



Hemophilia of Iowa, Inc.

We have a duty to encourage one another. Many a time, a word of praise or thanks or appreciation or cheer has kept a man on his feet. Blessed is the man who speaks such a word.

~William Barclay

Volume 23 • Issue 3

Fall 2009

From the President . . .

By Kari Atkinson

It is hard to believe that half of summer is over. Well, at HOI, we have been busy to say the least. The 2009 Golf Tournament was held in Riverside. WOW is all I can say. My hat is off to Bill Laughlin and Carol Meyer, who were co-chairs of the event; and Jennifer Adams, who was in charge of the raffle. All three of these people, along with their committee members, did an awesome job. The numbers are not quite in yet but it is looking like the profit will blow the others out of the water. We had a record 24 golf teams this year—up by 9 teams from last year. New this year was Celebrity Derek Pagel, a former football player for the New York Jets and the Iowa Hawkeyes. Here is what Derek had to say about the golf tournament:

“Thanks for the day of golf. I know everybody from Iowa that attended had a great time. I will blame the wind for our high score!!!”

Our thanks to you, Derek, and to the other Iowa Hawkeyes who played golf in our event! As a side note, here are the names of the coaches and former Hawkeye players who were in attendance:

Derek Pagel, Scott Boleyn, Levar Woods, Dan Clark, and Charlie Bullen.

Two weeks ago was summer camp. I can't say enough about summer camp! It was my first year of leaving my 6 year old, Beau, at camp. As a mom, it is bittersweet because he is getting older, and since he is the youngest, it is hard to let go. He did great, and I have to say I did too. Thanks to the new addition of camp photos on Smug Mug, an online photo service where Flipper, the camp director, uploaded pictures every night, parents could see their bright smiling kids and know they were ok. It was great and my son had a BLAST. He is ready to go back next year already. A special Thank You goes to Tami and Karla at the HTC for all of their planning to make summer camp and family camp such a great success. HOI is very proud to be a donor to both camps.

Be sure to check out the scholarship winners listed in this issue of the *BloodLine*. Congratulations to all of our scholarship recipients. We are proud of all of you!

I also want to thank Dawn Humburg and her committee for their hard work in planning a great Adult Retreat. The retreat was a lot of fun for everyone and it was nice to visit the western part of Iowa.

Our summer activities are in full swing. In fact, by the time you receive this issue, we should have completed our first Family Fun Day at Adventureland and our Annual Meeting is right around the corner on August 21-23 at the West Des Moines Marriott.

Stay cool, enjoy your summer and stay safe!



EDITOR:
Nancy Patrilla

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First Time Campers Prove Benefits of Attending Family Camp

By James Giles aka "Cricket"

This week saw Camp Tanager host its annual camp for children dealing with hemophilia and other bleeding disorders. The camp runs from Sunday through Friday and is designed to help young people meet other children with bleeding disorders in an exciting and entertaining learning environment.

The campers vary in age from six year olds to 18 year olds. For many of the older campers, this summer will have been their 3rd, 4th, 5th, or even 10th year at Camp Tanager; while for most of the younger kids, this was their first full week at camp.

These younger campers, however, are no strangers to the camp environment. Most have attended a special family camp at Tanager, which has been running for the previous three years. The aim of this weekend-long program is to allow campers to familiarize themselves with the camp environment from an early age with the comfort of having family there to support them.

The success of family camp is clear to see. Of the group of six year olds making the transition from family camp into full camp, all completely enjoyed the experience and made the most of the time and experiences available. The process of family camp ensured that they were already familiar with

the sights, smells and routines of camp life. This allowed them to find their feet on their own extremely quickly.

With this smoother transition into the camp environment, homesickness and similar common behaviors were almost non-existent and the new campers are able to focus on what really matters: making new friends, having fun and learning to cope with their disorders.

(James Giles is an Assistant Camp Director at Camp Tanager, and is from England. He has been working at Camp Tanager for 4 years. He is a High School Physics Teacher in England.)

The First Step group, believe it or not, has had a couple of months with no activities. We had our big activities in the first quarter of the year, but we do have a special treat being planned for November. I don't have a date but I will give you a hint: It has something to do with chugga chugga chugga chooo chooo. HMMMMM not saying anymore. . .

Save the days of March 12-13, 2010, for our 4th Annual Family Fun Education Weekend. Our weekend will be held in Dubuque next year. Of course, more details will follow.

If anyone new is receiving this *BloodLine* and you are wondering what First Step is, it is a program offered through the National Hemophilia Foundation that is designed to provide education and support for families with children aged 0-8 who have a bleeding disorder. If you have a child that age, we would love to hear from you and give you the opportunity to be part of our fun outings. Please feel free to contact either Kari Atkinson, HOI President and Parent Coordinator, or Tami and/or Karla at the treatment center. We would be more than happy to help you and your family in any way we can.

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Continuous Changes at the Iowa Hemophilia and Thrombosis Center

By Karla Watkinson, RN

As mentioned before, Dr. Steven Lentz has taken a very active role as the Director of the Iowa Hemophilia and Thrombosis Center (HTC) and has incorporated weekly meetings with the HTC staff to ensure we continue to provide excellent care to all with bleeding disorders.

Dr. Rolla Abu-Arja has been promoted to Assistant Professor in the

Department of Pediatrics and Division of Hematology-Oncology. She will now be seeing the entire Pediatric population with bleeding disorders.

Dr. Mohamed Radhi has accepted a new position at Children's Mercy Hospital in Kansas City, MO. He will be working with the Pediatric Bone Marrow Transplant Program in Kansas City.

The HTC wants to say THANK YOU to Hemophilia of Iowa, Inc., for all the work they do promoting the Iowa Hemophilia and Thrombosis Center. We appreciate your support! We also want to say CONGRATULATIONS on your success and growth!

HFA to Launch New Website

The Hemophilia Federation of America (HFA) will launch a brand new website soon. The policy team is committed to keeping you updated on important state and federal issues that affect the bleeding disorders community. In the near future, HFA would like to send out *Friday Updates* that alert you to postings on the advocacy section of the new HFA website. In the meantime, the policy team would like to share short alerts and stories with the community.

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“Sleeping Beauty” Helps Correct Hemophilia A in Mice

Researchers from the University of Minnesota (UM) successfully increased factor VIII levels in mice with hemophilia A through a type of gene therapy that targets cells in the liver. The study was published in the *Journal of Clinical Investigation*. The lead investigator was Betsy T. Kren, PhD, Department of Medicine, UM Medical School, Minneapolis.

Kren and colleagues took nanocapsules (submicroscopic drug carrier systems made of an oily or watery core surrounded by a thin membrane) and coated them with hyaluronan, or hyaluronic acid, which helps cells bind more readily. They then enhanced the nanoparticles by encapsulating segments of DNA known as transposons. Also known as, “jumping genes,” transposons can move independently to different positions in

the genome of a single cell, making them ideal for carrying therapeutic genes into targeted cells.

Investigators used the so-called *Sleeping Beauty* transposon, which was first discovered more than 10 years ago when a laboratory found that the seemingly outmoded gene could be “awakened” to become a key vehicle for transporting genetic material into the nucleus of a cell.

The hyaluronan-coated/*Sleeping Beauty*-encapsulated nanoparticles, further customized with the FVIII therapeutic gene, were then delivered to the liver. Measurements taken 5 and 50 weeks after the injection showed that FVIII levels and clotting ability improved significantly in the mice with hemophilia A. In addition, no inhibitor antibody response was reported. Researchers hope that these successful

animal studies will eventually lead to human trials of this type of gene therapy.

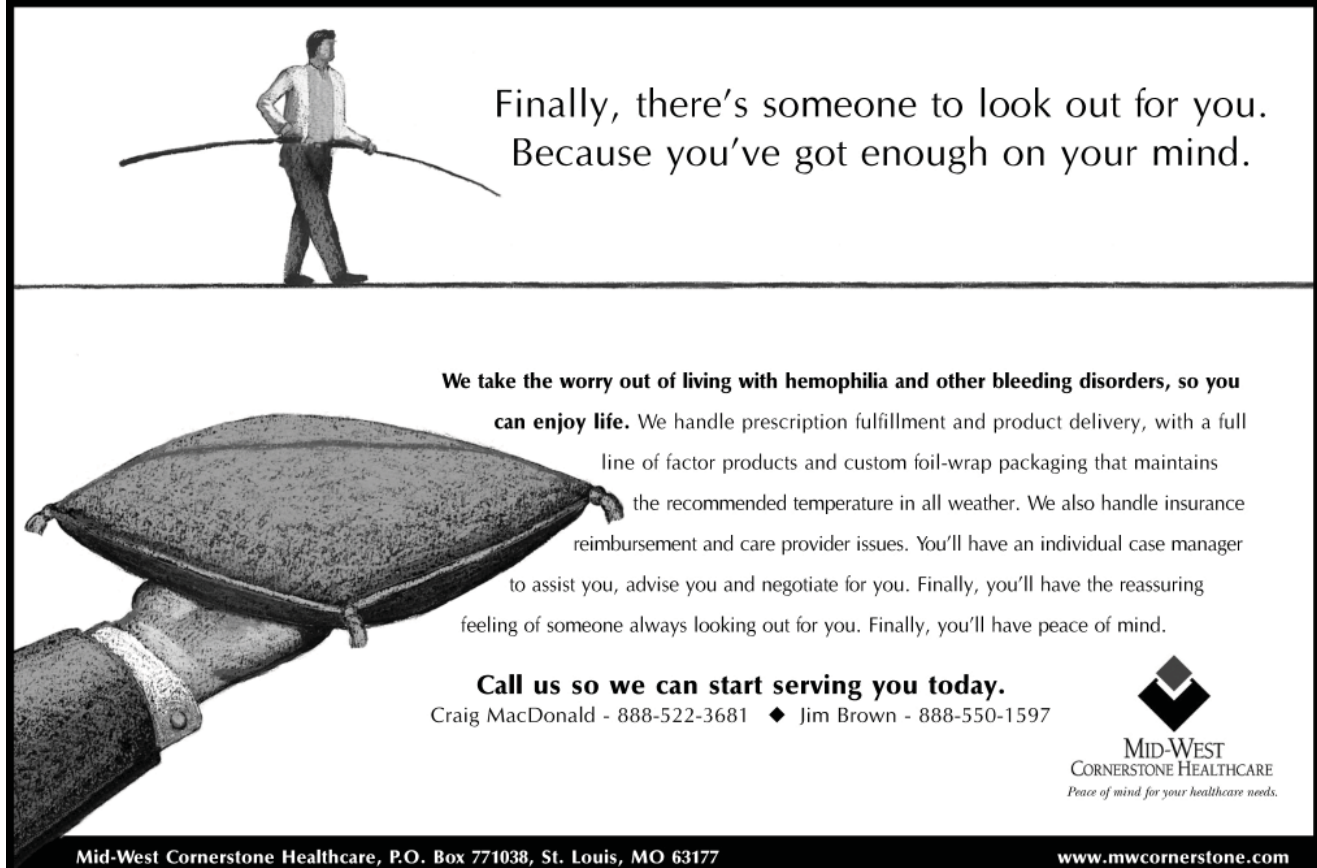
Source: Kren T, Unger G, Sjeklocha L, et al. Nanocapsule-delivered Sleeping Beauty mediates therapeutic Factor VIII expression in liver sinusoidal endothelial cells of hemophilia A mice. The Journal of Clinical Investigation, June 2009.



Wanted!

We would love to hear from you! If you have any interesting photos, articles, etc. that you would like to share with others in the *BloodLine* newsletter, please submit them to:

Nancy Patrilla
via e-mail at
hoi_bloodline@yahoo.com



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Synthetic Interferon

A New Option for HCV Patients

A recent study published in the journal, *Hepatology*, shows that a new combination therapy could effectively treat patients with chronic hepatitis C (HCV) who do not respond to the standard therapy of pegylated interferon (PEG-IFN) and ribavirin (RBV). The new approach uses interferon alfacon-1, also called consensus interferon (CIFN), a synthetic version of interferon, with RBV.

The lead investigator of the study was Bruce Bacon, MD, director of the division of gastroenterology and hepatology at Saint Louis University (SLU) School of Medicine and co-director of the Saint Louis University Liver Center in Missouri.

HCV can cause liver cancer, cirrhosis, end stage liver disease and lead to liver failure. The current therapy is costly, often causes severe side effects and has a significant failure rate. Approximately 50% of HCV patients on the PEG-IFN/RBV combination therapy fail to respond. Patients who go through a cycle of PEG-IFN/RBV therapy, which typically lasts either 24 or 48 weeks, and are unsuccessful at clearing the virus are called “nonresponders.”

The multi-center study, headed by SLU researchers, included 515 nonresponders. The patients, from 44 trial sites, received either one of two doses (a smaller and a larger) of daily CIFN with RBV, or no therapy at all.

The results showed that CIFN and RBV were effective in approximately 7% of patients given the lower dose and in about 11% of patients given the higher dose. Investigators reported that the therapy was safe and well tolerated by the patients. In addition, patients exhibiting less severe liver damage characterized by fibrosis (liver scarring) and who had responded to the initial treatment of PEG-IFN/RBV,

experienced a success rate of more than 30%. “This represents an important advance for difficult to treat hepatitis C patients who have failed to respond to traditional therapy,” said Bacon.

“Retreatment of PEG-IFN and RBV non-responders with CIFN and RBV is safe and efficacious and can be considered a retreatment strategy for patients failing previous therapy with PEG-IFN/RBV, especially in

interferon-sensitive patients with lower baseline fibrosis scores,” concluded study authors.

Source: Bacon B, Shiffman M, Mendes F, et al. Retreating Chronic Hepatitis C with Daily Interferon Alfacon-1/Ribavirin after Nonresponse to Pegylated Interferon/Ribavirin: DIRECT Results. Hepatology, June 2009; Volume 49 (Issue 6): pages 1838-1846



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Annual Dude Cremer Memorial Golf Tournament

By Bill Laughlin, Golf Outing Co-Chairperson

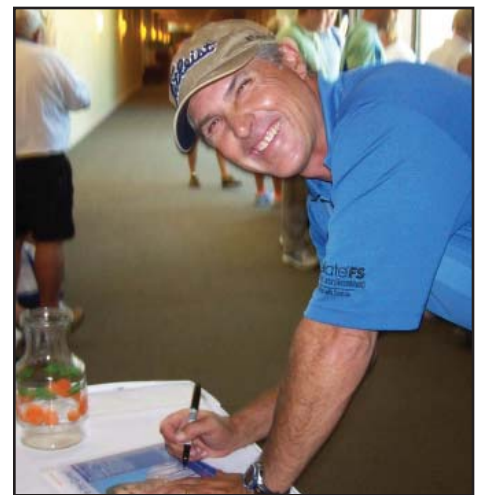
On June 29, 2009, we descended upon a new location for the HOI Annual Dude Cremer Memorial Golf Tournament. We landed this year at Blue Top Ridge Golf Course at The Riverside Casino and Golf Resort in Riverside, Iowa. We had a beautiful day except for a little wind for our biggest fundraiser of the year for Hemophilia of Iowa. The golf course facility, staff, and management were a delight to work with. They were very friendly and willing to do whatever they could to make our outing successful. The course was challenging and in excellent condition. We had 96 golfers; some say maybe our largest turnout ever. We had the pleasure of welcoming a group of former players and current coaching staff from the University of Iowa Football Program. This group did a wonderful job of helping raise a record amount for our chapter this year.

In addition to our golfers, we had numerous volunteers who helped run our event and others who were invaluable in obtaining auction and raffle prizes. I would like to thank everyone who participated on the golf planning committee: Jennifer Adams, Ashley Druckenmiller, Nancy Golden, Mark Weiner, Mike Lammer, Stacie Doree, Nike Nolte, and Ryan Hutchins. In addition to these committee members, I would like to thank Shane Kelley for making the connection for us to the University of Iowa Football

Program. I would also like to send a very special thank you out to my co-chairperson, Carol Meyer. Carol, thank you for everything; we could not have done this without you!

With the momentum we've got going, we expect next year's tournament to continue to grow. If you have any interest in playing, volunteering or securing auction and/or raffle prizes, please start now. If you have any questions or comments, Please contact Carol Meyer at cmeyer@netins.net or call 319-330-9830. Encourage your family, friends, and co-workers to support Hemophilia of Iowa through this wonderful event. Information on next year's tournament will be published in the *BloodLine* as soon as it becomes available.

Thank you again for everyone's hard work this year. I look forward to seeing you next summer!



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Hemophilia of Iowa would like to thank all of sponsors for such a wonderful golfing experience!

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Wyeth and Catalyst to Develop FVIIa Products

Wyeth Pharmaceuticals and Catalyst Biosciences, Inc., announced that they have formed an exclusive worldwide collaboration to develop factor VIIa (FVIIa) products to treat hemophilia and other bleeding conditions. According to the agreement, Wyeth will support the discovery, research and preclinical development by Catalyst of FVIIa products, including CB 813, Catalyst's investigational drug candidate.

Source: Wyeth news release (partial) dated June 30, 2009

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The Kaiser Family Foundation has put together a great tool to help decipher and compare the health care reform bills. If you don't have time to read thousands of pages of documents filled with legislative language, this tool provides easy-to-read, side-by-side comparison summaries of sections of the major health care reform proposals. To use the tool go to <http://www.kff.org/healthreform/sidebyside.cfm>

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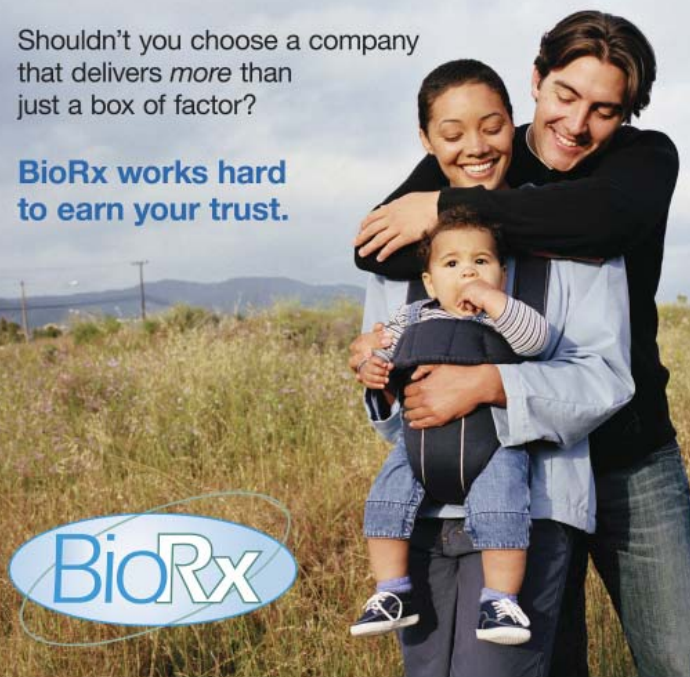
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Adult Retreat 2009



Group picture in downtown Pomeroy, Iowa

You ask what's in Pomeroy, Iowa? Well, some of the best kept secrets in Iowa await you in Pomeroy. First of all, Byron Stuart, who owns and operates Byron's Bar (www.downtownpomeroy.com/byron's) in Pomeroy, has hosted an annual fundraiser for kids with bleeding disorders to attend Camp Tanager in Mount Vernon, Iowa, for the past 14 years. It is absolutely amazing and heartwarming to see the small community of Pomeroy, Iowa, donate between \$2,000 and \$3,000 annually just for Byron's benefit for our chapter. As the mother of three children who have attended camp in past years, I, for one, would like to say "thank you" to this small community and personally to Byron. We love you, Byron!

Okay, there's more in Pomeroy! After arriving at the Community Hall in Pomeroy, we split into two groups. One group stayed and enjoyed tie-dying with Roger Feldhans, The TyDyGy. Roger is a multi-talented artist who is eager to share his love of tie-dye. Participants were able to tie dye their own white cotton shirt with the HOI logo and clever inscription on the front. Roger also had spin art available.



Leonard demonstrating the lathe

The other group walked across town (one block) to the Kaleidoscope Factory (www.kaleidoscopefactory.com), owned and operated by Leonard Olson. Leonard or Dr. Leonard as his friends call him, led us through a world of discovery in his storefront and workshop. We all manufactured our own kaleidoscope and learned of Dr. Leonard's world (The College of Leonard). After this, the groups switched.

After all of the artistic activities, we enjoyed a wonderful meal from The Palmer House. The crowd was entertained by Mr. Rob Lombard, blues singer, during our meal. Rob performs regularly for Byron's.

The group then proceeded to Byron's for our evening entertainment. Tequila Sunrise, a very popular rock and roll band, performed many hits and provided many a dancing number.

A very HUGE thank you goes out to Byron Stuart, Roger Feldhans and Leonard Olson for all of their hours of preparation for our Adult Retreat weekend!

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The Adult Retreat weekend would not have been possible without the generous support of the following companies:

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Byron's in downtown Pomeroy, Iowa



Roger Feldhans demonstrating tie-dying



ADVOCACY – *Is It for You?*

By Nancy Patrilla

If you are like me, you probably don't know much about "advocacy." I do know that it is important to the bleeding disorders community, but I need specifics not just that it is a good thing to do and beneficial to people.

Well, this week, I had the chance to get some of my questions answered. We had a good meal in a nice restaurant in Cedar Rapids and a great chance to ask some serious questions of each other. Key points that I took away from the meeting are as follows:

- Our Hemophilia Advocacy Committee will be a resource for people who have concerns about healthcare and insurance—not individual concerns but broader in nature. We will work for changes that affect the entire hemophilia and bleeding disorders community.

- One of our first goals will be to recruit people who would be willing

to attend a short training session on being a voice for the bleeding disorders community.

- Our second goal is then to have our advocates meet with their State legislators to try to get insurance lifetime caps raised significantly. (Did you know that if the lifetime caps are raised by the Federal government, it will apply to self-insured companies? At the State level, it will apply to companies who are not self-insured.) The training session will prepare advocates to meet legislators.

- We are going to study some additional issues so that we can make a list of items that we want changed. We will work our way steadily and surely through the list.

This type of work needs to have a personal touch—we need people to meet with legislators. Letters are nice, but now what we need are 8-10 people who are willing to complete advocacy training. I

have already signed up and am looking forward to being involved.

Are you willing to step up and become a voice for our community? If you don't, who will?



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Hemophilia Summer Camp, 2009

THE AMAZING RACE . . .

By Karla Watkinson, RN

The first day of camp began on the longest day of the year and the first day of summer! And, boy, did summer arrive with the hottest and most humid week we had experienced so far this year! Neither the kids nor staff had a chance to become acclimated to the changing season; we just tried to find ways to stay cool! Thanks to the Camp directors, many of our activities were rescheduled in the air-conditioned winter lodge or, if held outside, it involved water!

Camp this year was one of the smallest groups, 43 campers; but what a great group we had! Over half were 11 or under, and 17 of the entire groups were first-time campers! Most of us were a little leery of having that many first timers, but they showed us they had NO FEAR! Believe-it-or not, homesickness was minimal!

Activities during the week included the basic camp activities such as swimming, dancing, karaoke, water games, parachute, archery, art, nature, and camp fires. A new game, called GaGa Ball, was held in the new GaGa Arena on the Camp Tanager campus. GaGa Ball is also known as Israeli Dodgeball that requires players to hit the ball with their hand or fist, instead of catching and throwing the ball, and aiming below the waist of other players. It also allows wall shots. For pictures, go

to www.ultimatecampresources.com

Our special activities included:

- Karing for Kids Program, which are age-appropriate educational activities developed by Diane Horbacz to teach children more about hemophilia and bleeding disorders. Diane and Vicky Tody came to camp on Monday, June 22, and presented the following programs to the campers: 1) My Amazing Blood where the younger kids explored the circulatory system, played with coagulation slime, blood sundaes, and clotting races; and 2) Junior Scientist was for the older group and taught advanced concepts such as molecules, DNA, and genetics. Days later the campers were still informing us what they had learned from this hands-on activity! (Diane Horbacz, Director for Karing for Kids, is a graduate of Seton Hall University with a degree in Psychology and a Masters in Education in Special Education from William Patterson University. She also has 2 sons with severe hemophilia. Vicky Tody is a Registered Nurse and has also designed and developed games to educate others about bleeding and clotting disorders.)

- Bell's Farm field trip is an annual event but always a special treat. Darrel and Carolyn Bell and family have provided Hemophilia camp an opportunity to spend the day with them for almost 30 years! They give hours of time to prepare their

home, yard, pond, and food each year to provide us with one of the best days of the week. This year they added a pontoon boat and gave us generous rides around the pond. Fishing, swimming, walking, kayaking, eating, and rides around in the "gator" were just some of the favorite activities we participated in during the day. (Darrel and Carolyn Bell and their family live south of Lone Tree, IA. Their son, Brian, was treated for a brain tumor at the University of Iowa Hospitals and Clinics when he was young boy. While receiving treatment, they became good friends with Dr. Tom Kisker, the founder of the Hemophilia Treatment Center and camp. Thus, their gracious support of Hemophilia camp began.)

- The Skyore Program presented stories about Greek Mythology and Astronomy.

- The Leading Edge Program, with Pat Torrey, is an adventure educational program for youth in the bleeding disorder community. This program was for the campers ages 12 and up and assists with developing self-esteem and cultivating personal responsibility by introducing concepts and tools, then to provide an opportunity for participants to reflect and self-evaluate how to use this in their daily lives. Pat captured the attention of all the older campers and they were amazed at how fast the day went with him! If you



A WORLD ADVENTURE

have a chance, check out the article that was in the Cedar Rapids Gazette. (From the NACCHO Leading Edge brochure: Patrick Torrey is an internationally recognized facilitator and trainer known for his powerfully engaging programs that inspire kids, teachers, CEO's to believe in their own ability to function at their optimal level and challenge themselves to grow.... He is genuine....)

- Pinewood Derby Cars were prepared by the campers and raced on the final day of camp. Everyone was a winner, and they each received a trophy by completing and carrying out a project!

- Dental Bingo, with Gayle Gilbaugh and Cathy Skotowski from the University of Iowa provided a fun, educational activity on dental health.

- Overnight campout at Palisades National Park.

- Home Therapy education was provided by Tami Bullock, RN, and Karla Watkinson, RN, to all age groups using the new BayCuff home infusion educational kit. This new kit contains life-like skin and veins that strap onto the person who needs infusions, and the care provider (or the patients themselves) teaches the appropriate steps of home therapy without risk of injuring the vein.

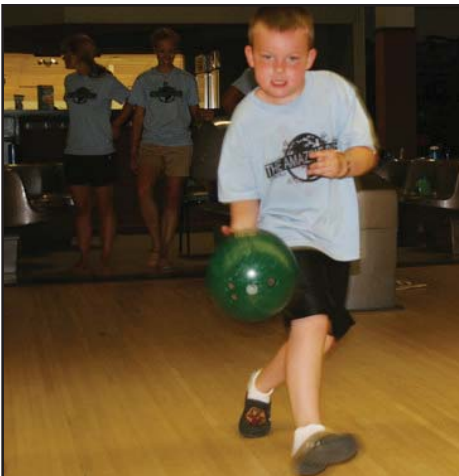
- Bowling and Laser Tag was a welcome relief to the heat outside! Our campers and counselors had a great time perfecting their games!

- Amazing Race around the World, another educational game, taught the campers facts about hemophilia care in other areas of the world as well as interesting facts from that country. The campers' Passports had stamps from countries such as France, Italy, Mexico,

and Botswana to name a few.

- The Grand Finale was the Talent show. The stars were the campers who each were awarded individual certificates for determination, persistence, and behavior shown throughout the week of camp.

Hemophilia Bleeding Disorders camp could not happen without the support, time, and donations of so many people, companies, and the Hemophilia of Iowa chapter. A special thank you goes to the following people and sponsors who provided generous support to ensure a wonderful camp experience for the campers: Donald Pirrie, Kari Atkinson, Michelle Krantz, Stephanie Lasister, Craig Looney, Terry Morrow, Sheri Bosch, Mike Pelcher, Mike Lammer, Joel Lee, Gayle Gilbaugh, Cathy Skotowski, Nancy Golden, Andy Zinn, Stacie and Perry Cowen, Jennifer Adams, Diane Horbacz, Wendy, Dr. Rolla Abu-Arja, Darrel and Carolyn Bell and family, Baxter Healthcare, Bayer, Wyeth, Novo Nordisk, CSL Behring, Grifols, Caremark, BioRx, Factor Health Management, Acredo-Hemophilia Health Services, Walgreen-Option Care, Pindar, Alliant Energy, and the University of Iowa Homecare Program.



What sport do you play?

By Vance Patrilla

In our society, like it or not, many persons judge our young people from a sports perspective. Water cooler conversations often revolve around how little Johnny or Jane did during the most recent weekend's sporting performance. As young people and parents in the bleeding disorder community, this can apply tremendous pressure to the parents and health implications for our young people. As a family, we faced and worked through these challenges with a good deal of success. Our son, a severe factor VIII deficient hemophiliac, provided us the opportunity to be faced with and make life-significant decisions. **(Please note that any decisions regarding participation in rigorous sporting activities need to be made in concert with your health professionals' recommendations.)**

Our son, like many young persons, needed to participate in school activities to establish and maintain acceptance of school friends. For him, this meant soccer or basketball, both of which were all that was offered at his small, Christian high school. Either of these activities would provide a physical outlet for youthful energy, provide a team experience, and an improved sense of self worth and acceptance. Early sport discussions with our son revolved around football; he wanted to play football by open enrolling in our local school district. After much talk and the realization that football is a strenuous, full contact sport with significant risk of serious injury to a

hemophiliac, he grudgingly let go of this ambition. Not a popular decision and one that was revisited on several occasions during his junior and senior high school years. Our son came to the realization that basketball was going to be the sport of choice. It offered everything he needed with manageable risk. He actually started playing organized basketball in 5th grade and attended several day and residential camps. The basketball experience provided him with many elements essential to the development of a young person, especially one from the bleeding disorders community. The self reliance and independence gained from the demands of traveling with a team and all that is involved with being responsible for yourself and your actions was well worth the effort involved. We watched—sometimes in amazement—as he developed the ability to deal with his disorder and its unique demands as he played a sport with teammates all across the Midwest. At times, he was unable to participate because of bleeds due to sports injuries. These situations prepared him for the realities of life for a person with a bleeding disorder.

Not to say that all of this personal development was easy or accomplished without parental input; it wasn't. As parents, we spent many hours discussing, researching, praying and fretting over decisions to participate in sports. Baseball was an option through junior high. Many hours of beneficial practice and a lot of

games were enjoyed when he open enrolled to the public school. Pitching and first base were the positions of choice but as the players got older and the ball traveled faster, this sport lost its appeal to a great degree. For dad, baseball became a non-option when we witnessed a pitcher get hit in the chest by a line drive. There was no time for him to react; the ball was just moving too fast. What if our son had been pitching and took that batted ball to the head? Baseball had lost its appeal by the end of 8th grade.

The sport of archery has also played a role in our son's personal development. It involves "lifting" weights and walking; it is a life-long sport enjoyed by millions. Our son was introduced to archery almost as soon as he could walk. It was a family sport in our household and enjoyed by our extended family as well. Through junior high, high school and into college, our son pursued archery. He eventually competed at the national level against other collegiate archers from every geographical region of the country. Schools such as UCLA, Michigan State, Arizona State, and other lesser known colleges and universities were represented at annual national contests. What an experience for any young person, let alone from the bleeding disorders community!

With all of this being written, what is to be taken from our family's experience? Simply stated, if a young person, who just happens to be dealing with a bleeding





disorder, desires to experience a sport and all it offers, there are many opportunities at all levels. Working with their healthcare providers and using common sense can yield lifetime experiences of invaluable wealth through sports.

(Vance Patrilla is currently working with neighborhood youth as a coach through the National Archery in the Schools Program. It is a school-based program that anyone can get involved in if offered by the local school district. If your child is interested, contact your local school district to see if it is offered or look up the National Archery in the Schools Program (NASP) at www.nasparchery.com)

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Navigating the Insurance Jungle – Keeping Coverage and Handling Problems

By Andy Copeland

Well it is almost time for graduation from the school of basic health insurance knowledge. But first we have one more installment. We have already discussed enrolling for insurance, tracking/recording keeping of information and documentation. Now we will cover avoiding lapses in coverage and being an advocate.

Continuation of Coverage

Just as important as getting insurance is keeping insurance. But, from time to time, your access to coverage may be limited so it is important to know what options are available to avoid gaps in coverage.

Credible Coverage is Essential!

It is important that you maintain continuous credible insurance coverage. Credible coverage is coverage you receive from a third party private insurance company or from a federal or state insurance program (example: Medicare or Medicaid). Let's say you lose your insurance due to a qualifying event (which we will discuss later) or you are starting a new job. It is important that you maintain coverage to avoid a lapse in insurance. Depending on the new insurance plan you are enrolling in, continuous credible coverage can often save you from having to wait for an open enrollment period and help you avoid pre-existing condition exclusions.

Qualifying Events

If you receive group health coverage from your or your spouse's employer and you experience a loss of coverage, there are things you need to be aware of. Loss of group coverage is typically the result of what is known as a "qualifying event." Qualifying events include changes in employment status, reduction in number of hours worked,

change in marital status or a host of other reasons. You can experience a qualifying event and still maintain your coverage through a couple of different programs.

COBRA vs. State Continuation

Continuous coverage can be obtained in a couple of different ways. Let's use the example where you are starting a new job and your new insurance will not be effective until you have worked there for 90 days. You obviously cannot go three months without health insurance coverage particularly if you are affected with a chronic disorder. So there are options available to avoid a lapse in coverage.

COBRA

In 1986 the Federal Government passed the Consolidated Omnibus Reconciliation Act (COBRA) health benefit provision. This provision gave beneficiaries receiving insurance from a company's group health plan that employs 20 or more people the option to continue their group health benefits if they were lost as a result of a qualifying event.

If you were to lose your insurance as a result of a qualifying event, you have the option to continue your coverage for up to 18 months. Here is how it works. When you experience a qualifying event, the employer has 30 days to give you the necessary documentation to request COBRA benefits. It is a good idea to take the initiative yourself and follow up on this issue with the employer. Once you receive your information on your option for COBRA, you have 60 days from the date of your qualifying event (not the date you received your information from the employer) to enroll and pay the premium for the benefits. Failure to do so will result in cancellation of your coverage and a

lapse in your benefits. COBRA is the continuation of your existing insurance benefits, but plans have the option to charge you up to 150 percent of the premium costs. So it can be extremely expensive.

STATE CONTINUATION

Similar to COBRA, State Continuation of insurance benefits is available in most states. These programs are typically available to individuals working for employers who employ 2-19 employees and are all unique and have different requirements. If you were to fall into this category, contact your state's health department to inquire about programs available to you to help you fill your gap in insurance.

THINGS TO REMEMBER WHEN DEALING WITH INSURANCE ISSUES

Finally, we want to provide you with a few tips you can use when working through issues with your insurance company. The most important thing to remember is: There are no rules! Every situation is unique and every outcome may be different.

The second thing to remember is: Don't Give Up! Don't assume the first answer you get is the correct answer or the final answer. The customer service representative you initially speak with may not have the authority or the ability to get you the answer you want. You always have the right to have your issue escalated or addressed by a supervisor. But always be respectful, write down names and work through the chain of command.

If you are dealing with a specific claim, often you have the ability to go before a peer review committee. Many insurance companies have panels that are made up of community members

(Continued on pg. 15)

Part of Something Bigger

By Stephanie Lasister

The Region VII Annual Meeting was held in Kansas City on May 19-20, 2009. Dave Brustkern and I had the honor of representing Hemophilia of Iowa. All Region VII treatment center doctors, nurses, social workers, and physical representatives as well as each chapter attended the meeting.

Dave attended the meetings of the Region VII Advisory Council. The Council discussed issues including a regional patient satisfaction survey, grants and cooperative agreements update, evaluation of HTC performance, adding new HTCs, 340B programs, NHF Standards of Service, state legislative activity, and a MASAC update and recommendations review. All chapters and HTCs were represented on the council.

The second day included "Region

VII-Part of Something Bigger," presented by Becky Dudley. The presentation included updates and the future direction of Region VI. Karen Cox, RN, PhD and FAAN, Executive Vice President and Co-Chief Operating Office of Children's Mercy Hospitals and Clinic presented "Unleashing the Power of Four Generations," which discusses communication and work styles of different generations. Val Bias, CEO of NHF presented on "Access to Care Today, Achieve a Cure Tomorrow" discussing the updated mission and direction of NHF.

After a working lunch, Jay Bryant-Wimp with Missouri Health Net Clinical Services discussed "Positive Clinical and Financial Outcomes for Hemophilia Patients Receiving Care at Missouri Hemophilia Treatment

Centers," and while the presentation was specific to Missouri, there were some interesting discussions on financial needs of patients. The meeting then broke into workshops and Kathleen Roach and Val Bias discussed strategic planning for chapter leaders. A great discussion on fundraising and planning better structure for the chapters finished off the afternoon.

On Wednesday, Dave attended the meeting in which ATHN and conversion to the ATHN dataset was discussed. Dr. Ganesh Kudva presented "Challenges in the Diagnosis of von Willebrand Disease," followed by Dr. John Puetz' presentation of "Study of FFP and rVIIa Use in Neonates," and Dr. Brian Wicklund finished the conference with "Innovative Treatment of Rare Bleeding Disorders."

Insurance Jungle

(Continued from pg. 14)

who listen to appeals from patients. This is a good opportunity for you to get in front of people who may be sympathetic to your cause.

Always remember to be your own advocate. Nobody else is going to care as passionately about your issue as you are. Patients and family members are the most effective persuaders and negotiators. Don't be afraid to tell your story, the problems you have had, and the trials you have been through.

Conclusions

To sum it up, avoid any gaps in coverage as it can present problems in obtaining insurance. Know what programs are available in your state if such a thing happens. When you do encounter problems, try to remain clam, stay focused and remember you are your best advocate.

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With each donation of \$100 or more, you will receive a copy of the *Bloodline* each quarter. If your donation was under \$100, this will be your only hard copy of the *Bloodline* but if you send your e-mail address to hemophiliaoflowa@gmail.com we will be happy to deliver an electronic copy to your e-mail account each quarter. Of course, if you are a dues-paying member of Hemophilia of Iowa, then you will continue to receive your hard copy of the *Bloodline* unless you notify us that you would rather have an electronic version.

2009 Hemophilia of Iowa Scholarships

By Shane Kelly



On behalf of the Hemophilia of Iowa Scholarship Committee, I am pleased to announce our 2009 Scholarship Awardees for 2009.

Scholarship Recipient	Amount	College or University
Nickolas Folkerts	\$ 1,300.00	University of Northern Iowa
Alex Baker	\$ 1,300.00	Western Iowa Tech
Matthew Patrilla	\$ 1,300.00	Allen College
Benjamin Meyer (John Heisner)	\$ 1,800.00	Iowa State University
Brad Jones	\$ 1,300.00	South Dakota State University
Ryan Hutchins (Dude Cremer)	\$ 1,800.00	University of Iowa
Kelsey Ledger	\$ 1,300.00	Drake University
Dylan Humburg (John Heisner)	\$ 1,300.00	University of Northern Iowa
Enrico Roth (HS Senior)	\$ 1,300.00	Marshalltown Community College
Bryce Kubik	\$ 1,300.00	University of Northern Iowa
Andrew Meyer (Part Time)	\$ 650.00	University of Iowa
Keslie Humburg	\$ 600.00	University of Iowa
Alyssa Dyall (HS Senior)	\$ 600.00	University of Northern Iowa
Tyler Kubik (HS Senior)	\$ 600.00	Kansas University
Heather Hauser (HS Senior)	\$ 600.00	Hawkeye Community College
Tom Recker	\$ 600.00	Kirkwood Community College
Matthew Hauser	\$ 600.00	University of Northern Iowa
Jacob Meyer	\$ 600.00	Kirkwood Community College
Kasey Van Wyk	\$ 600.00	Universal Technical Institute
Kendra Zantingh (Part Time)	\$ 300.00	Keller Graduate School of Management
Total Awarded	\$ 19,750.00	



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

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Kid's Corner



Sea Critters



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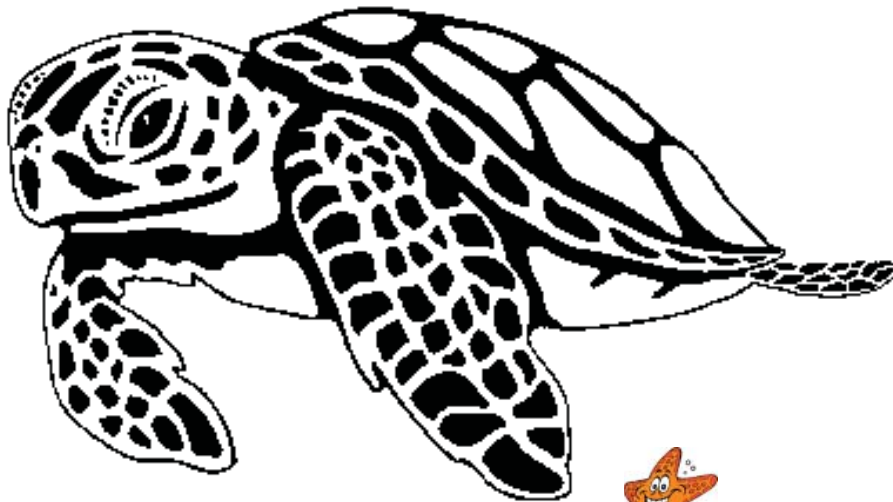
H C R A F I S D R O W



Here I am at Grand Cayman Island, playing with the baby sea turtles at the island's turtle farm!



Color Me!



Did you know this about sea turtles???

- >They can sleep underwater for several hours at a time without coming up for air!
- >The leatherback sea turtle can grow to be 7 feet long, 5 feet wide, and weigh up to 1300 pounds!
- >Girl sea turtles can lay up to 250 eggs in their nests at one time!
- >Most sea turtles live to be around 80 years old or older!



Created By: Keslie Humburg

Hemophilia of Iowa
2009 Membership Application

Name: _____

Address: _____

Phone #: _____ Cell #: _____ E-mail: _____

Please check the best option for you:

Best time to contact me: AM PM

Would you be willing to serve on a committee? Yes No

Membership January 1 – December 31, 2009
Single, Family, Industry Representative, & Friends of Hemophilia of Iowa – \$20.00

(Family includes residents in the same household with dependent children up to the age of 25. (Dependent children do not have to reside in the parent's home if away at school or living on their own.) Relative would be a sister, brother, grandparent, aunt, uncle and/or cousin to the person who has a bleeding disorder. Friends of Hemophilia of Iowa are people who do not have a relative with a bleeding disorder but are support people and friends of those who do have a bleeding disorder.)

I would like to make an additional donation of \$ _____. (This is tax deductible.)

This donation will be recognized in the BloodLine unless the following box is checked.

Please complete the following information so Hemophilia of Iowa can be of best service to you.

What is your association to the bleeding disorder community?

- I have a bleeding disorder or my spouse has a bleeding disorder.
- I am a parent of a child with a bleeding disorder.
- I am a relative of a person with a bleeding disorder.
- I am a friend/support person for someone who has a bleeding disorder.

If you are a relative or friend/support person for someone with a bleeding disorder, please list the last name of the person who has the bleeding disorder. _____

If you have a child with a bleeding disorder, Hemophilia of Iowa now has a program called 1st Step. This program is designed to provide a mentor to families with a child, aged 0-7, who has a bleeding disorder. Mentors are parents of child(ren), aged 8 +, who have a bleeding disorder.

- I would like to join First Step. I have a child 8 yrs or older and would like to be a mentor.
- I would like more information before I decide to join. Please contact me.

Please do not let cost of membership prevent you from joining Hemophilia of Iowa. Contact Kari Atkinson, HOI President, at 1-866-464-8061 for confidential financial assistance. This membership scholarship program is available for people directly affected by a bleeding disorder and their caregivers.

Please mail membership application and annual dues (Payable to Hemophilia of Iowa) to:

Kari Atkinson, HOI President, PO Box 415, Central City, IA 52214

If you wish to pay via credit card please fill out the below information: (circle one) Visa or MasterCard

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Check out our website:
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And Finally . . .

By Nancy Patrilla

Laurie Kelley has published a new newsletter that I think is very beneficial. It is called *PEN's Insurance Pulse*. It had some great articles on insurance concerns as well as hints and tips. If you would like to see an electronic version of that newsletter, go to www.kellycom.com. If you have already seen the newsletter and want to see it continue, please call their office at 1-800-249-7977 and tell them that.

Speaking of newsletters, if you want to continue receiving the *BloodLine*, please join Hemophilia of Iowa today if you haven't already. There are so many benefits to being a member: The annual meeting at very little cost, family camp, summer camp for the kids, college scholarships, and the quarterly *BloodLine* to name a few. If the cost of membership is just not possible for you right now, please contact our president, Kari Atkinson, and speak with her about it. All calls are confidential, and I am sure she will help you work something out.

Please consider training as an advocate. We plan to have a table set up at the annual meeting for those of you who have more questions and/or who would like to sign up. It promises to be a very interesting experience. And what a way to help your fellow members of the bleeding disorders community!



The medical information contained in this newsletter is for information purposes only and is not to be taken as medical advice. If you have any questions or concerns, always, check with your healthcare provider.