2014 HNC Hemophilia Walk

Now that we have a tough winter behind us, it is time to prepare for and celebrate the 2014 HNC Hemophilia Walk! The Hemophilia Walk is our largest fundraiser of the year, and HNC and its members will see 100% of the profits! We will be hosting our Walk at Lake Crabtree County Park on October 11th, 2014. This year, we plan to have an even BIGGER and BETTER Walk than we have ever had before and we cannot do it without you! We have a goal of $100,000 to reach again this year, so we had better get started early.

We would love to see our teams registered early this year. If you register and raise at least $100 by July, the National Hemophilia Federation will be providing you with a special prize for your early efforts!

Although the Walk is a few months away, a lot of the “behind the scenes” work is already taking place. Grifols will be providing team t-shirts again.

Why I Walk
By Erin Otey,
Team Captain for “Wonderfully Made”

I look forward to participating in the Walk each year because it gives my two sons an opportunity to share with people that they are Wonderfully Made and that no matter what challenges they face due to hemophilia, they are always in the Lord’s hands. It also gives my team a chance to educate the community about bleeding disorders and to raise funds that are vital for continuing research and improving the quality of life for people with bleeding disorders. I am very thankful for Hemophilia of North Carolina as the programs and resources they provide have been a huge blessing to my family!

HNC’s Newest Addition:
Lakia Poole, Assistant Director

By Charlene Cowell

Please join me in extending a warm welcome to Lakia Poole, who joins us as HNC’s new Assistant Director. We have spent the last few months in an extensive search process, and Lakia was a clear standout from the beginning.

Lakia is originally from North Carolina, born and raised in Elizabeth City. She studied Media Writing and Women’s & Gender Studies at the University of North Carolina at Greensboro, then travelled to the Midwest to pursue a career in the non-profit sector. After landing in Iowa her work ranged from helping homeless youth find employment, to running an after-school program for middle and high school girls in Des Moines. These assignments inspired her with a passion for serving families and the larger community. She is very excited to bring that passion and her skills to Hemophilia of North Carolina, and is looking forward to making many new connections and partnerships with the HNC community.

Lakia’s interests include travel (beach trips especially), movies, reading and dancing — particularly salsa. The middle child of three daughters, she is a proud aunt of the greatest kids in the world.

She is already hard at work on the job, so if you happen to be in the Morrisville area I encourage you to stop by and introduce yourself.
Hemophilia of North Carolina is a non-profit organization dedicated to improving the quality of life of persons affected by bleeding disorders through advocacy, education, promotion of research and supportive programs and services.

MISSION STATEMENT
Hemophilia of North Carolina is a chapter of the National Hemophilia Foundation, a chapter member of the Hemophilia Federation of America, a member agency of Community Health Charities of North Carolina, a chapter member of the NC Center for Nonprofits.
From the Executive Director

Dear Friends,

It’s hard to believe that it’s been over six months since my promotion to HNC’s Executive Director. I want to begin by thanking everyone for his or her support and assistance with a smooth transition. I’m confident that with our talented members, dedicated staff, and board of directors, HNC will continue to be an invaluable resource for the NC bleeding disorders community.

My first order of business involved staff development with a focus on growth. I felt strongly that in order to fulfill the goals of enhancing our organization’s services and outreach, we needed to hire a full-time Assistant Director.

During this search process, Rita Brown agreed to return part-time during the transition. Rita had previously worked with HNC in a variety of roles since 2011. On behalf of the board, I want to thank her for her commitment to HNC and our members. I personally must thank Rita for her continuous encouragement and willingness to step in and assist throughout this period. Her patience and hard work allowed myself, along with consults, to be able to take the time to select the most qualified individual.

I’m delighted to announce that the search is over and Lakia Poole has joined HNC as our new Assistant Director. From her first day, Lakia did not hesitate to jump in and roll up her sleeves! With two conferences already under her belt, she hasn’t wasted any time getting to know our community. I am confident that she is a great addition to the organization and will be a passionate advocate for the bleeding disorders community.

Warmest Regards,
Charlene

From the Assistant Director

Deciding to take on the role of Assistant Director at HNC is a decision I’m thrilled about. From my first meeting with Charlene, I knew that this was an organization that I wanted to be a part of. I immediately sensed the compassionate work that goes on, from everyone involved: members, staff and volunteers. Advocacy and partnership are concepts I fully believe in, and while I’m just a couple of weeks into my work, I find that HNC is a glowing example of those values.

While my professional background is with youth programming, I do have much experience navigating the non-profit sector, particularly program development and capacity building. I want to bring these skills to the table here at HNC. There is an impressive network of resources that keeps this organization thriving, and I’m excited about the room for expansion and further development in our programs and services.

I have quite the learning curve as an Assistant Director here; I am not personally affected with a bleeding disorder, nor do I have family members who are. I do want to make a point that I approach HNC and the bleeding disorder community with humility. I wish to learn all I can while working alongside our members, remaining respectfully and passionately supportive of keeping their collective voice heard and shared.

In one of my longer chats with Charlene, I confided in her that the two of us are going to make a great team. You know that feeling when things just work out? When, for some strange reason, a situation just falls into place and before you know it, you’re right where you want to be? That’s exactly how I feel about HNC. And something tells me I’ll feel that way for a very long time.

With Much Respect,
Lakia
Hemophilia of North Carolina (HNC) hosted our 7th annual “Hearts for Hemophilia” Casino Night event on Saturday, January 25, 2014. Fortunately, there was no luck involved in our continued growth of attendees and proceeds. The hard work of our planning committee, generous sponsors and those who attended the event helped assure that this evening was a big success.

New this year, Triangle Catering hosted the event at its beautiful venue, Cardinal Hall in Raleigh. Some of the new location highlights included a built-in bar area, perimeter floor lighting, seating areas with couches, and plenty of free parking.

Each guest was greeted at the door and received a big bag of ‘fun money’ play chips to ready themselves for play at the gaming tables. There was blackjack, craps, poker, and new this year, the big wheel and slot machines.

Everyone enjoyed delicious food throughout the evening and an open bar of handpicked local beer and wine. Some of the food choices included chef-attended stations serving grilled shrimp, beef and chicken kabobs, and grilled marinated Asian flank steak. Other options included Fontina risotto balls, lemon chicken, and snow peas skewers, Southern fried green tomatoes with chow-chow relish, a fruit and cheese display, and a large selection of desserts.

Back by popular demand was the fabulous quintet from the UNC-Chapel Hill Jazz Band, who entertained throughout the evening.

For a small donation, guests were invited to participate in the Grand Prize Tech Package raffle drawing. The winner received over $1,000 in items including an Apple iPad 2, Fitbit Flex Wireless Activity & Sleep Band, a Chromecast digital media player, Bluetooth speakers, and a $50 iTunes gift card. Special thanks go to Kedrion and several anonymous individual members for their donations toward the raffle prize package.

Our popular live auction featured a Disney Getaway package that included two tickets to Disney World, two round trip flight tickets to Orlando, and $250 toward hotel and other expenses. Also auctioned off were a pair of Richard Petty Driving Experience tickets, and an original painting by local artist Dan Campbell. With the help of our talented new auctioneer, Cheri Faux, money was also raised for HNC’s Financial Assistance program.

Throughout the night, silent auction items were on display for bidding. Some of the most popular items included a one-night stay and breakfast for two at the Graylyn in Winston-Salem, a one-night stay and breakfast for two at the FourPoints Sheraton in Asheville, four tickets to an NCSU basketball game, tickets to the NC Symphony and dinner for two, Seagroves pottery, and many gift baskets.

At the end of the night, we had lots of winners that cashed in their chips for raffle tickets and a chance to win restaurant gift cards, specialty coffee, sweets, and other great prizes.

The night concluded with a very special thank you to all of our sponsors, guests, organizing committee and volunteers. Each attendee received a special gift of chocolates as a thank you for their support and for being our guest for the evening. HNC raised over $20,000 and all proceeds will help us to continue our goal of promoting opportunities to improve the quality of life for those affected by a bleeding disorder. It is our vision for everyone to achieve their full potential without barriers or limitations, until a
HNC 7th Annual Casino Night  Continued from page 4

cure is found. Those that supported our event continue to make this vision a reality.

The HNC Board of Directors would also like to acknowledge the hard work and tireless effort of the planning committee that included Rita Brown, Charlene Cowell, Tiffany Holland, Matt and Tat’yana Igelman, and Charles Register.

Catherine Wilson, Sharon Ingram and Sue Cowell

Don’t our NC chapter fellas look dapper?

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FREE
2014 HNC Hemophilia Walk  

Continued from page 1

this year, so start thinking about your t-shirt design! We are looking forward to seeing some original and amazing designs, so be prepared for the T-shirt Contest. Speaking of the contest, this year we are switching things up a little. Instead of a costume contest, we are going to have a crazy hat contest. We want to see the craziest hats possible, which means a chance to win prizes!

We are also currently working on getting all our previous vendors back again this year, including the massage chairs from Miller Motte College.

The Walk Kickoff event is always a great way to meet other team captains and bounce ideas off one another. We will have materials available to help you make the most of our 7th annual Walk. We’re still working on the details but look out for the Kickoff event in late July! Bring as many team members as you can for a day filled with sunshine and good friends.

More information will be available as the Walk event approaches, so keep your eyes peeled for emails and Facebook posts. If you’re already planning a team fundraiser, please let us know so we can support you in your efforts. We look forward to seeing you in your walking shoes!

Visit the HNC website for more information and resources.

Donate to the Walk

You can make an online donation to HNC’s 2014 Hemophilia Walk through the National Hemophilia Foundation web site. Just follow these easy steps:

• Go to www.hemophilia.org/walk
• Click NC (Raleigh) on the right-hand side.
• Click on the blue DONATE button.
• Click on “click here”.
• Fill in your name, address, and credit card information (all the places marked with “*”). Don’t worry, this is a secure website, so your information is safe.
• Click the blue Continue button at the bottom to confirm your donation.

That’s it! You don’t have to “log in” to anything.

You can also use this same website to credit your donation to a specific Walk team or an individual team member. You’ll be hearing more about that soon!
This year, the Hemophilia Federation of America (HFA) held its annual Symposium in Tampa, Florida. The event was exceptionally special, as HFA’s service and advocacy to the bleeding disorder community has hit its 20-year mark. Over 800 people were in attendance, including families, chapter members and community supporters.

HFA is a non-profit 501(c)3 organization incorporated in 1994 to address the evolving needs of the bleeding disorders community. HFA is an active consumer advocate for safe, affordable, and obtainable blood products and health coverage, as well as a better quality of life for all persons with bleeding disorders.

A plethora of breakout sessions were offered, along with a new Inhibitor track. Attendees also enjoyed FitFactor (morning walks were a favorite) and Health and Wellness lounge activities. A very poignant addition to the Symposium was the History Room, an area not only celebrating HFA’s 20th anniversary as a grassroots organization, but a collection of archival documents, stories and photographs about bleeding disorders over the past 70 years.

Hemophilia of North Carolina supports HFA, and among other collaborative activities, HNC hosts an active Blood Brotherhood group. You can find information about the Symposium, including the History Room exhibit, on their website at www.hemophiliafed.org.
Dear Fellow Hemophilia Families,

We hope everyone is surviving the seemingly endless winter. Hemophilia of North Carolina (HNC) reached out to us to write about our experience during the past NHF Washington Days meeting in our nation's capitol this past February 26th through 28th.

I once heard someone say elections have consequences, so it is our responsibility to make sure the candidates we put in office have our best interests in mind. Once the candidates are in office, they have to be educated on the issues that directly affect your family, community, and livelihood. The quality of your family’s life can be greatly affected by the votes of your elected officials. As parents of a hemophiliac, Tiffany and I both know that living with hemophilia is challenging enough; we cannot afford to have politicians voting on laws or setting budgets on issues without proper education on what they are voting for.

Our family took advantage of the invitation to go to Washington DC for the opportunity to speak with our local representative about the issues that are important to the hemophilia community. This letter would be much longer if I wrote about all of the issues affecting our community. But the hot topic on this past trip was House Bill 460 and how it relates to the hemophilia community. When the government passed the Affordable Care Act (ACA), the hemophilia community felt a large victory had been won in that the insurance companies can no longer deny coverage based upon pre-existing conditions. However, we will need reasonable co-pays and caps on the cost of factor and treatments in addition to the removal of denying pre-existing conditions.

We learned during our NHF meetings in Washington DC that House Bill 460 does just that: it prevents insurance companies from putting factor in a pharmacy specialty tier category. Traditionally, insurance companies can charge extremely high co-pays on all medications in these specialty tier categories. For example, if the specialty tier co-pay percentage is 20% and your factor costs $1,000,000 per year then you have to shell out $200,000 in co-pays. House Bill 460 will prevent this from happening. Factor is not a medication that we can live without, or settle for a generic brand. Our son Zackary could not live a normal life without factor, so we have to make sure his factor is readily available while being affordable at the same time.

With the newly gained knowledge of House Bill 460 and some proper etiquette tips about visiting the halls of Congress, we set out with other members of HNC to meet with our representatives. Tiffany and I found our representative Howard Coble and his staff to be very friendly and inviting and seemingly interested in what we had to say. From what I understand you are lucky to get thirty minutes of time with a representative or their aides, and we were there for over an hour, which was a miracle considering we had three young kids with us. We explained what hemophilia is, the importance of what House Bill 460 means to our family and the community, and also developed a rapport with the representative.

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The Hargett Family

Some of our NC Chapter members at the event.
NC Hosts Regional Hemophilia Treatment Center Meeting

By George McCoy

Charlotte, NC played host to almost 120 HTC staff and advocates from the eight-state Southeast Hemophilia Region on March 16-18, 2014. The meeting provided technical assistance and training for those present. The agenda was crowded with experts in such areas as orthopedic/physical therapy procedures, transition issues for older patients, management of pregnancy in women with bleeding disorders, and cardiology issues for older patients.

A big highlight of the busy conference was a talk by Dr. Laura Noonan, from Levine Children’s Hospital in Charlotte. Dr. Noonan talked about “Health Literacy.” In her talk, she explained how important it is to be sure that doctors and patients understand each other. She gave examples of how both language and attitude can interfere with clear communication. When people do not fully understand the doctor, they may take medicine in the wrong dosage or on the wrong schedule. They may not tell the doctor all their symptoms, or the doctor may not understand what problems the patient is facing. Lack of health literacy by either the doctor or the patient may get in the way of good medical care. She stressed that it is important for all of us to spend time talking to each other using clear language to make sure the best medical outcome is reached.

In addition to the presentations made for everyone to hear, there were individual sessions for people to meet with others like them. The session for chapters/consumers was very powerful, with lots of good conversation and sharing of ideas for how to improve Chapters and how to serve people better. Doctors, nurses, social workers, physical therapists, and data coordinators also met together to share ideas.

We are very proud that North Carolina hosted such a big and important meeting to talk about people with bleeding disorders. Many of the best presentations were by medical staff from NC, and several HNC staff and members attended. We all came back with new ideas and enthusiasm. Perhaps next year you will join in the learning! Watch the HNC website and The Concentrate for news about the 2015 meeting!

NHF Washington Days

Hits Close to Home  Continued from page 8

with small talk of home. When our representatives can put a face with a cause, then the chances are good they will support and vote for bills that will benefit that cause.

The trip was informative about current issues affecting our community and the workings of our federal government. We definitely enjoyed meeting new families from across the country and hearing what challenges and opportunities they encounter while living with hemophilia.

To advocate about what is important to you means you have to be there to be heard. The representatives in Washington are voting on bills all the time, and it is imperative that we as a nationwide community stand together and voice what is important to us. We definitely enjoyed the trip and look forward to seeing all of you next year!

Thank you,
Brandon, Tiffany, Nickolas,
Zackary, and Kameron Hargett
My husband has a bleeding disorder called hemophilia. Prior to beginning a relationship with him, I did not have an understanding of hemophilia and the intrusive nature it can have on someone’s life and marriage. My miniscule understanding of hemophilia only consisted of someone “bleeding a lot” if they had an open wound. It was explained to me that a hemophiliac may bleed a little longer than normal and may need to take medicine to stop it.

I was curious about the limp Warren had (or, as he calls it, his “swagger”) when he walked. He shared information with me about the unseen debilitation and physical damage that someone with hemophilia could experience, depending on the severity of his or her disorder. The effects of hemophilia could include disability in the joints—ankles, elbows, shoulders, knees, and hips. Warren was extremely open and very comfortable in sharing that, in 1986, he had undergone a bilateral hip replacement due to bleeding. Because of that surgery, his hips are not quite level, hence, he has a swagger.

Later that night, during a phone conversation Warren shared more information about the complications of hemophilia because of tainted blood products. While he was very specific and detailed in the account of his story, I noticed for the first time heaviness and sadness in the tone of his voice. As I carefully listened, not asking one single question or interrupting him, I knew that he was sharing the trajectory of his life. His pain was not only physical, but also extremely mental and emotional. There was silence on the phone, and I realized that he was waiting for my response. I said cheerfully, “Well we’re friends — let’s see where this friendship takes us.” Those were my words, but my heart thought that it was hopeless to continue.

To fast-forward, Warren began taking me to doctor visits with him and the doctors were very kind to discuss various situations and discoveries with me. I became less anxious, and interested to learn more. Soon, I would take trips to Washington DC and meet the spouses of his friends who would tell their stories and share what was working for them. Warren and I eventually got married, and every day we pray for continued better health. After lengthy conversations and visits with my husband to his hematologist, I had knowledge about what hemophilia was. But it was not until my life began as a wife, caregiver, and cheerleader fifteen years ago, that I really did grow to understand it. Although at times I desired just a “normal” day, I discovered early on that I had to adjust to a new normal. For example, several of the traditional husband and wife duties were divided up differently in our household. Chores such as yard work, car maintenance, and caring for our girls, were shared and became a different situation for us compared to most. As a child, my husband’s father would take him for all of his doctor appointments. So scheduling checkups and dental appointments for our girls was not only comfortable for Warren, but also enjoyable.

Since being married to Warren, my life has taken on a richness that I cannot really put into words, but that I have been able to show through my actions; in particular, with my involvement in the bleeding disorders community. Educating and sharing with those who may have an undiagnosed bleeding disorder, along with sharing with other spouses at rap sessions about the importance of self-care and open communication with one’s spouse is powerful and inspires me every time I do it.

Sharon has been involved with advocacy and outreach in the hemophilia community for over 14 years along with her husband, Warren, who has severe hemophilia A. Sharon’s love for the hemophilia community is evident by her ongoing volunteerism and the support she constantly provides. Sharon and Warren live in Charlotte, North Carolina with their two daughters, Emma and Jasmine.

“At the end of the day, we’re just like any other couple making the adjustments to assist each other on this journey called life.”

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A Sweet Start to 2014

By Erin Otey, Team Captain for “Wonderfully Made”

To kick off fundraising efforts for Hemophilia Walk 2014, Team Wonderfully Made held a bake sale around the holidays. The star bakers, Renee Gilbert and Kathy Otey, spent countless hours in the kitchen and provided an assortment of homemade holiday treats, including: fudge, gingerbread cookies and sugar cookies, German chocolate cake and red velvet cake, Christmas tree cupcakes, brownies, chocolate Christmas tree pretzel rods and peppermint bark.

Childcare Network in Lewisville, which proved to be the perfect place for such an event, hosted the two-day bake sale. Several staff and parents of the childcare facility went above and beyond by contributing goodies to the sale as well. Because of the generous purchases and donations from parents, students and staff at Childcare Network, the bake sale was a huge success and raised $400 for this year’s upcoming Walk!

Save One Life

Save One Life is a registered non-profit international organization that offers individuals, families, companies and/or organizations the opportunity to sponsor a child or adult with a bleeding disorder in a developing country.

Save One Life offers sponsorships directly to individual children or adults. Unlike many other child sponsorship programs where sponsor funds are pooled, Save One Life beneficiaries receive money directly from their sponsors, with only a small percentage given to the national or local hemophilia non-profit organization that registers and cares for them.

Hemophilia is a devastating inherited blood disorder that can cause severe pain, damage and even death when untreated. In developing countries, there is usually no substantial budget to purchase the blood-clotting medicine needed to sustain life. And for a disorder as rare as hemophilia, governments and social agencies usually cannot help. For under a dollar a day, you can sponsor a child or adult with hemophilia.

Save One Life is dedicated to the bleeding disorders community. It uses funds carefully and diligently, and has strong personal relationships with the non-governmental organizations (NGOs) in developing countries that manage its programs. Save One Life acts as a humanitarian bridge to encourage individuals and families in developed countries to engage in and give back to the rest of the world on a personal basis.

More than just a charity, Save One Life is also a development tool that helps promote long-term care and NGO capacity building by training, monitoring for progress, and rigid accountability.

Save One Life was founded in 2000 by Laureen A. Kelley, author and President of LA Kelley Communications, and mother of a child with hemophilia.

For more information, you can visit the website at www.saveonelife.net.
HFA Kit de Regreso a La Escuela

Ya es toda una tarea para ayudar a su niño a manejar su trastorno hemorrágico. Pensar en su hijo manejando en la escuela puede parecer desalentador. Sin embargo, hay muchos recursos que la Hemophilia Federation of America (HFA) ha aportado para ayudar a informar a la maestra de su hijo o hija acerca de lo que necesitan saber. Recursos incluidos son:

- Presentaciones de anteriores eventos, webinars de HFA, y diapositivas de PowerPoint que explican trastornos hemorrágicos al personal de la escuela de su hijo o hija.
- Artículos, apuntes y folletos que ayudan a personal de la escuela proporcionar la atención adecuada a su hijo/hija.
- Formas útiles para usar para documentar las necesidades de la asistencia médica de su hijo/hija.

Usted puede encontrar estos materiales gratuitos en la Web de HFA: http://www.hemophiliafed.org bajo la página llamado “Resource Library”.

¡Hola! HemAware ahora en español

HemAware está atendiendo una necesidad cada vez mayor de artículos en español, con la creación de HemAware en español. Este nuevo sitio de Internet contiene más de una decena de artículos publicados anteriormente en HemAware y traducidos al español, y de ahora en adelante, HemAware traducirá un artículo al mes.

Los artículos de HemAware en español, además de materiales educativos y conversaciones, saldrán en sus cuentas de Facebook y Twitter. Si tiene ideas para artículos de HemAware en español o simplemente quiere unirse a la comunidad, nos puede encontrar en Facebook y seguirnos en Twitter.

2014 CONFERENCIA EDUCATIVA SOBRE Inhibidores

Los temas que se presentarán incluyen:
- Asuntos de portadoras
- Tratando la Hemorragias de las Articulaciones
- Intervención Quirúrgica para Pacientes con Inhibidores
- Terapia de Tolerancia Inmunológica
- Profilaxis Utilizando Desvió de Agentes
- Tratamientos del Futuro
- Asuntos de Escuela
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Observe por favor: Esta conferencia y todos los materiales educativos serán presentados en español. No habrá traducción en inglés simultáneamente.
Por Favor de la Bienvenida a Lakia Poole,
La Nueva Directora Asistente de HNC

Por favor acompaníame en extender un calida bienvenida a Lakia Poole, quien se une a nosotros como nuevo Director asistente de HNC. Hemos pasado los últimos meses en un proceso de búsqueda extenso, y Lakia era destacado como un candidato ideal desde el principio.

Lakia viene de Carolina del Norte, nació y se crio en Elizabeth City. Estudió Medios de Comunicación y estudios sobre Mujeres y Genero en la Universidad de Carolina del Norte en Greensboro. Luego viajó al medio oeste para perseguir una carrera en el sector sin fines de lucro. Después de llegar en el estado de Iowa su trabajo incluyó ayudando a los jóvenes sin hogar a encontrar empleo, y ejecutando una programa extraescolar para nes de escuela intermedia y de secundaria en Des Moines. Estas asignaciones le inspiren con una pasión por servir a las familias y la comunidad en general. Tiene mucho entusiasmo sobre traer esa pasión y sus habilidades a Hemophilia de Carolina del Norte, y está mirando adelante a hacer muchas nuevas conexiones y alianzas con la comunidad HNC.

Intereses de Lakia incluyen viajes (especialmente viajes a la playa), cine, leyendo, bailando — en particular bailando salsa. Ella es la hija mediana de tres hijas, y es orgullosa tía de los mejores niños del mundo.

Ya esta trabajando diligentemente en el trabajo, así que si se encuentra en el área de Morrisville le animo a pasar por aquí y presentese.
SOAR Members Attend the NOW Conference

By Crystal Hoernlein


Adult attendees could participate in a number of informative breakout sessions — with topics ranging from advocacy to parenting — while the younger crowd had a fun-filled agenda of their own that included swimming and science experiments.

One of the goals of the conference was to provide attendees with information and ideas to bring home to their local organizations and communities. HNC’s participants learned a lot about the importance of joint health at this year’s conference. As a result, Heidi inspired us to start a walking group in Charlotte, NC. The group will begin meeting on June 7th at the Four Mile Creek Greenway on Rea Road.

Where the Girls Are:
Bleeding Disorders Camps Welcome and Nurture Girls

By Heather Boerner

When Michelle Cecil’s dad offered to send her to Europe in 2010, the Grafton, Wisconsin, teen hesitated. It would be the first time the 17-year-old would miss camp since she was 6.

“Without camp, I wouldn’t be as grown up as I am. I wouldn’t be as social,” says Cecil, who has type 1 von Willebrand disease (VWD). And she wouldn’t feel as accepted as she does today. Camp Bold Eagle in Holton, Michigan, was the one place Cecil and her sisters could go every year as a child to be surrounded by other kids with bleeding disorders.

But the camp experience for Cecil wasn’t all good. Although her “hemo homies” will always be her family, Cecil says she sometimes felt slightly excluded from camp activities because she didn’t have hemophilia. That picture is about to change. As more girls attend bleeding disorders camps, and as the National Hemophilia Foundation’s (NHF) Victory for Women campaign focuses on the role of camp in girls’ lives, camps are becoming more girl friendly.

When NHF’s manager of education, Patrice Thomas, held discussion groups at the 2011 NHF Annual Meeting in Chicago to identify what young women wanted from their chapters, the answer was nearly unanimous. They wanted more information at a younger age about what they could expect as they reached puberty. They also wanted details about how their bleeding disorders could be managed, particularly around their periods.

“I asked them when and where they thought the information should be offered, and they all said camp,” Thomas says. “They all felt like that week at camp is a wonderful opportunity to talk with nurses or counselors and older girls with bleeding disorders to help them understand.”

Infusion of Girl Power

One of the complications of having a bleeding disorder is menorrhagia, long and heavy periods. It’s a topic that just about every girl avoids discussing. But it’s essential for girls with bleeding disorders to learn to talk about their periods and find out how best to treat them. For instance, many young women use hormone therapy to regulate their periods. Others infuse around their periods to prevent excessive bleeding.

All girls should learn to infuse — for themselves if they need it, but if not, for their loved ones, says Marion A. Koerper, MD, former director of the Hemophilia Treatment Center at University of California, San Francisco, and co-founder of Camp Hemotion, the northern California bleeding disorders camp.

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Managing Menorrhagia

By Crystal Hoernlein

Menorrhagia (heavy menstrual bleeding) is common in women with bleeding disorders. Coping with menorrhagia during menstruation can be taxing and often affects the quality of life for women and girls with bleeding disorders. But there are some steps you can take to make this time a bit more bearable.

1. Talk to your doctor. If your bleeding causes you to miss work or school or limits the amount of sleep you get, then you may want to discuss it with your doctor. It is helpful to bring a chart of your menses to your appointment, so that your doctor can estimate how much blood loss is occurring. Your chart should include how long your bleeding lasts as well as the number and strength of feminine products that you use in a day.

Your doctor won’t know the details of your particular situation unless you speak up. Medications are available and may help you manage your symptoms, so don’t be afraid to discuss this with your healthcare team.

2. Pack a bag. You never know when things will go from bad to worse, so it’s helpful to be prepared. Keep a stocked bag in your car, locker, or filing cabinet. Your bag may contain extra underwear, dark pants, a sweater or jacket (to tie around your waist), feminine products, wet wipes, and pain relief medication. Some women also keep a dark towel in their car to prevent damaging car seats.

3. Ease bed-time worry. It’s hard to rest when you’re up multiple times during the night dealing with a bleed, but you may want to set an alarm to help prevent breakthrough bleeding. Sleeping in dark garments on dark towels or blankets may help prevent obvious staining. Some women find the use of menstrual cups helpful at night, and a mattress cover may be a good investment if you don’t already have one. If breakthrough bleeding does occur, use cold water to remove the stain. Remember that the dryer will set in the stain, so skip the dryer until the stain is removed.

4. Request a hall pass. Students may want to consider requesting an unrestricted hall pass from the school nurse to save time and avoid embarrassment when getting to the restroom.

5. Seek the support you need. Talking with a family member, friend, or SOAR member can help you cope with menorrhagia and your bleeding disorder.

Where the Girls Are: Bleeding Disorders Camps

“Camp has two important functions: education and empowerment,” says Koerper, who is also NHF’s medical advisor. “Once girls understand their disease, they take control of it. Even though not every girl needs to self-infuse, we let all the girls who want to learn how.”

Changing Times

At the annual meeting of the National Association of Camps for Children with Hemophilia and Other Bleeding Disorders (NACCHO) this year, Shelly Mattson, 26, who has VWD, gave a presentation about how camp counselors can talk to girls about their bleeding disorders and their periods. Her advice: Make it private, listen more and try to have an adult woman with a bleeding disorder there to share her experience. NHF’s Victory for Women Task Force is creating a toolkit to help camp staff talk to girls about their periods.

Campers themselves are taking action, too. Last year, when Cecil was a senior counselor at Camp Bold Eagle, she got another counselor to cover her cabin of boys so she could attend a meeting with the camp director. About 15 chairs were set up around the room, filled with preteen and teenage girls as well as female counselors. The topic was changing camp language to make it more inclusive. The girls provided lots of feedback. They asked the director to be more mindful that not everyone at camp has hemophilia, that it’s not a “brotherhood” and that they wanted more programs for girls.

The camp director took the girls’ suggestions seriously, changing the language at the awards ceremony at the end of the week. Meanwhile, counselor Alexandra Johnson, 21, of East Lansing, Michigan, unveiled the new Ladybug Award. It was her solution to the coveted Butterfly Award, given to a boy camper who learns to self-infuse for the first time. The girls didn’t have an equivalent award, and Johnson, who has mild VWD, thought it was time.

To win the award, the girls had to learn all they could about their bleeding disorder. Then, at the end of camp, they took a test. Every girl who got a perfect score was given an award, a handmade ladybug necklace. Some of the winners did not even know their diagnoses at the beginning of the week, Johnson says. But by the end of camp, they not only knew their diagnoses, but also their treatments.

The girls gained something even more rewarding at camp that year — a sense of belonging. “They felt included and proud,” says Johnson. “They had a sense of self-confidence you didn’t see four days earlier.”

Save the Date!

We’re making strides with SOAR and coordinating a new support group to encourage physical and mental health. Please lace up your walking shoes and join us at 9:00 am on Saturday, June 7, 2014 at the Four Mile Creek Greenway for our first walking support group.

The Greenway is located at 6418 Rea Road (Bevington at Rea Road) in Charlotte, NC. For more information, please contact Crystal at crystal.hoernlein@hemophilia-nc.org.

We hope to see you there!
Upcoming Events

2014 HNC Annual Meeting
Sharing Our Stories, Preparing Our Future
May 3, 2014
Charlotte, NC

Come out and join us for Hemophilia of North Carolina’s 41st Annual Meeting. As always, this is a great opportunity for you to network with fellow members and to hear from the experts. The Annual Meeting will have programs for children ages 2-11, and teens ages 12-17. Meals and refreshments will be available free of charge to the HNC membership through the support of generous grants and contributions from our community.

First-Time Attendees!
There is a special session for anyone who has never been to one of HNC’s Annual Meetings. Whether you’re new to the community or have just never experienced our Annual Meeting, we encourage you to join us from 8:30am-9:00am for the “First-time Attendee” session. We are offering gas cards for those present at the First Time Attendee session. You must contact HNC about a hotel room on or before April 11th.

In addition to our usual door prizes, we will have a separate raffle (at no cost to enter) for anyone interested in winning a trip to the National Hemophilia Foundation (NHF) Annual Meeting in Washington DC on September 18-20, 2014. Save the dates if you plan to enter the raffle!

Traductores estaran disponible en la reunion para asistirle en Español.

Please visit our website for additional information and online registration.

NHF Annual Meeting
Educational Participant Grants
September 18-20, 2014
Washington, DC

The 66th Annual Meeting of the National Hemophilia Foundation (NHF) will be held September 18-20, 2014 in Washington, DC. To provide a more inclusive Annual Meeting, NHF offers a limited number of Educational Participant Grants to individuals and/or families with bleeding disorders attending the Annual Meeting for the first time. NHF would especially like to provide assistance to those unable to attend due to personal obstacles or other barriers. Awards will be based on these factors as well as on need. Grants will cover airfare/mileage and hotel accommodations. Applicants may apply for grants in one or more of these categories, for a maximum of three nights and four days.

NHF is requesting that applicants apply online, and forms are available in English and Spanish. Grant applications must be completed online by Friday, May 2, 2014. If you missed the deadline this year, make sure to mark your calendar for next year’s opportunity. For more information, visit www.hemophilia.org, and select Educational Conferences, then Annual Meeting, then Educational Participant Grants from the menu at the top of the page.

2014 Educational Scholarships
BioRx / Hemophilia of North Carolina Educational Scholarship Program

The Hemophilia Scholarship Program is funded by BioRx and administered by Hemophilia of North Carolina. Each year, BioRx awards scholarships ranging from $500–$3000 to individuals who are affected by hemophilia or other bleeding disorders. This can include patients themselves, or their siblings, parents or other caregiver. At least one of these scholarships is awarded to an applicant pursuing education in a health-related field. The application deadline is May 1, 2014.

There are many other opportunities for scholarships in the bleeding disorder community. For more information about the BioRx/HNC Scholarship, as well as links to additional resources, visit the HNC website at www.hemophilia-nc.org. Your high school guidance counselor and your college financial aid office should also be able to help you find monies for your continuing education.

“Education is the most powerful weapon you can use to change the world.”
— Nelson Mandela

Upcoming Events continued on page 17
Upcoming Events

2014 HNC Legislative Day

May 20th, 2014
Raleigh, NC

It is time to make your voices heard! Hemophilia of North Carolina’s Legislative Day, being held on May 20th, 2014, provides an opportunity for families and individuals across the state to meet with their elected representatives and staff to convey some of the critical issues the community faces and ask for their support. It is a chance to let your voices be heard and share your personal stories. We encourage you to bring your family, along with pictures and any information you’d like to share. We need your voice!

There will also be an optional dinner and training on May 19th at the HNC office in Morrisville. Anyone traveling more than 30 miles to be at the training will be provided a hotel room, upon request.

We will have an exhibit booth available on May 20th in the Legislative Building and, along with the individual meetings, will help to raise awareness amongst the Legislators and general public concerning issues in the bleeding disorders community. If you are interested in participating, please contact HNC staff at 800-990-5557 or by email at info@hemophilia-nc.org.

Calling All Teens!

July 25-27th, 2014
Location TBD

Mark your calendars for July 25-27th and prepare for another exciting Teen Retreat! Once again, North and South Carolina are collaborating on a fun, educational weekend designed especially for teens in the community.

If you’ve never been to one of our Teen Retreats, please check out the HNC Facebook page for photos and information. The Retreat is a great opportunity to make new friends, share laughs, challenge yourself and prepare for your future.

Teens will be allowed to bring 1 friend or family member with them (she/he must also be a teen). All of the details will be available on the HNC website as soon as possible, but please contact the HNC office if you’re interested in hearing more about the weekend.

NHF Inhibitor Summits

Phoenix, AZ | Albuquerque, NM | Baltimore, MD
May 30-June 1, 2014 | July 10-13, 2014 | July 24-27, 2014

National Hemophilia Foundation’s Inhibitor Education Summits were designed to specifically cater to the needs of patients, caregivers and members of the support network of people with inhibitors. NHF understands the day-to-day challenges that come with having hemophilia with the added complication of an inhibitor.

Come join this dynamic event and interact with expert healthcare professionals as well as other patients and their families for a weekend of education designed to improve your overall health and quality of life.

The Summits provide:
• Travel and lodging assistance provided for eligible patients and their caregiver(s)
• Both locations accessible to wheelchairs and other mobility devices
• Four different educational tracks tailored to suit your needs as a patient or caregiver
• An Interactive Education Camp for Youths, including an off-site activity (Ages 4-12) Childcare for infants-3 years old

Please call 877-560-5833 or send an email to inhibitorssummits@hemophilia.org for more information, or if you need assistance during the registration process.

*Atención: los representantes hablan español.
Upcoming Events  Continued from page 17

2014 HNC Family Retreat

August 10-12, 2014
Pine Knoll Shores

It’s almost time for our annual Family Retreat! Come out and join us at the Outer Banks! It will take place August 10–12 at the Trinity Center in Pine Knoll Shores, NC. We invite families with children who are affected by a bleeding disorder to join us for a fun-filled, educational retreat at the beach. The Family Retreat is a time to gain practical tools, feedback from other families and share your own experiences.

We’ll have an opening night full of fun and games with an opportunity to meet other families in the community. There will also be a talent show so be sure to bring anything you might need to show off your skills!

Everyone had a blast at last year’s retreat!

Blood Brotherhood Update

By Matt Igelman

Blood Brotherhood is a national program of Hemophilia Federation of America (HFA). It is for adult men living with hemophilia or von Willebrand disease. The program is designed to be a multi-avenue outreach, to provide education and support, promote good health, and establish a sense of community for adult men.

Our local Blood Brotherhood program is continuing to grow here in North Carolina. We recently held our game night on April 12th and everyone enjoyed a great time, good food, and some competitive cornhole! We have several meetings still to come this year and want to welcome all adult men affected by bleeding disorders to our program. The next meeting will be at our HNC Annual Meeting in Charlotte during the breakout sessions. The group will also meet in Asheville on July 19th where we look forward to returning to the Asheville Glass Center and trying our hand at glass blowing. Our final meeting for this year will be our Annual Retreat at Kure Beach, on September 13-15. Space is limited at the retreat and priority is given to active participants so GET INVOLVED!

If attending our great local meetings is not your thing or is just too much, we invite you to get involved on the private online Blood Brotherhood forum. HFA is proud to sponsor a secure site for adult men with bleeding disorders to meet other Blood Brothers from across the country. In this private format, this forum offers an opportunity for men to share their experiences and support each other.

For more information about the private online forum or Blood Brotherhood nationally, visit www.hemophiliafed.org/programs/blood-brotherhood/
We are excited that the HOPE program has been active within our bleeding disorders community these past few months. Partnering with HPC Specialty Pharmacy, HOPE held a pool party on March 9th at the YWCA Gateway Fitness Center in Winston-Salem. The turnout was great, with families coming from around the state to join in the fun. It was evident watching the kids playing together in the pool, and the parents socializing, that everyone had a great time. The feedback from the community was positive and everyone wanted to know when the next pool party was going to be! Stay tuned to the HNC website for information about our next event to be held in late spring or early summer.

HOPE is an HNC program for families with children from birth to twelve who are diagnosed with a bleeding disorder. Open to any member of HNC, Enjoying the awesome indoor pool!

Continued on page 21

2014 Friends of HNC

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2014. We extend a sincere thank you to our supporters, some of whom have contributed several times during this period.

Donors
John and Patricia Bartlett • Daisy Blaquiere • The Cowell Family • Sue and W. Allen Heafner
Roger and Maria Hoernlein • Sara Miller and David Howell • Matt and Tat’yana Igelman
David and Susan Nickell • Brenda Nielsen • Maria Schnaith-Ivan
Janet Stolp • PenniTharp • Anthony and Erika Wilson

In Loving Memory of Edwin Wilson
Antonio and Judith Gibson
2nd Annual Car, Truck & Bike Show Benefiting HNC raised over $1,300!

It was a beautiful day at O’Reilly Auto Parts in Spring Lake with over 30 featured vehicles for the Blaquiere family’s 2nd Annual Car, Truck & Bike Show. The event was held on March 1st in honor of Hemophilia Awareness Month. Daisy Blaquiere, mom of Andy, has generously donated her time and efforts into organizing this wonderful event again this year to benefit Hemophilia of NC. In addition to impressive cars, participants had the option to take advantage of some great raffles, including a 50/50 raffle.

With the event growing each year, it was incredible to see how many people came out to support Andy and HNC. The volunteers did an excellent job with preparing for the event and judging the winners, HNC staff and volunteers were in attendance to raise awareness about bleeding disorders and ended up with the winning ticket for the 50/50 raffle! Graciously, the recipients chose to donate their earnings back to HNC.

Thank you to everyone who supported Daisy, her family and HNC!

Spectators were able to check out the variety of cars and their detail.

The event featured a range of great-looking cars.

NHF My Life, Our Future

The National Hemophilia Foundation (NHF) is pleased to announce 12 new sites, including the Harold R. Roberts Comprehensive Hemophilia Diagnostic and Treatment Center at the University of North Carolina in Chapel Hill, have received Institutional Review Board (IRB) approval to participate in My Life, Our Future.

My Life, Our Future is an NHF nationwide campaign for progress in hemophilia. Leaders in the community have come together to offer a free genotyping test, so that one may gain a deeper understanding of his/her diagnosis, while helping to advance the breakthrough treatments of tomorrow. For more information, or to sign up to receive regular updates, please visit www.MyLifeOurFuture.org.

This important project will be the subject of a panel discussion at HNC’s upcoming Annual Meeting in May.
NHF Announces Its New Advocacy Website

On February 2014, the National Hemophilia Foundation (NHF) announced the debut of their new advocacy website. The website has been developed to serve as a one-stop destination for information about state and federal advocacy efforts. Real-time updates from NHF’s social media accounts play a prominent role in the website. By engaging the community across major social media platforms, NHF hopes to stay up to date on the issues and topics that are important to you.

By uniting, mobilizing and leveraging our collective resources, NHF hopes to be able to provide consumers with the resources needed to successfully advocate on behalf of themselves, their family, and the bleeding disorders community.

For more information, visit www.advocacy.hemophilia.org.

HOPE Update  Continued from page 19

programs are geared towards the unique needs of these families – to educate and support them so that their children can lead fulfilling lives.

For more information, please contact Gillian Schultz, Volunteer Program Coordinator for the HOPE program, at gillian.schultz@hemophilia-nc.org or Charlene Cowell, Executive Director of HNC, at info@hemophilia-nc.org or call the HNC office toll free at (800) 990-5557.

Attendees were able to collect important resources to help their children with bleeding disorders.

Having issues with co-pays or gaps in coverage for your hemophilia A treatment

We may be able to help.

Bayer offers a range of programs that can help you navigate insurance questions about your hemophilia A treatment. If you’re having issues with co-pays or gaps in coverage, we may be able to offer assistance. Speak with one of our case specialists to find out more.

Call 1-800-288-8374 and press 1 to speak to a trained insurance specialist!

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Steps for Living is a comprehensive online resource that provides information on bleeding disorders for kids, adolescents, adults, parents and health educators to promote healthy living for all life stages. The website provides information on treatment and basics of bleeding disorders, and addresses the psychosocial and quality of life issues that may be related to living with a bleeding disorder. The content on the website was created by NHF staff, parents, patients and health care professionals from the bleeding disorders community, and is reviewed by the CDC, medical advisors, and HANDI, NHF’s information resource center.

The website is organized by life stages:
- The Basics of Bleeding Disorders (for everyone)
- First Step (Birth–8 years)
- Next Step (9–15 years)
- Step Up (16–25 years)
- Step Out (26+ years)

Topics include treatment, maintaining a healthy body, childcare, school (including information for school personnel), family life, social life, planning for the future, living environments, workplace issues and financial health.

There are also fun video games, a variety of downloadable resources, and easy-to-share links to pages through Facebook, LinkedIn, Twitter and email.

Some specific resources:
- 10 Things Everyone Should Know About Bleeding Disorders
- Explaining Your Child’s Bleeding Disorder to Others
- Babysitter Tool Kit
- School Tool Kit for People With Bleeding Disorders
- Playing It Safe—Bleeding Disorders, Sports, and Exercise
- Health Plan Comparison Guide/Worksheet
- Pain Checklist

Hemophilia Federation of America (HFA) has an area featured on the website devoted to providing advocacy resources for those in the bleeding disorder community. There is a variety of information, from webinars to sample letters you can use to contact your legislator:

- Effectively message advocacy issues
  - Words That Work
  - Webinar on Messaging
- Build and advocacy coalition
  - Build & Sustain Successful Coalitions
  - Webinar on Coalition Building – Recording of HFA’s webinar with Community Catalyst
- Run an advocacy campaign
  - How to Run a Winning Campaign
- Participate in online advocacy
  - Keys to Successful Online Advocacy
- Communicate with my Legislator
  - Arranging Meetings in Your Members District
  - Tips for Successful Legislative Visit
  - Writing Your Legislator
- Stay informed about issues that affect the bleeding disorders community
  - Sign Up for our Legislative and Policy updates
  - Find out about Relevant Legislation in My State
- Issue Briefs, Position Statements and Resources
  - Specialty Tiers

To access these tools, please visit www.hemophiliafed.org/advocacy/advocacy-tools/
Many women with bleeding disorders deal with pain, and it’s not easy to handle. Heather Mary Doherty, 47, knows that from experience. Besides managing type 1 von Willebrand disease (VWD), she copes with daily pain from fibromyalgia, lymphatic colitis and other ailments, such as arthritis.

Doherty’s VWD symptoms are chronic. “I bruise really badly, and I get swelling,” explains the Torch River, Michigan, resident and former medical assistant. “At any given time, I have 20 bruises on my body from barely bumping into things. Sometimes they can take a while to heal.” In addition, she has pain when the blood vessels sometimes burst in her hands, along with backaches and general fibromyalgia soreness.

The average woman may find some relief with an over-the-counter or prescription nonsteroidal anti-inflammatory drug (NSAID) like aspirin or ibuprofen; however, Doherty cannot. That’s because NSAIDs can interfere with platelet function and are not appropriate for most people with bleeding disorders. And although acetaminophen (Tylenol®) might be an option for some people, long-term use and overuse carry a risk for liver damage. Other prescription pain relievers, such as opioid or narcotic drugs, also can cause injury or death if misused, particularly in women. New data from the US Centers for Disease Control and Prevention (CDC) show that overdose deaths from prescription pain relievers among women have increased more than 400% since 1999, versus 265% among men.

These data suggest that because women with chronic pain are at increased risk for misuse, abuse and overdose, women with bleeding disorders need to be careful when treating their pain. Talk with a doctor or healthcare practitioner to make sure you understand how to take your medications in the safest way possible.

### Individualized treatment options

“It’s really important to be assessed for your pain issues,” says Michelle Witkop, DNP, FNP-BC, a bleeding disorders nurse practitioner at Munson Medical Center in Traverse City, Michigan. If you start with your provider at your hemophilia treatment center (HTC), you may save a trip to a pain specialist.

But be aware that treatment results can vary. For instance, if you have joint damage from bleeds, pain can persist. And if you’re dealing with a bruise, you’ve already sustained damage to the muscle. “Until the damage caused by the bleed resolves, alternative methods of pain management such as rest, ice, compression and elevation (RICE) are some methods of dealing with the pain,” Witkop says.

Further, women are more likely to have chronic pain; to have chronic conditions such as fibromyalgia and migraines; and are more likely to experience chronic conditions at the same time, research finds. “We have a prevalence of women in pain centers as opposed to men,” says Michna. This may occur, in part, because women are more likely to reach out for treatment.

### Avoiding complications

Women with bleeding disorders typically should not take most NSAIDs, as they carry a risk of gastrointestinal bleeding. Instead, ask your healthcare provider about safer remedies. COX-2 inhibitors, such as celecoxib (Celebrex®) and meloxicam (Mobic®), are types of NSAIDs that may be suitable for people with bleeding disorders, says Michna. “They have less of an effect on platelets and sometimes can be safely used,” he explains. But these medications, like others, carry side effects, so ask your doctor about the best option for you.

Frances Cabot, 62, retired office manager from Scottville, Michigan, has been careful about the pain medications she takes since 2003, when she was diagnosed with type 1 VWD. Total knee replacement surgery left her with lingering knee pain. She also has knuckle pain from arthritis. To ease the aches, she uses acetaminophen, which is not an NSAID. “It takes about a half hour or so and then I feel better,” says Cabot. “I don’t use it every day, primarily just at night so I can sleep.”

Cabot recently learned that taking acetaminophen for extended periods, and at more than the recommended dose, can cause liver damage. Acetaminophen overdoses are the leading cause of acute liver failure in the US, according to the Harvard Medical School. “A lot of people in our community feel that acetaminophen is safe,” says Witkop. But Maximum Strength Pamprin® and Midol Complete Menstrual Relief® each contain 500 mg of acetaminophen. So heed the warning by the US Food and Drug Administration (FDA) to not take more than 4,000 mg of acetaminophen in a 24-hour period. Ask your doctor about the dosage that is right for you, and how long to take it.

Although opioids, such as Vicodin® (hydrocodone) and OxyContin® (oxycodone), may be warranted for some patients,
they should not be the first treatment for chronic aches. “Doctors should prescribe nonopioid medications first,” says Michna. “In those very resistant cases, opioids can be an option, but there needs to be a thorough evaluation of the patient.”

To avoid overdoses or dangerous interactions, always take medications as directed. Store them in a secure place, do not share them with anyone and tell your doctor about everything you’re taking, including “natural” remedies, or dietary or herbal supplements.

Alternative treatments

It may be tempting reach for the pain pills when you’re hurting, but Michna stresses the need to assess each situation. “Don’t take something just to take it,” he says. “Not all pain that you have needs to be treated with medication.”

Doherty, who experiences daily pain, understands the hard truth of treating some pain and tolerating others. Though she takes a muscle relaxer and tramadol, a narcotic-like medication, under her doctor’s supervision for her fibromyalgia pain, she avoids acetaminophen and NSAIDs for VWD pain. “I’ve gotten used to dealing with it,” she says.

For short-term pain relief, Doherty uses alternative therapies like heating pads and stretching for back pain. A transcutaneous electrical nerve stimulation (TENS) unit, which emits a low-voltage electrical current, also helps. Studies have found that physical activity can help with pain. Doherty knows that some movement is helpful. Walking her dog and outdoor gardening help her feel better.

“There is no magic pill,” Witkop adds. “Oftentimes, the combination of many things can help.” That means enjoying the good parts of life and asking for help when needed can have positive results. “People who incorporate pain into their lives can be more resilient,” she says.

Baxter’s vision is a life without bleeds

At Baxter, we will not stop until our vision of a life without bleeds is a reality for all.

Over the years, Baxter has been the leader in providing support and resources for the community.

Today, we are continuing to improve treatment for bleeding disorders. We have seven ongoing clinical trials, including those targeting hemophilia A, hemophilia B, inhibitors, and von Willebrand Disease.

For people with bleeding disorders, the future has never been brighter. As we increase the time between infusions, someday regular infusions, as we know them, may be distant memories.

To us, continuing to make a meaningful difference one person at a time is our passion and what’s behind our unwavering commitment.

Pursuing life without bleeds

Learn more about Baxter resources and support at ThereForYou.com.
Administration Faces Opposition To Changes in Medicare Prescription Drug Program

By Mary Agnes Carey

Medicare’s prescription drug program was controversial when it arrived, but a decade later it is widely considered to be a Washington success story. Now, though, the Obama administration is proposing a series of significant changes to fix what critics say isn’t broken.

Administration officials say they want to help beneficiaries make good choices and save taxpayers money. But some patient groups, pharmaceutical manufacturers and lawmakers in both parties are pushing back against various elements.

The regulation would affect several aspects of the Medicare drug program, also known as Part D, ranging from new limits on the number of plans insurers could offer consumers to new rules about what drugs those plans must cover. It also would prohibit exclusion of pharmacies from a plan’s “preferred pharmacy network” as long as they agree to the plan’s terms and conditions.

The administration’s proposal would “touch everything from formularies to bidding, to the interaction between plans and pharmacies, to audit requirements, to which providers are going to be eligible to prescribe Part D drugs,” said Lisa Joldersma, vice president of public programs policy at Pharmaceutical Research and Manufacturers of America, an industry trade and lobbying group. She worked at the federal Centers for Medicare & Medicaid Services (CMS) in legislative affairs when the drug benefit was created and in a second stint where she focused on the health law. “There is something [in the rule] that touches every single stakeholder in the Part D world.”

Critics of the regulation say it’s an example of classic government overreach – meddling with a successful program that seniors like and costs the government billions less than predicted. “Only in Washington would there be a big government solution in search of a problem that does not exist,” said Rep. Michael Burgess, R-Texas. But Jonathan Blum, principal deputy administrator for CMS, said while it’s important to celebrate Part D’s success, its vulnerabilities must also be addressed.

Blum says the Part D changes are part of the agency’s ongoing effort to strengthen the program, which was created in 2003, while giving its 38.5 million beneficiaries better choices. The proposal was released in January and next Friday is the deadline for public comments. CMS has given no timeframe for when final regulations would be issued.

CMS’ plan to alter Part D has hit heavy opposition. In a letter to CMS, more than 200 groups representing patients, seniors, health insurers, drug makers and business urged the agency to withdraw the proposed rule. The groups say it would “dramatically expand the federal government’s role in Medicare Part D despite the fact that there is no compelling reason for doing so.” If it becomes law, “millions of seniors and beneficiaries with disabilities would lose their current plan of choice or face changes in coverage,” they wrote.

Opposition is growing on Capitol Hill as well. A bipartisan majority of the Senate Finance Committee wrote to CMS Administrator Marilyn Tavenner on Friday to object to the proposed rule. Given Part D’s “remarkable success, we are perplexed as to why [CMS] would propose to fundamentally restructure Part D by requiring immediate, large-scale changes to the program that have direct consequences for beneficiaries. Many of the proposed changes are untested and unstudied and could result in significant loss of beneficiary choice, access and consumer protections.”

But some of the proposal’s elements have won praise from seniors’ advocates. A plan to limit the number of Part D plans a company can offer in any one region – a proposal criticized by some Republican members of Congress for restricting seniors’ choices for coverage – may actually help ease confusion among seniors, said Joe Baker, president of the Medicare Rights Center.

“We observe that older adults and people with disabilities find choosing among a large number of Part D plans a dizzying experience,” he said. “Most people with Medicare fail to reevaluate their coverage options on an annual basis, largely because there are too many options and too many variables to compare.”

According to the Congressional Budget Office, the Medicare Part D program cost the federal government 45 percent less than forecast from 2004 through 2013. But CMS expects costs to climb. Government subsidies for insurers in high-risk markets and low-income cost sharing subsidies continue to increase, Blum told the House Energy and Commerce subcommittee on health

Continued on page 26
At CSL Behring, we are committed to providing treatments and supportive services that make a meaningful difference in the lives of people with bleeding disorders and those who care for them.

We set out on this journey with you more than a century ago, starting with the development of treatments for those with rare and serious diseases.

As we look to the future, we see the promise of new innovations and opportunities—just as we always have.

Over the years, we have never lost sight of what matters most: you and the countless others who inspire our efforts every day.
Your support makes it possible for Hemophilia of North Carolina to continue its many programs and services to the bleeding disorders community. It means education for young parents, scholarship opportunities, financial assistance to families in crisis, and much more. Your dollars make a difference.

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You may also donate online at www.hemophilia-nc.org with your credit card.

Thank you!

Fundraising IDEAS

There are lots of ways you can raise funds for HNC.

Here are just a few:

✓ Organize a yard sale or garage sale
✓ Have a bake sale
✓ Collect change in a donation container
✓ Offer a babysitting/parents’ night out
✓ Have a spa night
✓ Ask for birthday donation pledges in place of gifts
✓ Have a game day pizza party

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Donate to HNC

Your support makes it possible for Hemophilia of North Carolina to continue its many programs and services to the bleeding disorders community. It means education for young parents, scholarship opportunities, financial assistance to families in crisis, and much more. Your dollars make a difference.

Name: ____________________________________________
Address: __________________________________________
City: ___________________ State: _____ Zip: __________
Home Phone: ___________ Cell Phone: ___________
Comments: _______________________________________
Amount: _________________________________________

Please make checks payable to Hemophilia of North Carolina. We are a 501c(3) non-profit organization, so your donation will be tax deductible to the extent allowed by law. We will send you a receipt for tax purposes.

You may also donate online at www.hemophilia-nc.org with your credit card.

Thank you!

The Concentrate

Spring 2014
Save the Date!

Check-in begins at 9am, Walk starts at 10am

Saturday, October 11, 2014

Lake Crabtree County Park
Morrisville, NC

Face painting
Fun, Games, and Prizes
Dogs are welcome too!

www.hemophilia.org/walk