

Hemophilia Headlines

FALL 2003

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20 Years of Summer Camp

BY MONICA DICKEY

This year marked the 20th anniversary of the Hemophilia Foundation of Oregon Summer Camp being held at Camp Tapawingo. It was with this in mind and the spirit of the founders of that camp, Mike Charles, Doug McAllister, Pam and Joe Kennedy, Joe Singler, and Patty Adams, that the camp committee initiated planning of this year's summer camp program.



Happy campers!

returning crew to become acquainted, renew old friendships and begin the week on the right track.

Many activities implemented in this year's counselor orientation program were learned at the NACCHO conference held last March. There were some great ideas on staff training and helping campers to have the best possible experiences in their week at summer camp. I think all the staff can attest to this being one of the best camps ever!

The bus arrived right on time this year loaded with excited campers. We had 13 first time campers as well as 8 first time staff members. The youngest boys cabin had 5 first timers, and this year marked the end of an era

Continued on page 4

Once again camp started a day early for the staff of this year's camp. The staff spent the day at a challenge course in Beaverton. This program has become an integral part of camp for our staff as it helps facilitate a team approach to the camp program. It's a great opportunity for the new staff and



Horseback riding

TABLE OF CONTENTS

From the Editor's Desk	2
A Passion for Plants	2
Friday the 13th a Lucky Day . . .	3
Parent Support Group	3
504 Plans	6
News from the Treatment Center	8
News from Industry	9
Baxter Announces Expiration Date Change	10
Membership Dues, Memorials and Contributions	11
NHF's Annual Meeting	12



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From the Editor's Desk...to the New Editor's Desk

BY MIKE CHARLES (MDCHARLES@COMCAST.NET)

If you have been wondering whether the HFO is still publishing a newsletter, rest assured that is still the case. I've had some health challenges in the past several months, making it difficult to put together *Hemophilia Headlines*. But this issue brings positive changes to the newsletter's future. With this issue, I hand the editorial reins to a long-time member of our local hemophilia community, who is also a talented and creative editor – Jamie Dessellier.

Jamie first got involved with camp in 1989 with her then fiancé, Bruce Dessellier, and stayed involved for many years. She has also been involved in various leadership roles with the HFO since then. Jamie helped start a women's support group in the early 90's, held the Board Secretary position for a number of years, and she has recently rejoined the Board as a Trustee. Although her husband Bruce recently passed away from complications from his hemophilia, Jamie says she feels it's important to remain a part of the community that's given her so much support over the years.

It's been a pleasure serving as your editor for the past ten years, and the support from you has been invaluable! I know the future will bring even more good things for the HFO. I hope Jamie will receive the support, input and encouragement I was given when I took over what seemed like an overwhelming task back in 1993! I have no doubt I am leaving *Hemophilia Headlines* in extremely capable hands.

I look forward to staying in touch and seeing you at future HFO events!

A Passion For Plants Results in a Fundraiser For The Foundation

BY DAVE WORTHINGTON

As Dona and Don Koepke were working in their garden this spring dividing, relocating and rearranging their planting, they had an idea. What if they could sell some of the extra plants they had grown and donate the proceeds to the foundation?

The Koepkes put their idea in motion and momentum began to build quickly. It started with a need for some empty containers for the plants. This led to plant donations from neighbors, involvement by volunteers from the Montavilla Garden Club, donations from Dennis' Seven Dees Landscaping, an article and photo in the *Lake Oswego Review*, and a raffle for a donated truck-load of compost from Grimms Fuel. The success of the sale was ensured with Dona and Don's gorgeous garden as a backdrop. It couldn't help but inspire any purchaser to buy.

After all was said and done and the refreshments were pouring for the hard working crew, the final tally came in at over \$1,100.00 raised for the Foundation which exceeded everyone's expectations.

Thanks to Dona and Don and their crew for their hard work to create a successful sale. Dona says this may just become an annual event!

Friday the 13th Lucky Day for HFO

BY JAMES T. MCALLISTER, HFO BOARD MEMBER

Friday the 13th of June 2003 proved to be a very lucky day for the Hemophilia Foundation of Oregon. David Snodgrass and his staff from Dennis' Seven Dees Landscaping conducted their annual Golf tournament and fundraiser. The weather at the Oregon City Golf Course was perfect and the staff of Seven Dees got into the spirit of helping children with bleeding disorders.

Once again Dave and his staff made the decision to give the profits from a day in the sun to the Hemophilia Foundation of Oregon. The golfers got into the spirit of giving and raised a record breaking \$1,740.00 from their purchase of raffle tickets for a truckload of donated prizes.

For the first time, Dave Snodgrass was on the winning golf team and will have his name on the perpetual trophy. But, more important was the fact that he and his staff raised a record contribution on behalf of the children of Oregon with bleeding disorders.

But wait, there is more. For the first time, this year the Aventis Behring Company pledged to match every dollar raised by the golfers. So this year the HFO received two checks from the Friday the 13th Golf Tournament. One check from Seven Dees and one check from Aventis Behring. Each check is for \$1,740 for a grand total of \$3,480 to support the programs of the HFO.

Our hats go off to Dave Snodgrass, the entire field of golfers, and to John Self of Aventis Behring for their commitment to the children of Oregon with bleeding disorders. Our camping experience was more complete this summer because of the generosity of these individuals.

It is hard to believe that a group of men and women having so much fun could make such a positive impact on our children. Once again a huge "thank you" to Dave and his wonderful staff at Seven Dees and to John and his crew at Aventis Behring. Because of each of you, this summer was truly "hole-in-one" experience for our campers and their families. May God continue to bless and keep each of you.

Parent Support Group Meeting Back On!

BY PATINA FIEKEN

We will be having our next support parent group meeting on December 2, 2003. The parent support group is a great opportunity for parents and grandparents to get together to talk about issues that come up in our lives, as well as ask questions of other parents who have been through similar problems. It's also a great opportunity for the kids to all play together in a safe environment. Please contact Patina Fieken (503) 625-6508 or patinaf@aol.com for meeting details.

Please make sure to RSVP at the above number or email so there is enough food!



Golf tournament

PARENT SUPPORT GROUP MEETING DATES FOR 2003-4:

December 2, 2003

April 6, 2004

June 1, 2004

August 10, 2004

October 5, 2004

December 7, 2004

Summer Camp

(CONTINUED FROM PAGE 1)

CAMPER CONNECTION RAISES \$2,325

This year, the Camper Connection program raised \$2,325 to support our summer camp program. The Camper Connection program asks members from our community to sponsored 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 very appreciated, and we hope you'll participate again next year!

for our entire group of boys in the oldest boys cabin: Alex Ell, Alex Christianson, Joey Coffin, Daniel Diaz, Ben Coatney, Stewart Worthington and Ryan White! It's been a truly unforgettable experience watching these boys grow into terrific young men.

Sunday night started off with some terrific ice breaker games with our favorite camp guest, Pat "Big Dog" Torrey of Team Synergo. The camp then spent the rest of the evening on a scavenger hunt with their cabin groups. This was a great way for all of our new campers to get a quick glimpse of the camp grounds. After an entertaining evening campfire, it was back to the cabins for a good night's sleep before our busy week.

Monday morning came bright and early with our 7:00 a.m. bongo serenade by our own favorite drummer and assistant arts and crafts director, Jim "Bongo" MacDermot. After a brisk morning polar bear swim and breakfast, the day's activities included "Big Dog" games, making pinewood derby cars in arts and crafts, archery, nature center, a session for our oldest cabins on self esteem with Brian Craft, horse back riding, swim lessons for the younger cabin groups and afternoon pool and pond time. It was another fun evening play-ing group and team building games with Big Dog.

Tuesday brought thunder, lightening and Corey and Perry Parker from the Aventis Behring "Getting in the Game" program. With a little rearranging and a lot of creativity we held some great sessions in the activities building. There were golf lessons, batting practice, pitching practice and even a putting green, as well as the pinewood derby construction and nature center all at the same time! A little crazy, but it worked and sure enough, the sun came back out in the afternoon for a great game of baseball in the field and some awesome golf lessons. We actually found some golf balls all the way in the horse pasture later that day!

The rock wall crew joined us on Wednesday this year. Once again it was a

hit with both young and old. The wall is a great self-esteem booster and can be as challenging as the climber wants to make it. Wednesday evening brought everyone's favorite—the Camp-Wide Relay. This year we added some new events just to keep it even more exciting, while still having the all-time favorites of "dizzy bat," "cookie whistle," "bubble gum pie" and the "dangling donut".

Thursday brought more fun on the rock wall, Big Dog games, kick ball, basketball, field hockey, finishing up the pinewood derby cars for Friday's big race, swimming lessons, horseback riding, and the anticipation of the big camp out at the pond for the



Arts and crafts

oldest cabin groups. Thursday night was also the talent show this year. It's always fun to see what the campers and staff come up with. We had some songs, skits and some great Celtic dancing by Erin and Josie Oleson. After the talent show, the oldest cabins headed for their campout by the pond. The staff brought back movie night in the activity building for the kids who weren't old enough to go on the campout. The kids enjoyed s'mores while watching a movie on a big screen. It was a treat for all of us!



Rafting

Friday is always bittersweet. Everyone is exhausted from the long week of non-stop activities and fun, but sad that the week is coming to a close. We ended the week with our pinewood derby races. The first place car was built by Raefael Jones, 12 years old; the second place car was constructed by Ryan White, 15 years old; and the third place car was built by Christian "Duke" Heiner, 7 years old. It was an exciting race! Congratulations guys!

Although we didn't have any "first sticks" this year, we presented awards to all of the young men in the biggest boys cabin who took control of their bleeding disorders this week. They were solely responsible for their infusions and their care during the week (with a nurse and doctor overseeing, of course). It was a huge step worth being acknowledged! Scott "Crocky" Torrey, our nature program director also presented awards to all of the kids. Camp nurse Sonya "Mango" Karanjia presented some special bravery awards for kids who overcame and conquered some huge fears this week.

We had our second annual "Mike Charles Outstanding Camper" award to present this year. The staff nominates campers who they feel display traits shown by Mike Charles, such as honesty, respect for self and others, leadership, integrity, and bravery. This year, we had a tie. The staff absolutely could not agree on just one person, so the award went to two equally deserving campers.

Joey Coffin of Klamath Falls and Alex Ell of Portland are the recipients of the 2003 Mike Charles Outstanding Camper award. We were all very proud of these two outstanding young men and look forward to their continuing contributions to the bleeding disorders community in the years to come. Congratulations, guys!

Friday evening Chris "Squirrel" Leland, with help from Dave Oleson at the HTC, put an amazing slide show together with photos covering the past 15 – 20 years at Camp Tapawingo. There were very few dry eyes left after the show. It made us all realize that we are a part of an amazing history. We planted a dogwood tree next to the Camp Tapawingo sign in memory of all those who have come before us and in honor of the hope that lies ahead of us.

Overall, camp 2003 was, as usual, a truly amazing week. We laughed, we cried, we made many lasting memories and friendships. And we can't wait to do it all over again next year!

A BIG THANK YOU!

The HFO would like to thank the following companies for their support of our annual Summer Camp:

- Alpha Therapeutics
- Aventis Behring
- Bayer Corporation
- Dennis' Seven Dees
- Juan Young Trust
- Lockett Construction
- Novo Nordisk
Pharmaceuticals, Inc.
- Stockamp & Associates, Inc.
- Weyerhaeuser Company
Foundation



Rock wall climbing



Family Focus

504 Plans and Your Child's Education

SUBMITTED BY HEMOPHILIA HEALTH SERVICES

When you have a child with a bleeding disorder, there are many things you have to learn. Besides noticing signs of a bleed or mastering infusion techniques, parents also have to learn how to tell others what hemophilia is. This is especially important with dealing with schools and day care centers. In this case, you often have to educate the educators.

Also, teaching those at your child's school about hemophilia is not something you do only once. Through your child's school career, there will be new teachers, new schools, and new situations. It may seem like you are starting from scratch each fall. Remember that while your family has been living with hemophilia for some time, hemophilia is rare and most schools and teachers will not have prior experience dealing with the issues it incurs.

Even with the best planning, some problems can arise. Some challenges you may face include your child missing several days of school due to a bleed, having to be on crutches reducing his mobility, and having his arm in a sling and not being able to write. He may even need to have an extra set of books for the home, so he isn't weighed down by a heavy backpack.

If you feel your child is not receiving the accommodations he needs, there is recourse: Section 504 of the Rehabilitation Act of 1973.

What is a 504 Accommodation Plan? What Does it Do For My Child?

Section 504 provides for non-discrimination and equal access to educational opportunities for students with disabilities. This may mean modifying the regular education program and providing any necessary services.

In order to meet the criteria for a 504 Accommodation Plan, students must have an impairment in one of their major life functions: caring for one's self, performing manual tasks, walking, etc. This impairment must significantly impact across all academic areas. Many states recognize hemophilia as one of the conditions covered by Section 504.

While 504 Plans are part of federal legislation, all states have them. A 504 plan can be obtained from your State Education Department or your local school district. You will need parts 200 and 201 relating to the education of students with disabilities. (See an example of a 504 Accommodation Plan following this article.)

Once the process starts, a meeting will be scheduled with the student's parents and several people from the school to develop the 504 Accommodation Plan. Parents should be prepared and supply pertinent documentation to assist in writing the plan. Once the plan is set, it is signed by participants and filed at your child's school. The document must be reviewed once a year, and parents must be invited to participate in the review.

The 504 Accommodation Plan is useful for several reasons:

- They are binding and legal documents and will be upheld in a court of law.

CONTACT THE EDITOR

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

- The information contained in them must be carried through.
 - As your child progresses through the school system, this document will help inform all teachers and staff of his or her special needs.
 - Older students are asked to participate in the development of their plan.
- HACA News, February 2003;

Example of an Actual 504 Plan Recommendation

Name: XXXX **DOB:** xx/xx/xx
Grade: 2nd **School:** XXX
Date of Meeting: xx/xx/xx **Date of Review:** xx/xx/xx

Describe the nature of this concern: XXXX is a student with a medical diagnosis of severe hemophilia A (Factor VIII). Hemophilia is a rare bleeding disorder, which affects a person’s clotting ability and usually affects tissue, muscles, joints, and internal organs. Students with severe hemophilia often are subject to limited motor ability during bleeding episodes, which may result in the need for crutches, wheelchairs, splints, and slings. Some severe bleeding episodes may result in bed rest or hospitalization. Bleeding episodes may affect XXXX’s attendance and performance in both class and gym. XXXX has target areas: toe joints, right elbow, and (most severe) nose bleeds.

Describe the basis for determination of handicap: Diagnosis of severe hemophilia A (factor VIII).

Describe how handicap affects a major life area: Bleeding episodes may cause an unusual amount of absences, a need for physical accommodation, or adaptive Physical Education.

Describe the reasonable accommodations necessary to provide a free appropriate education (FAPE):

XXXX should be given an opportunity to make up missed work. (It is expected that XXXX will make up all missed work.)

XXXX may require adaptations to school environment based on bleeding episode (crutches, wheelchair, splints, slings).

XXXX should be allowed to participate in all regular Physical Education programs, unless indicated otherwise. If XXXX is unable to participate physically, he should be involved in coaching, score keeping, or as a referee.

XXXX’s grades should not reflect late work or absences due to bleeding episodes, either in the classroom, or in physical education classes.

All rooms should contain rubber gloves with a bleach- and -water solution.

Home tutor as needed – due to bleeds that require bed rest.

Participants: (name and title)

XXXX, Parent **XXXX, School Psychologist**
XXXX, Principal **XXXX, Teacher**

I have read the accommodation plan and am aware of my due process rights to appeal this plan if I am not satisfied.

Parent Signature / Date

Cc: Psychologist, Building Principal, Classroom Teacher, Guidance

HAPPY BIRTHDAY,
CAMPERS!

October

Josie Olsen
Jonathon Pool
Ryan White
Stewart Worthington

November

Christina Cacouris
Janelle Heiner
Amanda Wignall
Justin Williams

December

Daniel Diaz
Christian DuBois
Cody Holma
Erin Olsen
Lizzy Nelson
Ricky Ramos
Kayla Schadle
Tanner Siri



News from the Treatment Center

Hemophilia Treatment Center (HTC) Update

SUBMITTED BY ROBI INGRAM-RICH

Personnel Update

There have been lots of changes at the Hemophilia Treatment Center (HTC). As of September 8, family nurse practitioner Joann Deutsch has joined the staff as the nurse coordinator and nurse practitioner. Karen Granger will continue to work half-time Monday thru Wednesday. Sandy Puckett has resigned from the HTC, and we are currently searching for a new part-time clinical nurse.

Weddings have been plentiful this spring and summer. In the office, Theresa Garrett-Furber (appointments and clinic visit scheduling) married in April, Becky Curry (receptionist, filing, shipping, etc) married in July, and Tamara Vogel (office manager/patient financial coordinator) married in August. Dr. Betsy Mead married in June and relocated to the Cornell University area in New York.

Insurance Information

With insurance open enrollment coming up, please be sure to contact the HTC with any insurance changes or coverage loss. Also, if you need any assistance with making a choice, give the HTC a call.

Oregon tax payers should contact the office when they turn 21 and enroll in HAP. There have been proposed changes to HAP and letters have been sent out to current HAP participants.

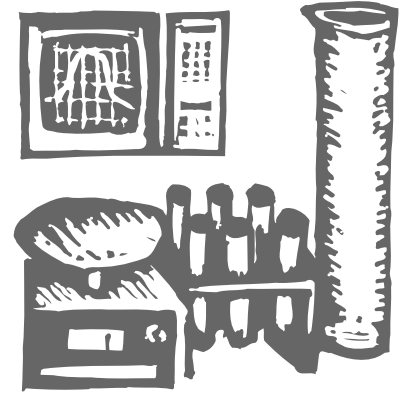
News from Industry

First Plasma/Albumin-Free Method Recombinant Factor VIII Approved

SUBMITTED BY CHAD FLETCHER, BAXTER

Baxter's new hemophilia A therapy – ADVATE Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method (rAHF-PFM) – is now approved by the FDA.

To learn more about ADVATE rAHF-PFM, contact your healthcare professional, visit www.advate.com, or call 1-888-4ADVATE.



Grifols Acquires Assets of Alpha Therapeutic Corporation

SUBMITTED BY CARY BOTE, GRIFOLS

Grifols has acquired certain assets of Alpha Therapeutic Corporation. As a result of this acquisition, Grifols will be responsible for the manufacturing and distribution of the products Venoglobulin®-S, Alphanate®, AlphaNine® SD, Profilnine® SD, and Albutein®. For more information regarding Grifols, visit www.grifols.com.

Information contained in News From Industry is provided for the benefit of HFO members and supporters. Publication of any material does not imply the HFO's endorsement of any particular activity, product or service.

AUGUST 11, 2003

Baxter Announces Expiration Date Change Related to RECOMBINATE® Products

August 8, 2003— Baxter BioScience has announced a change in sterile water for injection (SWFI) manufacturers that affects the expiration dating on cartons of its RECOMBINATE® clotting factor products. Baxter began manufacturing its own SWFI, also known as diluent, in March 2003. Due to the change, the expiration date on the clotting factor concentrate vial and the date on the SWFI vial may differ, with the SWFI, at times, having an earlier expiration date. Consumers, however, should be aware that U.S. Food and Drug Administration regulations require the earliest expiration date of packaged items to appear on the outside carton. Thus, the expiration date on the carton may be that of the SWFI and not the RECOMBINATE® itself.

Because expired SWFI can develop bacterial or other contamination, consumers should not use bottles of expired sterile water. Users of RECOMBINATE® are encouraged to check the dating of the SWFI vial with the factor vial and the carton prior to infusion. Consumers in possession of expired vials of SWFI should contact their product provider for replacement vials of sterile water. The RECOMBINATE® is still good until expiration date on its vial.

This material is provided for your general information only. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends treatment for specific individuals and in all cases recommends that you consult your physician or local hemophilia treatment center before pursuing any course of treatment.

Membership Dues, Memorials and Contributions

The Hemophilia Foundation of Oregon thanks the following individuals and companies for 2003 dues payment and other donations. Dues are \$20 for individuals and \$35 for families and are payable each calendar year. This list reflects donations received as of August 10, 2003.

Adams, Fred & Patty
Amos, Mike & Sharon
Bernstein, Mike & Tina Marie
Baskin
Cannizzaro, Santo & Shirley
Carpenter, E. Powell
Charles, Ed & Judi
Charles, Mike & Linda
Chvatal, David & Marci
Kociemba
Cook, Tom & Jean
Dansie, David & Family
Deneffe, Richard
Dessellier, Jamie
Dickey, Jim & Sharon
Dickey, Tom & Monica
Dieringer, Andrea
Evans, Lori & Philip
Fisher, Lisa
Franklin Contracting
Gassaway, Lee & Linda
Gibson, David & Sharon
Gobel, Paul & Family
Greer, Elwin & Diane
Gruher, Jim & Monica
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Heffernan, Kevin & Jana
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Hillgoss, Adair & Dorothy
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Lieberman, Art & Gail
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Wagner, Edward
Walker, Jennifer & Family
Wells, Ellen
Wile, Mike & Family
Worthington, David & Family
Worthington, William & Nancy
Zwetschke, Linda

HONORING

Mike Charles
from Doris Greenfield
Mike & Linda Charles
from Doris Greenfield
Anne Pagenstecher
from Nancy & Bill Worthington
Nancy Worthington
from Walter & Sheila Hoffman
from John & Mary Pelton
Nancy & Bill Worthington
from John & Mary Pelton

IN MEMORY OF

Philip Mason Burnett
from Bill & Nancy Worthington
Bruce Dessellier
from Mike & Sharon Amos
from Catherine Austin
from Elizabeth Austin
from Neil & Dolores Austin
from Lisa Bruce
from Selmer & Cecelia
Christianson
from David Chvatal
from Cross Program Section of
the Oregon DEQ NW Region
from David Dansie & Family
from George & Irene Dessellier
from Jamie Dessellier
from Vincent & Shirley
Dessellier

from Rosella Jones
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from Susan Squire, Alicia
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from Mary Laam

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from Jim & Marjorie McAllister

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from Anne Pagenstecher

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from George & Debbie Tester

Tom Watson
from Maria Ernst

Stanley Woodruff Smith, Jr.
from Bill & Nancy Worthington

DONATIONS/GIFTS

Anderson, Renee
Austin, Catherine
Jones, Alan & Jill
Kurilo-Burrell, Sharon
Lunt, Roger & Freddy
Malek, William
Olson, Debra
Page, David, Patty & Adam
Pierce, Doug & Cynthia Secrest

Porter, Donald & Clara
Seefeldt, Michael
Shirley, Patricia
Thomas, Gregory & Martha
McMurry
Timmen-Shaha, Sharon
West, Edward
Wolf, Wesley
Worthington, Bill & Nancy

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American Red Cross
Aventis Behring
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Bayer Corporation
Dennis' Seven Dees
Lockett Construction
Novo Nordisk Pharmaceuticals,
Inc.
Stockamp & Associates, Inc.
Weyerhaeuser Company
Foundation
Wyeth-Ayerst Pharmaceuticals
Juan Young Trust

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Platner, Kert
Porter, Donald & Clara
Ravencraft, Lily & Franklin
Schuyler, Bill
Shirley, Patricia
Wile, Mike & Nancy

NHF's 55th Annual Meeting

NOVEMBER 6 – 8, 2003

GRAND AMERICA/LITTLE AMERICA HOTELS

SALT LAKE CITY, UTAH

Don't miss the largest, most comprehensive meeting for the bleeding disorders community, complete with a captivating and informative exhibit hall!

Register online at www.hemophilia.org.



The Hemophilia Foundation of Oregon
5319 SW Westgate Drive #126
Portland, Oregon 97221

Address correction requested