentist they are comfortable with, but offers a note of caution. "Make sure the dentist and treatment center are in contact with each other."

HTCs and local National Hemophilia Foundation Chapters and associations can refer you to dentists who are familiar with treating people with bleeding disorders. Word-of-mouth recommendations from others with a bleeding disorder or parents of children with a bleeding disorder are another way to identify dentists who will understand your needs.

"Any dentist can and should see hemophilia patients," says Richard Burke, DMD, director of the division of pediatric dentistry at the University of Iowa Hospitals and Clinics in Iowa City. "The only thing required is appropriate consultation with the physician and a desire to help."

CDC Helps Ohio Amish

The Hemostasis and Thrombosis Center at Akron Children's Hospital in Ohio cares for the largest concentration of hemophilia B patients in the world. The 160 people with hemophilia B in the local Amish/Mennonite community represent about 5% of hemophilia B patients in the United States.

For a number of reasons, preventive dental care is not often part of the cultural habits of this tightly knit traditional group, notes Jeffrey Hord, MD, director of pediatric hematology and oncology at the Akron hospital. Distance from providers, the costs of paying drivers to transport them, the cost of dental care and different cultural norms are among the barriers to the Amish community's access to preventive dental care. "They have no third-party payers and few dentists," Hord says. "Consequently, it is not uncommon to see a child of 3 or 4 years of age who has never seen a toothbrush, or to perform total extractions by the age of 13, 14 or 15."

A new proposal by the HTC to increase the use of preventive dental care among the Amish could begin to change some of those scenarios. The program received a \$320,000 award through the Centers for Disease Control and Prevention's (CDC's) Promoting the Health of Individuals with Bleeding and Clotting Disorders Grant Program.



The CDC grant, which began in January 2008, provides culturally appropriate dental education for Amish people with hemophilia B, but could also benefit the entire local Amish community. The program teaches them to increase use of preventive dental techniques such as brushing, flossing and obtaining early intervention, as well as providing regular access to a dental provider. It also encourages early treatment of bleeding episodes by educating individuals or family members about how to infuse clotting factor themselves.

Previous article taken from HemAware.org, an online publication of the National Hemophilia Foundation 2/4/11.

LIAM O'NEILL WINS THE PRESTIGIOUS DAD VAIL REGATTA



Drexel University's Liam O'Neill, age 22 with severe hemophilia, won the prestigious Dad Vail Regatta in Philadelphia in June. Liam and his family have been active members of the Delaware Valley Chapter since Liam was born. To read his heartwarming story and how he honored his father on his own day of triumph, go to: www.sports.espn.go.com and search LIAM O'NEILL. It's a story you will remember all your life.

LEGISLATIVE UPDATE

UPDATE ON PENNSYLVANIA'S BUDGET AND STATE SUPPORT TO THE SEVEN HEMOPHILIA PROGRAMS

In the summer issue of *The Winning Spirit*, we told you about the immense state budget crisis in Pennsylvania and Governor Corbett's proposal to cut funding to the seven hemophilia programs in Pennsylvania by 43%. In the end, the budget passed on time, but included a 29% reduction in funding to the hemophilia programs. "Although the reduction in funding for the hemophilia programs in Pennsylvania was less severe than anticipated, it is devastating to these programs that provide key services to patients. The Centers for Disease Control and Prevention (CDC) states that patients seen by hematologists connected with Hemophilia Treatment Centers have better outcomes than those treated by outside hematologists," says Ann Rogers, DVC Executive Director. "It will be hard to provide the same level of program staffing and service to local patients with this level of reduction in state support. It doesn't make sense to reduce or eliminate services provided through these centers of excellence, as these programs have a demonstrated track record of improving the lives of patients with bleeding disorders. Improved outcomes and diminished complications equate to cost savings for the Commonwealth and for insurers."

Some diseases lost all state support and others were cut by a larger percentage. We appreciate the help of many patients, families, medical providers and Senate and House members who helped carry the message regarding the importance of state support for these specialized programs that care for people with bleeding disorders. Our collective efforts did make a difference, although the outcome will certainly have an impact on what these programs will be able to offer to patients.

Update on HB 635, *The Hemophilia Standards of Care Act*

Right now, *HB 635* is sitting in the House Insurance Committee, waiting for consideration. Representative Larry Curry reintroduced this bill in February 2011. Please contact Representative Nick Micozzi, Chairman of the House Insurance Committee and urge him to bring *HB 635* up for consideration in his committee immediately. We need his leadership. nmicozzi@pahousegop.com 717-783-8808



**CAMPAIGN
FOR OUR FUTURE**

PHASE II:

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for all bleeding and clotting disorders



Delaware Valley Chapter Support Network

In an effort to increase our service and help to families in areas outside of the central Philadelphia area, we have established five branches of the Delaware Valley Chapter. The purpose of the branches is to help network patients and families affected by hemophilia and von Willebrand Disease (VWD). If you are a patient or parent/s of a patient and would like to socialize with others who share your issues, please contact one of the following team leaders to get involved. These branches meet informally, in private homes, for social events and support. There is no charge for being involved.... just networking with families just like you!! These branches are not open to any person who works or has a family member who works for any industry or company directly or indirectly involved in products or services for patients with bleeding disorders.

Delaware Branch Gail & Luke Vannicola 302-378-1278	Mount Carmel Branch Jolene & Sam Scicchitano 570-339-4137
Lititz/Lancaster Branch Lorie & Brian Kerstetter 717-626-9679	Reading/Pottstown Branch Tina & Jeff McMullen 610-582-1731

All DVC families are encouraged to send current email and cell contacts to the Chapter. We are trying to reduce our paper communications and do more electronically. Send information to kimb@hemophiliasupport.org.