

# Hemophilia Headlines

S U M M E R 2 0 0 4

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## May Day Plant Sale Benefits the HFO

A sunny day on May 1 provided the perfect weather for the perfect plant sale! Don and Dona Koepke held the second annual plant sale in their backyard in Lake Oswego, with all plant and raffle ticket sales directly benefiting the HFO! Dona and her friend Maxine were on hand to answer questions and help the customers envision how the various plants would work in their own gardens, and sales remained brisk all day. Don Koepke and Dave Worthington helped transport plants to customers' cars, and Linda Charles handled plant and raffle ticket sales. The raffle prize of a unit of garden mulch was donated by Grimm's Fuel, and John Lazo was the lucky winner. This wonderful event brought in \$1,176 for the HFO's programs and services! Our heartfelt thanks to the Koepkes for their hard work and creativity in hosting this fundraiser!



## Calling Gardeners for the HFO Garden Club!

The plant sale was so successful, we want to start our own HFO Garden Club and get more of you involved in this annual fundraiser! Do you have a green thumb? Do you have friends with green thumbs? Do you have plants in your garden that could be separated and sold in next year's plant sale? Would you be willing to plant seeds and tend to them so the plants could be sold next May? Do you have a yard that would work for the plant sale next year? Would you like to volunteer at next year's event?

If you answer yes to any of these questions, please contact the HFO office now (503-297-7207; [hfo@easystreet.com](mailto:hfo@easystreet.com)) and let us know how you'd like to become involved!



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# President's Message

BY LINDA CHARLES

The HFO has some new tools to make communication easier and more cost-effective: our revamped web site ([www.hfo.info](http://www.hfo.info)) and our new "Hemophilia eLines" email alerts!

We hired web designer Nicole Moles to give the web site a new look, so you'll want to check it out—she did a fabulous job! Nicole will update the web site on a regular basis from this point forward. If you have questions regarding upcoming events, programs, and opportunities, you'll find the answers on the web site. The new site includes the following regular features: Contact, About, Programs & Services, Medical News, Events/Camp, Women's Issues, Resources, and FAQs.

We have a great photo gallery from last year's camp (and will have new photos available shortly after this year's camp)! We'll also include a photo gallery from the upcoming Jr. National Championship in Golf and Baseball in August and will do the same after the Annual Meeting at the Zoo in September. Your kids will have a great time looking at the photos from the events they participated in, and they can share the experience with family and friends.

The other new communication tool is our new "Hemophilia eLines" email alerts! We can quickly and cost-effectively notify each of you about upcoming activities, social events, fundraisers, and other time-sensitive information. I encourage each of you to send an email to [hfo@easystreet.com](mailto:hfo@easystreet.com) to sign up for the "Hemophilia eLines" email alerts—just give us your name and email address, and ask to be added to the alerts. You'll be kept up-to-date, and the HFO will save lots of money on postage and mailing costs!

This is an exciting time for the HFO, and I hope you take advantage of these two great new tools!

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Jamie Dessellier  
[editor@hfo.info](mailto:editor@hfo.info)

The Hemophilia Foundation of Oregon is a 501 (c)3, not-for-profit corporation and an equal opportunity employer.

Material provided in this newsletter is for general information only. The HFO neither gives medical advice nor engages in the practice of medicine. The HFO under no circumstances recommends particular treatments for specific individuals, and in all cases recommends you consult your physician or HTC before pursuing any course of treatment.

## Applications Due July 28 for Scholarship to NHF Meeting in Dallas, Texas!

The HFO is pleased to offer one scholarship to attend the National Hemophilia Foundation's (NHF's) 56th Annual Meeting in Dallas, Texas on November 4-6, 2004! The scholarship is for up to \$2,000 reimbursement of travel and meeting expenses. It can be used for an individual, a couple, or a family with children, as long as expenses do not exceed \$2,000.

### Qualification Requirements:

- Must be directly affected by a bleeding disorder (i.e., self, parent, sibling, carrier, caregiver, etc.)
- Cannot have attended the NHF Annual Meeting in at least 3 years
- Financial need is a consideration but not a requirement

To be considered for this scholarship, complete and return the enclosed application to HFO's PO Box by Wednesday, July 28, 2004.

Our thanks to Wyeth for making this scholarship possible!

# Do Infusions Mean Confusion When Trying to Find Supplies?

MIKE CHARLES

It was four years ago when I stumbled upon what for many in the hemophilia community is a holy grail of sorts: The perfect “infusion kit.” And I found it not at a medical supply store, or a doctor’s office...but at my corner hardware store!

Perhaps you have had the same problem: When it’s time to infuse—yourself or your child—you need to have all your infusion equipment and supplies easily accessible and at a moment’s reach. The container must be large and sturdy



enough to hold a generous supply of butterfly needles, alcohol wipes, tape, band-aids, EMLA, etc. but small enough to be lightweight and portable and able to withstand being dropped or turned upside down.

After using cardboard boxes, containers of all sizes and even “factor carriers” given to me by home care companies, I finally found what worked best for me. It was a simple,

hard plastic tool box I ran across at Ace Hardware.

I chose a very simple box (see photo). Its lid easily snaps open and shut, and has a place for a small lock should you need to keep it safe from prying hands and to protect the lid from being



forced open. Inside, it has a removable tray, with a large bottom area perfect for storing syringes and other large supplies. In the tray I keep my butterfly sets, rolls of tape, alcohol preps, band-aids, and sterile gauze 2x2s. Some of the larger tool boxes even have enough room to hold a small sharps container as well! I can keep up to three months worth of equipment

in the kit; I only need a very small corner in a bureau drawer to keep extra supplies in case of emergencies.

The hard plastic variety has several advantages over older metal tool boxes. The plastic is virtually unbreakable, yet extremely lightweight. The tool boxes come in virtually every size and configuration. Finally, they are inexpensive—I paid \$6.97 for mine!

So if infusion time means confusion time (where did I put that box of alcohol pads?), consider a quick trip to any department or hardware store—you’ll be organized before you know it!

## CONTACT THE EDITOR

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Do you have any suggestions or comments? Contact Jamie Dessellier, Editor of Hemophilia Headlines, at [editor@hfo.info](mailto:editor@hfo.info).

# Summer Camp Staff Attend National Training

BY MONICA DICKEY

## HAPPY BIRTHDAY, CAMPERS!

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### April

Kristin Boni-Burden

Hope Coatney

Matthew Walker

Reafeal Jones

Lindsey Bulfinch

### May

Jake Puckett

Kylier Holman

Kylan Kirsch

Luis Angluo

Bryan Dagenais

### June

Marilyn Walker

Tylor Groling

Mario Magana

Sean Doyle

Jakob Fieken

Marcus Magana

Brian Schoenheit

Daniel Ramirez

The Hemophilia Association of Arizona organized and hosted the 2nd annual NACCHO (North American Camping Conference of Hemophilia Organizations) conference in February this year. Over 150 people attended the conference in sunny Arizona. The HFO was able to send four representatives—Tom and Monica Dickey (HFO camp directors), Chris Leland and Pat Torrey.

The NACCHO conference is dedicated to summer camps that serve children with bleeding disorders. The conference offered nationally known presenters who shared useful camp resources and techniques, offered sessions that explored new camp programs and activities and facilitated productive networking and problem solving sessions. At NACCHO, people exchanged resource materials with other camps, met with representatives from the NHF, picked up new ideas and shared successful stories with others. NACCHO was created for people responsible for planning, organizing and operating bleeding disorder summer camps. The people attending included the best camp counselors, camp directors, infirmary staff, fundraisers, activities leaders and camp committee members from all over the country. Through all of the learning, the participants had a lot of fun and great food, and they all continued to strengthen the bond they share as camp collaborators.

This conference was generously funded through a grant from Wyeth Pharmaceuticals.



Dwayne Whitis, Chris Leland, Pat Torrey, Monica Dickey, Tom Dickey, Zuiho Taniguchi, and Scot Evans (L-R) from Camp Tapawingo attended the 2nd Annual NACCHO in Tempe, Arizona. NACCHO—conducted by the Hemophilia Association in Arizona and funded by a grant from Wyeth—brings members of the community together to discuss best practices for operating hemophilia camps. This year, 165 volunteers, nurses and social workers from 34 states, Canada and Puerto Rico attended.

# Woman to Woman

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## Ladies Summer Luncheon

You are invited to a ladies luncheon hosted by HFO July 24. This will be a time for all women related to the bleeding disorders community (self, wife, mom, daughter, friend, etc) to get together and meet others with similar issues. We'll have good food, good conversation and good fun. The event will be at Rivers at the Avalon Hotel, 0470 SW Hamilton Court in Portland (cross street of Macadam). Lunch will be from 11:00 a.m. until 2:00 p.m.

If you'd like to attend, please RSVP to the HFO office (503-297-7207; hfo@easystreet.com) no later than July 19. Hurry! Space is limited!

This luncheon is generously sponsored by a grant from Hemophilia Health Services.

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## Bleeding Disorders Related to Women

REPRINTED FROM

[HTTP://WWW.SHEMOPHILIA.ORG/WOMEN/BLEEDING.HTML](http://www.shemophilia.org/women/bleeding.html)

Symptomatic carriers of hemophilia and women with von Willebrand disease or other bleeding disorders have special gynecologic and reproductive concerns. These include excessive menstrual bleeding and excessive bleeding after childbirth or miscarriage. Longer and heavier menstrual flows often lead to low iron levels. Therefore, it is recommended that women with bleeding disorders routinely be tested for anemia. To help control menstrual bleeding, doctors may prescribe birth control pill or Stimate<sup>®</sup> nasal spray. These will boost factor VIII and von Willebrand factor levels. Decisions about what path to pursue should be based on personal preference, family planning goals, and severity of bleeding problems, and discussed by a woman and her doctor.

During pregnancy, levels of factor VIII and von Willebrand factor usually increase in women with bleeding disorders. For women with vWD, postpartum bleeding may be treated with desmopressin acetate or a von Willebrand factor-containing concentrate. A woman who becomes pregnant should see an obstetrician as soon as possible. This will ensure that the doctor can work with the local hemophilia treatment center to provide pre- and postnatal care for the woman and her fetus and testing of the baby.



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**A BIG THANK YOU TO  
OUR 2004 INDUSTRY  
SPONSORS!**

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## Family Focus

### Summer Rollercoaster Fun As I See It—Theme Park Summer Fun: How to Relax While Weightless

BY RICHARD LIPTON, MD MPH, FACP

*Source: Bloodlines, August/September 2003, Volume 23, Issue 3, San Diego, CA. Originally reprinted from the August 2002 Issue of The Parent Empowerment Newsletter (www.kelleycom.com)*

#### HOW DO I MAKE MY OWN "CAMPER CONNECTION"?

Each year, the HFO sponsors a fabulous camp program for our youngsters living with bleeding disorders! The costs associated with the camp have skyrocketed, and we need your financial support to continue to offer this great program. Sponsor a camper for as little as one-half day or as much as the entire week—it's up to you. Simply write your tax-deductible check to the HFO and get connected to your camper. See the insert page of this newsletter for all the details!

Summer is here, and millions of families will seek adventure and thrills at theme parks like Six Flags, Disney World or Universal Studios. What a wonderful day a family can have at a theme park! Kids and parent love the rides, water slides, entertainment and general excitement. Are there any special safety concerns or precautions for families with a child with hemophilia? Yes!

Think of a theme park as a very big playground, but with an atmosphere favoring less parental control—a setting that can lead to impulsive behavior by children. Imagine yourself at a typical theme park. You'll have general health concerns. Parks can be crowded, hot and sunny—so apply sun block and drink plenty of water.

Theme parks have pave surfaces, harder than public playgrounds, and filled with children running. Your child needs to wear appropriate footwear. Flip-flops or "Texas" might be suitable for water activities, but sneakers are safer for walking and running.

You'll also have concerns specific to the theme park you visit. "Mind Eraser," "Shockwave," and "Nitro"—what about these special high-end rollercoaster rides? Riders are frequently subjected to changing speeds that results in "G-forces" similar to those experienced by trained, appropriately suited and restrained combat fighter pilots. Your child becomes "Top Gun" in shorts and a T-shirt! Parents should remember that any person can experience head trauma on these specialize rides.

How is the head affected by a ride like the Mind Eraser? Recall that your brain is surrounded by fluid; it is floating inside your skull. This arrangement cushions the brain, and reduces movement, protecting your brain from direct trauma and sudden shifts in skull position. It works quite well in our daily activities and in automobiles (as long as we're wearing a seatbelt). Now imagining speeding over the crest in a rollercoaster. All of a sudden you're weightless, like an astronaut—this is called a Negative G-force. (You'll have no trouble recognizing this moment, because everybody screams!) Then, after the coaster speeds down and resumes its climb, you feel your backside being pushed into the seat. It feels like the force of gravity has suddenly increased. This is a Positive G-force. Although your body is restrained, high G-forces could exceed the protective cushioning of fluid surrounding the brain and could cause injury.

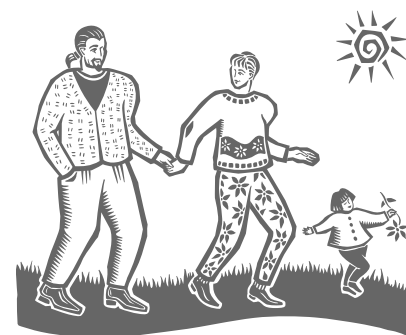
Interestingly, New Jersey became the first state to seek legal restrictions on the maximum allowable G-forces on amusement park rides. The regulations result from concerns raised by physicians about the association between

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neurological damage and high G-forces on these rides. Certainly, such injuries occur very infrequently, but serve as a cautionary note to all riders of high-end rollercoaster—with hemophilia or without.

My advice? Take some precautions. Level the playing field by giving your child a prophylactic infusion of factor the morning of your visit to a theme park. Yesterday's dose is not sufficient! Don't wait until your child reports the symptoms of a bleed—it may be too late. Besides, your child is not going to report the flop he took running to the haunted house until you're stuck in traffic on the long, long ride home.

Infuse first, then have a great time!



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## 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.

### Upcoming Dates

October 4 sponsored by Bayer  
December 7 sponsored by Curative

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## Junior National Championship in Golf and Baseball Returns to Oregon! Save the Date! August 14, 2004

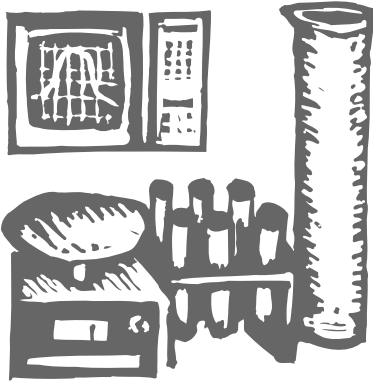
The National Hemophilia Foundation and ZLB Behring (formerly Aventis Behring) have again joined forces to offer the Junior National Championship in baseball and golf—and Oregon has been chosen for one of the regional events! Mark your calendars for this all-day event on Saturday, August 14, at Redtail Golf Course (formerly Progress Downs) in Beaverton. Kids between the ages of 7 and 18 can participate in the day's events. Separate invitations will be mailed soon outlining all the details and telling you how you can sign up!

This event is a great chance for kids to get physically active and participate in friendly competition. During the morning, all the kids attend a workshop where they learn how to safely exercise, get to know other kids with bleeding disorders, and meet the Gettin' in the Game athletes - golfer Perry Parker and baseball player Corey Parker. The kids also participate in baseball and golf clinics where, based on a point system for baseball and on general style and technique for golf, they can be selected by Corey and Perry for the afternoon regional event. All kids can participate in the clinics, but the afternoon championship is only open to the kids with bleeding disorders who are selected by Corey and Perry.

Other activities will be offered for the kids who don't take part in the afternoon event, and there will be activities for the parents, too!

### Prizes

Perry and Corey will ultimately select two regional event winners from each location—one for baseball and one for golf. The winners will receive a free trip for themselves and up to two accompanying adults to compete in the final competition (location to be determined). At the final competition, Perry and Corey will select two grand-prize winners, one in baseball and one in golf. These winners will receive great prizes, including a trip for three to the National Hemophilia Foundation's 56th Annual Meeting in Dallas, Texas.



## News from Industry

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### **Clotting Factor Consumption of On Demand and Prophylaxis Treatment Similar, New Study Says**

CONDENSED FROM ARTICLE SUBMITTED BY VICKY TODY,  
HEMOPHILIA HEALTH SERVICES

A multi-center European study compared clotting factor consumption and outcomes between on-demand and prophylactic treatment strategies and found that clotting factor usage was similar for the two groups. Additionally, the study indicated that patients treated with prophylaxis had fewer joint bleeds, better joint status, and more favorable health-related quality of life when compared to those treated primarily on demand.

These results indicate that a primary prophylactic treatment strategy leads to better outcomes at equal treatment costs in young adults with severe hemophilia. The high cost of hemophilia treatment has been one of the main factors hampering the introduction of prophylaxis in many countries. Prophylaxis is the recommended treatment for all children with severe hemophilia by both the National Hemophilia Foundation and World Health Organization.

The complete article can be found at <http://www.hfo.info/news.htm>

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.

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### **Results from International Study Present Factor Replacement Strategies for Surgery in Hemophilia**

CONDENSED FROM ARTICLE SUBMITTED BY PAUL GOBEL, BAYER

Preliminary data was presented at the XIXth Congress of the International Society for Thrombosis and Haemostasis (ISTH) in Birmingham, U.K on the utilization of factor VIII and factor IX concentrates in surgical procedures performed on hemophilia patients around the world. The study, funded by Bayer Biological Products (BP), is the first of its kind to document the different factor replacement protocols used in surgery around the world and compare their outcomes. The researchers hope to use these findings to formulate optimal protocols for effective clotting factor replacement that have the potential to serve as the universal standard for managing bleeding during and after surgery in hemophilia patients.

Analysis of the data collected so far shows that there is reasonable uniformity on the levels of factor required for surgery across treatment centers. However, there is a very significant variation in post-operative replacement practices (300-3000 IU/kg) for similar procedures with no significant difference in outcome or major complications, which are generally below 5 percent in most centers. Even though the benefits of continuous infusion of factor concentrates have been widely discussed over the last decade, more than two-thirds of centers continue to use bolus infusions and at differing intervals. The reasons for this need to be assessed.

The complete article can be found at <http://www.hfo.info/news.htm>

# News from the Treatment Center

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## Bone Health

BY JOANN DEUTSCHE, RN, FNP  
OREGON HEMOPHILIA TREATMENT CENTER

Dave Oleson and I recently attended an OHSU seminar on Osteoporosis. Osteoporosis is a significant loss of bony tissue (i.e., bone density) resulting in bones that are brittle and liable to fracture. Infection, injury and synovitis can cause localized osteoporosis of adjacent bone. Osteopenia is an abnormal loss of bone density and is a risk factor for development of osteoporosis.

Dave has been interested in osteoporosis and its relationship to hemophilia for some time now. An article published in 1994 found an association between hemophilia, premature fractures and osteoporosis. On x-ray exams, Dave has noticed osteopenia in even young children. We have seen a few unusual fractures in our adults as well. All this has led us to think that bone health education is important to share with the hemophilia community.

Osteoporosis prevention includes adequate calcium and vitamin D intake. According to a 1997 National Institute of Medicine report, for children and adolescents 9-18 years of age, 1800 mg/day of calcium is recommended. For adults 19-50 years of age, 1,000 mg/day of calcium is recommended. In addition, adequate Vitamin D intake is needed to enhance calcium absorption. For healthy adults, the presenter recommended 800 IU/day. A recommended amount for children was not made available.

The largest amount of calcium is found in milk products, sardines, and dark green vegetables such as collard and turnip greens. The presenter said that TUMS is the least expensive calcium supplement if the recommended amount cannot be gleaned from diet alone. Vitamin D supplements are included in multivitamins, but amounts vary, so check the label.



### “Do The Five”

- Get a comprehensive check-up at the Hemophilia Treatment Center
- Get vaccinated for hepatitis A and B
- Treat bleeds early and adequately
- Exercise
- Get tested regularly for blood-borne infections

# NHF and HCV: A Letter from NHF President Jordan Lurie, MD

FROM NHF ENOTES

The National Hemophilia Foundation (NHF) appreciates recent inquiries to our national office regarding the status of Federal compensation for persons affected by the hepatitis C virus (HCV). NHF has long recognized the impact and burden placed on individuals and families by this disease. We also respect the efforts of affected community members to pursue compensation legislation. NHF is committed to working with the bleeding disorders community to seek support for an independent review of the Federal government's responsibility in the spread of HCV through blood and blood products. However, similar to the community's successful campaign to achieve passage of the Ricky Ray Hemophilia Relief Fund Act, significant groundwork must be completed prior to the consideration of Federal HCV compensation legislation.

To build this foundation, earlier this year NHF broadened its outreach within the larger HCV community. Nearly four million Americans have HCV, with 10 percent of these individuals contracting HCV through blood transfusions. Like other HCV advocacy organizations, NHF's efforts over the last 15 years have focused on blood and blood product safety as well as improved diagnosis and treatment of HCV, including non-invasive mechanisms for liver biopsy, access to clinical trials, and increased Federal funding for HCV disease research. At this year's Washington Day program, NHF will join with other HCV organizations in seeking support for passage of the Hepatitis C Epidemic Control and Prevention Act (S. 1143/H.R. 3539). This legislation mandates additional resources and a more coordinated Federal approach for improving HCV prevention, treatment, and disease management.

The Centers for Disease Control and Prevention (CDC) estimates that 6,200 individuals in the bleeding disorders community have been exposed to HCV. On their behalf, NHF seeks the best strategies for addressing HCV, including compensation. As the Federal government's role related to HCV has not been documented in an authoritative manner and litigated court cases have not provided a strong advocacy base, an independent review is a first and necessary step towards any future Federal HCV compensation effort. We look forward to working with you and to keeping you informed of our steps in seeking this review.

Sincerely,  
Jordan Lurie, M.D.  
*President*

## HFO CALENDAR OF EVENTS

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Contact Monica Dickey for further details (503-297-7207; hfo@easystreet.com)

### June 30

Teen Activity, Mt. Hood Ski Bowl

### July 17

Men's Casino Night

### July 24

Ladies Luncheon

### August 1-8

Summer Camp!

### August 14

NHF ZLB Behring Junior National Championship

### November 4-6

NHF Annual Meeting, Dallas, TX

# Membership dues, Memorials and Contributions

Donations through May 28, 2004

## **BENEFACTOR (\$250)**

Providence Home Infusion

## **PATRON (\$100)**

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Franklin, Paula - Franklin Contracting  
Hemophilia Health Services  
Jones, Alan & Jill  
Lofland, Joan  
Page, David & Patty  
Schuyler, Dr. Bill  
Worthington, Bill & Nancy

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### **DUES (\$20 individual, \$35 family)**

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Gassaway, Lee  
Gobel, Paul & Family  
Greenfield, Doris  
Gruher, Jim & Monica  
Hammar, Don & Wilma  
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Harrison, William & Esther  
Heffernan, Bob & Francy  
Heffernan, Kevin & Jana  
Hillgoss, Adair & Dorothy  
Holmes, Steven & Lynne  
Hunt, Leslie & Howard Schechter  
Jablonski, Greg  
Koepke, Don & Dona  
Lindemann, Dr. James  
Malek, William  
McAllister, Jim & Marjorie  
McAlpin, Jim & Esther

Middleton, Don & Carol  
Nelson, Cliff & Kristy  
Pagenstecher, Anne  
Pagenstecher, Stewart & Deborah  
Petrick, Frankie & Colton Norton  
Platner, Kert  
Pool, Amy  
Porter, Donald & Clara  
Schuff, William & Louise  
Schuman, Steven & Theresa  
Sherwood, Neil & Nancy  
Stanley, Jess  
Swain, Merle  
Tester, George & Debbie  
Thomas, Dr. Greg  
Tschida, Dale & Anita  
Worthington, Dave & Pam  
Yokum, Ryan & Laura Diego

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*Joe Singler*  
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from Everett & Pierrette Lovrien  
from Kert Platner

*George "Red" Tester, Sr.*  
from George & Debbie Tester

## **DONATIONS/GIFTS**

Anderson, Renee  
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Thomas, Dr. Gregory & Mrs. Martha  
McMurry  
Timmen-Shaha, Sharon  
Wolf, Wesley

## **CORPORATE CONTRIBUTIONS**

Apex  
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# One Quick Email From You Can Help Save the HFO Thousands of Dollars!

## SIGN UP

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...for "Hemophilia eLines"—  
you'll be glad you did!

How, you ask? Simply send an email to [hfo@easystreet.com](mailto:hfo@easystreet.com), and in the body of the email give us your name and email address(es) so we can update your information in our mailing database. We can then send to you via email occasional "Hemophilia eLines" notifications to let you know about upcoming activities, social events, fundraisers, and other time-sensitive information, and we can also ask for volunteer help as needed and give each of you the opportunity to be more involved! These emails will supplement our quarterly newsletter, "Hemophilia Headlines," and will help us stay in better contact throughout the year while saving time and money!

Each mailing costs the HFO \$130-\$350 in postage, plus the cost of paper, labels, printing, and labor to get the mailing out. We can provide quicker information to those of you with email and save the Foundation thousands of dollars in the process.

"Hemophilia eLines" recipients will have total privacy. We will not share your email addresses with anyone for any other purpose.

Even if you think we already have your email address on file, please send it to us again to be sure. And if your family members want separate email notifications, feel free to give us several email addresses—we want to keep everyone informed!



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

*Address correction requested*