

Hemophilia Headlines

FALL 2007

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The Amazing Race!

BY PAT TORREY & MONICA DICKEY

Every year at the end of our summer camp program, the camp committee gets together and says, "How are we ever going to improve on this camp, this was the best camp ever!" Well, once again, Camp Tapawingo 2007 was voted to be the best camp ever as campers and staff alike enjoyed "The Amazing Race".

This year we expanded on our Counselor In Training and our staff training programs by making them not only longer, but more comprehensive as well. This amounted to an amazing camp staff this year. If you run into any of our camp staff during the year, please give them a big thank you as they all put in a very long, very demanding, yet very rewarding week with our kids.

If your kids came home from camp saying that they visited exotic places such as Egypt, Antarctica, Switzerland or the Amazon they were right.

If your kids came home from camp saying that they visited exotic places such as Egypt, Antarctica, Switzerland or the Amazon they were right. If your kids came home from camp saying that they visited exotic places such as Egypt, Antarctica, Switzerland or the Amazon they were right. they visited exotic places such as Egypt, Antarctica, Switzerland or the Amazon they were right. Upon arrival to camp, everyone was issued a passport, a travel bag and directions for their first leg of their week-long race with their cabin groups.

The groups raced around the world (as it was super-imposed on the actual Camp Tapawingo map!) to complete a variety of challenges which ranged from making humus to winding their way through laser beams without breaking the beam of light. At the completion of their challenge, they would be issued the next clue to continue on the race. Each day the kids learned about new countries, including their language, culture and even their weather. We even had country themed meals!

One of the highlights of the race was the auction held on Tuesday night where cabin groups bid against each other for items such as a can of beans, WD-40, breakfast in bed, and even a surprise field trip. While everyone thought the littlest cabin lost out with their purchase of the beans, in the end having the can of beans won the race for our youngest cabin group.

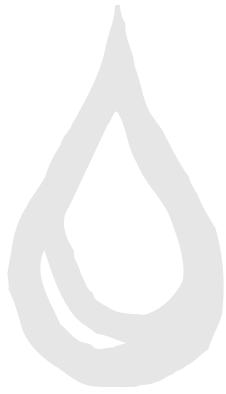
Amazingly enough, we even had time to fit in everyone's favorite camp activities during the day including horses, archery, making pine-wood derby cars in arts & crafts, fishing, eco circus, hiking, swimming, boating and blobbing and a variety of field games and activities. We also introduced our older kids to a new activity this year, mountain biking. Thank you to Santiam Bicycles and Robert Fox of the Bicycle Transportation Alliance for donating the use

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This issue sponsored by Wyeth



President's Message

BY CHRIS LELAND

Back to School, falling leaves and resetting the clocks! I hope that everyone had a fun and safe summer with many fun memories made. Camp was a blast this year, our fund-raising efforts successful, and many new and exciting programs are in the works. Our annual meeting attendance was higher than anticipated. It was great to see so many familiar faces, and I was glad to meet many people that I had not known before. I also want to thank everyone that turned in a survey at the annual meeting; this will help us greatly to help our community. Surveys are included with this newsletter if you did not attend, or did not get the chance to turn one in.

Summer camp was a huge success this year! We had 64 campers, more than any year prior. Patrick "Big Dog" Torrey took us for an incredible journey around the world with our Amazing Race themed camp, all while having campfire at the same place each night. We also had our surf camp this summer for our Junior Counselors where they surfed, had a blast working together and all grew from the experience.

We were very successful in our fundraising efforts this year. We partnered with the HTC in putting on the 2nd annual Shooting for the Stars pool tournament and auction. We are very pleased and excited to have worked with the HTC on this project and are very optimistic about the programs and services to come out of this relationship.

I am also very excited to have Patrick Torrey and Don Smith as new board trustee's this year. Pat has worked with youth and adolescent populations for many years, and we are excited to have that experience and wisdom in our group. Don has served on other bleeding disorder organization boards before, at the trustee and executive level. His experience and insights are invaluable to the board and me. He is also our newsletter editor, and is doing a wonderful job. Thank you to both Pat and Don for stepping up.

It has been an honor to serve as board president this past year, and I thank you for the opportunity of another year. My main goal this coming year is to reach out to those in the bleeding disorders community that we have not reached in recent years and to strengthen our relationship with the HTC to bring our community the most beneficial programs possible.

HEMOPHILIA FOUNDATION OF OREGON

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An Oregon Surfin' Safari

BY PAT TORREY

"You know in Southern California we don't even really consider going outside when it's raining, never mind going to the beach to surf." This was the early morning sentiment of Jim Dawdy as he peered out the window of our beach house, the morning of our surf camp at the Oregon coast.

Our group met the day before in Portland and had traveled together to Cannon Beach for pizza and some tide pool exploration at Haystack Rock before heading south to a beach house at Rockaway Beach that served as our home for the weekend. The group that attended this weekend were the 'Counselors In Training' (CIT's) for the HFO Summer Camp and other teens and young adults interested in an opportunity to connect with friends from camp, leadership training workshops and a chance to learn how to surf in some of the coldest water on the West Coast of the United States. Delicious and intricate meals were prepared from scratch by the group, which compelled many of the newer college students to give the younger members of our group the advice to "Pay attention now, because this is very important." Between ping pong and campfires with well toasted marshmallows and the experiment of crunchy peanut butter on a s'more (not to be missed), everyone enjoyed a cool Oregon early summer night.

The next day, after another big meal, a winding road and only one instance of car sickness, we arrived at Oregon Surf Adventures in Cannon Beach. We all shimmied, tugged and pulled ourselves into thick wetsuits looking like a cast for a new nautical X-Men movie, then grabbed surfboards and ventured down to Oswald West State Park, one of the most popular surf spots on the Oregon coast. Our instructors gave us entertaining and detailed instructions on surf technique, etiquette and safety and quickly got us in the water. Some members of our group were fairly tentative about even approaching the water, but after an hour there was no chance of getting them out. Pop-up after pop-up these brand new surfers were showing their pipe master potential. Catching waves, quickly 'popping up' onto their feet and adjusting themselves accordingly, our group rode their new boards on wave after wave, typically finishing with a splash and a paddle back out on their bellies for another round. Being an incredibly tiring sport, the one craving that got them off the waves was hunger. The afternoon was filled with a warm fire on the beach, a surf competition and general silliness in the surf.



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Meet Michael Recht, M.D., Ph.D

(REPRINTED FROM WWW.OHSU.EDU)

PARENTS SUPPORT GROUP MEETING

Meetings are held every other month at 6:30 p.m. at Bullwinkle's Family Fun Center in Wilsonville. Contact Patina Fieken at 503-625-6508 or PatinaF@verizon.net for further information.

Biography

Dr. Recht serves as the regional director for the federally-funded Hemophilia Treatment Centers in the states of Oregon, Washington, Idaho, and Alaska. He is also medical director of the Oregon Hemophilia Treatment Center. Before joining the faculty of OHSU in September 2007, Dr. Recht had been director of the hematology service and Hemophilia Center at Phoenix Children's Hospital for 10 years. His primary clinical focus is the treatment of children and adolescents affected by non-malignant blood conditions, particularly bleeding and clotting disorders. As a member of the Division of Pediatric Hematology/Oncology, he contributes to the care of patients with cancer and blood disorders at Doernbecher Children's Hospital and directs the Pediatric Hematology Consult Service. Dr. Recht has actively participated in over 30 clinical research trials testing new treatments for children with bleeding and clotting disorders. In addition, he is currently engaged in research studying the psychological and educational impact of chronic illness in childhood. After growing up in Milwaukee, Wisconsin, Dr. Recht received his BS in psychology, his PhD in human cancer biology, and his MD, all at the University of Wisconsin. He completed his residency and fellowship training at Yale University School of Medicine.

Professional Education

Degree(s):
MD: University of Wisconsin, 1992
PhD: University of Wisconsin, 1990
Residency: Yale New Haven Hospital
Fellowships: Yale University School of Medicine

Certifications

Pediatrics
Pediatric Hematology-Oncology

Clinical Interests

Childhood, adolescent and young adult bleeding and clotting disorders

Clinical Research

Development of new clotting factor products; neuropsychological consequences of chronic illness in childhood and adolescence

First Step: A Mentoring Program

BY PATINA FIEKEN

First Step is the National Hemophilia Foundation's program for parents and families of children newly diagnosed with bleeding disorders. The program was established in 1995 as a joint initiative of NHF and the Centers for Disease Control and Prevention. Chapters work with hemophilia treatment centers (HTCs) to offer First Step programs in their communities.

In April, Patina Fieken (representing the chapter), Lori Evans (representing the "consumer"), and Joann Deutsche (HTC), attended a two-day Train-the-Trainer workshop. The goal of the training is to prepare attendees to initiate or strengthen First Step Programs in their communities. The curriculum content will benefit families of even school-aged children. Oregon has never had a formal First Step program and we are excited about organizing an Oregon training workshop to be scheduled (hopefully!) sometime later this year.

We are looking for six to eight volunteers who would be willing to attend a 1-2 day training session (all expenses paid) that will instruct participants how to be a parent support/mentor for the community. Trained volunteers are expected to facilitate further relationship-building and encourage family-to-family support by being available by phone or other means. We want the peer support volunteers to be representative of the community (gender, diagnosis, geography, age, cultural background, etc). If you are interested, call Joann at 1-800-452-3563 or 503-494-8716, or Lori Evans at 541-878-4600.

CONTACT THE EDITOR

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

CEO Program Spells Success

BY DON SMITH

On September 22nd, several youth in our community gathered for a day of activities designed to address the issues of career and family choices as they relate to living with a bleeding disorder. Through a series of seminars and workshops, sponsored by Baxter BioScience, participants learned about the financial impact early choices can make. During one workshop they each got to "buy" necessities such as a home, car, insurance, furniture and entertainment. Depending on the "salary" they each had, some even got to learn about indebtedness!

The goal of the program was to teach each participant how important planning is in preparing for life as an adult, especially when faced with managing a bleeding disorder. Through fun activities, laughing and education, each participant came away from the day with a more complete view of the practical aspects of life.

Thanks again Baxter for sponsoring such a great opportunity for our youth!

Pool Tournament Raises The Bar

BY CHRIS LELAND

Our 2nd annual "Shooting for the Stars" fundraiser at El Gaucho was very successful. The Hemophilia Foundation of Oregon and the Hemophilia Treatment Center at OHSU partnered for the second year in this wonderful event that will help both of our organizations better serve the bleeding disorders community.

We had a full house at the El Gaucho Restaurant with over 130 guests showing up for our charity event. There were three pool tables set up, one of which was auctioned off during our live auction. Mike Massey, the 15 time world

trick shot champion came again to do an exhibition show which was enjoyed by all. The evening included a silent auction, live auction, pool tournament, poker tournament and a special appeal in which guest could give freely to our organizations.

On behalf of the HFO, the HTC, and personally, I would like to thank the McKay family for hosting this event and opening the doors of El Gaucho to so greatly benefit our mission. Special thanks to Todd Moore, Beth Rankin and Sherwood Dudley of El Gaucho for all of their hard work over the many months before this event to make it so successful. Thank you also to the entire El Gaucho staff there that night, you all made this a magnificent evening which would not have been possible without your hard work.

Thank you to Monica Dickey, Greg Jablonski of Wyeth, John Self of CSL Behring, and Tim Coffey for all of your months of prep work to make this evening possible.

I would lastly like to express a very sincere "thank you" to all of the participants of the event. Your participation and exceptional generosity will so greatly benefit the bleeding disorders community in Oregon and SW Washington.



SevenSecure

A patient assistance program created just for patients with hemophilia and inhibitors

SevenSecure is open to anyone with hemophilia with an inhibitor or factor vii deficiency regardless of what brand of factor they use

Benefits for enrolling now:

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- Get a head start on paperwork to apply for financial and insurance aid
- Begin thorough search for alternate insurance
- Special programs that may help with insurance premiums
- Up to six months of NovoSeven free of charge
- Help with certain medical and dental expenses
- Financial help for education and tutoring

SevenSecure is a private program supported by Novo Nordisk, Inc and is operated by an independent third party administrator. These administrators are committed to the confidentiality of your information. Your privacy comes first.

Contact sevensecure 1-877-668-6777 to enroll by phone.

<http://www.novoseven-us.com> for further information: click SevenSecure tab in upper right hand corner and enroll online.

The Place Was a Zoo!

BY DON SMITH

HFO's Annual Meeting was once again held at the Oregon Zoo on September 23rd. Following some "free time" to visit the exhibits, the community gathered for a look at the offerings from Industry, hear a fantastic presentation about Summer Camp, network with other community members and eat! Awards were presented and Camper of the Year was awarded to Cody Holman. Congratulations, Cody!

President Chris Leland spoke about the past year's accomplishments and hinted at what's to come. The Board of Directors was recognized and represents a broad base of the greater Portland community. It's evident that the leadership of HFO intends 2008 to be one of greater community involvement, expanded activities and more opportunities for all of us.



Cody Holman Accepts Camper of the Year Award

Amazing Race, cont'd.

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of their bikes and volunteering to come out and run this program for us. This was a fantastic program that was "geared" for all ability levels.

Evening activities included more Amazing Races, Capture the Flag, a visit from the White Rhino marimba band on Wednesday evening, camp out and movie night, and for the grand finale a celebratory dance on Friday evening hosted by Spotlight Entertainment out of Klamath Falls (thank you Heiner's!).

Thank you so much to everyone who helped make this week possible, especially the wonderful medical staff at the Oregon Hemophilia Treatment Center. They take such great care of all of our kids (and staff too!), we could not do this without their support.

Next year marks the 25th anniversary that the HFO has been at Camp Tapawingo. You can be sure that the camp committee is already working on making the 2008 Camp Tapawingo the best camp ever! Mark your calendars for the 2008 HFO summer camp, it will be held Sunday, August 3rd – Saturday, August 9th.

GoodSearch.com Benefits HFO

www.GoodSearch.com is an Internet search engine that can benefit The Hemophilia Foundation of Oregon. For every search performed, HFO receives one cent. That may not sound like much, but consider how many times you currently use Google or Yahoo! Just go to www.GoodSearch.com, enter "Hemophilia Foundation of Oregon" in the space labeled "Who do you GoodSearch for?" and start earning pennies for HFO!



Thank You!

HFO would like to thank the many industry personnel who give their time and energy to our community. Without the support of these individuals and the companies they represent we would not have the ability to offer the wealth and diversity of events and programs that we do.

To each of these individuals, please accept our gratitude:

John Self – CSL Behring

Chad Fletcher – Baxter

Greg Jablonski – Wyeth

Reid Morgan – Bayer

Dwayne Whitis – Care For Life

Kevin Finkle – Caremark

Andy Toshida – Factor Health

Vicki Tody – Hemophilia Health Services



Surfing, cont'd.

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We capped off our weekend with one more night at the beach house. The teens had one more challenge on their plate before they completed their weekend. When given the directions to make brownies and whipped cream, they knew that they needed to memorize them because the recipes would be taken away before they began. What they were not privy to was that they would all be blindfolded for this culinary challenge. The result was fairly edible with non-stop laughter and a great team effort demonstrated by everyone.

This event, along with our other recent teen events presented by the Hemophilia Foundation of Oregon, have been well attended and have received great reviews from all of the participants. Our next teen and young adult event will be a weekend of skiing and snowboarding (or just enjoying the mountain) at the Timberline Resort on Mt. Hood on December 21st and 22nd, including a night spent up at Silcox Lodge above the tree-line. This event is open to youths 15 – 25 and includes siblings.

HAPPY BIRTHDAY, CAMPERS!

NOVEMBER

Christina Cacouris
Zachary Pedersen

DECEMBER

Ricky Ramos
Chelsey Goshorn
Austin Olson
Cody Holman
Christian DuBois

JANUARY

Dimitri Cacouris
Alex Burden

FEBRUARY

Samantha Cosgrove
Crayson Neeley
Dekota Bradley
Taylor Stuckey
Christian Heiner
Lindsey Groling
Courtney Perkins
Caitlin Kirsch

From The Editor

BY DON SMITH

It is with sadness that I must announce that this will be my last issue of "Hemophilia Headlines." I have accepted a new career on the East Coast and will be leaving Oregon in the coming weeks. Although brief, my tenure as editor has provided me with a great sense of accomplishment and the opportunity to spend time with many fantastic people who make up our community. Rest assured, the newsletter itself will continue on and become ever better!

Don't be dismayed at good-byes. A farewell is necessary before you can meet again. And meeting again, after moments or lifetimes, is certain for those who are friends.

— Richard Bach

"I'm Goin' to DisneyWorld!"

Thank you to all of the families who applied for the 2007 National Hemophilia Foundation scholarship. We wish that we could have sent everyone who wanted to go, however with limited funds, we were only able to send two families this year. We hope that everyone will take the opportunity to apply for next year's conference as this is an amazing opportunity to learn from nationally know leaders in the bleeding disorder community and network with others from across the country.

The Holman family from Eugene was one of our winners this year. This family had never attended an NHF meeting before and was looking forward to this unique meeting experience. I think Denise Holman summed it up best when she said, "Throughout Cody's life, we've focused on how the trials and tribulations have made us stronger. In contrast, it would be nice to have the opportunity to focus on how fun, friendship, laughter and fellowship also strengthen us."

The second family chosen for this year's scholarship was the Fieken family. Many of you may know Patina Fieken from one of her many volunteer efforts over the past 10 years. Patina has been the leader of the family support group, served on the HFO board of directors, volunteered as a camp counselor and attended numerous conferences such as NHF's On The Road, the PEP training conference and the First Step conference this past spring. The Fieken family has some unique circumstances in that the entire family has VonWillebrand's. This was the first NHF annual meeting that the entire family had the opportunity to attend.

Membership Dues, Memorials and Contributions

Abken, Danial
Adams, Ken & Jamie
Adams, Patty & Fred
Aina, Rowena (*Patron*)
Allen, Harriet & Earl
Amos, Mike & Sharon
Anderson, Mary Lou
Angell, Charles & Shirley
(*Patron*)
August, Marilyn
Brassel, Susan
Bruce, Doris
Cameron, Phyllis
Carpenter, E. Powell
Charles, Linda (*Patron*)
Chvatal, Dave & Marci
Kociemba
Connolly, Beth
Cook, Thomas & Jean
Cunningham, Sandra
Di Pasquale, Gaye
Dickey, Jim & Sharon (*Patron*)
Dickey, Tom & Monica
Evans, Lori & Philip
Fieken, Tim & Patina
Finkle, Kevin & Kathy
Fisher, Lisa
Gassaway, Lee
Glenzer-Gelatt, Vicky (*Patron*)
Goldman, Jan
Gruher, Jim & Monica
Hammar, Wilma
Harper, Ken & Ingrid
Harrison, Esther
Heffernan, Bob & Francy
(*Patron*)
Heffernan, Kevin & Jana (*Patron*)
Heiner, Suzanne
Ingram-Rich, Tim & Robi
Jones, Alan & Jill (*Benefactor*)
Koepke, Don & Dona (*Patron*)
Kurilo, Sylvia
Laam, Mary (*Patron*)
Lapp, Forbes & Carol
Lapp, Jed
Lavelle Family
Leland, Chris
Liberman, Art & Gail
Lindemann, Dr. James
Lofland, Joan
Malek, William
McAlpin, Jim & Esther
McClure, Lester & Wanda
(*Benefactor*)

Meyer, Michael
Nelson, Cliff & Kristy
Nelson, Doug & Faye
Oleson, Dave & Marsha Parmer
Pagenstecher, Toni & Gary
Pedersen, April & Bernie
Petrick, Frankie
Pierce, Doug & Cindy Secret
(*Patron*)
Polo, Guillermo & Fanny
Polo, Oscar & Amy (*Patron*)
Porter, Clara (*Patron*)
Potwora, Tamara & Paul
Reutlinger, Ted & Catherine
Strong
Robinson, Linda & Charles
Ruff, Lola
Ruth, Eileen
Schuff, Arthur & Sharon
Schuman, Steven & Theresa
Sharbuno, David
Sherwood, Neil & Nancy
Stanley, Jess
Thurber, Alan & Kala
Tody, Vicky
Tschida, Dale & Anita
Wagner, Edward
Winn, Marilyn & Toby
Worthington, Dave & Pam
Worthington, Nancy (*Patron*)
Zwetschke, Linda & Chris

DONATION IN HONOR

Anne Pagenstecher
From Nancy Worthington
Ann & Gary Linn
From Mike & Sharon Amos
Steve & Debbie Olson and Family
From Mike & Sharon Amos
Sharon & Jim Dickey
From Mike & Sharon Amos
Nancy Worthington
From John & Mary Pelton
From Anne Pagenstecher
Kara Hakim
From Dr. Oscar Polo

MEMORIAL DONATION

Michael Lofland
From Joan Lofland
Nathaniel Kurilo
From Tom & Jean Cook
Mary Josephine Mohn
From Nancy Worthington

William "Bill" Schuff
From Marian Lahav

Gene Fukui
From Diana Hardy

Mike Charles
From Doris Bruce

CAMP

Alan & Kala Thurber
Cliff & Kristy Nelson
CSL Behring
Dave Oleson & Marsha Parmer
Eric & Ruth Bauer
Hemophilia Health Services
Howard Schechter
Jason & Sue Perkins
Katrina Brown
Naccho Cup - 2nd Place Award
Rhonda Boni-Burden
Sandra Cunningham
Steven & Theresa Schuman
Wyeth Pharmaceuticals

CAMPER CONNECTION

Anne Pagenstecher
Corey & Mindy Hill
Dale & Anita Tschida
Dick & Gail Taylor
Dr. Robert Heffernan
Faustina Dickey
Gaye DiPasquale
Jim & Sharon Dickey
Jim & Sylvia Kurilo
Kevin & Jana Heffernan
Krysten & Sam Wiseman
Louise Usher
Mike & Kris Mitchell
Mike & Sharon Amos
Sam & Krysten Wisman
Sandra Cunningham

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Novo Nordisk
Oscar & Amy Polo
Sylvia Kurilo
Ted Reutlinger & Catherine
Strong
The Standard
Vicky Tody
Weyerhaeuser Company
Foundation
Wyeth

PAYROLL DEDUCTION

Barbara Hillgoss
Don Smith
Gloria Brogan
Kristy Nelson
William Malek

ANNUAL MEETING

Baxter
Bayer Healthcare
Bayer Healthcare
BioRx
Care For Life
Caremark
Coram
Critical Care Systems
CSL Behring
Factor Health Management
Factor Support Network
Griffols
Hemophilia Health Services
Novo Nordisk
Recombi
Specialty Therapeutics
Wyeth

AUCTION

Bates WenDell Diamond
Brokers
Baxter
Bayer Healthcare
CSL Behring
Hedinger Family Trust
Novo Nordisk
Packouz Jewelers
Wyeth Pharmaceuticals



Article

Room for one more article...



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Address correction requested