Santa Came to Town!

On December 1st ninety-two of our community members joined together to attend the Hemophilia of North Carolina’s 2007 Holiday Celebration in Greensboro!

During the first hour the adults had time to relax, enjoy some hors d’oeuvres and visit with friends. The kids were busy making some fun crafts including a holiday photo frame, bookmarks, color-your-own 2008 calendars and getting ‘inked’ with holiday tattoos! They also enjoyed a snowman dartboard game (not real darts!) and showed the group their fancy footwork on the dance floor.

In an effort to work up an appetite for lunch, two limbo contests were held – one for the kids and one for the adults. ‘How low can we go’ was an easy task for the kids who managed to get under the bar at any height! The adults, well that’s a different story but we have to give them a valiant applause for their wonderful effort. Tyronna Hooker limboed her way to first place with some pretty impressive moves!

After lunch, our keynote speaker, Tim Grams, shared some insights with the group about his personal journey. Tim is a Gettin’ In The Game athlete from CSL Behring and lives in Littleton, Colorado. He is severe factor VIII deficient. Tim has earned numerous awards as a championship swimmer which include three school records while attending the University of Denver. In addition, Tim was a top-three finisher at the Pacific Collegiate Swimming Conference for three years.

Taking time out of their busy schedule, Santa and Mrs. Claus stopped by for a visit! Each of the kids took time to share their wish lists with Santa and everyone received a special holiday gift. Our special thanks to Santa and Mrs. Claus (alias: Terry & Becky Crotts) for making this such a memorable moment for the children!

All of the kids then received an extra treat of cars & trucks that were generously donated to us by Mr. & Mrs. Jerry Williamson. Jerry’s sister, Jean Poplin and Cheryl Hurst were on hand to make the smooth distribution!

We concluded the event with a special presentation to Mr. Ed Wilson for his years of dedication to HNC. Ed served in various positions on the Board of Directors, including President, for many years until leaving in June 2007. HNC would like to thank Ed for his years of service to the organization!

Although the kids left with arms full of goodies, each family was also given a ‘goodie bag’ full of the latest books and information along with some sweet treats in a very handy shopping bag compliments of the Umstead Hotel and Spa! Our thanks to all of the companies and individuals who donated items for the gift bags.

Our 2007 Holiday Celebration was made available to us through a generous contribution by:

CSL Behring
Biotherapies for Life™

We hope everyone had a wonderful holiday season!

The HNC Board of Directors

Inside
Chapter News & Events
Resource Center
On the Health Front
On the National & Legislative Front
Save The Date
Couples Retreat
March 1 & 2
Embassy Suites
Concord, NC
NHF Washington Days
March 5-7
Washington, DC
Victory Junction Gang Camp
Family Weekend
March 7-9
Randleman, NC
The Magic of Jim Passé
March 29
Cary Academy
Cary, NC
HNC Annual Golf Tournament
April 25
The Preserve at Jordan Lake
Chapel Hill, NC
HFA Educational Symposium
May 1-4
Little Rock, AK
HNC Annual Meeting
May 31
Lawrence Joel Veteran Memorial Coliseum Complex
Winston-Salem, NC
HNC Legislative Day
June 10
Raleigh, NC

PO Box 70
Cary, NC 27512-0070
(800) 990-5557
info@hemophilia-nc.org
www.hemophilia-nc.org
Hemophilia of North Carolina is a non-profit organization whose goal is to assist, involve and educate persons affected by bleeding disorders and to educate the medical community and the public about bleeding disorders.

Contact Numbers
Hemophilia of North Carolina
(800) 990-5557
Executive Director, Sue Cowell
(919) 460-1536
National Hemophilia Foundation Office
(800) 42-HANDI
www.hemophilia.org
Hemophilia Federation of America
(800) 230-9797
www.hemophilafed.org
Community Health Charities of NC
(919) 554-3272(Collect)
www.healthcharities.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.

Hemophilia Treatment Centers & Medical Resources

**East Carolina University**
Brody School of Medicine
PCMH 288 West
Greenville, NC 27858-4354
Phone: (252) 744-4676
Fax: (252) 744-8199

**University of North Carolina at Chapel Hill**
School of Medicine
W1022 Old Clinic Building
CB # 7016
Chapel Hill, NC 27599-7016
Phone: (919) 966-4736
Fax: (919) 962-8224

**Wake Forest University School of Medicine**
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

**Duke University Medical Center**
Hemostasis and Thrombosis Center
DUMC Box 3422
Durham NC 27710
Phone: (919) 684-5350
http://htc.medicine.duke.edu

**University of North Carolina**
Thrombophilia Program
CB 7035 Rm 932,
Mary Ellen Jones Building
Chapel Hill, NC 27599
Phone: (919) 966-3311

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

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

**The Factor Foundation of America**
1-866-843-3362
www.factorfoundation.org

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

**HIV/HCV Newsletter**
Hemophilia Association of the Capital Area
www.hacacares.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
From the Executive Director

I recently attended the National Hemophilia Foundation Annual Meeting in Orlando, FL. It was an invaluable experience and an opportunity to meet many new people, hear the latest information about what is happening in the community and share ideas with fellow chapters from across the country. The one message consistently shared amongst the attendees was that change is coming and much quicker than we think! There were a number of topics, including insurance and legislative action, that were discussed and the choices that will be impacted. What this means is that we need to stay ahead of the curve and be aware of what is happening in the community. As Val Bias, Managing Consultant for the Bias Group, so poignantly stated “we know what happens when we do nothing”.

It is inspiring to know that we have a number of leaders in the bleeding disorders community who are actively staying on top of the issues and a host of resources available to take part in the changes that are coming. I encourage everyone to stay informed, become as educated as possible on the latest information and get involved because you can make a difference!

Sincerely,

Sue Cowell
HNC Executive Director

¿Habla Usted Español?

Are you bi-lingual and do you want to help support the Hispanic community of HNC? We are in need of your assistance as a liaison for our organization to help translate and communicate our programs & services so that everyone has an opportunity to take advantage of what is offered. If you are interested, please contact Sue Cowell at (800) 990-5557 or by email at info@hemophilia-nc.org. Thank you!

Couples Retreat Weekend
March 1st & 2nd, Embassy Suites, Concord, NC

HNC invites you to a couples-only weekend retreat designed just for you, with plenty of time for relaxing with friends both old and new. The weekend’s highlight will be a special relationship-coaching workshop facilitated by Jack Kakolewski, a certified marriage and family therapist. This is a workshop developed specifically for couples with a bleeding disorder or who have a child with one. There is no charge for this weekend retreat—you’re hotel room for Saturday night and all meals are covered.

For more info, please contact Sue Cowell at (800) 990-5557 or by email at info@hemophilia-nc.org. Registration deadline is February 15th.

This limited one-time offer lets patients experience the benefits of Kogenate® FS with BIO-SET®...for free.

For enrollment information:
Call 1-800-288-8374
Visit http://www.kogenatefs.com

For more information, please contact your local Bayer HealthCare Account Executive, Spencer Miller, at (803) 319-7114, or by e-mail at spencer.miller.b@bayer.com.

Please consult with your healthcare provider to determine if Kogenate® FS is appropriate for you.

*Please note that patients previously enrolled in the Kogenate® FS Free Trial program and patients currently receiving Kogenate® FS therapy are not eligible to participate in the program. In accordance with government statutes, patients covered in whole or in part by federal or state healthcare programs, such as Medicare and Medicaid, cannot participate.

* Enrollment ends 12/31/07.

BAYER, the Bayer Cross, and Kogenate are trademarks of Bayer. BIO-SET is a trademark of Bioniche SAS.

©2007 Bayer HealthCare LLC. All rights reserved. Printed in USA. NPT. 0927Y

Bayer HealthCare

THE CONCENTRATE

Winter 2008
HNC is excited to announce two shows that will be held on Saturday, March 29th at the Cary Academy in Cary, NC.

The Magic of Jim Passé show is filled with tons of exciting magic: illusions, impossible disappearances, classic parlor magic, mind reading and card tricks (that can be viewed by larger audiences via our projection television system) are all performed with a flair seldom seen in stage magic.

And, of course, there is always lots of good, clean humor and fun for everyone.

Tickets will be on sale soon and will include “family packs” so you can bring the whole gang!

Meet One of Our New Board Members:

Kathy Register

Kathy Register is an army brat who has lived in Durham, North Carolina for 41 of her 55 years. She has been married for 34 years to Charles Register, who has severe classical hemophilia. She and Charles met in 1970 as undergraduates at Duke University. Both are flautists, and Charles had a 27-year career as an administrator at Duke. They have two grown sons and their first grandchild, a girl, was born last June in Anchorage, Alaska. Kathy and Charles have served off and on as HNC board members and officers, including president, since its founding over 30 years ago. Kathy just completed two years as president of Community Health Charities of North Carolina, a federation of the nation’s top health charities. In addition to her service on the HNC board, she continues to serve on the CHC board as an at-large member.

About the photo: While visiting family in Alaska, Kathy found this near her son’s home in Eagle River.
"Aces for Action" Charity Tennis Tournament

October 20, 2007

We couldn’t have asked for better weather for our 1st Annual “Aces for Action” Charity Tennis Tournament for Hemophilia of North Carolina! The sky was clear blue and crisp fall temperatures welcomed us to the beautiful Cary Tennis Park on Saturday, October 20th for our tournament.

Participants came from far and wide to join in the event including from Michigan, the eastern part the state and the Charlotte area! Each person was checked in and greeted with a gift bag filled with lots of goodies including our event visor. Our teams consisted of 28 players making up 14 teams and covering 7 courts.

Our day started out with registration of the participants along with a delicious power breakfast that was donated by Whole Foods of Cary. Everyone then hit the courts for some warm up followed by the official start at 9:30am. Although all the women played hard, it wasn’t without some good laughs and lot’s of fun! In the end, we had our winners for each category. Our congratulations to Trudie Laches & Olga Tiselsky (winners of the 2.5/3.0 division), Karen Heinemann & Jean Domanico (winners of the 3.5 division) and Maggie Deutsch & Cheryl Bock (winners in the 4.0 division).

After some great tennis, our group enjoyed their box lunches that were donated by Bear Rock Café and included a tasty sandwich, chips & a cookie! Raffle winners were then announced and prizes included gift certificates from local restaurants and Tennis Warehouse. We also featured a beautiful shadow box with the history of the tennis racquet that was generously donated by the Brill Family and a Prince AirO Racquet with a bag of balls donated by the Barnes Family. Tracy Kelly needed an extra car to get all her prizes home!

The tournament ran smoothly with the help of our team of volunteers that included Rossa Ward (HHS), Sharon Ingram & her daughters, Charlene Cowell and Kathy Register. They worked tirelessly at icing down the drinks, distributing the bags, selling raffle tickets and scoring the event.

We would like to thank our “Aces for Action” Committee who worked hard to put the event together. The committee included Kathy Register, Sharon Ingram, Sue Cowell, Terry Lamb and LaQuenta Caldwell.

We gratefully acknowledge our presenting sponsor, Bayer Healthcare, whose generous contribution made this event possible.
Dads in Action!

On Thursday, November 8th our Dads got together at Logan’s Roadhouse for a casual dinner and good conversation. The event was directed by Matt Igelman, HNC’s North Carolina representative for the Hemophilia Federation of America (HFA). The Dads In Action program was created by HFA in 2003 as a proactive response to feedback received from fathers within the bleeding disorders community. It provides support, education and interaction to fathers who want to be involved. For more information on the program, visit the HFA website (Dads In Action) www.hemophiliafed.org.

This program was made available to HNC through a grant from the Hemophilia Federation of America and Baxter.

We would love to expand our Dads In Action program to other regions. If anyone is interested in helping to organize one in your area, please contact Sue Cowell, Executive Director. It’s a great chance to get together, relax and enjoy a great meal!

Hemophilia of North Carolina’s 2007 Volunteer of the Year

As you know, it takes an army of volunteers to effectively operate a non-profit organization. It is the time and talents of those volunteers that are the lifeblood of any good operation!

It is with that in mind that Hemophilia of North Carolina recognizes the extraordinary efforts of one of our members – Mr. Charles Register. We are honored to recognize his contributions and select him as our 2007 Volunteer of the Year.

Without his endless hours of guidance and expertise, HNC would not look as good as it does – literally! Charles has donated many hours of his time and lent his skills in a variety of areas including web site design, logo and publications design, and computer guidance for us “not-so-techy” individuals!

HNC has made great strides over the past year in the programs and services we offer. This is due, in large part, to Charles’ contributions and tireless efforts in meeting our goal to assist the bleeding disorders community in North Carolina.

Thank you Charles and congratulations to a well deserved 2007 Volunteer of the Year!

HNC heartily thanks all of the individuals who have given generously of their time to volunteer for our programs & services this year.

Contact Your Regional Care Coordinators:

Matt Igelman 919-699-1972 migelman@matrixhealthgroup.com
Matthew Compton 919-931-1761 mcompton@matrixhealthgroup.com
Donna Compton 919-270-8382 dcompton@matrixhealthgroup.com

Visit Our Website! www.matrixhealthgroup.com
2007 Regional Junior National Championship Winner

Written by: Cheryl Hurst (aka – Branson’s mom), 11/26/07

On October 6, 2007, Branson and I traveled from Salisbury, NC to the Virginia Crossings Resort in Richmond, VA for the regional Junior National Championship sponsored by CSL Behring. This is a baseball and golf skills clinic and competition for youngsters with bleeding disorders under the age of 18. Branson has played baseball since about age 3, so we opted for the baseball competition instead of golf. There were about 20 boys (and a few girls) in the competition and it was tough. Participants were judged using a point system on hitting, pitching, and catching. When the competition was over, the kids took on the parents and volunteers in a “real” game of baseball. Somehow, the kids managed to pull out a win.

After the game, we went back to the resort for the awards ceremony. Inspiring and heartfelt speeches were given by “Gettin’ in the Game” athletes, Perry Parker and Peter Dyson. It was obvious how much they truly care about the kids and how much this program means to them. All of the kids were encouraged to continue “Gettin’ in the Game” and were awarded a medal for their participation.

To my surprise, Branson was awarded first place in the baseball division. He won a huge trophy and a trip to the National Hemophilia Foundation meeting in Orlando, Florida, October 30-November 4. In Orlando, we had a blast! CSL Behring hosted a Halloween party, costume contest, and a talent show at the Radisson where the national winner was announced. Later in the week, we went to Wonder Works®, Sea World®, and Universal Studios®. Somehow, we still managed to attend a few meetings and visit the exhibit hall. We met new friends and reconnected with old friends from years past. The opportunity to hang out with our hemophilia family, even for a few short days, was a great experience and memory that will last a lifetime. Thanks, CSL Behring for continuing to promote this program.
More Scholarship Opportunities!
In our continuing effort to provide you with scholarship opportunities and information, we have listed some of the scholarships available and the companies that provide them. This list is not exhaustive and we recommend visiting the NHF and HFA websites for additional resources.

Project Red Flag Scholarships for Women
The National Hemophilia Foundation’s (NHF) Project Red Flag is offering two college scholarships to female students pursuing post-high school studies. Candidates for the Project Red Flag Academic Scholarships for Women with Bleeding Disorders must have been diagnosed with a bleeding disorder, such as von Willebrand disease, or be a hemophilia carrier. Ideal candidates are those who have had some community service experience, particularly within the bleeding disorders community. The scholarship deadline is May 31, 2008.

The scholarships were inspired by two young women who embody the spirit of giving back to the community—Lindsey Hanson and Josephine Droney.

To download an application, visit: http://www.projectredflag.org/source/PRF_scholarship.doc

Factor Support Network
Mike Hylton and Ron Niederman Memorial Scholarship - Five $1000 scholarships for MEN with Hemophilia or von Willebrand Disease and their immediate family members

Millic Gonzalez Memorial Scholarship - Two $1000 scholarships for WOMEN with Hemophilia or von Willebrand Disease.

The scholarships can be viewed and downloaded from their website www.factorsupport.com. All forms must be completed and emailed or post-marked by April 30th. For information contact toll free: 877- 376-4968

Factor Foundation of America
Dave Madeiros Scholarship Program
Continued Education for individuals with a high school degree, or the equivalent of, as well as Creative Arts Scholarships to assist children from ages 5 to 17. Applications for the annual scholarships will be made available in early 2008. For information visit their website at www.factorfoundation.org or call (561) 981-8814.

Hemophilia Health Services offers two different scholarships

HHS Tarbell Scholarship: HHS annually awards multiple scholarships starting at $1,500 for a full academic year. Application deadline each year is May 1.

For the HHS Memorial Scholarship:
Eligible to apply are U.S. citizens with hemophilia (factor VIII or IX), von Willebrand disease, factor I, factor II, factor V, factor VII, factor X, factor XI and factor XIII. Applicants must be high school seniors, college freshmen, sophomores, and juniors. Also eligible to apply are college seniors who are planning to attend graduate school, or students who are already enrolled in graduate school.

For the Scott Tarbell Scholarship:
Eligible to apply are U.S. citizens with hemophilia A or B severe. Students must be majoring or seeking a degree or certification in Computer Science and/or Math. Applicants must be high school seniors, high school graduates (or the equivalent/GED), college freshmen, sophomores, or junior.

Applications can apply at https://www.scholarshipadministrators.net Access key: HEMO or by calling Sally Johnson, Special Programs Coordinator, at 615-850-5175.

Bayer HealthCare Offers Summer Internship for College Students
College students can develop leadership skills during an eight-week paid internship program sponsored by Bayer HealthCare and held at their campus in Wayne, New Jersey. The internship runs from Monday, June 16-Friday, August 15, 2008. Now in its third year, the Hemophilia Leadership Development Program internship acquaints students with the production and promotion of recombinant factor VIII product. Students tour the manufacturing facility in Berkeley, CA, review state and federal legislative activities, and take classes on leadership, reimbursement and marketing. The internship culminates with an independent project.

Candidates for the internship are current college sophomores, juniors or seniors who have been touched by hemophilia and can demonstrate a commitment to and interest in future leadership in the hemophilia community. Applications are being taken now through Thursday, January 31, 2008, at 11:59 PM ET. For more information, call: 888.606.3780 or visit Bayer’s Kogenate® FS Web site: www.kogenatefs.com.

Note: An incorrect email appeared in the last edition for the BioRx Educational Scholarships. The correct email for information is cbarnes@biorx.net.

Applications and information on all scholarship programs are available through HNC at 1-800-990-5557 or by email at info@hemophilia-nc.org.
2007 Friends of HNC

We would like to acknowledge the following individuals who generously donated to HNC through December 2007. We extend a sincere thank you to our supporters… many of whom contributed several times during this period.

Donations Made In Loving Memory of Janet H. McDonald

Mr. & Mrs. Otis Baty
Ms. Taliaferro Beckett
Ms. Peggie Boone
Mr. Paul Bunce
Mr. & Mrs. Wadis Butler
Mr. & Mrs. Sam Byers
Mr. & Mrs. Billy Joe Davis
Ms. Janis Dempster
Ms. Barbara Diab
Mr. & Mrs. Paul Elliott
Mr. & Mrs. David Floyd
Ms. Mavis Godwin
Ms. Rebecca Gupton
Mr. & Mrs. John Hughes
Mr. & Mrs. Edward Hughes
Independent Builders Supply Assoc.
Mr. & Mrs. Robert Joneth
Mr. & Mrs. Sonny Lacy
Mr. & Mrs. Danny Queen
Mr. & Mrs. Joseph Rossignol
Mr. & Mrs. William Roumillat
Ms. Deanna Saylor
Ms. Sharon Simmons
Mr. & Mrs. O. Temple Sloan
Mr. & Mrs. C. Hamilton Sloan
Ms. Elizabeth Smith
The Simmons Family
The Sykes Family
WakeMed Acute Rehabilitation Dept.
Mr. & Mrs. Joe Walker
Mr. & Mrs. Woodrow Wells
Mr. & Mrs. Johnny Wood
Anonymous

Donations Made In Honor of Heather & Dalton Dawes

Mr. & Mrs. Horace Uffelman

Additional Donors

Ms. Jeannie Adair
Ms. Elaine Bardes
Mr. & Mrs. Matt Barnes
Mr. Randy Bostian
Mr. & Mrs. Jeffrey Brill
Ms. Kathy Clark
Ms. Nancy Combs
Mr. & Mrs. Charles Cowell
Dr. Margaret Deutsch
Ms. Jean Domanico
Mr. & Mrs. Russ Griffith
Mr. & Mrs. W. Allen Heafner
Ms. Jean Heinemann
Ms. Joyce Helton
Mr. Eric Hill
Mr. Jim Jarrett
Ms. Judy Jessop
Dr. & Mrs. Warren Jewett
Ms. Tracy Kelly
Ms. Marcy McKaig
Mrs. Joe Plemmons
Mr. Leonard Poe
Mr. & Mrs. Monroe Poplin
Mr. & Mrs. Charles Register
Ms. Jeannie Rinehart
Mr. & Mrs. John Sakakeeny
Ms. Nancy Smoak
Mr. & Mrs. Phillip Willis
Mr. & Mrs. Jerry Williamson

Thank you to our 2007 Honor Roll of Corporate Sponsors

DIAMOND ($15,000 OR MORE)
Novo Nordisk

PLATINUM ($10,000 - $14,999)
Baxter
MedPro Rx

GOLD ($5,000 - $9,999)
Bayer
BioRx
CSL Behring
Matrix Health
Wyeth

SILVER ($1,000 - $4,999)
Caremark
Critical Care Systems
Factor Health Alliance
Hemophilia Health Services

BRONZE ($500-$999)
Atlantic Health Resources
Grifols
HRF, Inc.
NuFactor

FRIENDS OF THE COMMUNITY
(Up to $499)
Hemophilia First
**Let the Games Begin!** HNC Casino Night

Hemophilia of North Carolina (HNC) hosted our first “Hearts for Hemophilia” Casino Night event on Friday, November 16th, 2007 at the magnificent Museum of Natural Sciences in downtown Raleigh.

Guests were greeted at the door with a warm welcome on a chilly night and given $10,000 in ‘funny money’ play chips to test their luck at the tables. Delicious hor d’ouevres were served along with an open bar of beer & wine. The group was entertained with music by our DJ and an open dance floor throughout the evening. Food was then switched over to dinner where a carving station of Maple Glazed breast of Turkey and Tenderloin of beef was beautifully presented.

We had the whole first floor of the museum to ourselves where guests were able to dine amongst the exhibits in the North Carolina Natural Treasures area and then move on to the two story high Coastal Carolina section for an exciting night of gaming.

Shouts and cheers were heard throughout the night from our winners who wagered on Blackjack, Roulette, Craps and Poker! Our dealers were more than patient with those of us who needed some instruction at any of the seven tables that were offered.

Once the tables were closed, a surprising number of winners cashed in their chips for raffle tickets. A 52 Pick Up 50/50 winner was selected and prizes were drawn for the raffle. HNC then took the opportunity to recognize a very dedicated member of the organization. Mr. Charles Register was presented with the 2007 Volunteer of the Year award.

Our evening meal was capped off with an offering of delectable desserts including a Bananas Foster station that everyone enjoyed.

Mr. Terry Lamb, our professional auctioneer for the evening, then took over the microphone for an exciting live auction! He rallied the crowd to bid on a variety of items including a week’s vacation in the Outer Banks donated by John & Peggy Chadwick, a beautiful pearl necklace by Pearl Paradise, sports memorabilia such as an autographed hockey stick from the Carolina Hurricanes, an autographed basketball and game passes from Coach Kay Yow, an autographed Duke Football team poster and signed cap by Coach Ted Roof, an autographed copy of Five Point Play by Coach Mike Krzyzewski and a custom DVD montage package by Digital Keepsakes by Karen, LLC. Pity those who were just scratching their nose!

The night concluded with thanks to our sponsors and guests. Each attendee received a chocolate favor in the design of a playing card as a thank you for being our guest and participating in this fun event!

HNC applauds the efforts of our “Hearts for Hemophilia” Casino Night 2007 Committee for all their hard work in planning the evening’s activities. Members of the committee are Andrea Brill, Sue Cowell, Terry Lamb & Pat Whitley!

We are especially grateful to the many individuals, organizations and companies for their generous support of our event:

- **King of Hearts**
  - Baxter

- **Queen of Hearts**
  - Novo Nordisk

- **Jack of Hearts**
  - Amy Shair Realtor
  - Caremark
  - CSL Behring
  - MedPro Rx, Inc.

- **Casino Table Sponsors**
  - FactorHealth Management, LLC
  - Hemophilia Health Services

- **Guest Table Sponsor**
  - Matrix Health

Victory Junction Gang Camp is a wonderful opportunity for children & families with Hemophilia and related disorders. The camp is located in Randleman, NC, just south of Greensboro. The camp offers an atmosphere of fun and support in a safe environment.

Victory Junction Gang Camp for Hemophilia/JRA Participants is designed for boys and girls age 10-17 affected by Hemophilia and related disorders. The July 27-31, 2008 session is a peer camp opportunity. Camp attendance is limited to 64 participants, ages 10-17. Camp is staffed by physicians, nurses and other volunteers who provide necessary medical support and emotional encouragement. The camp is held at Camp Don-Lee, located on the Neuse River near Arapahoe, NC. Goals in providing this camping experience include: building self-confidence and independence, helping理解 blood disorder, and providing specialized support and educational sessions. Camp visits are funded by donations; participation is free to all children. Applications for admission to Victory Junction Gang Camp are available at www.victoryjunction.org or call 877-854-2267.

Victory Junction Gang Camp is hosting their 19th Annual Family & Summer Camp Information – March 7-9. This weekend is full of fun and activities, with Hemophilia and other related disorders. The weekend is designed to provide peer support for children and their families.

Victory Junction Gang Camp is hosting their 19th Annual Family & Summer Camp Information – March 7th – 9th. The camp is held at Camp Don-Lee, located on the Neuse River near Arapahoe, NC. Goals in providing this camping experience include: building self-confidence and independence, helping understand the blood disorder, and providing specialized support and educational sessions. Camp visits are funded by donations; participation is free to all children. Applications for admission to Victory Junction Gang Camp are available at www.victoryjunction.org or call 877-854-2267. For more information visit them at www.victoryjunction.org or call 877-854-2267.

Victory Junction Gang Camp is hosting their 19th Annual Family & Summer Camp Information – March 7th – 9th. The camp is held at Camp Don-Lee, located on the Neuse River near Arapahoe, NC. Goals in providing this camping experience include: building self-confidence and independence, helping understand the blood disorder, and providing specialized support and educational sessions. Camp visits are funded by donations; participation is free to all children. Applications for admission to Victory Junction Gang Camp are available at www.victoryjunction.org or call 877-854-2267. For more information visit them at www.victoryjunction.org or call 877-854-2267.
Family & Summer Camp Information

We realize with flurries in the air and the chill settling in, most people aren’t thinking about summer camp. Despite the temperatures, it really is time to start planning, marking your calendars and making your reservations for an exciting summer!

Victory Junction Gang Camp

Family Weekend

Victory Junction Gang Camp is hosting their family weekend for families & children with Hemophilia/JRA from March 7th – March 9th. This is a wonderful opportunity for the whole family to visit this amazing facility! The theme of the camp is “Spring Into Time Warp Weekend”. Applications are being accepted now and due by February 22nd. For information visit www.victoryjunction.org or call 877-854-2267.

Summer Sessions

Victory Junction Gang Camp is located south of Greensboro in Randleman, NC. The 2008 summer camp for children & teens ages 7 to 15 with hemophilia is July 27th – July 31st. Sibling week will be held August 10th-August 14th.

Victory Junction is completely funded by donations. Summer applications begin December 15th and end on March 15th. For more information and application forms visit them at www.victoryjunction.org or call 877-854-2267.

Camp Carefree

Camp Carefree is located just north of Greensboro in Stokesdale, NC. Camp Carefree is open to all children regardless of their treatment center and they even welcome kids from neighboring states! The 2008 summer camp for children & teens – ages 6 to 16 – with hemophilia and other bleeding disorders is July 20th - July 26th.

Also offered at Carefree are additional camps for well siblings who have a brother or sister with a chronic medical condition (June 15th - June 21st) and one for well children of ill/disabled parents (July 13th – July 19th).

This camp is completely funded by donations, there is no charge to attend this beautiful 22 acre facility.

For more information and application forms contact Camp Carefree, Inc., (336) 427-0966 or on the web at www.campcarefree.org.

Camp Rainbow

Camp Rainbow is a summer camping experience for children with cancer or hemophilia treated by the Brody School of Medicine at East Carolina University. Camp Rainbow is a week long experience with an estimated 100 campers attending each year. The camp is staffed by physicians, nurses and other volunteers who provide necessary medical support and emotional encouragement. Camp Rainbow is held at Camp Don-Lee, located on the Neuse River near Arapahoe, NC. Goals in providing this camping experience include: building self-confidence and independence, emotional and social development and well being, and learning and sharing support with others who are living with a chronic blood disorder. Camp activities include sailing, canoeing, swimming (lessons adapted for handicapped), arts and crafts, music, campfires, nature, and specialized support and educational sessions.

Summer camp for 2008 will be held June 15th – June 21st. For more information about Rainbow Services programs, camps volunteer opportunities and donation opportunities, please contact Jacquelyn P. Sauls, MS, CCLS – (252)744-4102 or saulsj@ecu.edu or Shannon W. Skinner, BS, CCLS – (252)744-1170 or skinners@ecu.edu.
Many Treatments Can Ease Chronic Pain

Relieving drugs. These are often used in combination with specific pain-and muscle relaxants like baclofen (Lioresal) and dantrolene sodium antiepileptics like gabapentin (Neurontin) and pregabalin (Lyrica); the S.N.R.I. 's like venlafaxine (Effexor) and duloxetine (Cymbalta); part of the pain control armamentarium -- antidepressants, especially Several classes of drugs originally marketed for other uses are now with acetaminophen (Tylenol).

If the pain is not severe, nonsteroidal anti-inflammatory drugs, Nsaids with one another or any aspirinlike drug, but they can be used safely prone to a heart attack, stroke or ulcers. Nsaids must not be combined the heart and gastrointestinal tract, and may be inappropriate for those (Celebrex), are available by prescription. All have risks, especially to sold over the counter. Others, like diclofenac (Voltaren) and celecoxib for short, are often tried first. Some, like ibuprofen and naproxen, are

Most chronic pain patients end up taking a cocktail of pills that complement one another. These are three categories of drugs useful medicating pain treatment, obliging them to learn as much as they can about pain patients have changed doctors at least once, and more than a patient's pain seriously or treat it adequately, nearly half of chronic-pain patients seek medical care. Yet because physicians often do not take a persistent pain, if not eliminate it.

But it does not have to be this way. There are myriad treatments - drugs, devices and alternative techniques -- that can greatly ease under control.

By JANE E. BROD Y, Published: Many Treatments Can Ease Chronic Pain

There are available endorphins, chemicals that block pain signals from reaching the brain. It may be effective in relieving headaches, facial and low back well as intermittent pain, is thought to work by increasing the release acupuncture, another increasingly popular treatment for persistent as unlike drugs, TENS has no side effects or interaction with drugs, and pulses transmit signals to the brain that compete with the pain signals.

Other Remedies

Methadone, a synthetic opioid, is another option for managing chronic opioids have on hand a fast-acting one like Percocet (oxycodone with acetaminophen) to treat breakthrough pain. Pain specialists also recommend that patients taking slow-release

The usual side effects -- sedation, nausea, confusion -- soon disappear reduce the medication patients need. These drugs minimize or eliminate the hills and valleys of pain and

for treating chronic pain: (- drugs, devices and alternative techniques -- that can greatly ease under control.

by JANE E. BROD Y, Published: Many Treatments Can Ease Chronic Pain

- drugs, devices and alternative techniques -- that can greatly ease under control.
Many Treatments Can Ease Chronic Pain


There is one undeniable fact about chronic pain: More often than not, it is untreated or undertreated. In a survey last year by the American Pain Society, only 55 percent of all patients with noncancer-related pain and fewer than 40 percent with severe pain said their pain was under control.

But it does not have to be this way. There are myriad treatments -- drugs, devices and alternative techniques -- that can greatly ease persistent pain, if not eliminate it.

Chronic pain is second only to respiratory infections as a reason patients seek medical care. Yet because physicians often do not take a patient’s pain seriously or treat it adequately, nearly half of chronic-pain patients have changed doctors at least once, and more than a quarter have changed doctors at least three times.

In an ideal world, every such patient would be treated by a pain specialist familiar with the techniques for alleviating pain. But “very few patients with chronic disabling pain have access to a pain specialist,” a team of experts wrote in a supplement to Practical Pain Management in September.

As a result, most patients have to rely on primary care physicians for pain treatment, obliging them to learn as much as they can about treatment approaches and to persist in their search for relief.

Medications

Most chronic pain patients end up taking a cocktail of pills that complement one another. These are three categories of drugs useful for treating chronic pain:

If the pain is not severe, nonsteroidal anti-inflammatory drugs, Nsaids for short, are often tried first. Some, like ibuprofen and naproxen, are sold over the counter. Others, like diclofenac (Voltaren) and celecoxib (Celebrex), are available by prescription. All have risks, especially to the heart and gastrointestinal tract, and may be inappropriate for those prone to a heart attack, stroke or ulcers. Nsaids must not be combined with one another or any aspirinlike drug, but they can be used safely with acetaminophen (Tylelenol). Several classes of drugs originally marketed for other uses are now part of the pain control armamentarium -- antidepressants, especially the S.N.R.I’s like venlafaxine (Effexor) and duloxetine (Cymbalta); antiepileptics like gabapentin (Neurontin) and pregabalin (Lyrica); and muscle relaxants like baclofen (Lioresal) and dantrolene sodium (Dantrium). These are often used in combination with specific pain-relieving drugs.

By far the most important class of drugs for moderate to severe chronic pain are the opioids: morphine and morphinelike drugs. Patients often reject them for fear of becoming addicted, a rare event when they are used to treat pain. Doctors often avoid prescribing them for fear of addicting patients, being duped by drug abusers or being raided by the Justice Department. Pain societies have established clear-cut guidelines to help doctors avoid such risks, including ways to identify patients who could become addicted.

Many patients and physicians do not know the difference between physical dependence on a drug (withdrawal symptoms result if the drug is abruptly stopped) and addiction (loss of control over drug use, cravings and continued use despite harm). As with other medications, like steroids and antidepressants, patients have to be gradually weaned from opioids to avoid withdrawal symptoms.

For patients with chronic, continuous pain, using a slowly released opioid like oxycodone (Oxycontin), morphine or fentanyl (administered through a skin patch or lozenge on a stick) is preferred. These drugs minimize or eliminate the hills and valleys of pain and reduce the medication patients need.

The usual side effects -- sedation, nausea, confusion -- soon disappear except for constipation, which can be treated.

Pain specialists also recommend that patients taking slow-release opioids have on hand a fast-acting one like Percocet (oxycodone with acetaminophen) to treat breakthrough pain.

Methadone, a synthetic opioid, is another option for managing chronic pain, especially neuropathic pain, but it has to be taken several times a day. It is metabolized in the liver, along with other drugs that can affect blood levels of methadone.

Other Remedies

Some patients in chronic pain use a technique called TENS, for transcutaneous electrical nerve stimulation, in which pulses of low-intensity electric current are applied to the skin. The theory is that the pulses transmit signals to the brain that compete with the pain signals. Unlike drugs, TENS has no side effects or interaction with drugs, and it can be used at home.

Acupuncture, another increasingly popular treatment for persistent as well as intermittent pain, is thought to work by increasing the release of endorphins, chemicals that block pain signals from reaching the brain. It may be effective in relieving headaches, facial and low back pain, and pain caused by shingles, arthritis and spastic colon.

Continued on page 14
Treatments Ease Chronic Pain continued from page 13

Guided imagery, meditation, relaxation therapy and hypnosis or hypnotherapy are often useful adjuncts to pain treatment, because they can reduce stress and take one’s mind off the pain. Likewise, cognitive behavioral (“talk”) therapy can help patients think and behave differently with respect to their pain. Other options include massage and hydrotherapy, the use of hot or cold water to reduce inflammation and promote healing.

Many chronic pain patients can benefit from physical therapy and exercises to strengthen weak supporting muscles and relax tight joints (which for the last two years has helped me control sciatic pain), or occupational therapy to learn new ways of moving, sitting and lying down to reduce irritation of or dependence on painful body parts.

Finally, a mental adjustment may be necessary to improve the quality of life of chronic pain patients, who have to accept that they may always have some degree of pain. Chronic pain tends not to go away, and changes may have to be made both at work and at play. The goals should be to reduce pain to an acceptable level and to learn how not to make it worse.

For Further Information

Here are some groups that can provide information on managing chronic pain:

AMERICAN CHRONIC PAIN ASSOCIATION E-mail: ACPA@pacbell.net; Web site: www.theacpa.org. P.O. Box 850, Rocklin, Calif., 95677-0850; (916) 632-0922 or (800) 533-3231.

AMERICAN PAIN FOUNDATION info@painfoundation.org; www.painfoundation.org. 201 North Charles Street, Suite 710, Baltimore, Md., 21201-4111; (888) 615-7246.

NATIONAL FOUNDATION FOR THE TREATMENT OF PAIN Pain@cwo.com; www.paincare.org. P.O. Box 70045, Houston, Tex., 77270; (713) 862-9332.

This is the third of three columns. Previous columns covered the causes of chronic pain and the ways that family can help.

HNC Note: Copies of the additional articles are available through HNC at (800) 990-5557.
As part of our mission, HNC monitors all actions relating to the bleeding disorders community and to remain vigilant on all issues relating to safe, effective products. We have included two informational letters that follow addressing recent concerns in the community of cross border plasma collection. Further information and documents, including the FDA letter, are available through HNC by contacting us at (800) 990-5557 or by email at info@hemophilia-nc.org.

November 29, 2007

An Open Letter to the Manufacturers of Clotting Factor Products and the Government Agencies who Regulate Them:

Individuals affected by bleeding disorders depend on the availability of safe and efficacious clotting factor concentrates for their very lives. In the 1980s, the community was ravaged by the proliferation of HIV/AIDS and HCV tainted plasma derivatives. Many lessons were learned during that period about the importance of vigilance, and today we are fortunate to have an adequate supply of safe products, both recombinant and plasma-derived. However, recent events have created the perception that vigilance has started to wane.

The record of progress in addressing safety issues in recent years must not result in reduced vigilance as known and unknown pathogens continue to pose threats to the end users of clotting factor concentrates and our nation’s blood supply. The need for vigilance never diminishes.

In the spirit of ongoing vigilance we are writing to express substantial community concern regarding recent issues that have potential implications for the safety of plasma derived clotting factor concentrates. Fortunately, the issues in question, which include but are not limited to cross-border plasma collection and regulatory violations at one collection center outlined in an FDA warning letter, did not result in tainted product or any other immediate danger to consumers. Nevertheless, there is genuine concern that these matters may not have initially been taken as seriously as they should have been. Furthermore, consumer organizations first learned of these issues from the media or other second-hand reports. We are appreciative of the recent efforts to provide us with answers to questions and other information addressing our concerns. However, our concerns do not end there, and neither should efforts to address them.

As organizations representing consumers with heightened sensitivities and, more importantly, critical vulnerability, we need a higher level of communication on an ongoing basis. In particular, we request the following:

1. When an issue comes to light that may have implications for product safety on any level, we want to know about it – and by that we mean that we want direct, proactive communication.
2. Communication should include an explanation of the problem itself, an analysis of its potential impact on product safety and patient health, and a description of the steps that are being taken to rectify it if necessary.
3. Historically, issues of blood and blood product safety have been addressed on a site by site and/or event by event piecemeal basis. Although much progress has been made, what is ultimately needed is a national blood policy as exists in other countries. A national blood policy would provide an expanded regulatory framework within which many of the questions and issues we are identifying could be addressed in a more comprehensive and timely manner.

By working together to improve our vigilance and our communications around blood and product safety issues, we can all help ensure that safe, effective treatments will remain available for all who need them.

Sincerely,

Corey S. Dubin
President, COTT

Carl Weixler
President, HFA

Raymond W. Stanhope
Chair of the Board, NHF

Mark W. Skinner
President, WFH
Dear Community Members,

As part of our commitment to open dialogue with the community, we want to provide you with an update regarding the recent FDA Warning Letter received by the PlasmaCare plasma center in Columbus, Ohio. We are pleased to report that FDA has acknowledged our response to the Warning Letter and has indicated that it addresses each of the items listed in the letter. FDA specifically noted the specific corrective actions and more general preventive actions outlined on our response.

Although we are confident in quality and safety of the collection practices at the Ohio plasma center, we continue to closely monitor the quality systems in place at this center. We remain committed to maintaining full compliance with FDA, international and industry quality and safety requirements at all Grifols plasma centers. Our prompt action in response to the Warning Letter and FDA’s recent acknowledgment underscore this commitment.

As a result of this recent event, we better appreciate the need for open and ongoing dialogue with the community. We look forward to communicating with you in the future about Grifols initiatives that will further enhance consumer and provider confidence in the therapies they use.

As always, please contact with me with any questions or concerns you may have.

Sincerely,
Chris Healey
Vice President, Government and Public Affairs
Grifols, Inc.
How You Can Save a Life

By Jeannine Cardoza

Last year, the television show Grey’s Anatomy made famous the song “How to Save a Life,” by a little known rock band called The Fray. I remember thinking how great it would have been if Save One Life, our international sponsorship program for children with hemophilia, had used that song for marketing.

As the song gained national attention, I wondered whether every American would “tune in” and sponsor a child. Without access to world media attention, spreading the news of our small but important humanitarian work is not easy. This is why I am happy to share our story with the North Carolina Chapter of the NHF.

How Save One Life Began

Save One Life was founded in 2000 by Laureen A. Kelley, whom you may already know. She is the mother of a 20-year-old with hemophilia, author of numerous parenting, and children’s books on hemophilia, and president of LA Kelley Communications, Inc., a worldwide source of free educational resources on bleeding disorders.

From 1996 to 2000, Laurie often visited developing countries to provide leadership training to hemophilia nonprofits and to donate medicine. During her many trips, she witnessed the devastating effects of untreated bleeding and extreme poverty. She realized that education and training would help patients only in the long term. What about the short term? Donated medicine would stop bleeds, but patients also required funds for food, vitamins, school, and transportation to clinics. Most of the patients Laurie met lived in households earning only about $1 a day.

In 1999, while consulting with the hemophilia society in Karachi, Pakistan, Laurie visited the three-room home of eight-year-old Muhammad Ali, who suffers from hemophilia. Disturbed by the overwhelming needs of this family, Laurie asked Muhammad’s father how she might help. He explained that $20 a month would keep Muhammad in school, thus ensuring the child’s future, and as he is the first-born male, the future of the entire family. Save One Life was born.

What Makes Us Different

While many charities donate medicine or medical expertise, only Save One Life brings financial aid directly to families, reducing the burden of costs associated with food, travel, school, or medicine. As a registered 501(c)3 nonprofit, we match children and young adults who have a bleeding disorder with sponsors in the United States. Sponsors donate $20 a month to help defray the financial costs of living in poverty with a chronic, life-threatening disorder. We differ from most other sponsorship programs in that 100% of a sponsor’s donation directly supports the individual who needs help. Most of the money is sent to the family, and a small amount goes to the local hemophilia nonprofit that provides care for the child. Save One Life closely monitors the use of funds.

Save One Life now operates in eight countries: India, Nepal, the Dominican Republic, Romania, Belize, the Philippines, Egypt, and Pakistan. Currently we provide sponsorship for more than 233 beneficiaries who otherwise would never receive assistance. Our quarterly newsletter OneVoice keeps sponsors, donors and beneficiaries updated on our site visits, developments, and impact on individual lives.

More than a charity, Save One Life also teaches nonprofits in the developing world about principles of good business management: accountability, bookkeeping, report writing, teamwork, communication, fiscal responsibility, and social outreach. Local nonprofits, which care for families with hemophilia, learn to improve their systems to achieve measurable outcomes.

Our Support is Improving Lives

Our country partners annually report where sponsorship dollars are doing the most good. About 39% of our beneficiaries spend them on medical supplies and/or medical services; 37% spend them on education expenses; 16% on nutritious food; 12% on transportation to and from school or clinic; and 5% used their funds on clothing.

Among the local hemophilia organizations we partner with, 35% do not take the small percentage allowed them, and 65% use the funds to provide educational programs for their patients or to defray costs associated with program administration.

Allowing for Hopes and Dreams

In the last year, we’ve received positive feedback from all of our country partners. Dr. Maganti Prasad, president of the Vijayawada
Save a Life continued from page 17

Chapter of the Hemophilia Federation (India), one of 14 participating chapters of the HFI, reports fewer bleeding episodes among the 29 registered beneficiaries. The general condition of the beneficiaries is improving and the children have learned the importance of exercise in maintaining good health. One boy, who has won some local swimming competitions, now dreams of national success!

Sudha Chandrasekeran, a founding member of our board, visited India in June, where she met with the Pune Chapter of the HFI. She witnessed an amazing transformation in one child in particular. In 2005, Prashant Dalvi suffered severe crippling in his hips, knees, and ankles, leaving him crooked in stature and unable to walk. His mother had to carry him; he could not move on his own. His Save One Life funding was used to pay his travel expenses to the hemophilia center for daily physical therapy. With funding help from the local chapter, he had surgery to correct his right leg. During Sudha’s visit, she saw him move around, using crutches, all by himself!

Another patient, Malikarjun Shilwant, until recently lived in a rented one-room home with his family. With funding help from the local chapter and Save One Life, the family now owns a home. Malikarjun’s health has improved; he has fewer bleeding episodes and told Sudha during her visit that he is dreaming of becoming a cricket player!

Expressions of gratitude pour in: “This illness causes me a lot of bleeding troubles and hinders me to do the things I would like to do. The gift you gave me is very helpful because both of my legs need to be operated on,” shared a beneficiary from Romania. “It was solely due to Save One Life funds that Siriam completed high school,” credited the parents of Siriam, of India. These are just a few examples of the hope sponsorship provides our beneficiaries and their families.

What You Can Do

In this season of charity, think of the blessings you and your child with hemophilia have received: excellent medical care, plentiful factor, and the best medicine in the world, living in the richest country on earth. Could you give back?

You can be a part of our effort to create a better future for thousands of children with bleeding disorders. Visit www.SaveOneLifeInc.org to learn about our beneficiaries and to find out how you can support our mission. Help us change the lives of hemophilia families around the world—one at a time. We have over 50 beneficiaries waiting for sponsorship. Or, make a one-time donation to help offset our operating costs. In the coming months we will visit Zimbabwe, the Dominican Republic and India. Your donation can help us to reach more children living in poverty.

And as a sponsor, you’ll receive direct assurance about how your dollars can help a child with a bleeding disorder. Kerry Fatula, mother of three boys with hemophilia and executive director of the Western Pennsylvania chapter of the NHF, is a sponsor. She writes, “Thank you for providing a viable way for people to share with those less fortunate within our small, special community.” And Tamer Hanna, a young man with hemophilia from Egypt, expresses his appreciation as a beneficiary: “Thanks to Save One Life for helping me, as well as many other hemophilic patients around the world, to overcome the obstacles in our way, and helping us to make life better.”

Jeannine Cardoza is executive director of Save One Life, and has worked in the bleeding disorders community for six years. She was first introduced to the community while working at LA Kelley Communications, as assistant to the president. She left to spend several years in manufacturing, gaining experience in business management. She joined Save One Life as executive director in February 2006 and can be reached at jeannine@saveonelifeinc.org.
The Development of One National Data Source for Bleeding and Thrombotic Disorders Gains Momentum

Kathleen Van Gorden - 11/01/2007  Source: American Thrombosis & Hemostasis Network

CDC Funding and the Launch of Collaborative Initiatives Propel ATHN

Riverwoods, ILL. -- The American Thrombosis and Hemostasis Network (ATHN), announced the award of a milestone grant from the Centers for Disease Control and Prevention (CDC) to fund a national disaster preparedness plan for the hemostasis and thrombosis community that will preserve access to comprehensive care and avoid disruption of care in case of an emergency. The announcement was made today at the National Hemophilia Foundation’s 9th Annual Meeting and Exhibit in Orlando, FL.

“Coordination and readiness are two key elements needed when an emergency arises,” said Diane Aschman, President and CEO of ATHN. “The CDC grant will enable ATHN to work with Hemophilia Treatment Centers (HTCs) to develop a plan to safeguard patient health information and to respond in a disaster, when patients are unable to get care from their regular HTC care provider. The program should also give patients the comfort and security of knowing what to do in case of a disaster to ensure that appropriate treatment can be received in a timely manner.”

ATHN is collaborating with Hemophilia Treatment Centers (HTCs), non-profit organizations and government agencies to collect core health data in a standardized electronic format and then use it to restore care to pre-disaster levels. This same data will be used to advance the science and practice of care to better understand the epidemiology, genetics, natural history and treatments of bleeding and blood clotting.

Two other collaborative ATHN initiatives also announced today; the ATHN Affiliate Program, focused on the providers of care and the Community Liaison Group, to gain input from the broader community and create the affiliations enabling one national data source.

“Each of these initiatives is central to ATHN becoming a valued community resource,” explained Aschman. “Collaboration is the cornerstone of ATHN’s values and as the steward of the one national clinical database for the hemostasis and thrombosis community, it is fundamental to our success. The programs launched today combined with the disaster preparedness grant from the CDC, further our efforts to support and improve care for this community.”

ATHN Affiliate Program

The ATHN Affiliate Program will create formal relationships with HTCs and thrombosis sites funded through the U.S. Department of Health and Human Services Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau and the CDC. The centers — ATHN Affiliates — will commit to collect data for use by the community through ATHN. The CDC will provide access to state-of-the-art security and data protection by hosting the software. By pooling their non-identifiable patient data, ATHN Affiliates will create a robust data source that expands the evidence base needed to establish clinical guidelines, evaluate outcomes, contribute to fact-based advocacy and improve care. Ten percent of HTCs have signed on in the first weeks.

Tangible benefits for ATHN Affiliates include:

• Access to data manager support, up-to-date training and technical assistance;
• Insights from the data to facilitate care improvement and research initiatives;
• An improved data collection process, easier data entry and more time for patient care;
• Leadership role by serving on the ATHN Board of Directors, a committee or project review panel and weighing in on policies pertaining to data, research, publication and Affiliate status;
• Participation without a fee for becoming an ATHN Affiliate.

Community Liaison Group

The ATHN Community Liaison Group has been designed to bring together an advisory group representing the broader hemostasis and thrombosis community to enable two-way communication between these various groups and the ATHN Board of Directors, and to facilitate continuous alignment with broader community needs. The group will focus on collaboration and work to bring together the various perspectives in the community to ensure the ATHN database will be beneficial to all. Collaborating organizations that have appointed a representative are:

• National Hemophilia Foundation (NHF) with its Medical and Scientific Advisory Committee (MASAC),
• Hemophilia Federation of America (HFA),
• National Alliance for Thrombosis and Thrombophilia (NATT) through its Medical and Scientific Advisory Board (MASAB),
• Hemophilia and Thrombosis Research Society (HTRS),
• Anti-coagulation Forum,
• World Federation of Hemophilia (WFH),
• Committee of Ten Thousand (COTT)
• HRSA Maternal and Child Health Bureau (MCHB),
• U.S. Food and Drug Administration (FDA),
National Data Source continued from page 19

• National Heart Lung and Blood Institute (NHLBI),
• Centers for Disease Control and Prevention (CDC) Division of Blood Disorders,
• CDC National Center for Public Health Informatics (NCPHI).

ATHN’s collaborative efforts to-date include a significant unrestricted five-year grant from Novo Nordisk to help establish and grow the organizational leadership and operational infrastructure of the network; and a joint effort with the Centers for Disease Control and Prevention (CDC) to develop the greatest degree of protection and security for individual patient and center data with the maximum amount of flexibility.

About ATHN

The American Thrombosis and Hemostasis Network (ATHN) is a non-profit corporation founded in July 2006. ATHN is committed to one national data source for the hemostasis and thrombosis community and dedicated to advancing and improving the care of individuals affected by bleeding and blood clotting disorders. ATHN will provide stewardship of a secure national database, adherent to all privacy guidelines, which will be used to support clinical outcomes analysis, research, advocacy, and public health reporting. Visit ATHN at http://www.athn.org. ATHN’s Emergency Preparedness Program is supported by Cooperative Agreement Number U27DD000319 from the CDC.

Mark Your Calendar

for HNC Legislative Day

Tuesday, June 10, 2008 - Raleigh, NC

It is time to make your voices heard! HNC will be hosting its Legislative Day at the NC State Legislative Building in Raleigh, NC on Tuesday, June 10th. The days events will include a Talking Points session where we will discuss the latest topics and how best to communicate our needs to the legislators. This will be followed with an opportunity to meet with our legislative representatives and share our thoughts and ideas.

HNC will be providing transportation to the location from various locations around the state. Included in the program will be all the information needed to make an effective presentation to your officials, meals and transportation!

This event creates a wonderful opportunity for the North Carolina bleeding disorder community to participate in the policy decision-making process that impacts our day-to-day lives. We encourage you to take advantage of this exciting opportunity! For more information on how you can become involved in this effort, please contact HNC at (800) 990-5557 or by email at info@hemophilia-nc.org.
We Will Not Go Back

By Val D. Bias, Source: Hemophilia Innovation, November/December 2007

The Chapter Staff Organization (CSO) invited me to speak recently at their luncheon held during the National Hemophilia Foundation meeting in Orlando. My topic was to be the activities of my company The Bias Group - founded out of a great passion and desire to serve the chronically ill community. It represents my personal commitment to strengthening national and community based organizations while addressing the special needs of philanthropy, industry and research as they relate to the chronically ill individual and their family.

While speaking to the CSO, I also took the opportunity to comment on some of the issues The Bias Group has focused on in the past 18 months. The bleeding disorders community faces many challenges, and I feel very strongly that we are not focusing as a national community and are distracted instead by the many possible issues before us. It is time to focus.

I often hear a resounding shout from my community to maintain “choice” of provider and “choice” of product as a basic entitlement for individuals and families in the bleeding disorder community. Although Laurie Kelly had repeatedly warned us in her series “The Coming Storm,” we have clung to this outdated premise of absolute choice of provider and product. Though, as a community, we don’t seem to realize it yet, we have already lost the right to choice of provider. My insurance company (HMO) made this choice for me, and has for the past ten years that they have provided coverage. In England, a country with a national health care plan, their choice of product has been limited to three; two recombinant products and one plasma-based product. Can you imagine this in the US? No?

Well, this is EXACTLY what is about to happen here! Unless we as a community unify for a higher purpose, and are no longer distracted by conflict of interest issues or bickering about the reorganization of The National Hemophilia Foundation, we will, quite frankly, be left in the dust wondering where we lost not only choice of provider, but choice of product AND access to our Hemophilia Treatment Centers as well.

Please understand I am not minimizing the issues of conflict of interest and the reorganization. I understand these issues are indeed critical and that continued discussion is a must, but unless we are willing to set aside our differences and communicate constructively, they will distract us from the task at hand and the survival of our standard of care.

We MUST set aside our differences and focus.
We MUST compromise with each other to reach consensus.
We MUST change the buzzword from “choice” to “access”, when speaking with those who will be able to protect this for us.
We MUST come together and mount a national campaign declaring “WE WILL NOT GO BACK”.
We MUST NOT return to the days where people with bleeding disorders are crippled, diseased, or die because our medical system does not recognize our unique and expensive standard of care.

If we don’t IMMEDIATELY mount a national effort to alert Congress, aggressively educate state legislators, engage major insurers, and educate our employers, I truly fear we will lose much of what we have struggled to build to free our community.

SAVETHE DATE! Wednesday, March 5 - Friday, March 7, 2008

NHF’s annual Washington Days empowers individuals in the bleeding disorders community to impact the legislative process. Join us to:

- Become more informed on critical issues that affect your continued access to high quality care
- Learn effective grassroots advocacy techniques
- Meet face-to-face with legislators and staff who shape national healthcare policy

Mark your calendars to walk the halls of Congress and make your voice heard!
For more information, please contact HANDI at (800) 42-HANDI or handi@hemophilia.org.

Hemophilia of North Carolina is planning on sending a group to participate in Washington Days. If you are interested in attending, please contact Sue Cowell, Executive Director at (800) 990-5557 or info@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 applications to:
Hemophilia of North Carolina
P.O. Box 70
Cary, NC 27512-0070

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.

How You Can Help

It is now possible to make a donation from the HNC website at www.hemophilia-nc.org.

Double Your Dollars! Many companies match their employee’s donation to registered non-profit organizations such as HNC. If your employer provides matching donations, please do let us know. This is an easy way to double your donation. All you will need to do is mail in the matching contribution form from your company with your employment identification. We will provide the details on HNC and also send in our tax exempt status.

Please consider remembering HNC with a bequest in your will, a gift from your stock portfolio or as a beneficiary of your life insurance or retirement plan. For additional information, you may wish to consult with an attorney.

Honor the memory of a loved one with an In Memory donation to HNC. Remember someone special by giving a gift in their memory. HNC will send a letter acknowledging your thoughtful donation to the person of your choice.

Give a gift to honor someone close to you for a birthday, an anniversary, a wedding, to celebrate the birth of a baby, or other special occasion. HNC will send a card acknowledging your thoughtful donation to the person of your choice.

Shop & Search to Help. HNC is a registered participant of the Food Lion Shop & Save Program. Each time you use your card, a portion of your purchase will be donated to HNC. Register your card today! Set your search engine to GoodSearch.com. We are a registered organization on this search engine and every time you use it, money goes to HNC. Select HNC as your designated charity.

Host Your Own Fundraiser. Do you have an idea for a fundraiser? Programs hosted by members of other chapters include a Bowl-A-Thon, Texas Hold’Em Tournament, Flea Market and BBQ. HNC will assist with the set up, communications and any support needed.
When you need us, Baxter will be there.

Through Therapies
Providing innovative recombinant factor, plasma-derived, and inhibitor management therapies highlights our commitment to choice and illuminates our investment in research and development.

Through Participation
Offering initiatives for patients, families, physicians, and nurses and supporting local and national organizations and community events, in addition to volunteering.

Through Progress
Improving current therapies and developing new and better ways to manage hemophilia A—innovations inspired by listening to you.

For more information on Baxter programs and services, visit www.thereforyou.com.

www.medprorx.com
(888) 571-3100
North Carolina Pharmacy

• Factor Replacement Therapies for Hemophilia and other Bleeding Disorders
• Full-time Nursing Director
• Staff of Experienced Infusion Nurses

NO MATTER WHERE YOU ARE, WE ARE THERE FOR YOU.
Opportunities for Programs & Participation:
Please tell us if you or a family member would be interested in assisting with any of the following programs or opportunities that are taking place in 2008:

Call for more details and volunteer opportunities at (800) 990-5557

- Annual Golf Tournament (April 25)
- HNC Annual Meeting (May 31)
- HNC Legislative Day (June 10)
- Family Retreat (August 13-15)
- Tennis Tournament (September 20)
- Hemophilia Walk (October 18)
- Casino Night (November)
- Holiday Celebration (December)

- Advocacy - chaired by Leonard Poe
- Education - chaired by Jeannie Adair
- Outreach - chaired by Andrea Brill & Warren Jewett
- Finance - chaired by Kathy Register
- Fund Development - chaired by Richard Atwood & Matt Barnes

All chairpersons are available through the HNC website or by phone at (800) 990-5557.

We invite you to visit our new, enhanced website at www.hemophilia-nc.org for more information and pictures on all of the programs & events offered during 2007. Also, look at the highlights of the programs & services planned for 2008.