Mind, Body & Soul – Taking Care of Yourself!

HNC 2011 Annual Meeting

HNC hosted our 2011 Annual Meeting on Saturday, May 14th in Winston-Salem where 150 people, including attendees & sponsors, gathered together for a full-day event and learned about topics such as Research & Clinical Trials, Understanding Inheritance Patterns, The Importance of Dental Health, The Right State of Mind – Understanding the Impact of Mental Health, HFA’s FitFactor Program, Health Care Reform & Advocacy and a panel presentation about programs and services offered by HNC.

On Friday evening before the meeting, HNC hosted the Special Guest & Volunteer Dinner to acknowledge all those who have helped support us throughout the year with their time, talent & resources. Sixty people attended the dinner and enjoyed an inspirational presentation by Tim Grams, CSL Behring Gettin’ in the Game athlete.

On Saturday, our vendor exhibit hall was open and available during breakfast and throughout the conference. We graciously thank our sponsors for their participation and support of this event, which allows us to offer the meeting free of charge to our membership. In our vendor hall, we also had a poster presentation by Christopher D. Porado, PhD, Wake Forest Institute for Regenerative Medicine, relating to his research into the basic biology and treatment of hemophilia.

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VWD Weekend Educational Program

On April 1-3, Hemophilia of North Carolina hosted dozens of women, men and teen girls from throughout state at the beautiful Graylyn Conference Center in Winston-Salem for a VWD Weekend Educational Program. The weekend was specifically designed for those with von Willebrand disease, using information from the Von U program (Von Willebrand University: Raising Awareness of VWD One Patient at a Time – a CSL Behring sponsored program).

The weekend was available to adults with VWD, parents of children with VWD and affected teen girls. Topics included “What We know Today About VWD”, genetics, current treatment options, living & thriving with VWD, OB/GYN issues, effective communications...

Continued on page 6
MISSION
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.

VISION
Hemophilia of North Carolina’s vision is for all persons affected by bleeding disorders to achieve their full potential without barriers or limitations, until a cure is found.

Contact Numbers
Hemophilia of North Carolina
(800) 990-5557

Executive Director, Sue Cowell
(919) 319-0014

National Hemophilia Foundation Office
(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 M oy e 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

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) 684-5350
http://htc.medicine.duke.edu/

Presbyterian Blume Pediatric Hematology & Oncology Clinic
301 Hawthorne Lane, Suite 100
Charlotte, NC 28204
Phone: (704) 384-1900

Resource Information

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

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

Bleeding Disorders Legal Hotline
1-800-520-6154

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 form health professionals.

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

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

HIV/HCV Newsletter
Hemophilia Association of the Capital Area
www.hacacares.org

LA Kelley Communications
1-800-249-7977
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
514-875-7944
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.

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.
From the Executive Director

Happy New Year to HNC (our new fiscal year that is)! As of July 1st we will be transitioning into our new fiscal year with our newly elected Board of Directors and strategic plan for 2011-2012. Our past year has been filled with activities & projects that have been led by outstanding volunteers and staff members. We’ve expanded our outreach efforts in a number of areas and continue to build our programs through the support of our members, industry partners and national organizations. Although the statistics are not all in place yet from the close of year, we have continued to grow considerably in the number of members and support. Our next newsletter will feature our accomplishments of this past year. For this upcoming year, we have a number of exciting projects already in the works including our HNC Adult Retreat, the HNC Family Retreat, Family Programs, our Latin Union Retreat, the Blood Brotherhood Retreat, our annual Holiday Celebration, a family needs assessment project, an HNC educational DVD project, the Aging Research Team, a Teen Advocacy Program, a Leadership Conference, more SOAR programs for women & girls, and of course, our 4th Annual Hemophilia Walk taking place on October 15th. As in past years, we need your feedback on how we are doing. What would you like to see us addressing in our strategic plan? Are you interested in sharing your story? Do you have time to help out with one of the projects or have input into one of the areas we are currently involved with? Please take the time to write, email or call to let us know if our programs are working for you and your family. Thank you for all of your wonderful support and enthusiasm over the past 12 months and we are looking forward to a great year ahead!

Sincerely,
Sue
Susan Cowell
HNC Executive Director
HNC 2011 Annual Meeting continued

Our keynote presentation by Nigel Key, MB, ChB, FRCP, about Research & Clinical Trials started the program for the day. Dr. Key, Chief of Hematology/Oncology and Director of the UNC Hemophilia and Thrombosis Center, shared his expertise and valuable information on the definition and types of research, the importance of research to clinical care, treatment products for hemophilia and the importance of patient participation and support for research.

A panel presentation consisting of Emma Ingram (Teen Program), Guillermo Sanchez (Latin Union Program), Matt Igelman (Blood Brotherhood) and Sue Fletcher, PhD (SOAR/Women’s Program, Family Needs Assessment and Aging Research Team) then shared information with our members about these HNC programs and highlights about the importance and impact they have on members of the bleeding disorders community.

After our morning break, Leonard Poe, VP Advocacy Chair of HNC, spoke about the ever evolving process of health care reform, pending legislation on developing the health benefits exchanges in North Carolina and why it is important to everyone to be an advocate for themselves and the community.

The HNC Business Meeting took place where HNC President Richard Atwood, Treasurer, Kathy Register and Executive Director, Sue Cowell presented information on the accomplishments of HNC over the past year and financial information about the organization. The election of the 2011-2013 Board of Directors took place and we welcome new board members Steve Peretti (President), Wayne Cook, Tiffany Holland, Maria Schmaith-Ivan, Amy Shair and Ann Skinner. Also elected for a returning two-year term were Scott Andrews and Warren Ingram. Contact information and bios for all board members will be available shortly on the HNC website. Kathy Register presented outgoing President Richard Atwood with an award for his years of service to the community and many thanks for his leadership and dedication to North Carolinians with bleeding disorders. Please check out our website for more information and pictures of the presentation.

After lunch, Kristy Lee, MS – Certified Genetic Counselor at UNC School of Medicine, presented ‘Understanding Inheritance Patterns’. Along with providing a better understanding of this topic, Kristy quizzed us on the top 10 questions related to this area, which was very informative. Following this session, Terry Lamb, provided highlights about Hemophilia Federation of America’s FitFactor program. The program, Fit Factor: Strength, Flexibility and Wellness, offers services designed to improve health, fitness, and quality of life through regular physical activity and proper nutrition. We encourage you to check it out at www.hemophiliafed.org and register today.

Our afternoon sessions continued along the theme of the meeting about taking care of yourself and included a very informative and humorous presentation on the Importance of Dental Health by J. Timothy Wright, DDS, MS – Chair and Distinguished Professor of Pediatric Dentistry, Dental Research at UNC School of Dentistry. He shared the importance of maintaining good dental health, particularly with someone affected by a bleeding disorder, and the complications that might arise if not treated properly. The session on The Right State of Mind - Understanding the Impact of Mental Health was presented by Alexandra Boeving Allen, PhD – Assistant Professor at Wake Forest School of Medicine. Dr. Boeving Allen, a child psychologist, helped provide a better understanding of how to recognize and manage stress as well as understanding how it affects the mind, body and behavior in many ways. She led us through breathing and relaxation techniques that can benefit everyone in their daily lives.

The younger children were busy all day with the Ted-E-Bear Program where they created bears, took them to the ‘clinic’, shared stories, built hot air balloons, did plenty of arts & crafts along with joining in a musical program provided by Sing & Hum. This would not have all been possible without coordinator Judy Igelman’s planning and assistance along with a great team of volunteers who kept things moving along throughout the day. Our teens took to the road with coordinators Charlene Cowell and Spencer Brill for a day of service at the Forsyth County Humane Society where they assisted the staff in a variety of projects. After returning to the hotel, they enjoyed a dip in the pool for some fun and relaxation.

We closed out the meeting with our Vendor Visit Raffle and Attendance Raffle drawings along with several company sponsored raffles. After the meeting, attendees were welcome to enjoy a light dinner and special rock laser planetarium show at SciWorks.
GRAHAM — Wearing a tiara and a long red cape, Tyronna Hooker crossed the gym floor at Graham Middle School.

As students cheered, she struck a pose. They cheered louder, stomped their feet and did the wave.

Showing a sense of humor, Hooker motioned with her arms for more noise a couple of times when the cheers faded.

Hooker found out in April she’d been chosen as North Carolina Teacher of the Year. Students at the year-round school have been on an extended break for much of the time since she received the statewide honor.

Friday was their chance to celebrate during a rally at the end of the school day.

Interim Alamance-Burlington Superintendent Del Burns told students Hooker will meet many people during her time as Teacher of the Year.

But “nothing will mean more to her than be honored and recognized by you,” he said.

Some Graham Middle teachers wore T-shirts with “Got Hooker” on the front and “Graham Middle School does” on the back.

Once more of the shirts are made, teacher Joe Little said, they’ll be sold and the profits will go to Hemophilia of North Carolina. Both of Hooker’s sons have bleeding disorders, and the organization works to help people with that condition.

School administrators had worked to keep the extent of the celebration a surprise.

“Ms. Hooker knows that there’s going to be something,” Assistant Principal Deborah Brogden told people invited to join the school’s celebration. Those included local school board members and June Atkinson, the state’s superintendent of public schools.

Minutes later, Hooker walked through hallways, stopping often for hugs and high-fives as students chanted her name. She carried a bouquet of paper flowers that were later replaced by roses.

As she entered the gym, students held streamers in the school’s colors, red and black, over her head.

A few students talked about how Hooker has helped them. Eli Rodriquez presented a poster that said “Look at the seeds you helped plant.” Around the edges were small plastic bags filled with seeds and labeled with words including “Love,” “Hope” and “Pride.”

“We can all say that you’ve planted a seed in our hearts,” he said.

Atkinson reminded students Hooker is still in the running for an additional honor: “I’m betting that this lady will also be chosen as the National Teacher of the Year.”

Hooker told students she didn’t achieve success on her own.

“I struggled,” she said. “I needed a little help.”

Hooker’s grandmother would ask teachers if they were “believers” — people who believe children from a non-traditional background can thrive with the right attention and guidance.

“My grandmother knew the power of being a believer,” she said. “They push you to places that you don’t even know you can go.”

Source: www.thetimesnews.com, May 07, 2011 4:22 PM
Have you ever had something happen that just changed your life in ways you never would have imagined? Well, in 2010, I had my life changing moment.

I've always been a compassionate person, but I guess I've never really felt the drive to go out of my way. I'm either too busy, forget, or just have more important things to take care of. After all, that's pretty normal.

In August of 2010, my husband, Mark, and I welcomed our first child, Miles Landon Davis, into the world. There were complications, and we were in the hospital for close to two weeks with him. In short, he was diagnosed unexpectedly with Severe Hemophilia A. This was a complete shock, as Hemophilia does not run in our family. During this time, we received so many visitors, cards, emails, meals, gifts, and most importantly, PRAYERS, that we just felt an overwhelming amount of support. I can honestly say this was the most exciting yet scary time of my life, and we are still working through the difficult time of settling in with this new adventure and blessing that God has given us.

We are very straightforward about our faith and will tell anyone that we have a relationship with God. During this difficult time in our life, we have not turned away. Our faith has strengthened, and continues to every day. Knowing that God is watching over our baby boy is what keeps us going. With all the support we have received, and with God’s strength, this situation in our life has prompted me to be more active in my giving. I feel a very strong urge to help others in any way I can, and these days I make time for it. Now that I have that push, I am realizing it really doesn’t take a lot of time or effort to help someone in need. You just have to get up and do it.

We have been introduced to several families in North Carolina who have gone through the same situation, and with Hemophilia being so rare, these people have quickly become family to us. Anyone diagnosed, whether we've met them or not, is considered family. I would do anything to help my family, and this Collection Drive was my starting point.

I decided I wanted to do something to help our Hemophilia Community, so I reached out to Susan Cowell with Hemophilia of North Carolina (HNC). Susan collected lists of what was needed for three organizations: The Hemophilia Treatment Center at Chapel Hill, Camp Carefree, which hosts summer camps for children with bleeding disorders, and the Ted E Bear Clinic for children at the 2011 annual HNC meeting, which our son was able to participate in with the help of his daddy.

I started this drive off with our Sunday School class at Peace Church in Wilson, NC and then decided it'd be a good idea to create a page on Facebook, Hemophilia Collection Drive - In Honor of our Little Man. From there it exploded.

Once again, I was overwhelmed with support. Friends I haven’t been in contact with for years began emailing me wanting to donate, and co-workers at my mother’s school, Vinson-Bynum Elementary School in Wilson, NC, immediately stepped forward with bags of donations.

The drive went on for a little over a month. We ended up collecting enough to donate about 2-3 boxes to each group, as well as a cash donation for HNC!

I want to specifically thank our friends, family, Peace Church, and Vinson Bynum Elementary for their donations. Without the support of friends like you, and without God’s Hand in our lives, we would not be where we are today.

Even though our situation isn’t something we ever dreamed of, we know that it could be so much worse. I know how hard it has been on me particularly, and I know that there are others out there in much worse situations. Sometimes it takes being able to empathize with someone to actually feel the need and passion to help.

They always said that having a baby would change everything, and in our case, it absolutely did! We love you Miles Landon Davis! This one’s for you!

VWD Weekend Educational Program continued

skills and resources for those with VWD. Also included were breakout sessions where groups were able to share information and learn about topics specific to their needs. We also enjoyed some fun, social time with a scavenger hunt and a “Beach Party” dinner on Saturday evening. Our many thanks to the staff at the Wake Forest University Baptist Medical Center for their support of the program and excellent speakers. Presenters throughout the weekend included Mary Ann Knovich, MD, Karen Gerancher, MD, Anita Smith, NP, Keya Glover, LCSW, Sue Fletcher, PhD, Kim Walsh-Ebsworth, RN and Gina Raymond-Duncan. Our thanks to CSL Behring for making this opportunity available to our members.
The Blood Brotherhood program is continuing with our next event scheduled for June 16th in Concord on the topic of life insurance, long-term care and financial planning. Summer programs are scheduled for July 21st with the location to be determined and a conference call in August. We are also preparing for a comprehensive weekend retreat planned for September 16-18th in Atlantic Beach. We encourage all the men in North Carolina to get involved! For more information, please contact HNC at (800) 990-5557 or by email at info@hemophilia-nc.org.

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Research and Special Programs at HNC

Exciting things are happening at HNC! We have received funding to begin a new research project and expand one of our programs and are working on developing new programs and services for the newly diagnosed—but we need your help!

Health-Related Quality of Life Among Older Men with Hemophilia

HNC has received a 2-year grant from Bayer Health Care to investigate the impact of the aging process and disease status on quality of life for both the person with hemophilia and their designated partner if applicable. The results of this study will help establish a comprehensive best practice model to meet the needs of this important population. We will be asking men aged 50 and over with hemophilia who reside in the Region IV North (NC, SC, KY, TN) area to participate. Partners of participants will also be asked to join the study. Keep your eyes open for our recruitment literature! All participants will be compensated for their time.

New Families

In order to effectively serve the newly diagnosed, we are conducting 15-30 minute interviews with members to discuss the strengths and weaknesses of our programs and resources as well as ideas for new programs. Many thanks to those who have already agreed to participate but we need more input! Members’ expertise in navigating the health care system, choosing medical providers, and enhancing daily life is invaluable! We hope people in our community of all ages and diagnoses will agree to be interviewed. Help us help others!

SOAR Program

Our program for girls and women with bleeding disorders has received two grants! The first is from NHF to address issues related to intimacy and family planning. There will be three different locations (to be determined) for the dinners and two dinners will be offered at each location. The first set of dinners will focus on intimacy and self-esteem and the second set of dinners will focus on family planning and genetics. We will be asking women to commit to both dinners, all to be held in private rooms. Mothers of girls with a bleeding disorder will also be invited to attend.

The second grant is from CSL Behring to hold a retreat for current SOAR members. We will be redefining our strategic plans in order to increase impact and begin the development of a new one-to-one support program.

SOAR jewelry is now available online. For a suggested donation you will receive the jewelry that will not only help raise funds for SOAR but is also a great way to increase awareness to friends and co-workers! Please check the website - http://www.hemophilia-nc.org/SOAR/jewelry/orderform.html. Additional information about SOAR may be found by clicking on “for girls and women” under Programs and Services on HNC’s homepage.

For more information please contact: Sue Fletcher, PhD, sue.fletcher@hemophilia-nc.org.
Perfect Weather, Perfect Golf at the 7th Annual HNC Charity Golf Tournament

After a week of storms, the beautiful weather moved in right in time for the 7th Annual HNC Charity Golf Tournament that took place at The Preserve at Jordan Lake in Chapel Hill on April 29th. It was a terrific day of perfect weather, good company and all for a great cause! We would like to thank our Tournament Sponsor, Pfizer, for their generous title support of the event.

A team of terrific volunteers was very busy getting everyone checked in, distributing golf gift bags and providing instructions for the day’s events.

A field of golfers teed off at 12:00 noon with mulligan packages and their Beat the Pro chance tickets in hand. Our special guest player and golf pro, Perry Parker, was on hand for a swing analysis prior to the start of the tournament. As we gathered for the start he welcomed the crowd and shared some valuable insights into living with hemophilia and the benefits of supporting the local Chapters for the families and individuals. He then headed off to hole #17 to test the golfers skills at the ever fun, Beat the Pro contest. It is always a challenge to beat Perry and those few that were successful received a customized “I Beat the Pro” visor, a chance to win a special prize along with bragging rights for the year! We would like to thank our eagle sponsor, CSL Behring, for their continued generous support in sponsoring Perry’s attendance at the event again this year.

Lunch, which was provided by Rudy’s of Apex, and a delicious dinner was generously sponsored by Bayer Healthcare. Our thanks to Apex Wings who donated the chicken wings for the event. The non-alcoholic beverages that kept the golfers hydrated during the day were donated by the Women of the Moose at the Lexington Moose Lodge again this year and we are very grateful for their continued generosity and support of HNC.

After dinner, prizes were awarded for teams that placed 1st, 2nd & 3rd along with the Most Honest team. There was a 3-way tie for 1st place this year and thankfully the club determined the winners through careful calculations of their play on the course!

1st Place – The Barnes Team  
Matt Barnes, Mark Reyner, John Blake & Kip Harvey

2nd Place – The Smith Team  
Tommy Smith, Amir Ansari, Bobby Haynes & Kyle Rodino

3rd Place – The Zamboni Team  
Bill Zamboni, Pete Hufsey, Doug Piner & Alex Martin

Most Honest Team – Gilbert Russell, James Whitmire, Aaron Funderburk & Sharon Ingram

Closest to the Pin – Bill Kuhn

Longest Drive – Ford Perry

Longest Putt – Michael Armstrong, MD

Beat the Pro - Raffle Prize Winner – Don Edwards

During the tournament, there was a very special entrepreneur, Mr. Nick Carbone, who set up a lemonade stand on one of the holes again this year. After the tournament, Nick presented HNC with an amazing donation of $206 from the proceeds of the stand – thank you Nick and friends for your generous support!

As the golfers headed in from the course to the clubhouse for dinner, live entertainment was provided on the deck by the Resonance Acoustic Band. We thank them for being a part of our event and volunteering their time and talent to host a great evening.

A raffle followed the prize presentations where golfers purchased tickets to win some prizes including dinner certificates, NC symphony tickets, sports memorabilia, golf accessories and other great packages. Our thanks to the many donors who helped support our raffle with donations of many wonderful items!

This year we also offered Crowns for a Cure, a program to honor loved ones with crowns that were displayed in the clubhouse and on the greens. Our many thanks to all those who contributed to this program in honor, memory and celebration of someone special in their lives. Many crowns were on display with heartwarming messages.

The night concluded with a thank you from our President, Richard Atwood, to the players and contributors. HNC would like to thank all of our sponsors, gift bag donors, raffle donors, players, volunteers & committee members.

We gratefully acknowledge our sponsors and players for their generous support. Thank you!

Tournament Sponsor

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A Special Thanks to Our Golf Committee Members

Ben Barker ◆ Matt Barnes ◆ Sue Cowell
James Fullam ◆ Todd Holder ◆ Jim O’Malley

In-Kind Donations – Apex Wings; Matt & Chris Barnes; Chapel Hill Country Club; Durham Bulls; Georgina’s Pizzeria & Restaurant; Lexington Moose Lodge; NC State University – Football and Women’s Basketball; The Preserve at Jordan Lake; Rudy’s; Tee to Green; Twelve Oaks Golf Club; UNCG Athletics – Women’s Golf

Tee Signs – Ameriprise Financial Inc., Bio Rx LLC, Coram, Griffols, MedPro Rx & Talecris Biotherapeutics

Team Sponsors – Coram, David Draper, Kelly’s NC Erosion Control LLC, MedPro Rx, Tommy Smith, Twin Oaks Nursery & many other individuals who supported us with their participation in a team at the tournament.

9THE CONCENTRATE

Summer 2011
HNC Adult Retreat

**July 30-31, 2011**

**Holiday Inn &**

**US National Whitewater Center**

**Charlotte, NC**

We’ve just added our annual HNC Adult Retreat to the calendar for July 30-31st so save the dates on your calendar! Inalex Communications will return this year to present the Managing Your Stress: You have the POWER! This Inalex workshop was created especially for the bleeding disorder community and teaches, reliable and effective methods for identifying life stress and reducing it. Using relaxation and awareness techniques, participants learn tools to relax and reduce their struggles, frustrations and anxieties quickly, effectively and on demand. Also emphasized is the power of the human mind to create positive change through the process of creative thinking to help better manage your stress and your life. This workshop is both extraordinarily practical and empowering. The workshop will help to improve the problem solving and opportunity awareness of participants; leading to life changing insights and solution. Our facilitator for the program will be Ken Glickman. Ken is a well-known marketing professional and public speaker and has been a guest on NBC, CBS, ABC (The View with Barbara Walters), FOX, MSN, CNBC, CNN, the Family Channel and on radio shows throughout the country. He was heard for many years each week on over 500 radio stations as guest expert on Associated Press’s Business Minute. Ken Glickman graduated from Rutgers Law School with honors, and taught at the undergraduate school and Graduate Business School.

After the program, we will be visiting the US National Whitewater Center for dinner and activities. Information is available on the HNC website at www.hemophilia-nc.org or by calling (800) 990-5557.

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**2011 Friends of HNC**

We would like to acknowledge the following individuals who generously donated to HNC during this quarter of 2011. We extend a sincere thank you to our supporters… many of whom contributed several times during this period.

**Donors**

- Drew & Shannon Alexander
- Bruce & Pat Andrews
- Stephen & Amanda Barnes
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- Adam & Valerie Cook
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- Sharon Lawson
- Adam Miller
- National Hemophilia Foundation
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- Maria Schnaith-Ivan
- Bob & Heidi Traficanti
- Women of the Moose – Lexington Chapter
- Robert Worrel

**Donation Made In Honor of Lee Connelly**

Roland & Lynn Connelly

**Donations Made In Loving Memory of**

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  - Bob & Louane Frey

**Donation Made In Loving Memory of**

- Chris Connelly
  - Roland & Lynn Connelly

**Donations Made in Loving Memory of**

- Beryl Alexander
- David Alexander
- Clifford Bullard
- Martha Paris

**Donation Made in Honor of**

Lloyd Sanford Gravely, Jr.
Warren Jewett’s first major bleeds from hemophilia began in infancy. But by age 11, he was already showing the ingenuity and drive to invent medical devices that would make life easier for people. During his many lengthy childhood hospital stays he was allowed to fight boredom by observing laboratory technicians track blood clotting times and perform other tests thought to be essential to hemophilia. He was already dreaming up improvements to some of the processes by using spools and broken alarm clock mechanisms brought to him while in hospital by his father. His career was underway.

Like the others in this story, Warren endured all the challenges of living with hemophilia before biotherapies were available including severe internal and joint bleeds. Despite missing many months of school as a child, he eventually earned his doctorate in science. By the 1970s he was traveling as a consultant to the World Health Organization in New Guinea and other places far from his home in the US. He would carry clotting factor in his attaché case as he learned and taught others how to invent and build tools to help diagnose and treat people with serious and rare diseases.

Warren credits his father with teaching him to pause, look at problems from different angles, study them with a clear mind and know that somehow, somewhere a solution can always be found. When he went to work for the World Health Organization he was particularly proud of helping children whose lives were threatened by dysentery and typhoid. He developed a simple water purifying method that kept the children hydrated. In addition, when incubators for ailing newborns were too expensive for developing countries, Warren created an alternative to incubators using light bulbs for warmth and having only the most essential functions but costing less than a fortieth the price of commercial models.

One of Warren’s own inventions turned out to be the centerpiece of a memorable summer at Commonwealth Serum Laboratories (CSL)* in Parkville, Australia. Warren had first toured CSL headquarters in 1969 and remembers watching the staff milk poisonous snakes to capture venom that would be made into treatments for snakebites. He recalls, “The lifesaving aspect of it was most impressive and permeated the atmosphere at CSL.” Years later, in 1983, while spending the summer as a lecturer at the University of Melbourne, he returned to CSL to visit friends and check on a machine he had invented, one of which CSL had purchased. Warren invented and patented “acoustic conditioning” to improve blood plasma fractionation by inserting small vibrating paddles into the fermentation vessel in which fractionation took place. The invention was meant to substantially decrease the time necessary to yield lifesaving blood fractions. However, this particular machine’s locking mechanism had failed and the Scottish manufacturer of Warren’s invention refused to send a technician to Australia to fix it. So he and his teaching assistant rolled up their sleeves and, lacking proper parts, spent several weeks trying to repair it. Unfortunately, they did not succeed, although his invention was working well in other locations around the world. Warren used CSL hemophilia treatments during this extended stay and for many years thereafter. Reflecting today on his adventure that summer in Parkville, he said, “My friends at CSL and I were very disappointed about the machine, that was the only unhappy part of a special trip “down under”.

Today, Warren still copes with chronic joint problems and those associated with aging, but he remains an active and passionate inventor. He credits decades of improved biotherapies for giving him the independence to accomplish his dream of impacting lives through medical devices. He has, also, devoted many years in advocacy for the hemophilia community including serving as president of the National Hemophilia Foundation.

*NOTE: The Commonwealth Serum Laboratories, Limited (CSL) was established as an Australian government facility in 1916 to produce vaccines and sera for bites of poison reptiles (all snakes in Australia are poisonous). In 1950 CSL undertook, for the Red Cross, blood fractionation for Australia and New Zealand. The Commonwealth Serum Laboratories became a publicly traded company in 1994. Their subsequent merger with Behringwerke, a company founded by Emil von Behring in 1904, formed CSL Behring, creating one of the world’s leading biotherapeutics companies.
Gracias Richard, te deseamos lo mejor!

Este mes de Junio, Richard Atwood terminó sus tres años como Presidente de Hemophilia of North Carolina. Años atrás, Richard se retiró, después de 17 años, como Coordinador para el Centro de Tratamiento de Hemofilia de la Universidad de Wake Forest. Sin embargo continua escribiendo para distintas publicaciones acerca de la fascinante historia de la hemofilia y otros desordenes sanguíneos. Existen pocas personas que como él cuentan con un amplio conocimiento acerca de la hemofilia y su historia.

Definitivamente Hemophilia of North Carolina fue muy afortunada de tenerlo como Presidente. Richard ha liderado a HNC a través de su mas grande expansión y crecimiento. Los últimos cinco años de vida los ha dedicado con devoción y compromiso para todos los que formamos parte de HNC.

Algunos de los programas que se establecieron durante el liderazgo de Ricard y que han alcanzado excelentes resultados son: La Unión Latina (en español), el Grupo de Mujeres, El Grito de Adolescentes, el comienzo del Programa BloodBrotherhood (hombres) y muchos otros.

Thanks Richard, we wish you the best!!!

El Grupo de La Unión Latina se complae en presentar a LaTroya Hester como parte de nuestro Equipo de Trabajo. LaTroya ocupa el lugar de Manager para nuestro Programa, y ayudara a la planeación de eventos, elaboración de material educativo y de difusión, y apoyara los esfuerzos para expender nuestros servicios a través del Estado. El haber trabajado durante dos años como Coordinadora de Proyectos Especiales para la Asociación de Hemofilia del Estado de Georgia y realizado servicios de interpretación al español, le han dado una amplia experiencia en el desarrollo de programas, de la cual nuestro Grupo se vera beneficiado.

Como buena hija de militar, LaTroya ha vivido en muchos lugares, sin embargo considera la ciudad de Atlanta como su hogar. Recién casada, vino a vivir a Raleigh junto con su esposo, quien se encuentra trabajando para el estado de NC. LaTroya cuenta con estudios de licenciatura y maestría en Relaciones Publicas y Periodismo por parte de la Universidad de Georgia, y cuenta además con experiencia dentro de las áreas corporativa, académica y dentro de organizaciones sin fines de lucro. Después de atender al College trabajó como maestra en la ciudad de Cali, Colombia. Y antes de graduarse de la escuela, trabajó con La Asociación de Hemofilia de Georgia en la planeación de eventos para las familias de habla hispana. LaTroya actualmente se encuentra trabajando para la Organizacion “Communications Manager for Youth Empowered Solutions (YESI), la cual se orienta en adolescentes, brindándoles entrenamiento en Organizacion Comunitaria y la lucha para incrementar el acceso a los cuidados de salud, creando comunidades libres de tabaco, prevención de consumo de alcohol en menores de edad, y promoviendo la nutrición y el ejercicio.

Esta es una publicación para la Comunidad Latina de Hemofilia de Carolina del Norte y para todos aquellos interesados en crear un lazo de amistad e intercambio con esta Gran Familia Latina.

This is a publication for the entire Latino Community with Hemophilia living in North Carolina and for all those willing to establish a bond of friendship and exchange with this Great Latino Family.

Calendario de Reuniones
- Meeting Calendar -
Julio 09, 2011
Unión Latina de Hemofilia
La Fiesta Festival
Raleigh, NC
Sábado 8- Domingo 9 de Octubre
Retiro de Familias Latinas y Participación en el "Festival Latino Americano"
Charlotte, NC
Sábado 15 de Octubre
Caminata de Hemofilia
Lake Crabtree
Morrisville, NC

HNC tiene ahora un nuevo número de teléfono gratuito para el grupo HNC Unión Latina y los miembros que hablan español:
1-855-HNC-LATN (1-855-462-5286) (en español solamente / sin cargo)
O escribenos un email,
unión.latina@hemophilia-nc.org
Reunión Anual 2011

La Asociación de Hemofilia de Carolina del Norte celebró su reunión anual número 38 en Winston-Salem, NC. Al igual que cada año los participantes tuvieron la oportunidad de aprender información importante para mejorar su salud e informarse acerca de lo que está sucediendo en el mundo de la hemofilia. Todos disfrutaron de las agradables e interesantes presentaciones por parte de los presentadores que nos hablaron de distintos temas como: Los avances en el tratamiento para la hemofilia, La genética de Salud, La importancia de la Higiene Dental, y Entendiendo la Importancia de la Salud Mental. La reunión anual también ofreció actividades y sesiones de información para menores de edad y adolescentes. En La Clínica del Oso Ted (Ted-E-Bear Clinic) los menores se divertían mientras aprendían a realizar una infusión de Factor y se enseñaban a cuidar el Oso Ted. Los adolescentes que asistieron a la Reunión Anual tuvieron la oportunidad de discutir en grupo asuntos de interés de acuerdo a su edad y la grandiosa experiencia de visitar el alberge para mascotas Forsyth Humane Society, para finalizar con una alegre fiesta en la alberca del hotel donde se realizó la Reunión.

Recuerda estar al pendiente el próximo año para que asistas a la Reunión Anual de Hemophilia of North Carolina para que aprendas y disfrutes junto con otras familias relacionadas con algún desorden sanguíneo.

1, 2, 3... por ti!

¿Tu o alguien de tu familia tiene hemofilia, o algún otro desorden sanguíneo?

y además hablas español?

Te estamos buscando!

If you are a Friend, Social Worker, Physician, or just happened that you know someone from Latino America living with a bleeding disorder, tell them to contact us, we provide with a great educational and networking opportunities in their language: Spanish.

Help us now and give the opportunity to change a life!!!

Llámanos hoy!

Para nuevos lectores y miembros / For new readers and members

Misión: Hemofilia de Carolina del Norte es una organización no lucrativa, dedicada a mejorar la calidad de vida de personas afectadas por algún desorden sanguíneo, brindándoles apoyo en educación, promoción de estudios de investigación y promoviendo programas y servicios para esta comunidad.

Nuestra Visión: que todas las personas afectadas por algún desorden sanguíneo logran el desarrollo total, sin barreras o limitaciones, hasta que se encuentre una cura.

Consejo Rápido

El conocimiento es la clave para una vida saludable.

La información en español siempre está disponible en los centros de salud.

Te recomendamos que siempre que visites al médico preguntas por material de información en español acerca de tratamientos, medicamentos, vacunas, servicios médicos, asistencia financiera, etc.

Todos los folletos y otros materiales que recibas, colócalos en un mismo lugar en tu hogar, así comenzaras a construir tu biblioteca médica y de otros recursos en español.

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Llámanos hoy!

Latino Supplement – Supplemento Latino

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www.hemophilia-nc.org

THE CONCENTRATE

Summer 2011
HNC Welcomes New Board Members

Beginning July 1st, 2011 our newly elected board members will take their seats for the 2011-2013 term. Current members Scott Andrews and Warren Ingram will be returning for another 2-year term. We welcome our new members that include Steven Peretti (President), Wayne Cook Ill, Tiffany Holland, Amy Shair Miller, Maria Schnaith-Ivan and Ann Skinner. Information on our new board members as well as those currently serving is available on the HNC website at www.hemophilia-nc.org.

HNC Lauds Outgoing President Richard Atwood

At its annual meeting on May 14, 2011, Hemophilia of North Carolina recognized outgoing president Richard Atwood for his years of service to HNC and to the bleeding disorders community. Following are HNC Treasurer Kathy Register’s presentation remarks:

In June, Richard Atwood will be retiring after three years as President of HNC. Furthermore, he has asked for time off from serving on our Board of Directors – time off that he well deserves.

A few years ago, Richard retired from his day job after 17 years working at Wake Forest University as the Region IV North Coordinator for the Hemophilia Treatment Center Network. He continues to write for diverse publications about the fascinating history of hemophilia and bleeding disorders and their treatment. There are likely few people who are as knowledgeable about hemophilia history as Richard Atwood. And we in NC have been lucky. This hemophilia scholar has devoted the last five years of his life to HNC (two as Secretary, three as President) – to us – as a very able and committed president. He lead HNC through its largest (by far) expansion and growth, with a thoughtful, deliberate eye toward the prize he holds most dear – a prize which is stated in HNC’s vision statement: For all persons affected by bleeding disorders to achieve their full potential without barriers or limitations, until a cure is found.

Richard’s leadership style has been thorough, consistent, and above all, compassionate. It seems like not a board meeting went by in the last three years without Richard’s repeating to us that the most important thing we do is to provide assistance – financial, emotional, practical – to folks in the trenches – people with bleeding disorders and their families who find themselves in difficult straits – which is most of us at one time or another. Richard has comported himself with utmost integrity, yet with a dry wit which sometimes borders on the hysterically funny – this is a side of Richard that most of you don’t see.

Most important – under Richard’s leadership, we have gotten phenomenal results:

- Established a working relationship with Loreen Kelley and her company LA Kelley Communications which provides resources worldwide for people with bleeding disorders
- Our Charity Golf Tournament, and Hearts for Hemophilia Casino Night fundraisers and growing and expanding
- Annual Holiday Celebration kicks off the winter season with fun for families
- We’ve sponsored Internships for young people whose future is in healthcare advocacy
- Expanded staff
- We administer a nationwide Scholarship program for BioRx
- Hosted this year’s CSL Behring Junior National Championship
- Host education seminars on Insurance, health care, pain management, dental care … and more
- Established outreach groups for men, Spanish speaking people, women, teens, and families in our Blood Brotherhood, Latin Union, Women’s Group - SOAR, Teen Program, Family Retreat, and CEO Teen-Parent Retreat
- We’re about to embark on our Fourth Annual Hemophilia Walk – a very fun and successful fundraiser and public relations event
- Expanded mailing list/membership
- Award-winning Web presence
- Quarterly publication of The Concentrate, the HNC Newsletter
- We’ve re-established the HTCs’ Advisory Board for Bleeding Disorders
- Noticeable presence and impact with the NC Legislature and with the NC deligation of the US Congress in our Legislative and Washington Days advocacy programs
- Received recognition at the national level from : NHF, HFA, WHF

Richard – on behalf of the Board of Director and membership of Hemophilia of North Carolina, I’d like to thank you for all you’ve done. This acrylic crystal award which will bring a daily rainbow to your living room, as long as the sun is shining. It says: “To Richard Atwood, President, 2008-2011, with appreciation for your leadership and dedication to North Carolinians with bleeding disorders.”

I know that we can call on you in future years for your profound knowledge of bleeding disorders and their treatments, and everyone in this room can only hope you will be back soon as an active member of the Board of Directors.
Alex Nolan’s 4x800 meter relay team places 4th in the state of NC

Does Prophylaxis treatment matter? It does to Alex Nolan in the 10th Grade at Metrolina Christian Academy in Indian Trail, NC.

Alex attends Metrolina and much like other students he plays sports as an extracurricular activity. So why is this so special? Alex is living with Severe Hemophilia A. However, over three years ago thanks to a new insurance plan with an unlimited cap, he was able to begin prophylaxis treatment without the fear of running out of insurance money to buy factor. Today, he enjoys a very normal life and he is excelling in his new sport.

“We didn’t know how Alex’s body would respond to the constant pounding of running. After all joint bleeds are one of the biggest concerns we have to deal with. But, we supported Alex’s decision to go out for track. I simply told him if he started to have problems, he would have to stop. And, we had to infuse on a tight schedule,” says his father, Brad Nolan.

Alex was running on varsity 2nd team most of the season this past Spring at his new school, Metrolina Christian Academy, which competes in the North Carolina Independent School Athletic Association (NCISAA). Yet, as the season progressed his times improved. He ran at regionals with the first team and qualified to run at the state wide meet competing for top honors. The meet was held at UNC-Charlotte and was a banner day for the young relay team comprised of one 8th grade student, two Sophomores(including Alex) and only one Senior. They placed 4th in the state. So, I guess the competition better look out for them next year!

Hemophilia, even with his severe diagnosis, is not holding Alex back. He is an example of how successful improvements in treatment are improving the lives of patients with Hemophilia. Congratulations Alex!!!
Save The Date
Walk Kick-Off
Saturday, August 6th
4:00pm-6:00pm
Followed by ballgame at 7:05pm

Join us at the 2011 Hemophilia Walk Kick-Off Event on Saturday, August 6th at the Durham Bulls Athletic Park. We’ll enjoy some fun activities & food prior to the game. Get the latest information about the Walk and hear from current and past team captains who will share their expertise on how to build a successful walk team and raise funds. HNC staff and our Walk Event Manager will be on-hand to answer any questions.
Information and invitations will be available soon for our 2011 HNC Family Retreat. We are excited to be featuring a number of excellent speakers and program facilitators this year. The agenda for the adults will include the “Pulse on the Road” program that will be hosted by Laurie Kelley, President of LA Kelley Communications and long-time advocate for the community. This program discusses information about health care reform and insurance changes that impact families with bleeding disorders. We will also be hosting a teen track at the event this year, which will be facilitated by one of our favorites – Patrick “Big Dog” Torrey. Dr. Alexandra Boeving Allen of Wake Forest University will also be joining us to conduct a workshop on siblings of children with bleeding disorders. There will be a number of other programs and activities planned during the weekend.

The event will be open to those families who have children with bleeding disorders (recommended ages 4-17). HNC Research & Special Programs Coordinator, Dr. Sue Fletcher, has gained valuable insight into the needs of families through her phone interviews with new and long-time members. Through this information, we have put together an agenda that we feel will provide resources along with the opportunity to meet others in the community. We are looking for families that will be engaged and active during the educational sessions to attend the retreat.

Learn. Explore. Connect
With Our Hemophilia Community on Facebook.

Our Hemophilia Community

Find us on Facebook.com/OurHemophiliaCommunity

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Printed in USA/March 2011
Biosimilars, also known as follow-on biologics, are widely touted as a key ingredient to improving affordable access to biologic products, such as clotting factor concentrates. Historically, generic versions of chemical drugs, identical in safety, purity and effectiveness, have improved affordability compared to their brand-name drug counterparts. Manufacturers of generic drugs can market these products once the period of patent protection for the brand-name drug ends. A hot public policy topic is whether and how best comparable results can be achieved for biologics derived from living organisms as has been achieved through generic versions of chemical drugs.

In an era of government budget deficits and escalating healthcare costs, lower prices for biologics could greatly benefit both patients and those who are responsible for paying for them. With 75 per cent of the world’s population having limited or no access to treatment, pursuing strategies to improve access is an important objective. The cost savings resulting from the use of generic drugs is due to many factors, including the utilization of streamlined product development and regulatory requirements, such as reducing or eliminating requirements for clinical trials. Whether a streamlined regulatory approval process is appropriate for complex biologics is a central issue facing regulators today. While we would all welcome the arrival of new lower cost treatment, we should not be willing to accept an expedited regulatory approval process that places patient health and safety at risk.

Perhaps one answer to the debate is in the name used to describe the new product itself. The term biosimilars is used because the final product is fundamentally similar, but not identical, to the original. The complexity of large-molecule biological therapies and the intricacies of the manufacturing process make it impossible to exactly replicate a product. Unfortunately, even minute changes could have dramatic consequences for patients.

Today, the risk of inhibitor development has replaced pathogen risk as the most significant adverse event facing patients with severe hemophilia A. Quality of life for someone with an inhibitor is greatly reduced; treatment involves significantly higher costs and more intensive treatment regimens. It is vitally important to include an assessment of immunogenicity for biosimilar products, which is best achieved through appropriately designed clinical trials.

Clinical trials are essential in the regulatory approval process to ensure that biosimilars are safe and effective, including meeting an appropriate standard of immunogenicity. Skipping this important step could result in patients receiving treatment without adequate understanding of a product’s effect and potential adverse events. Rightly, in their guideline for biosimilars, the European Medicines Agency has insisted that plasma protein products and their recombinant alternatives must have the equivalent clinical dossier as the original innovator products.

Allowing a biosimilar to forgo human clinical trials makes it impossible to accurately claim that the follow-on product will have the same effectiveness and absence of immunogenic response as the reference product. This shortcut could result in therapies that promise to be effective, but are actually harmful to the patient.

Ensuring the development of safe, effective, and therapeutically equivalent biological products at a lower cost is a laudable goal, but it should not be achieved in a manner that risks the health and safety of patients. Biosimilars should be required to meet current safety and efficacy requirements with appropriate clinical studies that will ensure that the similarity of the biosimilar product in the laboratory with the innovator product is matched with acceptable responses in patients receiving the product. Until assurances can be made that patients will not respond adversely, any abbreviated regulatory approval process should take these issues into consideration and require follow-on biologics to demonstrate equivalent safety, quality, and efficacy.
Reviewing 20 Years of Gene Therapy Research at Penn

In April, the Daily Pennsylvanian, the University of Pennsylvania’s (Penn) independent student news organization, published an article providing an overview of the significant contributions made by gene therapy researchers. The piece recounts the challenges and successes encountered by Penn investigators during the past 20 years.

“You could fill up several issues of [The Daily Pennsylvanian] with all of the gene-therapy research Penn has been involved in,” said Susan Phillips, Chief of Staff, School of Medicine. Hemophilia, cancer, HIV, eye diseases and many other conditions have been targeted by Penn researchers, with the goal of developing genetically deliverable therapies or even cures. The actual delivery of genetic material to elicit the desired therapeutic response—for example, the production of clotting factor in hemophilia patients—continues to be one of the foremost challenges for researchers.

Many gene therapy trials conducted at Penn and elsewhere use adeno-associated viruses (AAVs, which do not cause disease) as delivery vehicles, or vectors, of healthy genes. Ideally, AAVs deliver the genetic material into living cells to sustain therapeutic effect without causing disease or triggering significant immune responses. However, finding the ideal vector for a specific disease can be tricky. “There’s a whole science around using the right virus vectors to try to eliminate tumor effects and eliminate other inflammatory effects or other negative consequences of the virus,” Glen Gaulton, professor of Pathology and Laboratory Medicine at Penn.

After the 1999 death of Jessie Gelsinger, an 18-year-old patient with a rare genetic disorder enrolled in a gene therapy trial at Penn, gene therapy trials nationwide came to a halt and were re-evaluated. Since then researchers have focused on developing optimal AAVs.

“I think what I learned from our early experience is that the technology that was available to us when we started … was not adequate,” said James Wilson, MD, PhD, the former head of Penn’s Institute for Human Gene Therapy, which dissolved after Gelsinger’s death. Wilson and his lab have worked on enhancing AAVs during the last 20 years. Their work generates approximately 2,000 AAVs yearly, which are distributed to more than 30 countries for use in laboratory and clinical trials.

In addition, investigators have acknowledged the importance of using animal models that more closely resemble humans biologically and genetically. “We have good animal models, which we didn’t really have back in the Gelsinger days,” said Arthur Caplan, PhD, director of Penn’s Center for Bioethics. “Much better animal work is being done prior to work in humans, which always is both prudent and safer.”

Katherine High, MD, a professor at Penn who conducted gene therapy clinical trials for hemophilia more than a decade ago, is now in the early stages of a new clinical trial. She says there have been “multiple examples of successful gene therapy that can be pointed to. Twenty years is pretty typical for a completely new class of therapeutics.”

“I think the future of gene therapy is actually strong,” said Caplan, citing its recent intersection with stem cell research. “It is very interesting to watch and very unexpected. I mean, nobody could have predicted it.”

Source: The Daily Pennsylvania, April 12, 2011
FDA Approves Two New HCV Drugs

In May 2011, the U.S. Food and Drug Administration (FDA) approved two new drugs to treat hepatitis C viral (HCV) infection. According to The New York Times, an estimated 3.2 million Americans have chronic HCV. Left untreated HCV can cause liver cancer, cirrhosis, end-stage liver disease and liver failure.

On May 13th the FDA approved Merck’s boceprevir under the brand name Victrelis™ and on May 23rd it approved Vertex Pharmaceutical’s telaprevir under the brand name Incivek™. Victrelis™ and Incivek™, the first new HCV therapies in 10 years, are protease inhibitors, a new class of drugs that thwarts the replication of viral enzymes.

The new drugs augment the current standard of treatment, which combines weekly injections of pegylated interferon (P-IFN) and a daily ribavirin (RBV) oral pill. Nearly 50% of patients do not respond to the current combination therapy alone. Even patients who do respond often experience debilitating side effects that can last the duration of the treatment—either 24 or 48 weeks. Interferon’s side effects include severe flulike symptoms, depression, fatigue and insomnia. Ribavirin can cause anemia, skin rash, fatigue and birth defects.

Both new therapies help boost the success of HCV treatment and protect the patient from the potentially severe and life-threatening impact of HCV symptoms. Success is measured by patients’ ability to “clear” the virus by achieving a sustained virological response (SVR) for at least six months after completing therapy. Though not technically a cure—HCV is often not completely eradicated from the liver—SVR is still the goal for clinicians. Lowering the viral load to undetectable levels in the bloodstream decreases the disease’s harmful effects.

In clinical trials in which Victrelis™ was used in combination with P-IFN/RBV, more than 60% of HCV patients achieved SVR vs. only 20-40% of patients on P-IFN/RBV alone. In clinical trials in which HCV patients received Incivek™ in combination with P-IFN/RBV, the SVR rate was 79%. This result signified an increase of as much as 45% when compared to patients receiving P-IFN/RBV alone. The promise of a shorter treatment cycle, 24 weeks for some patients on Incivek™ and 28 for some on Victrelis™ demonstrated in clinical trials, could also appeal to patients put off by the list of potential side effects.

One possible drawback of the new therapies is the number of daily pills that a patient must take to adhere to the treatment regimen. Victrelis™ is prescribed as 12 capsules a day--four pills, three times daily. RBV is prescribed as five or six pills daily or twice daily.

Another potential disadvantage of the new therapies is cost, which will undoubtedly balloon when the standard HCV regimen is combined with P-IFN/RBV. As it is, a cycle of P-IFN/RBV therapy could cost more than $30,000 according to The New York Times article published in July 010. A full round of therapy using Victrelis™ costs between $26,400 and $48,400; therapy with Incivek™ totals $49,200. Thus, patients on the combination therapy could see their HCV treatment costs more than double. Higher costs could become a challenge, particularly for those paying out-of-pocket. It should be noted that both Merck and Vertex offer patient assistance programs that provide free drugs to individuals who meet certain eligibility criteria, including income requirements. The companies may also assist with insurance co-payments.

“The availability of new therapies that significantly increase responses while potentially decreasing the overall duration of treatment is a major step forward in the battle against chronic hepatitis C infection,” said Edward Cox, MD, MPH, director, Office of Antimicrobial Products in FDA’s Center for Drug Evaluation and Research.

The approval of these drugs coincides with the issuing of a new recommendation concerning HCV therapies by the National Hemophilia Foundation’s (NHF) Medical and Scientific Advisory Council (MASAC). In it MASAC recommends patients with hemophilia and other bleeding disorders who choose these new therapies, particularly those already on anti-HIV treatment, undergo close monitoring. It also encourages providers and their patients to take into account possible safety considerations, including risk of bleeding, drug interactions and drug resistance.

A new law signed last month by Governor Bev Perdue (D) will lower state high-risk pool premiums by an average of 15 percent, while broadening eligibility and premium subsidy standards.

Over 6,500 new and renewing members of Inclusive Health will see premiums fall by up to 22 percent, depending on their plan option. H.B. 138 will also allow individuals to enroll in Inclusive Health prior to exhausting COBRA coverage, so long as their COBRA premiums exceed Inclusive Health premiums and they otherwise are eligible.

The new law also allows expands access to the Inclusive Health Assist premium subsidy program funded by a $2.1 million federal grant. Inclusive Health members who earn less than 300 percent of the federal poverty level can qualify for the subsidies between 20-43 percent of the premium, depending on income.

H.B. 138 will expand enrollment by allowing the state to supplement funding for the program up to the level of the federal grant. Only roughly 1,000 members are currently enrolled.

The changes all go into effect on July 1st. Inclusive Health was created in 2009; however enrollment was slow until premiums were initially lowered last year.

H.B. 138 does not affect the federal high-risk pool, also operated by Inclusive Health.

Health Benefit Exchange Bill Passed In N.C. House

On May 25th HB 115, legislation establishing a health benefit exchange in North Carolina passed the NC House of Representatives with a 83-34 vote. Those in favor of the bill stated that passing HB 115 was a necessary step in maintaining the integrity of the insurance system in North Carolina. Proponents stated that the bill may not be perfect but that it is a “skeleton” and foundation for a better bill to be composed. The bill is currently on its way to the NC Senate where it awaits further action.

During the floor debate, amendments passed unanimously that made the bill more “consumer friendly”. One such amendment that was adopted was to provide for “conflict of interest rules and recusal procedures”. In essence, these rules and procedures should require anyone with a conflict of interest involved in manners of the board to recuse themselves. Currently, there are two positions on the board reserved for insurers; seemingly this would mean that these Board members would have to remove themselves from all board procedures when representing their own industry.

Consumer advocate groups, including Hemophilia of North Carolina, have participated in committee hearings and continue to monitor the progress of the bill to ensure that it meets it gives consumers more control, quality choices and better protections when buying health insurance.

For more information on the HNC Advocacy Committee and their work in representing the bleeding disorders community in NC, please contact Leonard Poe, HNC VP Advocacy Chair at leonard.poe@hemophilia-nc.org.
The Hemophilia of North Carolina organization gratefully accepts donations in support of its programs and services. Your dollars directly impact the bleeding disorder community by providing education to parents, scholarship opportunities and financial assistance for families in crisis.

For new members, please complete the following application form.

For existing members, we are currently updating our database and would like to make sure we have the most current contact information for you. Please take a moment to fill in the application and check “currently active member – information update”.

Please mail completed application to:
Hemophilia of North Carolina
260 Town Hall Dr., Suite A
Morrisville, NC 27560

Please make checks payable to Hemophilia of North Carolina. Your donation may be tax deductible to the extent allowed by law. We are pleased to send you a receipt for your donation.

2011-2012 HNC Calendar of Events
We are continuing to plan events for 2011. We would like to share some of these dates in advance so that you can mark your calendars. Please check our website for a full schedule of additional programs and dates.

HNC Adult Retreat - July 30-31, 2011
Kick Off Event - Hemophilia Walk - August 6, 2011 HNC
Family & Teen Retreat – August 26-28, 2011
Blood Brotherhood Retreat – September 16-18, 2011
Latin Union Educational Weekend – October 8-9, 2011
Hemophilia Walk – October 15, 2011
NHF Annual Meeting - November 10-12, 2011
HNC Holiday Celebration - December 3, 2011
HNC Casino Night - January 21, 2012

The best resource for the latest information, registration and event updates is to visit the web site at www.hemophilia-nc.org.

Membership Application

Name: ____________________________________________________________
Address: ___________________________________________________________________
City: __________________________ State: __________ Zip: ________________
Home Phone: __________________________ Cell Phone: ______________________
Email: ____________________________________________________________

Check One

_____ I am a person with a bleeding disorder.
Type _____ (ie. VII, IX, VWD)

_____ I am a family member of a person with a bleeding disorder.
Relationship __________________________
Type of bleeding disorder __________________________

_____ I am a medical professional.
_____ I am an interested person.
_____ I am a currently active member – information update.
SAVE THE DATE
Saturday, October 15th, 2011
Lake Crabtree County Park • Morrisville, NC

Every step makes a difference!

www.hemophilia.org/walk

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.