

Hemophilia Headlines

FALL 2004

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Out Squirrelly, Out Polar Bear, Out Blob?

BY MONICA DICKEY

"Out Squirrelly, Out Polar Bear, Out Blob" was the motto for the week as Camp Tapawingo 2004 kicked off with a theme of "Survivor". We had another amazing week of summer camp this year with almost 60 campers attending. It was a young camp this year with 14 of our campers under 8 years old! We had 11 first time campers attend and 9 new staff members joined us this year as well.



We kicked off the week at camp with our counselor orientation session on Saturday. It was the counselors' opportunity to enjoy a day of camp like a camper. We spent the morning doing team building activities with our favorite Pat "Big Dog" Torrey. It was a great opportunity for everyone to reconnect and for all of us to get to know our new staff members which included 5 former campers from last year! We spent the afternoon enjoying horseback riding, swimming

and just getting familiar with the camp grounds again. In the evening, we learned some new campfire songs and games to help keep our campers entertained for the week from Andy "Lorax" Stone.

Sunday morning we spent continuing our staff training and getting ready for the campers to arrive. The bus arrived in the afternoon loaded with happy campers ready to have a fun week. After getting settled in their cabins and having their swim checks, the campers enjoyed a scavenger hunt and spent time getting to know the camp facilities. We spent the first evening playing ice breaker games with Big Dog.

Bright sunshine greeted us on Monday morning for our first full day of camp. Campers enjoyed lots of new activities this year. We had games with Big Dog at the Dog House, made tie-dye t-shirts with Kelly Craft, learned about the environment with Andy "Lorax" Stone at the Eco Circus, and learned to fish with



TABLE OF CONTENTS

Men's Meeting	2
Local Youth Show Athletic Skills	3
Family Focus	6
Woman to Woman	9
News from the Treatment Center	10
Membership Dues, Memorials and Contributions	11
Golf Tournament Raises Money for HFO	12

CONTINUED ON PAGE 4



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Men’s Meeting “One of The Best Ever!”

“This has been one of the most enjoyable HFO events I can remember!” exclaimed one participant as the HFO Men’s Group held its first Men’s Casino Night Saturday, July 17 at the offices of Seaport Administrators in Northeast Portland.

The Casino Night was sponsored by Bayer and began at 6:00 PM with pizza and soft drinks. Attendees began the evening with \$1,000 “HFO Bucks” which were exchanged for chips at the gaming tables. After playing about an hour, a separate Blackjack Tournament was held. Open play on the tables resumed after the Tournament, and at 9:30, table play closed and the awards were announced.

Proving you don’t have to be an experienced player to be successful at Blackjack, Jim Puckett was the Casino Night Champion, collecting \$2,900 in chips. In the highly competitive Blackjack Tournament, Jeff Johnson’s total of \$165 was good enough for first place. The door prize, a portable CD player, was won by Kristopher Zwetschke.



Jeff Johnson Wins Big

- The HFO extends special thanks to:
- Bayer for underwriting the event, and providing ample food and drink, as well as very nice prizes for the winners!
 - Ed Charles and Seaport Administrators for donating the use of the meeting space.
 - Wild Bill’s Casino for the discounted rental of the professional blackjack tables and gaming supplies.
 - Chris Charles for agreeing to deal for the event, then working the entire night without a break!
 - Bayer Representative Paul Gobel, for providing food, drinks and door prizes the day of the event, despite a family emergency. (Paul says everyone is okay!)

Congratulations to the evening’s winners and a big thank you to all who attended! See you next time!



Mike & Chris Charles Deal Cards

Local Youth Show Athletic Skills at NHF/ZLB Behring Junior National Championships

Can a youngster with hemophilia play certain sports safely? By “warming up” properly, can kids who play sports help prevent injury and build joint strength? Can a person with hemophilia ever hope to play professional sports? This summer, nearly fifty kids with bleeding disorders learned the answer to all three questions: a resounding “Yes!”

Red Tail Golf Club in Beaverton proved to be a fabulous facility as the 2nd annual NHF/ZLB Behring Junior National Championship once again came to town August 14. Professional athletes Perry and Corey Parker, who both have hemophilia, provided golf and baseball clinics. Afterwards, tournaments in both sports were held; each participant received an autographed photo and a medallion.



Corey Pierce, winner of the Golf Tournament

Corey Pierce of Eugene was the winner of the golf tournament for the second straight year, while Alex Ell came out on top in the baseball skills competition. Their victories mean the two teenagers will represent the HFO in the NHF/ZLB Behring Junior National Championship Golf Tournament & Baseball Skills Competition in Newport Beach, California!

The HFO congratulates Corey and Alex on their victories and wish them success in the upcoming national tournaments!

The Foundation would like to thank ZLB Behring and the National Hemophilia Foundation for bringing the Junior National Championship to the Portland area for the second consecutive year. Only four regional events are held each summer. Officials from ZLB and NHF cite HFO members’ large and enthusiastic turnout for the 2003 event at Langdon Farms Golf Club, along with our foundation’s organization and energetic volunteers, as reasons for returning to Portland in 2004.

Hole Sponsors:

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Alex Ell, winner of the Baseball Tournament

CONTACT THE EDITOR

Do you have any suggestions or comments? Contact Jamie Dessellier, Editor of Hemophilia Headlines, at editor@hfo.info.

CONTINUED FROM PAGE 1

Mike "Coyote" Amos at the pond. Monday night was the annual capture the flag tournament.

Tuesday morning brought back a camp favorite, Corey Parker and baseball. Thank you to John Self with ZLB Behring for arranging for Corey to come back again this year. The campers always enjoy getting some one-on-one time with Corey to practice their pitching, catching and hitting to warm up for our camp-wide baseball game.

Wednesday brought an exciting day of rock wall climbing and the "Flying Squirrel". That evening was everyone's favorite night—carnival night—with music provided by "White Rhino" marimba band lead by our own Kevin "Crooked Branch" Finkle. A big thanks goes out to the band for making the trek out to camp. It's always great to have them, and it was a lot of fun hearing them play during the carnival night.

Thursday was another great day of fishing, horseback riding, kick ball games, arts and crafts, swimming, rock wall climbing, Big Dog games, and Eco Circus. The oldest cabins spent the morning setting up their camp for their annual camp out night. The younger cabins spent the evening enjoying s'mores and relaxing watching Peter Pan during movie night.

Although Friday brought a stormy day to camp, spirits weren't dampened at all when we played our Survivor games out in

the field with Big Dog. The color teams had to work together to accomplish tasks and earn keys to open a locked case with a reward inside. Everyone worked together and enjoyed M & M's at the end. Due to the stormy day, we had to cancel the annual blob contest and canoe races, but the kids made extra arts & crafts projects, caught up on some sleep from the camp out, and played games with Lorax.

Friday evening brought the annual talent show and some amazingly talented kids. We have singers, dancers, musicians and comedians in our group. It's always fun to see what talented kids we have in our community. Friday evening concluded with our annual memorial ceremony to



CAMPER CONNECTION RAISES \$2,270

This year, the Camper Connection program raised \$2,270 to support our summer camp program. The Camper Connection program asks members from our community to sponsor a camper—from one-half day up to an entire week. In exchange for their tax-deductible contribution, each donor received a handwritten thank-you card from a camper sharing what they love most about camp. Thanks to everyone to who donated to this great camp fundraising program. Your support is much appreciated, and we hope you'll participate again next year!

remember those campers and staff who are not with us any more.

Three years ago, we started the Mike Charles Outstanding Camper of the Year award. Previous winners have all continued to be important leaders in our community, including Chris Kirsch, Joey Coffin and Alex Ell. We are sure this year's award winner will be no different. The staff was pleased to present Elizabeth "Lizzy" Nelson with the Mike Charles Outstanding Camper of the Year Award. We are looking forward to watching Lizzy continue to be a leader both at camp and in the community.

As sad as we are to see it come, the week always comes to a close on Saturday morning. With lots of hugs and tears, we send our campers off to grow another year. We hope that everyone had a great experience and maybe even learned a thing or two this year. And yes, we are already busy planning what to do for next year!

Thank you to all of our corporate camp sponsors this year, Baxter, Wyeth, and ZLB Behring. We also want to thank all of the companies who donated items to camp. Thank you to Wyeth for sponsoring our horse program this year. A big thank you to Dona Koepke and the Montavilla Garden Club who helped raise over \$2,000 for camp in plant sales. Thanks to all of the contributors through our Camper Connection program which



raised over \$2,000 for camper sponsorships this year. Thank you to Chris Leland for coordinating our camp slide show and DVD. It's amazing, and if you didn't get a chance to see your camper on the big screen at the annual meeting at the zoo on September 12, we still have copies for sale. Contact Monica Dickey at the HFO office to order your copy for only \$25 per DVD. And of course, thank you to all of the staff at the Hemophilia Treatment Center for providing medical care for our camp for the week. Last, but most definitely not least, thank you to all of the volunteer staff who make



this week happen. You are an amazing group to work with and we absolutely could not pull off this week with you all.

HAPPY BIRTHDAY, CAMPERS!

JULY

David Carmichael
Christina Diaz
Alli Dickey
Taylor Hernanded-Shafer
Flossy Marchese

AUGUST

Michael Brassel
Racheal Dagenais
Mitch Dickey
Christian Sanders
Natasha Singler
Jaydra Thurber

SEPTEMBER

Travis Davenport
Kevin Harper
Kyler Hoskins
Ryan Hoskins
Ian McGough
Shantell Moffit
Kurt Moreton
Caleb Pedersen
Gerry Tejada
Jesse Winn



Family Focus

The Prophylaxis Decision

BY DIANE O'CONNELL

SOURCE: CONDENSED FROM AN ARTICLE IN HEMALOG, SEPTEMBER 2004, VOL. 15, NUMBER 3, PG 3-5

Thirty-seven years ago, researchers in Sweden took the bold step of placing a generation of children with hemophilia on prophylaxis. Since that time, this once-revolutionary approach has changed the face of hemophilia treatment throughout the world. Today, prophylaxis is an accepted—and encouraged—form of treatment for those with severe hemophilia. In the US in 1994, and again in 2001, the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation recommended prophylaxis as the optimal treatment option for individuals with severe hemophilia, and the World Health Organization and the World Federation of Hemophilia also endorsed it.

With such heavyweight backing, it would seem that prophylaxis would be the dominant form of treatment in this country. Surprisingly, the US has been slow to embrace it—much slower, in fact, than our cousins to the north. According to a 2002 survey of North American hemophilia treatment centers, only 47 percent of US children under the age of 18 with severe factor VIII deficiency were on prophylaxis treatment, compared to 77 percent of Canadian children. [The Centers for Disease Control's (CDC) on-going survey of people with hemophilia], the Universal Data Collection Program (UDC), confirms that figure. According to UDC, 31 percent of all Americans with severe factor VIII deficiency are on primary prophylaxis, compared to nearly 59 percent who receive episodic care (also known as on-demand therapy). When broken into age groups, nearly 47 percent of children aged 2 to 5 are on prophylaxis—but that means the majority of children are not.

The Benefits of Prophylaxis

Prophylaxis is endorsed by so many for a number of reasons. Primary prophylaxis provides for infusion of factor VIII or factor IX into the bloodstream at frequent, scheduled intervals. (Secondary prophylaxis is initiating prophylaxis following the development of a target joint or after a certain number of infusions for various bleeds.) The goal is to “transform” the person with severe hemophilia into one with moderate hemophilia for as long as prophylaxis is continued, by preventing the individual's clotting factor from falling below 1 percent. The result of this treatment is near-elimination of joint bleeds and even life-threatening episodes such as intracranial bleeds.

“For children who are the most severe, the greatest risk of death is in the first five years of life and from intracranial hemorrhages,” says Diane Nugent, MD, medical director and director of hematology of the Hemostasis Thrombosis Comprehensive Treatment Center at Children's Hospital of Orange County, California. “Since we've started doing prophylaxis, not a single child here has had an intracranial bleed.”

In addition to its life-saving benefits, the long-term advantages of prophylaxis are obvious: because there are few, if any, joint bleeds, there is no joint damage. Children on prophylaxis can take part in sports and other active pursuits, which may have been deemed off-limits in the past because of the potential for injury resulting in bleeds. "One thing that's most striking to me is the change in family lifestyle when the child goes on prophylaxis," stresses Dr. Nugent. "The children don't bleed and they participate in all activities. In essence, they are living a normal life."

Prophylaxis also gives families much greater flexibility. Parents, who had been fearful of leaving their child in the care of another, now find they can relax while away, knowing that there is less risk of a bleeding episode. Parents are free to plan outings and vacations with little concern that a last-minute bleed—or one on the road—will interfere with their carefully made arrangements.

With all these benefits of prophylaxis, it would seem that every parent would be rushing to go this route. Why, then, aren't more American children being treated with prophylaxis? To find out, HEMALOG interviewed a number of expert observers who told us what affects the prophylaxis decision.

Treatment Center Limitations and Attitudes

One of the biggest factors in the decision-making process is the treatment center, itself. Not surprisingly, centers that are committed to prophylaxis tend to have a higher percentage of patients on this treatment. Dr. Nugent, whose center, she says, is "very pro-prophylaxis," believes that the manner in which the treatment center staff presents prophylaxis to the families makes a big difference. "We take a lot of time educating parents and presenting the pros and cons of it," she says. "You need to really educate families and give them the data from the long-range European studies."

Amy Shapiro, MD, medical director of the Indiana Hemophilia and Thrombosis Center in Indianapolis also points out the time involved in educating parents as part of the decision. "It is very difficult for a family with no history of hemophilia to absorb information about the disease early on—and if you add in a discussion of prophylactic treatment, well, that's a lot for them to digest," she says. "Making this choice requires continuing discussion, because if you take parents' first negative response as a final decision, it's likely they'll forget about it and move on." She says she has also found that sometimes the child must experience a bleed for families to make sense of prophylaxis as a treatment option.

However, there are some treatment centers that do not actively promote prophylaxis for several different reasons. They may not have sufficient staff to educate parents adequately, or they might be responding to the financial constraints imposed by their particular state's policies. And some may be reluctant to encourage prophylaxis as a treatment option based on the attitude of the center's medical director. "Not everyone in the treatment community universally accepts prophylaxis as the best course of treatment," Dr. Shapiro says.

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CONTINUED ON PAGE 8



Family Focus, cont'd.

PARENT SUPPORT GROUP

The Parent Support Group meets bi-monthly at Bullwinkle's Family Fun Center in Wilsonville at 6:30 p.m. Contact Patina Fieken at 503-625-6508 for further information.

The Time Treatment Takes

The time it takes to administer prophylactic treatment is an important issue for families. Prophylaxis is a demanding regimen, requiring infusions from twice a week to as frequently as every other day. Indeed, one recent study found that the biggest barrier to initiating prophylaxis was the parents' perception of how time consuming it was.

Difficulties With Venous Access

Another often-cited argument against prophylaxis is the need for frequent venous access, a problem especially with children. "To do prophylaxis on a very young child with a catheter is extremely difficult," says Dr. Nugent. Scarring happens quickly, further limiting the possibility of access veins for infusions. Then there's the trauma—for both parent and child—of sticking.

For these reasons, many families opt for a venous access system, usually a port, which is placed under the skin and allows easy access to the vein. However, these systems can have potentially serious problems of their own, namely infection and clotting. At Dr. Nugent's center, the preferred access device is a portacath, which is surgically implanted under the skin with the catheter inserted into a vein. This system is less subject to infection than Broviac lines, which extend outside the skin.

The Reality of Cost

The prophylaxis price tag in a country without socialized medicine is a huge issue for families evaluating the treatment. The cost of factor is substantial, and prophylaxis is significantly more expensive than on-demand therapy. It's true that long-term gains offset the cost of prophylaxis: a healthier body with healthy joints that do not require treatment and possibly surgery; not losing money from missed days of work. Still, those gains are far down the road, and in the meantime, insurance-coverage considerations loom. Many plans have a lifetime cap, and parents fear that the high cost of factor may force them to reach that cap all too soon. Furthermore, some insurance companies balk at the expense of prophylaxis vs. on-demand therapy.

Help in the Future: A Definitive Study

In a few years, parents considering prophylaxis will have much more information to help in making the decision. The Mountain States Regional Hemophilia Center in Denver is conducting an on-going study, commonly referred to as the "Joint Study," funded by the CDC. The Center started this in 1996 and has enrolled 65 children, initially under the age of two-and-a-half years, who had experienced no more than two bleeds in a joint; they were randomly assigned to either prophylaxis treatment, receiving factor every other day, or on-demand therapy entailing standard protocol to infuse in response to a bleed. The study is following children until they reach 6 years of age, which the last participant will do in 2005. Study authors expect to report results shortly after that time.

Woman to Woman



Ladies' Lunch a Success

In July, a number of ladies from the bleeding disorders community met for lunch at the Avalon Hotel. The group included women from all areas of our community: those with bleeding disorders, wives and mothers of persons with bleeding disorders and siblings. The afternoon was spent chatting, eating, and getting to know one another. Our thanks to Vicky Tody and Hemophilia Health Services for sponsoring our event.

Prophylaxis for von Willebrand Disease?

BY DIANE O'CONNELL

SOURCE: HEMALOG, SEPTEMBER 2004, VOL. 15, NUMBER 3, PG 5

Joint bleeds are not often thought of in conjunction with von Willebrand Disease (vWD), yet they do occur. In fact, Swedish studies have shown that, although the most common bleeding in young children with vWD is oral and mucosal, joint bleeds start in the school years and increase during adolescence. The result, especially in Type 3 vWD, can be a surprising incidence of joint disease and restricted range of motion that increases over time.

Although joint disease may be rare in Type 1 vWD, Thomas C. Abshire, MD, Director of the Emory Comprehensive Hemophilia Program in Atlanta, reported at the 2003 National Hemophilia Foundation conference that prophylaxis may certainly be justified in those with Type 3 vWD, in whom the incidence of joint disease may be as high as 40 percent.

Not all centers take this approach, however. At the Indiana Hemophilia and Thrombosis Center in Indianapolis, Type 3 vWD patients are treated intermittently with IV infusion of factor. "If a patient has a dental appointment and we know she's going to bleed, then we may administer factor prophylactically," says the center's medical director, Amy Shapiro, MD.

Part of the reason prophylaxis has not caught on for vWD is the small number of patients who could benefit—only about 100 nationwide, according to Peter Kouides, MD, Director of Research, and Associate Medical Director of the Mary M. Gooley Hemophilia Treatment Center in Rochester, New York. He says that even in his center, which specializes in treating vWD, only one of his patients is on prophylactic treatment for ankle and elbow joint disease.



News from the Treatment Center

AIDS Memorial Service in December

The Oregon Hemophilia Treatment Center and the Hemophilia Foundation of Oregon invite you to attend a memorial service to remember and honor loved ones in the bleeding disorders community who have died from AIDS and/or other complications from their bleeding disorder:

Saturday, December 4, 2004, 11:00 am to 12:00 pm

Doernbecher Children's Hospital

700 SW Campus Drive, Meditation Room, 10th Floor

Reception immediately following

If you would like to attend, please call Tammy Vogel, (503) 494-8716, by Wednesday, December 1. If you need a map to Doernbecher, let Tammy know and one will be mailed to you. You are welcome to bring a picture of your loved one(s) for display at the service.

SCHOOL/COMMUNITY VISITS

It's that time of year again!

Call the Treatment Center

(503.494.8716) to discuss the possibility of a school visit if you think your child would benefit.

Treatment Center staff can talk to teachers, playground staff, teacher assistants, administrators, school nursing personnel, and even local emergency personnel. Let us know how we can help you get important community members educated about hemophilia care.

Recombinant Factor VIII Choices

Patients have been asking about newer recombinant factor products that are now available. A great resource for detailed, objective information about the different factor choices is the National Hemophilia Foundation website. Under "Research" and associated with MASAC recommendation #151, is a chart listing all the products as well as information about the manufacturing process, storage, half-life, and diluent volume. (www.hemophilia.org/research/masac/masac151.htm)

The Oregon Hemophilia Treatment Center does not prefer one recombinant product over the other, but we do think it is important for patients to be aware of changing market choices. One of the qualities shared by all of the second and third generation products is a much smaller diluent size, anywhere from 2.3mL to 5mL. In comparison, older, first generation product uses a 10mL diluent.

Storage can also be an issue, especially when traveling. Some of the newer products need refrigeration, but some allow storage to be at room temperature for up to three to six months.

All manufacturers now offer some kind of financial or product assistance program. Many also offer sample product to patients interested in trying their product before switching to a new brand. Within the last year, the prices on all the second and third generation products have come down, making cost less of a factor in product choice.

Please call us if you have questions about any of this. The information can be overwhelming, and the environment is very competitive right now. Call the Treatment Center if you have any questions about new (or old!) recombinant factor VIII choices.

Membership Dues, Memorials and Contributions

Dues, memorials and contributions as of September 26, 2004.

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Worthington, Bill & Nancy

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Golf Tournament Raises Money for HFO

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newsletters. Don't miss out on
important information and
events!

The Hemophilia Foundation of Oregon was again the beneficiary of all monies raised as Dennis' Seven Dees Landscaping held its annual golf tournament July 9 at the Oregon City Golf Club.

The HFO team made one of its best showings in years. They were one of four teams shooting a total of 11-under-par, which was good for a tie for second place! The HFO team of John Self, Joe Kelly, Ed Charles and Mike Charles were one stroke off the winning score of 60.

At the banquet following the tournament's conclusion, company Vice President Dave Snodgrass from Dennis' Seven Dees Landscaping presented the HFO with a check for \$1,475. What's more, John Self announced ZLB Behring would match the total amount Seven Dees raised from the tournament; at the end of the day, the HFO was presented with checks totaling \$2,950.

The Foundation would like to extend a special thank you to David and Dean Snodgrass for their continued support—2004 was the 8th year the HFO was the sole beneficiary of the tournament. Also, thanks go to John Self and ZLB Behring, whose matching gift of \$1,475 was in addition to the funds they annually donate to our foundation. Thank you, gentlemen, and we'll see you on the links next summer!



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Address correction requested