

# Hemophilia Headlines

S U M M E R 2 0 0 5

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## Gorgeous Spring Day Brings Green to HFO Coffers

BY DAVE WORTHINGTON

It was an extraordinarily green spring for the HFO this year thanks to the Koepke's green thumbs at the third annual plant sale. Don and Dona Koepke started their work in the fall anticipating a spring plant sale. With generous help from members of the Boy Scout Troop #230 working toward their citizenship badges, Don and Dona managed to collect and heal in plants at Luscher Farms in Lake Oswego, divide and replant them in new pots in the spring and transport them to the sale. A generous donation of potting mix from Michael Cruz from Wilco Farm Stores insured the planting success.

The perfect spring day in the Koepke's gorgeous garden set the stage for the sale. Plant experts Maxine Wilson and Dwayne Duval from Villa Garden Club in Portland shared their expertise and wisdom throughout the day. Sandy Cunningham and Dave Worthington helped with the cash box and loading plants for customers.

The sale day was spent visiting with neighbors and friends in the Koepke's beautiful garden while raising over \$1,200 for the HFO.

That's my idea of time well spent! A hardy thanks to the Koepkes for making this possible for yet another year. Additional thanks to the Scout Troop #230 members Peter Foy, Jordan Schrader, Brian Hughes and his father Peter Hughes.



### TABLE OF CONTENTS

In Memory: Elwin Greer . . . . .	2
In Memory: Mike Charles . . . . .	3
Ten Ways of Showing Someone You Care . . . . .	4
Woman to Woman . . . . .	5
Family Focus . . . . .	6
Counselor-In-Training Program at Camp Collins . . . . .	7
Gene Therapy Completely Corrects Hemophilia in Laboratory Animals . . . . .	8
News from Treatment Center . . . . .	10
Membership Dues, Memorials and Contributions . . . . .	11
Family Day at the Zoo . . . . .	12



# In Memory

## Elwin L. Greer

It is with great sadness we share that Elwin Greer, 55, of Eagle Point, Oregon, passed away January 25, 2005. He was born on July 16, 1949 in Fruita, Colorado to Harley and Jean Greer. Elwin and his wife Diane moved to the Rogue Valley in 1990.

Elwin worked as a vocational rehabilitation counselor for the VA Domiciliary from 1990 to 2000. In his professional life, he always put the veterans first and treated his patients with dignity, compassion and respect – he gave them hope.

Elwin was a man of integrity and courage. He faced and overcame many challenges in his life – few of which were of his own choosing or making. He always carried himself with grace and dignity, never complaining. He had a strong sense of empathy and affinity for the underdog, qualities he developed when dealing with the many health challenges arising from his hemophilia. He had an incredibly dry and droll, yet always gentle, sense of humor.

Elwin was a former HFO board member and was also active with the Hemophilia Federation and the Committee of Ten Thousand (COTT). He traveled to Washington DC in March 1996 to participate in the Ricky Ray rally on the White House steps, helping to advocate for those infected with HIV in the early 80s through their clotting medications.

Elwin is survived by his wife Diane Greer; his father, Harley G. Greer and step-mother, Connie Greer; his sister, Connie Etcheverry and her family; his brother, Harley Kent Greer; his step-sisters; and his aunts, uncles, and cousins.

He will be dearly missed by all.

The following Memorial Donations have been made in his honor:

From Richard & Beverly Fisher  
From Terry & Judy Haines  
From Michael & Linda Mustain  
From Carol Ingelson

From Medford Fire Department  
From Mike & Linda Charles  
From Dr. Ruth Rabinovitch



Elwin Greer

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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.

# In Memory

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## Michael D. Charles

It is with a heavy heart we share that Mike Charles, 43, passed away from liver failure at his home in Vancouver, Washington, on May 2, 2005. Beloved husband, son, brother, uncle and friend, Mike touched the lives of all who knew him.

Mike served on the HFO's Board of Directors for over 20 years, and served as editor of Hemophilia Headlines for 10 years. He persevered in the need to bring reform and change to the care provided to all with bleeding disorders. During the hemophilia/HIV epidemic, Mike met with politicians and news reporters, both locally and nationally, to advocate for those in the bleeding disorders community. Mike was part of Committee of Ten Thousand's (COTT) Government Relations Working Group and the Peer Advocacy Working Group. His work on the class action lawsuit and the Ricky Ray Hemophilia Relief Fund Act positively impacted our community.

Mike had a 25-year involvement with the HFO summer camp, beginning as a camper in 1970. In 2002, the "Mike Charles Outstanding Camper Award" was established. This award has since been given annually to a camper selected by the Camp Director and Staff who exemplifies the attributes Mike modeled for so many years – leader, teacher, encourager, mentor and friend.

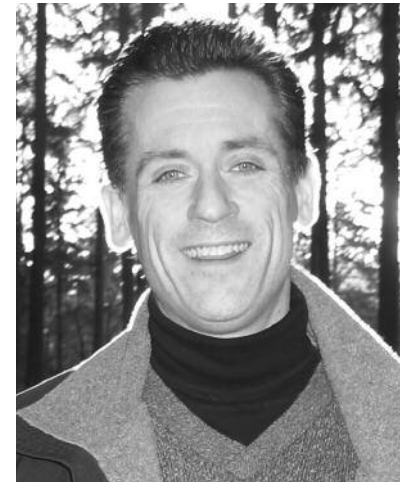
Mike is survived by his wife, Linda Charles; mother, Doris Greenfield Bruce, and husband, Glen; father Ed Charles, and wife, Judi; brother, Chris Charles, and wife, Samantha; nephew, Michael Allen; nieces, Monica, Kimberly, and Kyra Allen, and Paige and Lauren Charles.

We honor and celebrate the life of Mike Charles.

The following Memorial Donations have been made in his honor:

From Arthur & Carol Bergseng  
From Barbara & Gordon Jodoin  
From Carol Drew  
From Catherine Pedersen  
From Claudia Webster  
From Cleo Carlson & Signa Haygarth  
From Cory Kopstad-Garofalo  
From Dale & Carol Stewart  
From Dave Chvatal  
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From Diane & Tom Savoy  
From Diane Greer  
From Don & Dona Koepke  
From Doris Bruce  
From Doris Cameron  
From Ev & Pierrette Lovrien  
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From Jan Nelsen  
From Jim & Marjorie McAllister  
From Kerri Harding  
From Linda Coffey  
From Lothar & Hildegard Paesler  
From MAP Communications  
From Marci Ozawa  
From Marilen McGill  
From Marion Beebe  
From Marjory Morford  
From Mary Gidney Myrin  
From Melissa Bosworth  
From Michael Hergert  
From Michael Schmeer  
From Mike & Sharon Amos  
From Mildred Halm



Mike Charles

From Milt & Judi Stewart  
From Mr. & Mrs. Michael Bruce Berry  
From Mr. & Mrs. Newton  
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From National Cornerstone Healthcare Services, Inc.  
From Norma Perrone  
From Overton & Edith Bruce  
From Pacific NW Regional Council of Carpenters  
From Patrick & Pamela Cone  
From Patty Hanson  
From Pete & Ila McCallum  
From Richard & Elizabeth Gassner  
From Rupert & Bobby Jo Koblegarde  
From Simon & Mary Lou Kornbrodt  
From Susan England  
From Vicky Tody  
From Walter & Nelda Rupp  
From Western Partitions, Inc  
From Wild Bills NW Inc.  
From Willo Dillon

# Ten Ways of Showing Someone You Care

With the loss we've suffered in our community, we are not always sure how to respond or show the bereaved we care. Listed below are some ways of showing that we care. The list is taken from an article found in *Survival Handbook for Widows* by Ruth Loweinsohn.

- Call often. They need our calls more after the first couple of months. Don't expect them to call you back, since their energy level may be too low for them to make the effort even though they need to talk.
- Offer a specific date to do something. Think of "down" times – evenings and weekends particularly.
- Feel free to talk about the lost husband/wife/child. Don't avoid their name. It helps to deal with the reality if they can share memories of their loved one with friends or relatives.
- Realize that although they may seem to be "doing so well," they have a lot of grief to work through.
- Avoid pity. Imagine what it feels like to be pitied. Put yourself in their position, for a moment, of having others view you as incomplete. Care about them, but don't pity them.
- Treat them as a human being, as a real person, not like a china doll or someone without brains.
- Express your caring. If you feel like crying, it's okay. Crying is better than avoiding the pain.
- Say nothing rather than naïve clichés. A hug or squeeze of the hand means more than a hundred ill-chosen words.
- Bring food or invite them to dinner. As one woman said, "I have to eat, but it's hard to cook."
- Go for walks with them. Walking is good for depression and will allow them to "walk-off" feelings.

Most of us feel awkward around pain or suffering. That is normal. If we are fortunate enough to share moments of pain with relatives and friends, we will eventually share moments of joy with them as they emerge from the grief.

# Woman to Woman

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## Women with Bleeding Disorders Workshop

BY MONICA GRUHER

A workshop on bleeding disorders in women was conducted on June 4 through a generous grant to the Hemophilia Foundation of Oregon from ZLB Behring, and assisted by the partnering of HFO and the treatment center. The goal was to provide factual information on bleeding disorders specific to women and to reach both diagnosed women, as well as those in the general public who may be suffering from chronic undiagnosed bleeding symptoms. The workshop was the first of its kind in the area and was influenced by the current NHF program, Project Red Flag, designed for the same benefit.

Dr. Jody Kujovich from OHSU was a guest speaker and provided a good background on why people bleed, diagnoses, and treatments available. A good deal of the discussion was focused on vonWillibrands disease, the most common bleeding disorder in women. Joann Deutsche from the Hemophilia Treatment Center discussed the available services and benefits of the HTC for testing and treatment. Beth McDonald, an RN who came all the way from Kentucky, was also a guest speaker. Beth travels around the United States speaking from both a medical standpoint as well as a person with vonWillibrands. There was plenty of opportunity for women to network and obtain a wealth of written materials to bring back to their medical providers.

There is a great need to educate and help women who are suffering from chronic bleeding and are either diagnosed or misdiagnosed. As a result of the workshop, connections were made to a large women's clinic in Portland, and future educational sessions can be collaborated with both doctors and patients. We will also be exploring the possibilities of providing this type of education in conjunction with other women's health forums in the metro area.

If you missed the workshop and would like further information on women and bleeding disorders, visit the NHF website at [www.hemophilia.org](http://www.hemophilia.org) and go to the Project Red Flag link under the Programs tab.





# Family Focus

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## Transition: Leaving the Nest

BY MICHAEL FITZPATRICK

SOURCE: HEMAWARE, MARCH/APRIL 2003

A big change I will soon face is going away to college. I am both excited and nervous at the same time. I am excited and nervous about living on my own and making new friends. I ask myself, "Who will help me if I have a bleeding episode or trouble with my schedule?"

I have listed below some of the things that need to be done in order to help smooth the transition from the care of parents to making decisions for yourself.

- Start participating in decisions about your medical care when you are in high school. Talk with your doctors and nurses and help make decisions that are best for you. Be aware of what your own needs are concerning your health issues. Learn early to be proactive concerning your healthcare needs.
- Whether you are staying at the same hemophilia treatment center (HTC) or not, let your HTC know where you will be going. They will help you find the nearest HTC and local hospital. Contact the new center and introduce yourself. When you arrive at school make an appointment to meet with the healthcare services people immediately (if it is possible, you might do this before arriving). Have your current HTC send your medical information to an HTC at your new locale. The healthcare services and local hospital may want to contact your HTC to learn about your needs. This is something you may want to suggest.
- Depending on whether you self-infuse all the time, some of the time or not at all will influence your decision on where to store your factor and materials. Since I do not self-infuse (due to poor vein access), I will store some factor at both the healthcare services center and the local emergency room. If you self-infuse, you will need a refrigerator in your room (this is also good for snacks and soda).
- It is your choice who you want to tell about your bleeding disorder. Choose wisely.
- For those going to college, it will be important to let your advisors know if you cannot carry a full load due to health issues. Being honest with your supervisor may help to lessen problems in this area.

With planning, education and assistance, transition need not be frightening. I am not anticipating that the care surrounding my hemophilia will be a big problem. I want my biggest problem to be where to find the best French fries in town.

# Counselor-in-Training Program at Camp Collins

BY MONICA DICKEY

Counselor in training took on a whole new feeling this year. The camp committee decided after attending the North American Camping Conference of Hemophilia Organizations (NACCHO) that we needed to add some additional preparation to our younger staff members at camp. With the help of Pat "Big Dog" Torrey we've put together a new CIT program for camp this year, and the start of it included an additional day on the ropes challenge course at Camp Collins.

The day was sponsored by a generous grant from Wyeth Pharmaceuticals and was open to all youths between the ages of 15 – 21. We had a separate program in place for kids who aren't involved with our summer camp staff, however all of the attendees were members of our summer camp youth staff.

This day provided an opportunity for our core group of CITs to reconnect prior to getting down to camp. It was a great chance to catch up on all of the great things everyone has been up to all year as well as a time to start recreating a strong team for camp.

Some of the challenges during the day were mental as well as physical, and everyone had an amazing time learning about themselves and the group they're going to be working with in a couple of weeks. This facility has a lot to offer and all of the attendees felt the day was very worthwhile. Not only did this day get everyone excited to come back to camp, but everyone thought this would be a great way to start off our CIT training every year!

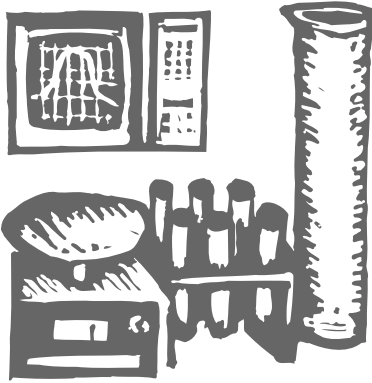


Dwayne Whitis, Monica Dickey, Chris Leland, Alisa Reidl (front row, left to right), Paul Dobry, Pat Torrey, Thomas Dickey and Joann Deutsche, NP (back row, left to right) from Camp Tapawingo attended the Third Annual North American Camping Conference of Hemophilia Organizations (NACCHO) in Tempe, Arizona on February 10-13, 2005. 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 conducting bleeding disorder camps.

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## Parent Support Group

Meetings are held at 6:30 p.m. at Bullwinkle's Family Fun Center in Wilsonville. The next meeting is September 13, 2005. Contact Patina Fieken at 503-625-6508 or PatinaF@verizon.net for further information.



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## HAPPY BIRTHDAY, CAMPER!

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### FEBRUARY

Michael Glenzer  
Joseph Ransom  
Crayson Neeley  
Eduardo Ramirez  
Taylor Stuckey  
Rafael Ramos  
Nathan Oleson  
Christian Heiner  
Ben Puckett  
Lindsey Groling  
Caitlin Kirsch

### MARCH

Josh Bulfinch  
Ray Winn

### APRIL

Kristin Boni-Burden  
Hope Coatney  
Matthew Walker  
Reafeal Jones  
Lindsey Bulfinch

### MAY

Jacob Puckett  
Kylie Holman  
Dylan Kirsch  
Luis Angulo  
Reed Thurber  
Bryan Dagenais

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# Gene Therapy Completely Corrects Hemophilia in Laboratory Animals

BY GWEN ERICSON

[HTTP://MEDNEWS.WUSTL.EDU/NEWS/PAGE/NORMAL/5117.HTML](http://mednews.wustl.edu/news/page/normal/5117.html)

April 18, 2005 — Newborn mice and dogs with hemophilia A were restored to normal health through gene therapy developed by researchers at Washington University School of Medicine in St. Louis. The technique introduced into the animals' cells a gene that makes clotting factor VIII, a protein missing because of a genetic defect.

"We are really pleased with the results, because the animals produced about 20 times more factor than has been achieved in prior attempts using gene therapy for hemophilia A in dogs," says senior author Katherine Parker Ponder, M.D., associate professor of medicine and of biochemistry and molecular biophysics.

In addition, the technique using newborn animals had the advantage of not prompting an immune response, which in many other cases eventually blocks the blood clotting activity of introduced factor VIII in hemophilic animals. Since treatment more than a year ago, the blood of the mice and dogs in this study has maintained a normal level of clotting factor activity, and the animals have had no incidents of bleeding.

The study will be reported in the April 26 issue of the Proceedings of the National Academy of Sciences.

Hemophilia is an inherited bleeding disorder caused by genetic mutations on chromosome X that prevent normal production of certain blood clotting factors. A defective gene for clotting factor VIII is responsible for hemophilia A, the form occurring in 80 percent of cases. Because females carrying a defective gene can rely on a normal copy of the gene on their second X chromosome, hemophilia almost always occurs in males. One in 5,000 males is born with the disorder.

"Hemophilia greatly restricts patients' everyday lives," says Ponder, a hematologist at Barnes-Jewish Hospital. "People with the disease don't heal well after injuries or surgery. Even running can cause bleeding into the joints."

For their own safety, hemophiliacs must be near a refrigerated supply of clotting factor at all times. Over the long term, hemophiliacs suffer from joint damage and other complications related to excess bleeding.

Gene therapy for hemophilia A has been especially challenging because the gene for factor VIII is quite large and therefore hard to fit into viral vectors, which serve as the gene delivery vehicle. The researchers eliminated parts of the factor VIII gene and other genetic components to minimize the material needed and used a large viral vector called gamma retroviral vector. The viral vector carrying factor VIII genes was injected into the blood of 11 newborn hemophilic mice and two newborn hemophilic dogs. The viral vector also contained a short DNA promoter sequence to make the gene active only in liver cells, one of the sites of factor VIII production in non-hemophiliacs.

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The normal mechanisms of viral reproduction enabled insertion of the genetic material from the engineered vectors into cells in the animals.

After treatment, blood tests demonstrated all of the treated animals were producing factor VIII. The mice achieved an average of 139 percent of normal factor VIII activity and the dogs an average of 115 percent of normal factor VIII activity in a blood clotting assay. This activity level has remained stable for one and a half years. In comparison, untreated animals with hemophilia A have less than one percent normal factor VIII activity.

“This level of expression of factor VIII in dogs is especially interesting, because in other attempts the results in large animals have not been successful,” Ponder says.

The researchers worked with newborn animals for two reasons. First, their livers are still growing. So genes integrated into a liver cell will be reproduced with each new generation of cells, increasing the number of cells containing functional clotting factor genes in the adult animal. Liver tests done when the animals were about a year old showed that the treated mice had an average of two factor VIII genes per liver cell. In the dogs, an average of one in eight liver cells had the new gene.

Second, newborn mice and dogs have a less mature immune system than do adults, making it less likely they will raise an immune response to the introduced factor VIII. The immune reaction, known as inhibitor formation, diminishes the activity of the clotting factor and has caused failure in previous attempts to correct hemophilia in mice using gene therapy. The animals in this study have not formed inhibitors against the factor VIII protein after more than a year of follow-up.

“Naturally, the ultimate goal is for gene therapy to work in humans, but humans have a more mature immune system at birth than mice,” Ponder says. “In animals more closely related to humans, there will probably be more risk of inhibitor formation, so the next step needs to be gene therapy trials in primates with hemophilia to see if we can prevent inhibitor formation.”

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## HAPPY BIRTHDAY, CAMPERS!

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### JUNE

Marilyn Walker  
Tylor Groling  
Mario Magana  
Sean Doyle  
Jakob Fieken  
Marcus Magana  
Brian Schoenheit  
Daniel Ramirez

### JULY

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

### AUGUST

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



# *News from the Treatment Center*

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## New OHSU Financial Policy

The OHSU Patient Business Office has a new financial assistance policy. The sliding scale discount now offers allowances for patients making up to 400% of the Federal Poverty Level. This means a family of four can earn up to \$77,400 and still receive a discount on services provided. If you would like to receive a screening for this discount, please contact OHSU Financial Registration at 503-494-8505.

Many facilities and providers offer similar discounts. If you receive care at a facility other than OHSU, please contact that facility or provider to request a financial screening.

# Membership Dues, Memorials and Contributions

Dues, memorials and contributions as of July 15, 2005.

## SUSTAINING (\$500 AND GREATER)

Heffernan, Robert

## BENEFACTOR (\$250)

Jones, Alan & Jill  
Oregon Hemophilia Treatment Center

## PATRON (\$100)

Franklin Contracting, Inc.  
Laam, Mary  
Porter, Don & Clara  
Schuyler, Bill DMD  
Smith, Donald  
Worthington, Dave & Pam

## INDIVIDUAL & FAMILY MEMBERSHIP DUES (\$20 INDIVIDUAL, \$35 FAMILY)

Adams, Fred & Patty  
Aina, Don & Rowena  
Amos, Mike & Sharon  
Anderson, Mary Lou  
Bernstein, Michael & Tina Marie  
Baskin  
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DiPasquale, Gaye  
Evans, Lori & Philip  
Fisher, Lisa  
Gibson, David & Sharon  
Greenfield, Doris  
Gruher, Jim & Monica  
Hammar, Don & Wilma  
Harper, Ken & Ingrid  
Harrison, Bill & Esther  
Heffernan, Kevin & Jana  
Heffernan, Pat & Tricia  
Holmes, Steven & Lynne  
Ingram-Rich, Robi  
Jablonski, Greg  
Koepke, Don & Dona

Lapp, Carol  
Lieberman, Art & Gail  
Lindemann, Sally & James  
Lofland, Joan  
Malek, William  
McAlpin, Jim & Esther  
McCartney, Robert & Margaret  
Morrison, Tami & Larry  
Nelson, Cliff & Kristy  
Pagenstecher, Anne  
Pagenstecher, Stewart & Deborah  
Petrick, Frankie  
Pierce, Doug & Cindy Secrest  
Ruff, Lola  
Sanders, Bruce & Jan  
Schechter, Howard & Leslie  
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Wagner, Edward  
Zwetschke, Linda

## DONATION IN HONOR

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From Jim & Sharon Dickey  
*Mike & Linda Charles*  
From Doris Greenfield  
*Judie & Dave Cox*  
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*Nancy & Bill Worthington*  
From John & Mary Pelton  
*Nancy Worthington*  
From John & Mary Pelton

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From Bill & Nancy Worthington  
*Katharine Howard Glass Coates*  
From Bill & Nancy Worthington  
*Bruce Dessellier*  
From Jamie Dessellier  
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*J. Frank Schmidt, Jr.*  
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From Richard Daily  
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From Prudence Volkerts  
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From Dennis & Joanne Keith  
From Robert Cray  
From Susan & George Mitchel

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Thurber, Alan & Kala

## DONOR CHOICE FUNDS

United Way of the Columbia-Willamette

# Family Day at the Oregon Zoo

Mark your calendar for Sunday, September 25, 2005. The HFO will be hosting its annual Family Day at the zoo followed by dinner and the HFO Annual Meeting.

## 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).

1:00-3:30 pm	Free time at the Oregon Zoo Organized HFO Activities in the Oregon Zoo VISTA ROOM
3:30-4:30 pm	Appetizers and beverages served; get information about HFO services; meet with industry representatives; check out this year's camp photos!
4:30-5:00 pm	Welcome/short program/annual meeting
5:00-5:45 pm	Dinner
5:45-6:15 pm	Zoo Show (TBD)



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*Address correction requested*