Charlotte Hemophilia Walk hits home for many!

The first Charlotte Hemophilia Walk was a great success! Held on June 20, 2015 at the ZMAX Dragway over 250 people came out to support the walk, braving the heat! After all was added up we raised over $30,000! The walk was held right on the dragstrip with all the vendors and sponsors lined up along the side. Many people mentioned what a great location for a walk and how exciting it was to walk where the cars have their races!

Coffee, bagels, munchkins, muffins, fruit, granola bars, juice boxes and water were provided. Doggy bags were provided for all 4 legged friends in attendance, donated from Wag Boutique. There were vendor passports for the raffle that was held later in the morning. Some of the activities included a large inflatable slide from Your Event Source, face painting by Corky Magic, a magician, Jared Molton sponsored by Grifols. Of course Jecoreiography was

Continued on page 4

Gillian Schultz, HNC Program Manager

I am excited to be coming on board permanently with HNC as the Program Manager! Many of you know me as I have been the HOPE Volunteer Program Coordinator as well as the 2014 Hemophilia Walk Chair and 2015 Charlotte Hemophilia Walk Manager. Volunteering and working in HNC over the past several years in these roles, I hope you have seen my passion for the organization!

My passion for working in the hemophilia and bleeding disorders community began after my younger son was diagnosed with hemophilia in 2010. I was welcomed by HNC with open arms. It didn’t matter my background, the organization was here to support my family as we learned about living with hemophilia! I was encouraged by the different events for all stages of life designed to educate and support people with bleeding disorders. Whether it was for families, which has become the HOPE Program, the Blood Brotherhood for adult men, SOAR for women & girls, and the Latin Union for the Spanish-speaking community, there was

Continued on page 6
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.

Contact Numbers

Hemophilia of North Carolina
(800) 990-5557
(919) 319-0014
(919) 319-0016 (fax)

National Hemophilia Foundation
(800) 42-HANDI
www.hemophilia.org

Hemophilia Federation of America
(800) 230-9797
www.hemophiliafed.org

Community Health Charities of NC
(919) 554-3272 (Collect)
www.healthcharities.org

Hemophilia Treatment Centers

East Carolina University
Brody School of Medicine
600 Moye Boulevard
Pediatric Hematology/Oncology
MA Suite 333
Greenville, NC 27834
Phone: (252) 744-4676
Fax: (252) 744-8199

University of North Carolina
At Chapel Hill
School of Medicine
Campus Box 7016
Physician Office Building
170 Manning Drive
Chapel Hill, NC 27599-7016
Phone: (919) 966-4736
htcenter.med.unc.edu

Wake Forest University Baptist
Medical Center
The Bowman Gray Campus
Department of Pediatrics
Medical Center Boulevard
Winston-Salem, NC 27157-1081
Phone: (336) 716-4324
Fax: (336) 716-3010

Additional Medical Resources

Carolinas Medical Center
Pediatric Hematology/Oncology
1000 Blythe Boulevard
Charlotte, NC 28203
Phone: (704) 381-6800

Duke University Medical Center
Hemostasis and Thrombosis Center
DUMC Box 3422
Durham, NC 27710
Phone: (919) 684-3530
htc.medicine.duke.edu

St. Jude Affiliate Clinic at Novant Health
Hemby Children’s Hospital
Hematology & Oncology Clinic
301 Hawthorne Lane, Suite 100
Charlotte, NC 28204
Phone: (704) 384-1900

Resource Information

National Hemophilia Foundation
www.hemophilia.org

Hemophilia Foundation of America
www.hemophiliafed.org

American Pain Foundation (APF)
1-888-615-PAIN (7246)
Hemophilia Chronic Pain Support Group
painaid.painfoundation.org

American Society of Pediatric
Hematology/Oncology
847-275-4716
www.aspho.org

Centers for Disease Control & Prevention
1-800-311-3435
www.cdc.gov

ClinicalTrials.gov
A registry of federally and privately supported clinical trials conducted and service of the US National Institutes of Health. It gives you information about a trial’s purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health professionals.

Committee of Ten Thousand (COTT)
1-800-488-2688
www.cott1.org

Inalex Communications
201-493-1399
www.inalex.com

LA Kelley Communications
1-978-352-7657
www.kelleycom.com

Patient Notification System
The Patient Notification System is a free, confidential, 24 hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls. 1-888-UPDATE-U
www.patientnotificationsystem.org

Patient Services Incorporated (PSI)
Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance. 1-800-366-7741
www.uneedpsi.org

World Federation of Hemophilia
1-800-520-6154
www.wfh.org

About This Publication
THE CONCENTRATE is the official newsletter for Hemophilia of North Carolina. It is produced quarterly and distributed free of charge to requesting members of the bleeding disorder community.

An electronic version may be found on the HNC website. If you would prefer not to receive a mailed copy of our newsletter, please contact the HNC office.

We maintain a membership mailing list. However, we never release any personal information without your permission.

Hemophilia of North Carolina does not endorse any specific products or services and always recommends that you consult your physician or local treatment center before pursuing any course of treatment.

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 member of the NC Center for Nonprofits.
Why I Serve

By Luke T. Waller, MBA-HCM

I must admit when I was asked to write this piece I became quite nervous. I had never really considered my volunteering with Hemophilia of North Carolina to be worthy of an article and was unsure if I could adequately convey why I feel the need to give back to the bleeding disorder community. As I began to contemplate what I would write, I soon realized that this opportunity presented me with a chance to briefly tell my story to the membership and hopefully convince others to serve as well.

Growing up in rural Eastern North Carolina with Severe Hemophilia A, I never really had the chance to relate to other hemophiliacs. In fact, my only interactions with other hemophiliacs could be counted using one hand. I always felt I was disconnected from other hemophiliacs and always wanted the opportunity to know others in the bleeding disorder community. I had questions about what others dealt with on a daily basis and what it would be like to grow up with the disorder. The only connection I had was with the numerous healthcare workers and medical providers I met during my days at the treatment center and in the local hospital. I witnessed their kindness and sincerity, along with the strong devotion they had for their profession. Due to these experiences, I learned from a young age that I wanted to devote my life to that type of career and help people much in the way I had been helped. After high school I pursued an education in healthcare management with the goal to give back to the medically underserved population of North Carolina. Several months after my graduation from college, I was fortunate to have a life changing conversation with someone from my treatment center. We discussed Hemophilia of North Carolina. I learned of the supportive programs and services that HNC offers to the bleeding disorder community, as well as the annual meeting of the membership and the chance at election to the board of directors.

In the past I might have had a limited connection to others with my condition, but during my first visit to the annual meeting I was able to finally gain the connection to the community I had always sought. One key experience during the meeting still sticks to me because I believe it made me realize why it was the right decision to contact HNC and decide to give back to the community by serving it. I was asked to speak to a group of children from within the community and when I approached the group several of them were discussing sports, including football. I proceeded to introduce myself and one of the kids asked me whether I had ever played the game. I have to say that I have done several “unsafe” things during my life especially considering I have hemophilia, but I have never played football outside of flag. The reason behind me admitting this personal fact is that I mentioned some of these “unsafe” instances, albeit excluding certain details, to the group of children. After I was done telling tales, one of the children spoke up and asked how I was able to do it all being I had hemophilia. My only response, besides once again caution to not follow in actions, was that I am not limited in life just because I have hemophilia. I conveyed to everyone in the group that they can still pursue their dreams and goals in life regardless of whether they do or do not have a bleeding disorder. I learned during this experience why I serve. I learned during this experience I serve HNC to ensure that all affected by a bleeding disorder never feel they are limited in life and cannot reach their full potential.
Charlotte Hemophilia Walk continued from page 1

there to get the crowd dancing. Sir Purr was around taking pictures before the walk and helped to kick off the walk. There were snow cones to help everyone cool off on such a hot day and a table to make sand art. Instead of a photo booth, pictures were taken by Tat’yana Igleman in front of the large Hemophilia of North Carolina backdrop. Children were given fun racing flags as they completed a lap!

Executive Director, Charlene Cowell, and Charlotte Walk Chair, Gillian Schultz helped to welcome everyone to the first Charlotte Walk. Board member Mike Hoernlein served as emcee for the walk. He helped to welcome returning walk guests JecoreiOgraphy to perform for us. Always a hit, the crowd was dancing and cheering them on.

Mike introduced Brey Curtis from Baxter, the National Presenting Sponsor. Brey presented the award to Wonderfully Made as the top fundraising team. Lois Geer from Novo Nordisk then recognized Erin Otey (team Wonderfully Made) as the top fundraiser. After the awards were presented, Jeff Bridges from Grifols came up to speak as the Local Presenting Sponsor.

Walk Chair Gillian Schultz, captain of team Hulk Smash brought her family up to the stage and spoke. She spoke about how excited she is to extend the Hemophilia Walk to the Charlotte area, how it will continue to grow, and how it brings new awareness to the Charlotte area.

Mike recognized the top 3 teams, Wonderfully Made, South Cows, and Hulk Smash. Combined they raised a total of $5,187.96! He then presented the Royal Droplet awards. Awarded at each walk to a man, woman, and child who show outstanding support for the walk, the King droplet award was given to Kevin Otey along with his wife Erin, who is one of two Queen Droplets and is receiving the award for the 2nd time! Tamblyn Bingley also went home with a Queen Droplet award for her hard work in making the Charlotte Walk a success. Last but not least, the Junior Droplet award was given to Dylan Stephenson.

Mike prepared everyone to start out the walk with the help of the cheerleading squad and Sir Purr. Team Hulk Smash started everyone off on a great walk! In order to complete the walk, walkers had to walk up and down the dragstrip 3 times for the full 5K, or 1 time for the short walk. There were kids activities along the way including hula hooping and limbo. To help people cool off there was a water break at the end of the track. When people finished the walk, kids were given shoe laces.

Continued on page 5
Charlotte Hemophilia Walk  

After the walk many raffle prizes were presented including the Grand Prize for the Vendor Passports, a Richard Petty Driving Experience package, and a donation from the Charlotte Knights baseball team.

The walk could not have gone off so well without the help of all our volunteers. From setting up Friday night and Saturday morning, helping with parking, registration, distributing items, cheering everyone on, helping at the booths and with children's activities, clearing everything up at the end, and more, a great thank you is extended to all the volunteers!

We are already planning for the 8th Annual Hemophilia Walk in the Raleigh area on October 17. We will again be at Lake Crabtree Park in Morrisville. So save the date, we hope to see you there! We are also beginning to plan for the 2nd Charlotte Hemophilia Walk to be held sometime in 2016, so keep your eyes open for that date. If you are interested in helping with either walk, please contact the HNC office at (800) 990-5557 or email Gillian Schultz at gillian.schultz@hemophilia-nc.org. We look forward to seeing you in Raleigh on October 17th, and at the 2nd Charlotte Hemophilia Walk in 2016!
1st Annual BBQ for HNC

It seemed like a cook-a-thon with 24 hours of preparation for the 1st Annual BBQ for HNC that was graciously hosted by Jeff & Sharon Neal on Saturday, April 11th at their home! The cooker went all night while Jeff, Sharon and Lee Houston got the rest of the delicious accompaniments ready.

Jeff & Sharon shared the idea of hosting a BBQ to benefit HNC a while ago and the plan came together beautifully this spring. With the help of friends, they opened their doors to anyone interested in coming together for good food, great friendship and a terrific start to the season. People visited throughout the day to enjoy the feast. Kids (and some adults) also enjoyed a bounce house with a huge slide!

Jeff & Sharon accepted donations and generously donated 100% of the funds collected to HNC. The donations are earmarked to support the Teddy-Bear-Clinic that Judy Igelman hosts each year at the annual meeting and other family events. The donations will be used to offset the cost of materials to make the bears. The children enjoy not only making their personal bear but also naming them, developing their story and taking them home to treasure for years to come.

Our many thanks to Jeff, Sharon and all the others who gave their time & and talent that made it such a successful event. We’re looking forward to the 2nd Annual BBQ already being planned for next year!
Blood Brotherhood Beach BBQ

On Saturday, June 13th the HNC Blood Brotherhood group met at Wrightsville Beach for the HNC Blood Brotherhood Beach BBQ! Jennifer Newman, Physical Therapist with UNC-CH, presented on hemophilia treatment around the world. Blood Brothers and their families got to enjoy some delicious food with a cool sea breeze. This event was made possible through a grant from Hemophilia Federation of America. Be sure to check the website for more information on the Blood Brotherhood Program here in NC.

Want to know more about treatment around the world? According to the World Federation of Hemophilia, an estimated 75 percent of people worldwide with bleeding disorders still receive very inadequate care or no treatment at all; their disorders remain undiagnosed. Read more by visiting www.wfh.org

Overview of Inhibitors & BBQ Dinner

On June 5, Hemophilia of North Carolina along with Grifols hosted a dinner entitled Overview of Inhibitors.

The dinner was held at Sticky Fingers Smokehouse in Concord. Guests were treated to a delicious barbeque dinner. The educational session was led by Virginia Kraus, RN, MSN. She started with a brief overview of hemophilia and inhibitors, what some of the risk factors for inhibitors are, how they develop, information on current treatments, and information about some clinical trials that are ongoing to learn more about the causes of inhibitors. The audience was actively engaged throughout the presentation, asking questions and giving personal insights of what it is like to have hemophilia and inhibitors.
Lighting up Charlotte for World Hemophilia Day

On April 17, Hemophilia of North Carolina (HNC) partnered with Biogen to host a very memorable World Hemophilia Day (WHD) event. As one of 17 sites across the world, HNC was proud to watch as the Duke Energy Center in downtown Charlotte was lit up red in honor of World Hemophilia Day!

The evening began with a delicious dinner followed by a short series of presentations about the spirit of the day and its impact worldwide. An inspirational video helped put into perspective how we shouldn’t forget that there are people living all over the world with bleeding disorders, many of whom do not have access to proper treatment or care. We salute the many companies, like Biogen, who are committed to filling the treatment gap by donating product to those in need.

After the announcements and video, it was time for some fun! Everyone had a blank canvas in front of them, just waiting to be painted. Sticking with the theme, everyone got to paint their very own trees to symbolize the many branches of support we receive from one another in the bleeding disorders community.

Once the masterpieces were done, the group traveled upstairs to the rooftop pool area to get a glimpse of the red building across the way. The feeling one got from the view was indescribable. We thank Biogen for making the night possible and also thank all of the companies and organizations that are working to close the gap overseas.
North Carolina Senate Honors World Hemophilia Day!

World Hemophilia Day was April 17, 2015. This annual event is sponsored by the World Federation of Hemophilia to raise awareness about bleeding disorders and the need to build a family of support for those living with them.

The North Carolina Senate recognized the importance of World Hemophilia Day in its full session on April 16, 2015. The occasion was saluted by the Honorable Dan Forest, Lt. Governor of the state of North Carolina. He asked HNC members present to stand and be recognized, to warm applause from the full Senate and visitors in the gallery. Later in the session, Senator Mike Woodard rose to read a proclamation calling for full recognition of the challenges faced by people living with hemophilia and their families, and commending our community for its contribution to North Carolina. Again, the full Senate responded with warm applause. After the session, Senator Woodard presented HNC with a signed, official copy of the proclamation for display in its office. Our thanks to Senator Woodard and his staff for their kind efforts in winning this honor and recognition for HNC and its members.

A SENATORIAL STATEMENT

RECOGNIZING WORLD HEMOPHILIA DAY IN NORTH CAROLINA

WHEREAS, hemophilia is a rare genetic bleeding disorder in which one of the proteins that causes the blood to clot is missing, or there is not enough of it to work properly, causing people to bleed longer; and

WHEREAS, without effective blood clotting, cuts and minor injuries have difficulty healing, and internal bleeding can result in pain and permanent damage; and

WHEREAS, hemophilia is typically a lifelong condition, which is primarily treated with infusions of a protein produced in blood clots; and

WHEREAS, it is estimated that more than 400,000 people worldwide are living with hemophilia; and

WHEREAS, approximately 20,000 people in the United States are living with hemophilia; and

WHEREAS, approximately 1,000 people in North Carolina are living with hemophilia; and

WHEREAS, hemophilia affects all populations and

WHEREAS, people living with hemophilia and those caring for and serving them, are strongly united in advocating for access to treatment and care;

NOW, THEREFORE, we join in celebrating April 17, 2015 as “World Hemophilia Day” in North Carolina.

IN WITNESS WHEREOF, the undersigned certifies that the foregoing statement was read in the Senate and placed upon the Journal on the sixteenth day of April, 2015.

Signed by Senator Mike Woodard
Senate Principal Clerk

WANT TO KNOW MORE ABOUT YOUR FACTOR OPTIONS?

When it comes to your factor therapy, you have choices. And at Biogen Idec, we recognize the importance of researching and delivering additional factors to the hemophilia community. See if now might be the right time for you to make a change—learn more about our therapy options as well as our range of financial, educational, and community support programs.

To learn more about these options, contact your CoRe Manager:
Nikita Lyons-Murry
Phone: 615.525.1003
E-mail: Nikita.LyonsMurry@biogenidec.com
The 2015 Hemophilia of North Carolina (HNC) annual meeting of members began with a grand opening. First thing on Saturday morning, May 2 in Fayetteville, the keynote session kicked off the meeting with a distinguished panel of speakers. Each of the three speakers is a nationally recognized author who had been raised in North Carolina. And each also happens to have hemophilia. All of the authors have written about growing up with hemophilia. Returning to our fine state to share their writing careers were Jim Grimsley of Atlanta, Craig McLaughlin of the Bay Area, and Shelby Smoak of Arlington.

Each keynote speaker chose a different style to write about how they dealt with hemophilia in their lives. Jim Grimsley wrote the critically acclaimed autobiographical novel Winter Birds (1994). Craig McLaughlin used captivating story telling for his memoir in Lions and Tigers and AIDS! Oh, My! (2013). And Shelby Smoak wrote a popular fictionalized memoir with Bleeder (2013). Each memoir is worth reading by itself, while all three provide a much broader perspective on the individualized experiences of having hemophilia.

In front of a rapt audience, the three keynote speakers told personal stories about their hemophilia and also about their writing careers. Everyone got to know the authors a bit better, and their skills as wordsmiths was evident. The keynote session was historically significant to the bleeding disorders community. Never before have three notable authors with hemophilia shared the same stage to talk about their hemophilia and their writing. Those in attendance were extremely fortunate to welcome back to North Carolina the accomplished authors

In addition to our keynote speakers, HNC was honored to have other speakers from around the country share their stories as fellow members of the community. They reminded us that every one of us has a story; we just need to find our voice and begin to share. We thank our speakers from the day: Chad Brown, Matthew Compton, Sharon Ingram (MA, CWHC), Jecorei Lyons, and George McCoy.

Breakout sessions were held for different HNC Programs including SOAR (women & girls), Blood Brotherhood (adult men), Latin Union (Spanish-speaking individuals), Spouses/Partners, and HOPE (for families of young children). Thank you to our speakers: Daysi Fardales (MSC, ARNP-C), Sue Geraghty (RN, MBA), Liliana Gomez, Sharon Ingram (MA, CWHC), George McCoy, Gillian Schultz, Dawn Smith, and Karla Zevallos.

Children and teens were also kept busy with plenty of fun-filled activities. Teens were invited to hear the keynote speakers and then join the adults again at the end of the day to listen to fellow community members share their stories. In between, they learned how DNA works through a very interactive program. Thank you to Nikita Lyons Murry for offering this to our teens. The teens also ventured off-site to Fun, Fun, Fun to play arcade games, laser tag, and much more. The younger children were similarly entertained with games and exciting activities, including the Ted-E-Bear.
42nd Annual Meeting

Clinic. For the first time we also offered childcare for infant children so adults could benefit from the programming worry-free. Thank you to everyone who made the infant, children and teen programming possible!

You can read more about the keynote speakers and their books on page 22 in Richard’s Review, a regular column in the PEN newsletter.

Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2015 HNC Annual Meeting:

Platinum & Volunteer Dinner Sponsors
- Baxter
- Biogen
- CSL Behring
- Novo Nordisk
- Pfizer
- Hemophilia

Gold Sponsors
- Emergent Biosolutions
- Grifols
- Homecare for the Cure
- Kedrion Biopharma
- Matrix Health
- Octapharma
- Walgreens Infusion Services

Silver Sponsors
- Accredo
- BioRx
- Drugco Health
- CVS Specialty Pharmacy
- MedPro Rx

2015 HNC Volunteer Dinner

May 1st

On May 1st in Fayetteville, NC, Hemophilia of NC hosted its annual Volunteer & Special Guest Dinner, recognizing the dedication and valuable work that HNC members have contributed to the organization and the larger bleeding disorders community.

The dinner featured Matthew Compton. Matthew, a North Carolina native living with Hemophilia A with inhibitor, shared his story with us and reminded us of why it’s important to give back. An important take away message was that you never know how much your actions can mean to someone else and what a lasting impression that could make.

The success of HNC comes from the tireless efforts of so many individuals, from our members, to community partners and supporters. HNC is immensely grateful for all that you do to provide effective resources and services to our members!
Calling all teens! As always this is 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.

Busing is available from Greenville and Morrisville, NC. Teens will be allowed to bring 1 friend or family member with them (she/he must also be a teen). All of the details are on the HNC website, including registration forms. We’ll see you there!

HNC Men’s Retreat
July 17-19, 2015
Rockfish Camp & Retreat Center
Parkton, NC

Whether you’re an adult male living with a bleeding disorder or a dad with a child affected, come and join us for the weekend on July 17-19 in Parkton, NC. We’ll be at the Rockfish Camp and Retreat Center, which you may remember from the 2014 Adult Retreat. This retreat will be designed to help our Blood Brothers and the dads of future Blood Brothers and Sisters to connect with one another through roundtable discussions and with programming provided by Inalex Communications. Our hope is that this retreat will be one of many opportunities for dads and Blood Brothers to unite. Registration and more details, including what fun activities we’ll have, are available on the HNC website.
Retiro Anual para Adultos HNC

28-30 de Agosto, 2015
Trinity Center
Pine Knoll Shores, NC

Recientemente incluimos en nuestro calendario para el próximo 28 al 30 de Agosto nuestro Retiro Anual para Adultos HNC, por lo que te invitamos a que tomes nota y apartes la fecha! The American Management Association (AMA) hará su reaparición este año a petición del público. Esta serie AMA está diseñada para mostrar a las personas que padecen algún trastorno hemorrágico, habilidades efectivas para su vida diaria.

Este año cambiamos la sede al Trinity Center, lugar donde hemos llevado a cabo anteriormente nuestro Retiro Anual Familiar. Estamos muy emocionados de estar cerca de la playa, tan solo a unos cuantos pasos para disfrutar de la mejor compañía.

Este retiro es para nuestros miembros adultos (18 años en adelante) que padezcan un trastorno hemorrágico o que sean padres de hijos con trastornos hemorrágicos. Únicamente está permitido llevar 1 solo invitado. Para más información y registro ingresa a nuestro sitio web.

Te esperamos!

Hola soy Carlos Diaz, nací en Perú, vivo en Charlotte, NC desde hace 15 años y pertenezco a la comunidad hemofílica de NC. Mi hemofilia es de tipo A severa.

He estado involucrado con el Chapter de NC (Hemophilia of North Carolina) desde hace 14 años. La organización ha tenido y tiene como misión ayudar a todas las personas afectadas por un desorden sanguíneo.

Esta misma entidad consciente y sensible de las necesidades de la comunidad hispana creó hace aproximadamente 6 años atrás la Union Latina, la cual se fundó con la meta de alcanzar y brindarle apoyo a la comunidad hispana a través de programas educativos en español. Una gran mayoría de los tópicos educativos fueron creados con las necesidades de la comunidad en mente. Muy pronto varias familias buscando apoyo y recursos educativos comenzaron a asistir y a beneficiarse de programas educativos presentados por educadores de habla hispana.

Actualmente el Chapter ofrece un promedio de 4 programas anuales para nuestra comunidad; personalmente estoy y estare muy agradecido por la calidad de de vida que me brindan y la diferencia que han marcado en mi vida actual. Representar a nuestra comunidad es algo que siempre he considerado importante. Voluntariamente he ofrecido mis servicios al Chapter de NC para ser uno de los puntos de contacto de la comunidad hispana respecto a programas y eventos que nos benefician a todos y pretendo desempeñar mi rol con toda la responsabilidad que amerita. Mi número de teléfono es: (704) 492-6386

La vida es nuestro mejor regalo, y por eso debemos apreciar cada momento, ya que viene a ser un verdadero milagro que debemos disfrutar al máximo cada día y en cada ocasión. Participemos todos juntos de este regalo manteniéndonos unidos y asistiendo cada día más a los eventos y programas que están preparados y diseñados para nosotros.

Atentamente, Carlos Diaz
College Health Project

Earl ier diagnosis of young women’s bleeding disorders

By Nancy Mann Jackson

Reprinted with permission from Hemaware

As many as 2 million American women have bleeding disorders and do not know it, according to the Office on Women’s Health of the US Department of Health and Human Services. Many women with bleeding disorders only learn of their diagnoses after complications from childbirth, injury or surgery. However, the National Hemophilia Foundation (NHF) has long worked toward earlier diagnoses to help young women achieve better future outcomes.

“It would be good for any providers who come into contact with young women to understand the symptoms of bleeding disorders,” says Patrice Thomas, MS, MSW, former manager of education at NHF. She was the organizer for the NHF-CDC College Health Project. She now serves as program services director at the Hemophilia Foundation of Michigan in Ypsilanti. “There are ways to train these doctors to diagnose young women, especially before they start having children,” says Thomas.

Through this collaborative project, NHF educated healthcare providers at several college campus health clinics. The focus was on preparing providers to recognize the symptoms of bleeding disorders in young women and refer them to hemophilia treatment centers (HTCs) for timely, accurate diagnosis.

Reaching young women

In a 2010 NHF survey of 1,243 women ages 18 to 24 across the country, researchers asked where they would seek care if they thought they had symptoms of a bleeding disorder. Approximately 20% said they would seek care at a college health clinic. Further, of the 2% of respondents who had been diagnosed with a bleeding disorder, 24% had received care at a college health clinic.

Based on those results, NHF organizers targeted their efforts accordingly. “Young women with symptoms often turn to their college health clinics for help, so that seemed a good place to start,” says Thomas.

The NHF-CDC College Health Project targeted women’s health clinics on four college campuses: Florida International University (FIU) and University of Miami (UM), both in Miami; Michigan State University (MSU) in East Lansing; and University of Pennsylvania in Philadelphia. HTC staff facilitated training for providers at each college health site. The training included the basics of bleeding disorders, challenges faced by women with bleeding disorders and assessing women with specific symptoms of a bleeding disorder. NHF provided pretests and posttests that measured changes in the college health providers’ knowledge. After the educational training sessions, personnel at the college health sites were asked if they had adopted any new policies for screening women for bleeding disorders. They were also asked if they had witnessed an increase in identified women who had then been referred to the HTC near campus for further testing.

Continued on page 5
Reaping results

One of the most important results of the project was simply building connections between the college health clinics and the HTCs nearby. “Many HTCs are located on or near college campuses. But this type of education and interaction with college health services had not been done before on the campuses we contacted,” says Patti Rhynders, PhD, MPH, MCHES. She is a consultant who served as a liaison between NHF and the college health centers. “College healthcare providers are eager to be involved, to increase their knowledge of women’s bleeding disorders so they will be able to identify and screen at-risk women,” she adds.

Working with college health centers, Rhynders and other organizers learned that most of the healthcare providers had limited awareness of educational resources about women’s bleeding disorders. In addition, few of them specialize in women’s health. As a result, NHF chapters, HTCs and local college health services have an opportunity to work together to raise awareness among college women and the healthcare professionals who care for them, Rhynders says.

Many of the successes of the program were anecdotal, Thomas says. For instance, the MSU health clinic reported that staff referred a number of women to the local HTC. NHF continues to prioritize early diagnosis for women with bleeding disorders, says Kate Nammacher, MPH, NHF’s director of education. Through a renewed partnership agreement with the CDC, NHF will target women ages 18 to 25 with an educational web portal about bleeding disorders. “We plan to focus on finding and developing partnerships with colleges, universities and other organizations to address the issue of bleeding disorders among young women,” Nammacher says.

http://www.hemaware.org/story/college-health-project
Our Young Voices is the latest supplement added to The Concentrate. It is designed to be a platform for the voice of youth that are a part of the Hemophilia of North Carolina (HNC) community. This supplement will feature creative writing, drawings and news for our youth, from our youth. If you are a young voice of HNC and would like to submit a written piece or visual art for upcoming issues, please contact HNC Staff at info@hemophilia-nc.org.

**Interview with Gerrard**

**What are your plans after high school?** My plans after high school are to attend Chowan University and to study Exercise Science and I also plan to help kids with hemophilia learn how to be active with no bleeds.

**When did you first get involved with HNC?** I first got involved with HNC when I was about 3 years old and going to different events.

**What have you done with HNC?** The things I have done with HNC are a lot of dinners and other events, camps, teen retreats, family retreats. I also have been able to volunteer at a lot of different events.

**What advise would you give someone with a bleeding disorder who is entering high school?** My advise to someone is don’t let it hold you back or as my family says: don’t let it beat you, you beat it.

**What would you describe as your greatest success so far?** My success so far is beating the odds when they say I can’t do something because I have bleeding disorder. Like some were saying I couldn’t play as many basketball games as I did over the last 5 yrs and am still playing but you have to stay on top of your treatments.
Upcoming Events  
Continued from page 12

HNC Adult Retreat
August 28-30, 2015
Trinity Center
Pine Knoll Shores, NC

Don’t forget to save the date for the HNC Adult Retreat on August 28-30th! Due to popular demand, the American Management Association (AMA) will return this year. This AMA series is designed to present effective life skills for individuals living with a bleeding disorder. Topics for this retreat will include “Win-Win Conversations” and “Making a Great Impression”.

We’re switching it up this year and going to the Trinity Center, which has historically held our Annual Family Retreat. We’re looking forward to being so close to the beach, only a tunnel walk away, while enjoying each other’s company!

This retreat is available to adult members (age 18 and over) with a bleeding disorder or parent(s) of a child with a bleeding disorder. One guest is permitted to accompany that attendee. Information and registration will be available on the HNC website as we get closer to the event.

NHF Annual Meeting
August 13-15, 2015
Dallas, TX

Registration for the 67th Annual Meeting of the National Hemophilia Foundation (NHF) is now open. The conference, themed Boots on the Ground, will be held August 13-15, 2015 in Dallas, TX. The three-day meeting will feature a variety of educational topics, including sessions regarding the basics of hemophilia, inhibitors, healthy cooking, music therapy for pain management, women and bleeding disorders, and much more.

To register, visit the NHF website at www.hemophilia.org, and select ‘NHF Annual Meeting’ under the “Events and Meetings” tab. For questions, contact the NHF Meeting Hotline, at 800-424-2634, ext. 4.

If you would like to apply to HNC for assistance with traveling to the NHF Annual Meeting, apply for a grant by going to: www.hemophilia-nc.org, click on “Programs and Services”, then click on the “grant application form”.

Upcoming Events Continued on page 19

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DrugCo Health is your local Southeast hemophilia specialty pharmacy.
Top 10 Ten Reasons Why I Walk
by Michael Hoernlein

10 I walk to raise HNC’s profile in the Charlotte area. I want to spread the word around Charlotte about the challenges that bleeding disorders present to individuals and families all over the State, and I want to highlight the great work that HNC does to support them.

9 I walk because it’s fun. The Hemophilia Walk in Raleigh every year is always a fun event; there’s no reason we can’t replicate that Charlotte-style.

8 Cool t-shirts.

7 It feels good to help people.

6 I walk because my whole family can do it together.

5 I walk because it’s good exercise, and I don’t get enough exercise.

4 Great entertainment.

3 I walk for my wife and my son, who both have von Willebrand disease. We want to raise awareness about a bleeding disorder that often goes undiagnosed for far too long.

2 I walk because it’s easy. I’m blessed: I grew up not worrying about joint bleeds or having to pay for factor. I took a lot of things for granted. Walking is a very easy way for me to contribute to HNC’s mission.

1 I walk to help raise money to support HNC’s programs and services. I walk for the families who can’t pay their rent or energy bills without HNC’s help, and I wish we could do more. Every little bit really does help.

This is why Team Vampire Bait walks, why do you walk?

HNC Morrisville Walk

October 17, 2015
Lake Crabtree County Park
Morrisville, NC

Be sure to mark your calendars for the 8th Annual Hemophilia Walk! The largest fundraising event for HNC is taking place on Saturday, October 17th at Lake Crabtree County Park in Morrisville. Registration begins at 9:00am and the walk is 10:00am.

The day will feature a 5K walk, food, music, games and all-around fun for family and friends (even the 4-legged ones). It’s never too early to get involved – start your walk team today! Info is available at www.hemophilia-nc.org to help you kick start your team! The site features information for sponsors, teams, individuals and volunteers.

Printed Sponsorship and Team Captain Packets are also available through HNC by calling 800-990-5557 or by email at info@hemophilia-nc.org. We are looking forward to another great event this year and hope to see everyone there!

Spend the holidays with HNC for the 2015 Holiday Celebration

December 5, 2015
Jamestown, NC

Are you looking for a way to stay warm over the winter? Join us in Jamestown (near Winston-Salem) for the 2015 Holiday Celebration the Castle McCulloch for an afternoon of inspiration and fun. Anita Smith, PNP, of Wake Forest University Baptist HTC will be speaking. Afterwards we may get a surprise visit from a bearded man with a jolly attitude and presents in hand!

We look forward to seeing you there!
2015 Friends of HNC
We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2015. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

Donors
Mark Buckley  •  Irene Cowell  •  Sue & W. Allen Heafner  •  Mr. & Mrs. William Katz
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It is summer! I know my kids are excited not to be woken up early for school, though that won’t stop them from waking up early anyway. I too am looking forward to the break from the monotony of the rest of the year. But I know by the second week of summer vacation my kids are going to be telling me that they are bored! Every summer I have to think of many activities to entertain my kids. But it is also nice sometimes to just enjoy the lazy days of summer.

One thing that I look forward to every summer is swimming. I grew up at a lake and spent my summers on the beach. Summers were always fun spent in the water. I am lucky to have a neighborhood pool where I live and expect to be spending many days there this summer. Swimming is a great activity to build muscle strength and endurance with no impact to our joints; a great activity for everyone, but especially our young ones with hemophilia! One of the few ways to cool down during the hot North Carolina summers, it is nice knowing that with all the fun the kids have in the water, it is also helping to protect their joints and hopefully prevent potential bleeds!

As I come on staff with HNC as the Program Manager, I am excited to begin planning more events for the HOPE Program. Some ideas I have are bowling, swimming, playdates, and educational sessions. If you are interested in seeing a particular activity, have any ideas for HOPE, or would like to volunteer, please let me know!

HOPE is a program of HNC for families with children from birth to age twelve diagnosed with a bleeding disorder. Open to any member of HNC, programs are geared specifically toward the unique needs of these families to include education and support so that they may HOPE to lead a fulfilling life.

For more information, please contact me at gillian.schultz@hemophilia-nc.org or by calling the HNC office at (800) 990-5557.
Theme ~ “Ladies You Are Amazing”

By Sharon Ingram, MA, CWHC

What a joy to join Karen Krzmarzick and the ladies from the Hemophilia Association of the Capital Area (HACA). Requested by the Hemophilia Federation of America (HFA) to facilitate a session on caregiving and the importance of self care at HACA’s annual Women’s Retreat, presented was an interactive time of sharing, caring and learning which promoted true transparency within the group. As ideas and situations were voiced and welcomed, the spirit of support, and validation filled the room.

I was truly honored to share with as well as receive from you.

You ladies of HACA rock and the great news is, you are only a few states away.

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**Which way next?**
Navigating life with bleeding conditions

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THE CONCENTRATE
Summer 2015
richard’s review
By Richard J. Atwood
Reprinted from PEN Newsletter, Volume 25, Issue 1

Telling Our Life Stories

Everyone loves a good story, whether it’s fiction or real life – or a little of both. There are so many ways to tell our life stories. These three authors all have hemophilia, and all were raised in North Carolina. Each chose a different style to describe growing up with hemophilia: an autobiographical novel, a fictionalized memoir, and storytelling.

Winter Birds
by Jim Grimsley
Algonquin Books of Chapel Hill 1994

Jim Grimsley (1955— ) was raised in poverty in rural eastern North Carolina, and graduated from University of North Carolina–Chapel Hill with the vision of becoming a writer. He worked for 20 years as a secretary at Grady Memorial Hospital in Atlanta before his first novel, Winter Birds, was published.

The narrator in this autobiographical novel is eight-year-old Danny Crell. Reminiscing through dreams, Danny recalls growing up with hemophilia and bonding with his sister and three brothers — one also had hemophilia — in their dirt-poor, dysfunctional family. The strength of Danny’s mother in times of distress was an inspiration. The physical abuse inflicted by Danny’s father culminated in an unforgettable Thanksgiving Day.

Like an accident gawker, I was transfixed by Danny’s plight. Thankfully, my discomfort with the vivid details was relieved by immersing myself in the emotional human story, as I almost forgot that hemophilia was involved.

Still living in Atlanta, Grimsley is an award-winning author and playwright who also teaches creative writing at Emory University.

Bleeder: A Memoir
by Shelby Smoak
Michigan State University Press 2013

Shelby Smoak (1972— ) was born in Indiana, and moved with his family near Charlotte, North Carolina. A large bruise led to a diagnosis of severe hemophilia when he was two. Smoak was a patient at the UNC-Chapel Hill hemophilia treatment center, where he was diagnosed with HIV in 1985.

Smoak graduated from UNC–Wilmington with a degree in English. But persistent health problems hindered a full-time career, at least until better HIV medications with less strict dosing regimens improved his compliance and increased his ability to work.

Having kept a journal, Smoak wrote Bleeder, his fictionalized memoir — he changed the names of people and events, but not the North Carolina locations — covering the years 1990 to 1998. That time period was probably the most taxing on his personal development.

His health status complicated dating: he didn’t know how to inform girlfriends about his hemophilia and HIV. I empathized completely with the memoir’s realistic descriptions of this adolescent awkwardness.

Smoak later earned an MA in creative writing and a PhD in American literature. He lives in Arlington, Virginia.

Lions and Tigers and AIDS! Oh, My!
by Craig McLaughlin
Herne Publishing 2013

Craig McLaughlin (1957— ) was born in Chapel Hill. With no family history of hemophilia, McLaughlin was diagnosed with hemophilia following his circumcision. After his parents divorced in 1972, McLaughlin lived with his mother and stepfather on an exotic-animal farm in nearby Pittsboro that housed tigers, jaguars, llamas, and monkeys. He graduated from Wesleyan University in Connecticut, and then earned a graduate degree in journalism from University of California-Berkeley.

Receiving the dual diagnoses of HIV and hepatitis C in 1985 forced McLaughlin and his wife to consider his premature death. The couple had a daughter using donated sperm. McLaughlin worked as an investigative journalist, a newspaper editor, a domestic violence counselor, and a creative nonfiction teacher.

McLaughlin took up storytelling, even performing his stories onstage, before writing Lions and Tigers and AIDS! Oh, My! This memoir contains 24 short stories, as well as 10 tips for storytellers. I became engrossed in these self-contained stories, and wished that I could listen to them rather than reading them, as each of the stories shared some personal insight about living with hemophilia.

McLaughlin lives in the Bay Area of California.

Maybe you want to tell your life story. Common advice for writers is to write about what you know. You can choose from a variety of genres to describe your experiences living with a bleeding disorder. The authors reviewed here all grew up with hemophilia in North Carolina, yet each has unique experiences to relate. Another sound piece of advice is to always employ the services of a qualified editor, especially if you decide to self-publish.

Take the time to learn about these three authors with hemophilia by reading their well-written stories.
The pool is an excellent place to exercise. Your body is buoyant in water, putting much less weight on your joints, and making getting in shape safer and less painful. But rest assured: It’s still a real workout. As you move through the water, you’ll encounter much more resistance than you would on land. That effort builds muscle, which helps to protect your joints from bleeds.

“Water exercise also builds endurance, so that you can sustain activities for longer periods and get some real cardiovascular benefits,” says Grace Volsen, MPT, a physical therapist at Confluence Health at Central Washington Hospital in Wenatchee.

Water therapy helped Larry Hammerness, 50, get back on his feet after surgery on both ankles. “I walked in the water to regain the muscles that had atrophied while I was in ankle casts for six weeks,” he says. Hammerness is a Los Angeles-based photographer with severe hemophilia A. After physical therapy ended, he continued using the pool, doing stretches in the water and exercises such as weighted leg lifts.

Cindy Bailey, PT, DPT, OCS, SCS, director of the physical therapy program at the Hemophilia Treatment Center at Orthopaedic Hospital of Los Angeles, stresses safety first for nonswimmers and pool veterans alike. “No one, not even an Olympic swimmer, should ever enter the water without a lifeguard in the area to watch, assist and be there for safety,” she says.

Diving in, slowly
Water workouts are ideal for just about everyone, from people just getting off the couch to competitive athletes. If you’re new to aquatic exercise, start slowly, says Volsen. At first, stick with water walking in the shallow end. Then, as you build strength and balance, move to deeper water, where you’ll meet more muscle-challenging resistance. “Walking’s the perfect first step,” says Volsen.

It will take time to adapt to your new exercise. Ask your PT what to expect. A couple of weeks of muscle soreness, for example, is normal. Push on and you’ll be rewarded. “After a month or so, you’ll notice your muscles getting stronger,” Bailey says.

Coprid/Thinkstock
After you get the hang of walking in the pool, add specialized equipment to your workout for a greater challenge. For example, Volsen likes to introduce foam ankle cuffs to her more advanced water walkers. “While wearing them, they really have to work their legs and their core to stay stable in the water,” she says.

Stationary running is another beneficial exercise, even if you have ankle, knee or hip problems. Strap on a flotation belt or life vest, and you can run in deep water without touching the bottom of the pool. “It will make you really, really tired,” says Bailey. Fatigue is a sign that you’re giving your body a solid workout. But before your first dip in the pool, talk to your doctor about any necessary precautions.

Other classes offered at your local YMCA, community center or commercial gym may include:
• Ai Chi. A pool-based spin-off of tai chi, ai chi uses slow, controlled movements to build strength, balance and stability.
• Shallow Water Aerobics. Performed in water that comes up no higher than your shoulders, shallow water aerobics will boost your strength and flexibility as your heart beats at a faster rate.
• Deep Water Aerobics. These no-impact cardio exercises work your core muscles, increasing strength and balance, and improving heart health.

Group classes are an ideal way to get in shape, says Bailey. She recommends finding instructors who have experience working with people with joint issues. For example, the YMCA developed a water therapy program in collaboration with the Arthritis Foundation, she says.

Taking part in classes makes aquatic exercise much more fun and rewarding. “You bond with your classmates, you make friendships, you stay accountable and you keep going,” Volsen says.
Dear Addy: Deductibles

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Dear Addy,
I thought I hit my deductible total recently based on my receipts and explanation of benefits. My insurer says I haven’t and they have a different total of how much of my deductible is left. What is going on?

Signed, Calculation Crazed

Dear Crazed,
You will need to check your health insurance policy for what exactly counts towards your deductible. Here are a few things that some insurance companies DO NOT count towards your deductible so watch out for them:

- Services you pay for that aren’t covered by your plan.
- Services that are exempt from the deductible, like preventive care received from an out-of-network provider.
- Charges for services exceeding benefit maximums, like the maximum for glasses every two years might be $150 every two calendar years; if you spend more than $150 on your glasses then whatever amount is over $150 does not count towards your deductible.
- Charges for services beyond benefit limits, like the annual benefit limit for physical therapy might be 8 visits; costs for more than 8 visits are not covered by the plan and do not count toward your deductible.
- Charges for out-of-network healthcare and non-network pharmacies that exceed the allowed amount.

Your insurer must include in your policy a list of what counts towards your deductible. Review this list and then update your calculations or call your insurer to reconcile their calculations and yours.

Sincerely, Addy

Hemophilia Federation of America (HFA) frequently receives questions from the bleeding disorders community related to advocacy issues. The questions often impact the entire community. In an effort to reach the largest audience possible with our responses to these widely applicable questions, HFA developed “Dear Addy.” Questions submitted to this column are edited in order to protect privacy and should be considered educational only, not individual guidance.

http://www.hemophiliafed.org/news-stories/2015/05/dear-addy-deductible
CDC Research Study: Female Hemophilia Carriers Have Joint Abnormalities

Reprinted with permission from HFA

Research has suggested that women who are carriers for hemophilia (see definition in box below) might have an increased tendency to bleed. Repeat bleeding into the joint can lead to persistent joint swelling, ultimately leading to limited joint movement, and reduced joint range of motion. **Given that there is an under-appreciation of the effects of being a carrier for hemophilia by the woman herself, many women may not seek needed treatment. Greater awareness that carriers may in fact exhibit bleeding symptoms is needed and appropriate treatment recommended.**

In order to learn whether hemophilia carriers reported joint bleeding and showed physical signs of joint damage or destruction, CDC conducted a study that looked at joint abnormalities among 451 women presumed to be hemophilia carriers aged 2-69 years. The women were enrolled in a national public health tracking project called the Universal Data Collection (UDC) system. The UDC was created in 1998 by the Centers for Disease Control and Prevention (CDC) together with the federally funded Hemophilia Treatment Centers (HTCs) to collect vital health information on people with bleeding disorders in the United States. A physical therapist or trained healthcare provider collected information on specific participant characteristics, such as race/ethnicity, income, and educational level, known as demographic information, as well as information on bleeding and infectious disease history, and range of movement measurements in five joints (both right and left shoulders, elbows, hips, knees, and ankles).

The American Journal of Hematology published the results of this study which concluded that female hemophilia carriers of all ages had evidence of joint abnormalities as early as the pre-teen years regardless of the severity of hemophilia symptoms, and suggested that joint bleeding might be occurring before the adolescent years.

**Main Findings from this Study**

1. The proportion of female hemophilia carriers reporting at least one joint bleed in the last 6 months increased as the severity of hemophilia worsened:
   - Approximately 1 in 7 females with mild hemophilia reported at least one joint bleed in the last 6 months; mild hemophilia means they have 6% to 40% of normal clotting ability.
   - Approximately 1 in 3 females with moderate hemophilia reported at least one joint bleed in the last 6 months; moderate hemophilia means they have 1% to 5% of normal clotting ability.
   - Approximately half of females with severe hemophilia reported at least one joint bleed in the last 6 months; severe hemophilia means they have less than 1% of normal clotting ability.

2. In addition, hemophilia carriers showed signs of joint abnormalities as reflected by reduced joint range of movement which worsened with increasing levels of severity of hemophilia.

**Critical Gaps & Future Directions**

The findings of this study are preliminary. The next step is to document joint disease with x-ray tests and other ways to look at the joint.

**More Information**

To learn more about hemophilia, please visit: http://www.cdc.gov/ncbddd/hemophilia/

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**What is Hemophilia?**

Hemophilia is an inherited bleeding disorder in which the blood does not clot properly. This can lead to spontaneous bleeding as well as prolonged bleeding following injuries or surgery.

Blood contains many proteins called clotting factors that can help to stop bleeding. People with hemophilia have low levels of either factor VIII ("factor eight") or factor IX ("factor nine"). Because of the way hemophilia is inherited, the condition predominantly affects males, while females with the genetic change in the clotting factor are typically referred to as carriers. Hemophilia carriers can have an increased bleeding tendency, such as heavy menstrual bleeding.

**How does hemophilia affect joints?**

Joint bleeding typically occurs in males with hemophilia, but it has been reported among 8% to 16% of female hemophilia carriers in various studies. Repeated bleeding in the joint can lead to persistent inflammation (swelling) ultimately to joint abnormalities including limited joint mobility (movement) and reduced joint function.

http://www.hemophiliafed.org/news-stories/2015/03
Patient Services, Inc. (PSI) State Policy Agenda

Save State Dollars by Helping Patients with Chronic, Rare Conditions Access Healthcare

PSI is a national 501(C)(3) non-profit patient assistance organization that helps patients in all fifty states access the treatments and therapies they need to live healthy productive lives by subsidizing the cost of health insurance premiums as well as copayments and coinsurance. The organization also advocates on behalf of our patients and educates lawmakers on both the state and federal level about the access challenges they face.

Issue 1: Help Patients Access the Medications They Need!

• Some commercial health insurance policies are now moving vital medications (mostly biologics with no generic options) into “specialty tiers” that utilize high patient cost-sharing methods. This “fourth tier (IV)” is now commonly requiring patients to pay a percentage of the actual cost of these drugs – from 25%-33% or more, often costing hundreds of dollars, even thousands of dollars, per month for a single medication – rather than a fixed, flat dollar co-payment.

• These practices are placing medically necessary treatments out of reach for average Americans.

• Legislation to address this issue by limiting Out-of-Pocket (OOP) costs for vulnerable patients may be active in your state. Contact PSI at kfitzgerald@uneedpsi.org to find out more and see how you can support!

Issue 2: Help Patients with Medical Histories Access Insurance

• For over 25 years, PSI has been proud to help hundreds of thousands of patients across the country with OOP costs such as health insurance premiums.

• Recently, the Centers for Medicare and Medicaid Services (CMS) issued conflicting information regarding premium assistance that is allowing private insurers in the newly-created “Exchange Marketplace” to not accept checks from PSI. Patients with rare, expensive disorders will be disproportionately affected by this practice.

• Patients, many of whom have life-threatening conditions, could lose their insurance and seek treatment from emergency rooms and help from safety-net programs like Medicaid putting a strain on already stretched state budgets.

• 28 plans in 22 states have elected to ban third party payments by nonprofit organizations.

• PSI is working with Congresswoman Doris Matsui (D-CA); Congressman Kevin Cramer (R-ND); Congressman Cedric Richmond (D-LA) and Senator Bill Cassidy (R-LA).

• We need your help to weigh in with your Congressman and Senator on this important issue and let them know how this practice could negatively affect your community and family Contact James Romano at PSI to assist at jromano@uneedpsi.org!

Issue 3: Help Vulnerable Patients in your State by Leveraging a Private Sector Solution

• PSI administers programs in several states that assist uninsured and underinsured patients with bleeding disorders obtain information about available health insurance plans and subsidizes insurance premiums.

• By obtaining insurance coverage, the patient gains access to comprehensive care and states receives significant cost avoidance because the patients rely less on public safety net programs, such as Medicaid.

• Since inception, these programs have assisted thousands of patients and saved millions of dollars in states like VA, KY, SC, PA and more! Let us help your state!
Actions are louder than words.

When it comes to commitment, we believe you are either “all in” or you’re not. There’s no in-between.

For a quarter-century, the people of Bayer HealthCare have been committed to helping people with hemophilia A and their families with a wide array of community programs and support services.

For information on Bayer’s Educational Patient and Community Resources, contact your Hematology Account Executive by calling 1-888-79-BAYER.