Who Are You Walking For in 2013?

By Laura Meyers, Walk Event Manager

The 2013 Hemophilia Walk is just a few weeks away! We are excited to see Teams forming, Walkers registering, and our thermometer gaining speed! We are also excited to update everyone on what this year’s Walk will include; some things that have gone from just favorites to being tradition like the photo booth and lunch provided by Jason’s Deli! We will also have the children’s costume contest (17 and under, please) and are pleased to provide gift bags for your four legged Walkers again this year from the generous people at Pet Mania. We also have reserved rooms at the Hilton Garden Inn located on RDU Center Drive for a group rate of $99 per night.

Of course raising funds is critical for the Walk’s success, but we also have another goal. Hemophilia of North Carolina would like to see an increase in attendance, which we think can translate into an increase of awareness for those not familiar with the community we serve. Please consider who you could invite to not just join in your fundraising efforts, but who could also join you at the Walk! See you on October 19!

Wonderfully Made Family Fun Night!

In August, Walk Team Wonderfully Made kicked off their second year of fundraising for and participating in the Hemophilia Walk, with a Family Fun Night. The evening was filled with fun children’s activities, food, and raffle prizes. Team Captain Erin Otey’s organizing and early start paid off – the event raised nearly $750 – almost 20 percent of their goal achieved in just one day! Thank you Team Wonderfully Made for your hard work for the 2013 Hemophilia Walk!
MISSION STATEMENT
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.

Hemophilia Treatment Centers

- **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
  - Fax: (919) 966-4736
  - htccenter.med.unc.edu

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

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.

We maintain a membership mailing list. However, we never release any personal information without your permission. You may occasionally receive information that is mailed from our office. Your response to these mailings will be of your own choosing and if you would like to “opt out” of all third party mailings, please contact us to remove your name from these mailings.

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.

Resource Information

- **National Hemophilia Foundation**
  - www.hemophilia.org

- **Hemophilia Federation of America**
  - www.hemophiliafed.org

- **American Pain Foundation (APF)**
  - 1-888-615-PAIN (7246)
  - www.painfoundation.org

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

- **Bleeding Disorders Legal Hotline**
  - 1-800-520-6154

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

- **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.

- **Inalex Communications**
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  - www.inalex.com

- **LA Kelley Communications**
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- **Patient Notification System**
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  - 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

About This Publication

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 and a member of the Better Business Bureau.
From the President

Dear friends,

In June of this year, following the resignation of our Executive Director, we were all wondering “What will happen to HNC and all of the programs we depend on?” Since that time, we are fortunate to have had the services of one of HNC’s founders, Charles Register, as our interim Executive Director, and he has worked closely with Charlene Cowell, Rita Brown and Laura Meyers to keep HNC responsive to our community, while we have conducted a thorough search for our next Executive Director.

I am delighted to announce that our search is complete, and that Charlene Cowell has agreed to be the HNC Executive Director. Her passion for our community members, her deep knowledge of the issues that face us and of the bleeding disorder community at large made a very positive impression on the search committee, as did her excellent performance as Assistant Director over the last 15 months. Please join me in congratulating Charlene on her promotion to Executive Director. We look forward to working with her to keep HNC effective and responsive to the needs of the North Carolina bleeding disorders community.

We still have many challenges ahead, with the ongoing implementation of the Affordable Care Act in the form of health-care exchanges, and with continued economic uncertainties across North Carolina as communities adjust to state budget changes. I am confident that under Charlene’s leadership, HNC will provide the support needed to allow all in our community to realize their dreams of a full, rich, complete life. HNC is in good hands!

Steve Peretti,
HNC Board President

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“The Carolina Crew”

by Sue Martin, HSC President

I am always amazed to learn just how bright and wonderful our Carolinian teens are. After completing another successful partnership between Hemophilia of North Carolina and Hemophilia of South Carolina, the hard work between the two chapters and the SCHTC has once again paid off. On August 16-18, in Charlotte, North Carolina, “The Carolina Crew,” as they now refer to themselves, joined up once again to rekindle friendships and make new ones too from across state lines. “My most favorite part of the weekend was the openness and friendliness of everyone,” said Kaylie Robinson (HNC). From presentations and working groups, to activities in solving problems, learning financial independence, career planning, team work and creating a logo, the weekend event provided something specific for all who attended, each receiving something uniquely important to themselves. “Given the opportunity, every single teen and family should try to attend this fabulous program,” said Suzanne Nash (HSC).

The weekend began on Friday evening with a casual dinner fit just for teens, with pizzas galore and all the extras to fill their hungry bellies. An ice breaker allowed the teens to get to know one another (maybe too close for comfort, but fun nonetheless) as they worked together to solve the “human pretzel.” Unfortunately, they were not able to solve the complex situation they found themselves in, even with the suggestions and assistance of the parents. This led into what the weekend held next for all: the Career, Education and Opportunity (CEO) program developed for the teen hemophilia and clotting disorders community by the Indiana Hemophilia & Thrombosis Center, working in partnership with Baxter. With parents in a focus group of their own and the teens with facilitators, parents and teens received an understanding of what makes them tick as they all took the Myers-Briggs personality test.

Saturday brought about additional teen group activities and the famous “Reality Store.” To the surprise of the teens, parents tried to trick them into purchasing more than what they needed as the teens now had careers, checkbooks and the thought of what they would be doing at the age of 27. Some were married with kids and some were still single. All had some type of career. What I was pleased to see was how smart so many of our teens were. They were learning to make good choices, thinking about what life will be like and how much money they would have to live on in their career choices. According to all the evaluations, this was one of the best activities of the weekend education. “A continuous repeat of the importance of managing finances until they understand” was important to Christine Evans of HSC.

With Sunday morning wrap-up, discussions played out on easels through Pictionary and Hang Man, parents and teens engaged in healthy discussions about all they learned throughout the weekend. The Carolina Crew conquers the rapids!
Fun and Sun at the 2013 Family Retreat
By Joyce Hall

Hemophilia Family Retreat was another great success this year. Nestled in the Outer Banks, North Carolina lays a great place called the Trinity Center at Pine Knoll Shores that was gracious enough to host us once again. We opened with a dinner and a getting to know one another ice breaker. Later in the evening was a fun carnival that got everyone mingling and taking great family photos in our photo booth that was from Crystal Coast Photo Booth. They did a great job and gave all the families wonderful photos to take home and enjoy remembering the event. On Saturday we had great education with the parents learning topics such as “Understanding the Challenges” and “The Art of Transition” to help you grow your bond with your child(ren). The children had a day full of activities from the Aquarium visitors to tie-dying and fishing. There was fun to be had by all.

That was followed by our talent show that featured our talented community and friends and a movie that was inspiring. Then we had breakfast, followed by our wrap-up talk and a day at the beach. We are just as excited about next year’s family retreat as we are going to have a nice surprise so keep checking in! A special thanks to all the volunteers and guests that made the event a success. We would like to give special thanks to our sponsors once again for their continued support in making these retreats possible, along with our generous donors for whom we are greatly thankful.

“The Carolina Crew” Continued from page 4

weekend. There is no doubt in my mind after this weekend that these teens were ready to conquer their worlds.

Of course the retreat wouldn’t be the same without some fun and exciting activity that helps us all conquer our fears and reach beyond our comfort zones, something Pat “Big Dog” Torrey advocated strongly for kids with bleeding disorders. Pat has worked with our teen groups before and he would be proud of our accomplishments of the day. So we lost a few overboard, but like life with a bleeding disorder, sometimes you just have to get back on the “raft and keep floating.” After the group whitewater rafting, everyone enjoyed a delicious barbeque lunch. Then the families were free to set out on their own and explore the US National Whitewater Center in its entirety.

The Chapters wish to thank and acknowledge Baxter for the sponsorship of this program and the continued excellence of its facilitators, which makes this program one-of-a-kind. We also give thanks and appreciation to Pfizer Hemophilia, Biogen Idec Hemophilia and Drugco Health for their sponsorships of the teen retreat. Thanks to Stacy Dunleavy, MS at the SCHTC for the planning assistance, and to Jennifer Meldau, RN, MSN,CPNP, and Robin Jones, RN for their assistance and participation as the nurses on-call for the weekend. And to the teens? Well, the logo and name says it all. What a great Crew we have! Until next time…

Hemophilia of North Carolina gratefully acknowledges the following companies for their sponsorship of the 2013 HNC Family Retreat:

Admirals of the Fleet

Commanders

The Carolina Crew

Continued from page 4

Close encounters with creatures from the NC Aquarium.
Our Adult retreat was spectacular! We met at the Hilton Wilmington Riverside which has a gorgeous view of the Cape Fear River. It started with a breakfast reception followed by a great learning experience that included positive communication, transition and the process of letting go. Thanks to Baxter, we were fortunate to have Inalex Communications back again this year. Inalex Communications had a lot to offer us on the subject “Reclaim and Recharge Your Life.” John Badalament did a great job with the presentation and he told us of his book “The Modern Dad’s Dilemma.” He also gave us a lot of skills we can use to help open the lines of communication with our loved ones and these skills can be used in every aspect of life.

We also learned how to be conscious of others and their feelings; and to step back and count before you react which is really what we all need these days. We broke for lunch and cookies and then headed out to the wonderful TheatreNOW dinner show via trolley from Wilmington Trolley tours. We enjoyed the entertaining show and relaxing dinner. They got the crowd involved and they are a talented bunch with shows changing from comedy to murder mystery. It was an early night, which gave friends a chance to mingle and visit the pool. Sunday morning we finished with a breakfast and we all said our goodbyes, while some stayed and enjoyed the pool and the beautiful waterfront.

So to wrap up, I want to thank all the wonderful staff and volunteers who helped make all the events possible, as well as our generous donors and sponsors.
Upcoming Events

Save the Date for the HNC Holiday Celebration!
Saturday, December 7, 2013

Who’s coming to town? Santa Claus is for our annual HNC Holiday Celebration! This year we are celebrating in Morrisville, the home of Hemophilia of North Carolina, at the Four Points by Sheraton located near the Raleigh-Durham Airport. The holiday festivities will go from 2:30pm to 5:30pm and include food, fun, games, and gifts for the children. We hope to see you all there!

Save the Date for the HNC Casino Night Fundraiser 2014
Saturday, January 25, 2014

Join us for an exciting night of good fun and fast action for a great cause! We’re moving this year to the beautiful Cardinal Hall in Raleigh featuring crystal chandeliers and Chiavari ballroom chairs. With our new location, there will be plenty of free, on-site parking including a covered entryway and drop off.

Tickets for the evening will include heavy hors d’oeuvres, music, beer and wine, our famous silent and live auctions, great prizes and plenty of “funny money” play chips. You can gamble the night away at blackjack, craps and poker. And new this year will be a Big Wheel and several slot machines!

For information on helping to plan the event, attending or sponsorships, please contact our office at 1-800-990-5557 or email at info@hemophilia-nc.org.

First Health Encounter
By Shirlene Taylor

On September 14, 2013 the Health Department of the Improved, Benevolent and Protective Order of Elks of the World had its very first health encounter. Dr. William Murphy contacted different health agencies from the area to come out and speak about the many different health issues that affect our community. I was asked to speak about the bleeding disorders that affect our family and the community. I spoke about von Willebrand disease and hemophilia and who has it and how it affects the family. I was talking with Daughter Lauretta Hayes about how my nephew can have a joint bleed in his knee. I also discussed how we have been active with the Walk for hemophilia and when it is and where it is located and had some decide that they may be interested in coming out to participate. It was well attended and we decided that we would have another one next year in the month of September.
Blood Brotherhood Cookout

By Matt Igelman

On August 3rd, the Blood Brotherhood group hosted a social cookout at the HNC office. Over 30 brothers and their families turned out to enjoy some great BBQ and company. Off the grill came traditional Carolina pork BBQ thanks to our Grill Master for the day Jeff Neal. The apple wood smoked pork made a delicious meal to enjoy while sharing stories from years ago. The sharing of experiences is one of the most beneficial goals of the Blood Brotherhood program, provided to HNC as a program of the Hemophilia Federation of America. In North Carolina, we meet six times a year for adult men with bleeding disorders to share, laugh, learn and have some fun. If you’re a blood brother reading this and not part of our program, I urge you to come out to some of our 2014 programs.

For more information on Hemophilia Federation of America and the Blood Brotherhood program, go to www.hemophiliafed.org. For more information on the Blood Brotherhood Program here in NC, look for events on the HNC website, www.hemophilia-nc.org and keep an eye out for dates posted here in The Concentrate. For adult men with bleeding disorders to enroll in the program please contact the HNC office at 800-990-5557.
HOPE Program Continues to Grow

By Gillian Schultz

Hemophilia of North Carolina’s HOPE program (Help, Opportunity, Partnership, Empowerment) is growing in our community. The mission of HOPE is to improve the quality of life for families of the newly diagnosed children through the age of twelve with bleeding disorders, so that they may HOPE to lead a fulfilling life. Open to any member of HNC, programs are geared towards families with children in order to educate, share experiences, and most importantly provide support.

At the HNC Family Retreat in August, HOPE was highlighted with a presentation by Gillian Schultz, our volunteer program coordinator of HOPE. Gillian outlined the goals of the program and shared why HOPE is important to her. Families were very excited about the prospect of opportunities to get together and learn from each other and support one another.

On September 10, 2013, HNC working with Pfizer Hemophilia and in partnership with Presbyterian Blume Pediatric Hematology and Oncology Clinic held an educational dinner entitled “Encouraging Early Independence” at Maggiano’s Little Italy in Charlotte. We had a great turn out of about 25 people. The program was presented by Daysi Fardales, RN, NP, CNE speaker. Parents had the opportunity to learn how to help our children take control of their bleeding disorder, beginning at an early age. Starting by helping with infusions as toddlers, going to camp, maintaining logs, self-infusion, ordering factor, and eventually becoming independent, parents were able to learn how to support their children and to provide them guidance so that they can advocate about their bleeding disorder to friends, teachers, and even their parents. The presentation was very interactive as parents and children shared experiences and feelings they have had along their journeys. Following the program, an overview of the HOPE program was presented.

Stay tuned for other events that will be held this fall and winter. If you have questions, or would like more information about HOPE, please contact Gillian Schultz, gillian.schultz@hemophilia-nc.org or Charlene Cowell, info@hemophilia-nc.org or call the HNC office at (800) 990-5557.

Gillian Schultz is the volunteer program coordinator of the HOPE program. Her second son Noah was diagnosed with moderate hemophilia A shortly after his birth. She has another son without hemophilia. Gillian works part time as a violin teacher and has spent many years teaching music to children of all ages. She lives in Matthews, NC with her husband and two sons.
2013 Friends of HNC

We gratefully acknowledge the following individuals who generously donated to Hemophilia of North Carolina during the past quarter of 2013, and we extend a special thanks to our supporters who contributed several times during this period.

Donors

Courtney Carr
Charlene Cowell
David and Sally Frost
Sue and W. Allen Heafner
Matt Igelman

Christine Mixon
Karl and Gillian Schultz
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We thank our sponsors for their continued support of the community.

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Successful Surgery for Women with Bleeding Disorders

By Kelly Hoots

It was long believed that “girls don’t get hemophilia.” We now know that not only can they get hemophilia, but many have another bleeding disorder known as von Willebrand Disease. Many women have difficulty getting diagnoses and go through many struggles and suffering as a result.

My mother, Cecelia, was one of the fortunate ones who knew early in life that she had a low factor VIII level. Being the daughter of a man with severe hemophilia and some bleeding episodes as a child prompted testing that proved what was suspected. Besides some trauma in accidents, she has been able to lead a life with good health and very little treatment for her low factor level.

Recently, Cecelia was diagnosed with severe aortic stenosis. This resulted in surgery for heart valve replacement. Although there were some reservations on the part of her cardiologist and heart surgeon; her hematologist stepped in and all the medical teams worked well together for a successful surgery.

Open heart surgery is very serious but we are so fortunate to live in an era where the outcomes for people with bleeding disorders are remarkable. With today’s treatments and therapies, there are many women with more severe bleeding disorders surviving complicated surgeries with less interruption in their daily lives.

The key is knowledge. Be educated about your bleeding disorder and educate others. You never know when you may meet that person who has been dealing with bleeding issues all their life and just thought it was “normal” in their family. Awareness and diagnoses will result in better outcomes for surgery that could potentially be life-threatening without it. In addition to providing a support network for women, SOAR is working to raise awareness in schools, physician’s offices, hospitals and the general public. I encourage all women with bleeding disorders to get involved in this effort!

Change the World . . . Share Your Story

SOAR members are committed to raising awareness for the undiagnosed. One of the easiest ways to do this is to share your story.

If you are comfortable speaking in front of others or have a passion for writing, then I would like to encourage you to become involved with SOAR’s outreach efforts. We will have several opportunities available over the next year from very casual settings to more formal events. All that is required is for you to be able to talk briefly about your experience of living with a bleeding disorder.

A short training session will be provided to all who want to become involved in this campaign that will surely “change the world” for women and girls with bleeding disorders.

Please contact us by email (soar@hemophilia-nc.org) for more information on this exciting opportunity!
Pregnancy with a Bleeding Disorder Requires a Comprehensive Approach

By Crystal Hoernlein

Women with bleeding disorders may experience anxiety at the thought of pregnancy and delivery. The good news is that significant bleeding problems are largely preventable with the proper care.

Women with bleeding disorders are at risk for hemorrhage throughout life. During pregnancy and postpartum, this complication can affect the health of both mother and baby. Fortunately, when obstetricians, hematologists, and anesthesiologists work together most women with bleeding disorders can experience a successful pregnancy and deliver a healthy child.

Tips for a successful pregnancy, delivery, and postpartum period:

- Talk to your doctor(s) about your bleeding disorder before becoming pregnant.
- Consider a team of specialists for optimal care. Your team may consist of a doctor who specializes in high-risk pregnancies, your hematologist, and an anesthesiologist.
- Talk to your doctors before having any prenatal tests or medical procedures (for example, amniocentesis) to address risks of serious blood loss.
- If possible, plan to deliver in a hospital with an on-site coagulation laboratory, pharmacy, and blood bank.
- Have your hematologist work closely with your obstetrician and discuss any safety measures that may be taken to avoid injury to the child (for example, not using forceps or a vacuum extractor to assist in delivery, if possible).
- Consider meeting with a pediatric hematologist regarding the evaluation of the baby after delivery.

If you have a boy and plan to circumcise him, you may want to wait until he has been tested.
- Seek support to ease anxiety: talk with other women with bleeding disorders about their pregnancies and deliveries.

These are just a few key points to discuss with your healthcare providers.

SOAR Summer Recap

SOAR members were able to connect with one another over the summer. On June 24, members gathered at the HNC office for dinner and a von Willebrand disease educational session from clinical educational manager Virginia Krauss. Ms. Krauss discussed a variety of topics such as testing, complications from the disease, and treatment options. The educational session was followed by a SOAR planning session during which members discussed roles, priorities, and goals for the coming year.

On July 24, SOAR members had another opportunity to join up at Maggiano’s Little Italy in Durham to hear Jeanette Cesta discuss the ever-changing challenges of women with bleeding disorders. For example, women with bleeding disorders who have children with bleeding disorders often focus on their family’s needs first. But it’s important for women to remember to address their own health needs as well. Members also learned about the many resources available to empower women to be in control of their health and shared with each other the real issues they face everyday.

Membership Information

For more information about SOAR, or to be added to the SOAR mailing list, please send your name and contact information, along with any questions you may have, to soar@hemophilia-nc.org.
Entrevista con Katherine Register – Parte 2
Interview with Katherine Register – Part 2
por Guillermo Sánchez / by Guillermo Sánchez

Esta es la conclusión de la entrevista con Kathy Register. La primera parte apareció en la edición anterior del concentrado, Verano 2013.

G(uillermo): Tomando en consideración que tu esposo Charles tiene hemofilia, ¿que mensaje dirigirías específicamente a los compañeros y compañeras sentimentales que viven con alguna persona afectada con algún desorden sanguíneo, en cuanto a las habilidades, actitudes, modos de ver la vida, o cualquier otro recurso que mas te ayudaron a enfrentar –en especial al inicio del matrimonio- esta complicada condición de salud?

K(athy): Deja primero te cuento un poco de nuestra historia. Cuando me casé con Charles en 1973, el tenía 22 y yo 21. Su hermano de 37 años, que también tenía hemofilia, había fallecido a menos de dos semanas antes de nuestra boda. En aquel entonces mi esperanza era que Charles sobreviviera por lo menos hasta pasado sus 30. El tenía hemofilia clásica y su inhibidor estaba alto hasta el cielo. Fue un milagro el que hubiera alcanzado los 40. A la edad de 41, su inhibidor fue erradicado utilizando el protocolo Brackmann “inmunoterapia inducida” (también conocida como el protocolo Alemán de Bonn) y desde entonces ha podido ser tratado tradicionalmente. Tuvo mucha suerte de mantenerse negativo en cuanto al diagnosticó de VIH, tan frecuente en esos años. Sin embargo ha presentado algunos episodios de sangrado severo, y ha estado muy cerca de morir a consecuencia de las más de 20 cirugías a las que se ha sometido. Apenas comenzaba el matrimonio y yo pasaba mucho tiempo preocupándome por su condición. Pero gradualmente comencé a entender que el estar preocupada era contraproducente.

Charles salió a delante a pesar de todas las adversidades y tubo una exitosa carrera profesional de 30 años trabajando para la Universidad de Duke. Y ambos estamos felices de dedicarnos a la música de cámara – los dos somos flautistas y aficionados a la música de renacimiento y barroca – de hecho hemos tocado (y cantado) en innumerables bodas y celebraciones.

Charles cumplió 63 en Julio pasado, y su salud es relativamente buena. Tenemos dos hijos de 33 y 36, y tenemos dos nietos adorables, de 3 y 6 años, quienes nos dan mucha alegría. La vida ha sido buena con nosotros, y vivimos muy ajustado de nuestro retiro.

Cuando pienso en el pasado, me es todavía difícil de entender de que forma pudimos sacar adelante nuestra familia al mismo tiempo en que enfrentábamos tantas dificultades. ¿Existe algún secreto con el cual explicar la buena fortuna de Charles y su larga vida? En realidad no. Aunque de seguro algo de buena suerte tuvo que

This is the conclusion of our two part interview with Kathy Register. The first part appeared in the last issue of The Concentrate, Summer 2013.

G(uillermo): Since you are married to Charles who has hemophilia, what would you say specifically to all partners living with someone with a bleeding disorder in terms of what is the most useful skill, attitude, philosophical point of view or any other resource that helped you to cope with this especially difficult health condition when you just got married?

K(athy): First a little background: When Charles and I married in 1973, he was 22 and I was 21. His 37-year-old hemophilic brother had died of bleeding less than two weeks before our wedding. I had little hope that Charles would survive past 30. He had severe classical hemophilia with an inhibitor that was sky high. His reaching the age of 40 was a miracle. At age 41, he got rid of his inhibitor with the Brackmann “induced immune tolerance” protocol (also known as the Bonn, Germany protocol) and has been treatable ever since. He was very lucky to have remained HIV negative during those years. He has had some very serious bleeding episodes, and has come near death following some of his more than 20 surgeries. For a good deal of our young married life, I was in a state of constant worry. But worry is counterproductive, and I gradually learned that lesson.

Charles defied all the odds and had a very successful 30-year career at Duke University. And both of us had a very rewarding semi-professional career as chamber musicians — we are both flautists and renaissance and baroque music aficionados — and have played (and sung) at innumerable weddings and other celebrations.

Charles will be 63 this July, and is in relatively good health. We have two sons who are now 33 and 36, and we have two adorable granddaughters, ages 3 and 6, who give us great joy. Life has been good to us, and we are comfortable in retirement.

Looking back, I sometimes cannot fathom how we got through so much difficulty while raising a family. Is there a secret to Charles’ good fortune
estar involucrada. O quizás la respuesta sea la siguiente: Charles y yo somos buenos amigos. Nos queremos y respetamos el uno al otro, reímos mucho, y vemos con buen sentido del humor casi todo. Nos consideramos con suerte al estar haciendo las cosas que a cada uno le gustan. Queremos a nuestras familias, y de nuestros amigos puedo decir que son fantásticos. Nunca nos vamos a dormir enojados. Tenemos en casa a un perrito de que adoramos, Riley, que nos divierte con su personalidad. Y lo más importante: Cuidamos de nuestros problemas de salud desde el primer minuto en que nos damos cuenta de que algo no anda bien.

Aquí les dejo algunos consejos prácticos:

1. Quieranse y respétense el uno al otro. Desarrollen y mantengan el buen sentido del humor. Todos tenemos desacuerdos y discusiones – pero los que hemos tenido la suerte de ser parte de la comunidad de desordenes sanguíneos hemos aprendido a darnos cuenta de lo que en realidad tiene importancia.

2. Si aún no saben como deben de aprender como mezclar el factor, encontrar una buena vena e inyectar el factor. Deben de aprender esta habilidad para cuando se presente la ocasión en que él no pueda hacerlo por su cuenta.

El personal de los centros de tratamiento para la hemofilia te puede enseñar, no es nada difícil.

3. Aprende a determinar cuando tu pareja puede hacerse cargo de un episodio de sangrado y cuando no. En esas ocasiones en que él no pueda inyectarse o detener el sangrado de otras formas, tú debes de tomar la iniciativa y entrar en acción para que utilice el factor. Debes de buscar ayuda inmediatamente, o mejor aun: tú debes de inyectarlo.

4. Cuida de tu salud – los dos tienen que hacerlo- come alimentos saludables, ejercítate diariamente, y acude a chequeos de salud de rutina.

5. Has tu vida de manera normal. Esto es lo que todos deseamos.

Ha sido un placer el haber conversado contigo Guillermo. Ahora me gustaría agradecer por aceptar el ser parte de nuestra Mesa Directiva para el periodo 2013-2015. ¡Serás un maravillo miembro dentro de la directiva!! Espero con gusto trabajar junto contigo.

G: Te agradezco mucho por tomarte el tiempo para platicarnos acerca de tu experiencia – en ambos roles – como compañera y activista dentro de la comunidad de desordenes sanguíneos y por compartir tu invaluable conocimiento y consejos para enfrentar con éxito esta interesante condición de salud.

and longevity? Not really. Certainly there is some luck involved. Or maybe it is this: Charles and I are best friends. We are respectful and loving to one another, and we laugh a lot, finding humor in almost anything. We are lucky enough to be able to do the things we love. Our family is cherished, and our friends are terrific. We never go to sleep angry. We have an adorable dog, Riley, who tickles us with her personality. Importantly: we take care of our health problems the minute we perceive them.

Here are some practical tips:

1. Love, respect and cherish one another. Develop or keep your sense of humor. We all have disagreements and arguments – but we who are lucky enough to be a part of the bleeding disorders community are able easily to understand what is really important.

2. Learn how to mix factor, and to stick a vein and infuse your husband, if you haven't already. You may need that skill for the very rare occasions that he cannot infuse himself. The Hemophilia Treatment Center personnel will train you. It is not difficult.

3. Know when your spouse can handle a bleeding episode, and when he cannot. In the rare instances that he cannot self-infuse or otherwise contain his bleeding, YOU must spring into action to get him infused. You must get help immediately. Better yet: learn how to do the infusion yourself.

4. Take care of your general health – BOTH of you – by eating healthful foods, daily exercise, and getting regular healthcare.

5. Lead a normal life. That is what everyone wants the most.

It has been a pleasure, Guillermo, to have this conversation with you. And now, I must thank YOU for agreeing to serve on our Board of Directors for the 2013-2015 season. You will make a wonderful addition to our board!! I so look forward to working with you.

G: Thank you very much for the time to talk about your experience in both roles, as a partner and activist within the bleeding disorder community and for sharing your invaluable knowledge and advice for dealing with this challenging health condition.
North Carolina Advisory Board for Bleeding Disorders

By Kathy Register

The North Carolina Advisory Board for Bleeding Disorders meets quarterly. Its members include staff from North Carolina’s Hemophilia Treatment Centers, as well as representatives from the bleeding disorders community. Hemophilia of North Carolina staff, board members, and volunteers are well represented. Membership is open to all interested parties.

This board is an offshoot of a mandate some years ago from the Maternal and Child Health Bureau, that the Hemophilia Treatment Centers convene an advisory board with consumer members in order to keep open the lines of communication between our community and our caregivers. We exchange important information to help carry out our respective missions.

Please watch for this new regular feature in The Concentrate. We want to keep you informed about the NCABBD’s activities. Our last meeting was Friday, September 6 in Morrisville. Present were Steve Humes, Tyronna Hooker, George McCoy, Charles Register, Richard Atwood, Sally Wright, Kathy Register, Helen Shapiro, and Charlene Cowell.

We received updates on HNC’s programs and activities, and the status of grants affecting CDC/ATHN patient surveillance and needs projects. We discussed the impending rollout of the Affordable Care Act and how we might help spread the word on how best to shop for insurance. The meetings are always lively, informative, and friendly.

Anyone interested in becoming a member of this advisory board, please contact Steve Humes at steven.humes@hemophilia-nc.org
Seven Ways to BEAT BLEEDS

What’s your first reaction when you experience a bleed? Some people with hemophilia A or hemophilia B have little or no reaction – they’ve become so accustomed to pain, swelling and stiffness that bleeding is now “just part of life.” But by working with your hemophilia clinician on a comprehensive treatment plan, and by using today’s therapies, you can beat bleeds.

Whether your reactions to a bleed and your long-term goals are to address pain associated with bleeds, stay active, or be there with your family, it’s never too late to start taking charge of your health.

Over the last 30 years, researchers and clinicians have discovered that the infusion of factor on a regular basis (often called prophylaxis) can actually prevent most bleeds. Today, hemophilia clinicians commonly recommend this approach. There are a number of options available for managing and reducing bleeds. You should partner with your Hemophilia Treatment Center (HTC) to find the treatment plan that works for you.

Here are some tips that you can think about and discuss with your hemophilia clinician:

**BEAT BLEEDS TIP #1: Know Your ABR**

The first thing you can do to reduce or prevent bleeds is to know your annual bleed rate (ABR), which is the number of times you bleed in a year. It’s an important number – like knowing your weight, blood pressure, cholesterol or blood sugar levels. Work with your HTC team to determine your goal.

**BEAT BLEEDS TIP #2: Track Your Bleeds**

Know how often you are bleeding. Begin by tracking your bleeds for a month, capturing the date, location and type...
Seven Ways to BEAT BLEEDS

(joint, muscle, other) of each bleed you experience. Keep in mind the common signs of a joint bleed: tingling, pain, stiffness, heat, and swelling. Be aware of common signs of a muscle bleed: pain, stiffness, warmth, swelling, tightness of skin, redness, and numbness (this is a late sign).

Notice if your pain has become worse over time, and if so, how. Record how often in a month you have had to miss school, work, or other activities because of bleeds.

BEAT BLEEDS TIP #3: Set Your Goals

Many people want zero bleeds. How many fewer bleeds do you want to have? What motivators might help you achieve your goals? What obstacles might get in the way of achieving your goals? Talk with your hemophilia clinician to set appropriate and realistic goals for you.

BEAT BLEEDS TIP #4: Make Your Plan

To beat bleeds, you need a plan. Work with your HTC to create a treatment regimen that will help you accomplish your goals. Your plan will also focus on overall health. Keeping your joints and muscles strong now and in the future can be critical to help prevent bleeds. Exercise and eating well are key to staying strong and reducing stress on joints by maintaining a healthy weight.

A good plan helps you take charge, reduce bleeds, and minimize pain associated with bleeding. A great plan will help you do it in a way that works with your life. The key is to create a routine you can stick with over the long term. That way, it’s easier for you to realize the benefits of reducing bleeds. Be sure to talk with your HTC about your overall health needs and goals.

BEAT BLEEDS TIP #5: Take Steps to Prevent or Reduce Bleeds

When factor levels are low, accidental bleeds and spontaneous bleeds are more likely to occur. Instead of only treating a bleed after it happens, infusing prophylactically can keep factor levels up, which has been shown to prevent most bleeds and reduce annual bleed rates (ABRs), or the number of times you bleed in one year. Work with your HTC to determine which regimen is right for you.

BEAT BLEEDS TIP #6: Track Your Progress

On paper, a computer or smartphone, create a simple tracking system that works for you. Record things like infusions, weight, bleeds (remember the info in Tip #2), and successes. While you’re tracking your progress, also note your patterns. What do you need to do to achieve your goals? What barriers are in the way? Every month, take a look at your data and take pride in your progress!

BEAT BLEEDS TIP #7: Start Today!

Don’t wait — put these tips into practice now to better manage your hemophilia, your health, or other areas of your life. By knowing the facts, setting goals, working with your HTC and making good choices, you can minimize the impact of bleeds on your life.

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As states are setting up their online health insurance marketplaces, officials are watching for look-alike websites that can lead consumers to be the victims of fraud or simply, confusion.

States are on the lookout for websites created by interest groups, private insurance companies and sometimes scammers that have similar web addresses and the appearances of the official state exchange websites. Officials are intervening in some cases and trying to make sure consumers are able to spot a fake site before they give out private information.

“These exchanges could range from deceptive but relatively benign marketing devices for legitimate insurance companies to malicious devices that are designed to steal your identity or insurance information,” said James Quiggle, communications director for the Coalition Against Insurance Fraud.

In California, for example, typing in Coveredcalifornia.com takes a user to an informational website, with a fine print disclaimer that it is not the state-run site Coveredca.com. State insurance officials monitor the website — run by the Health Exchange Consulting group as a source of information on the state exchange — because consumers may easily type in the wrong web address. Because the site is not being used for commercial purposes, however, the state has not interfered.
Hepatitis C With Mild to Moderate Hemophilia?

Consider this clinical research study.

Participants may receive, at no cost, study-required:
- Doctor visits
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We are now enrolling eligible males 18 and over who have:
- hepatitis C
- mild to moderate hemophilia
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For instant access on your mobile device scan here

Medical insurance is not needed to participate. Study-related time and travel reimbursement may be provided.

To learn more about how you may be eligible to participate, visit HepCHemoStudy.com

ON THE NATIONAL & LEGISLATIVE FRONT

Be On the Lookout For Fake, Look-Alike Exchange Sites

“We have been monitoring various sites to make sure they are not doing anything illegal or misrepresenting themselves as an agent of Covered California,” said Larry Hicks, spokesperson for the state’s exchange. “We do periodic searches and domain searches to see what pops up.”

Pennsylvania insurance officials intervened in July when a private insurance company welcomed consumers to the “Pennsylvania Health Exchange” with the state seal in the corner. The company took the website down immediately and apologized.

“We believe it was not done in a malicious manner,” said Melissa Fox, spokesperson for the Pennsylvania Insurance Department. “We do have an enforcement bureau to make sure that the folks that are selling, soliciting and negotiating insurance are complying with regulations.”

But the agency does take tips from consumers on top of their own monitoring.

The new state marketplaces, also called exchanges, were mandated by the federal health law and will open in every state on Oct. 1. They will allow consumers to compare insurance options available to them and choose a policy, akin to purchasing a plane ticket online. The application process, however, will be intensive, and ask for personal information such as Social Security numbers, employment information and tax records.

Sixteen states and the District of Columbia are creating their own marketplaces while the remaining states are defaulting to the federal government to run their exchange. Healthcare.gov is the administration’s main hub for information and purchasing options for the federal exchanges.

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Be On the Lookout For Fake, Look-Alike Exchange Sites
Be On the Lookout For Fake, Look-Alike Exchange Sites  

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Experts suggest that to avoid confusion, consumers first head to Healthcare.gov. On that site, they can find out if they will be using the federal exchange or they can get the link to their individual state’s exchange.

Consumers should look out for sites with little information or graphics or those that appear to have the sole purpose of getting individuals to sign up, said Quiggle. They should also be wary of providing information that seems unlikely to be needed to connect with the buying an insurance plan.

If they see something odd, consumers should notify their state insurance departments.

“Consumers have a responsibility to pay very close attention to the communications and alerts by the exchanges so they are certain of the identity of their site, whether it’s a federal or state exchange,” Quiggle said. “Know just what your exchange site is supposed to ask and what information you need in order to complete the transaction.”

Shortly after the law was enacted in 2010, Department of Health and Human Services Secretary Kathleen Sebelius sent a letter to state insurance commissioners and attorneys general warning of scam artists who “may be using the passage of these historic reforms as an opportunity to confuse and defraud the public.”

“The potential for fake exchanges to rear up is very serious and real,” said Quiggle.

He said scam artists could prey on consumers’ lack of experience in purchasing insurance and on the confusion accompanying the inauguration of the exchanges to lure people to a website that looks like the real thing.

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“Deceptive websites have enrollment engines that ask for your personal information including credit card and other health identifiers that form the core of identity theft,” Quiggle said. “They also might try to install malware on your website to steal sensitive information on the fly.”

Eight percent of medical identity theft occurs because consumers give their personal health information, such as blood type or medical history, to a fake or “ spoofed” website, according to Bill Barr, development coordinator for the Medical Identity Fraud Alliance.

Scammers can take this information, pair it with a false license number, and sell your identity on the black market, Barr said. It is often difficult to tell which websites are fake, he added. “These spoofed websites can be very convincing, scammers often copy from the real website,” Barr said.


[NOTE: North Carolina has chosen not to operate a health insurance exchange, so any website that appears to represent our state in this fashion should be assumed to be fake. North Carolina residents should consult the federally-operated Healthcare.gov website for health insurance marketplace options available in this state. — Ed.]

“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.
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.

**Donate to HNC**

You can make an online donation to HNC's 2013 Hemophilia Walk through the National Hemophilia Foundation web site. Just follow these easy steps:

- Go to [www.hemophilia.org/walk](http://www.hemophilia.org/walk)
- Click NC (Raleigh) on the right-hand side.
- Click on the blue [DONATE](http://www.hemophilia.org/walk) 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](http://www.hemophilia.org/walk) 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!

Please make checks payable to Hemophilia of North Carolina. We are a 501(c)(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](http://www.hemophilia-nc.org) with your credit card.

Thank you!
It’s Almost Time!

Saturday, October 19, 2013
Lake Crabtree County Park
Morrisville, NC

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

Dogs are welcomed too! (on leash)

Kids, put on your Halloween best for our COSTUME CONTEST!