NEWSLETTER OF
THE HEMOPHILIA
FOUNDATION OF
MINNESOTA AND
THE DAKOTAS

Veinline

Summer 2012

HFMD MISSION

We dedicate ourselves to advancing the quality of life of individuals and families affected by hemophilia or other bleeding disorders by providing a broad range of services and programs.

Inside this issue:

IMPROVING BLEEDING & CLOTTING DISORDERS TREATMENT IN THE REPUBLIC OF GEORGIA: THE LONG JOURNEY OF LEVANI MAKHALDIANI

By Stephen E. Calvit

Dr. Levani Makhaldiani

BACKGROUND: In 2004, a brilliant young physician named Levani Makhaldiani had just graduated from Tbilisi State University Faculty of Medicine. Three years earlier, the Georgian Government, working through the Ministry of Health, in collaboration with the Georgian Association of Hemophilia and Donorship, the Institute of Hematology and Transfusiology, and the World Federation of Hemophilia, initiated a National Hemophilia Program. As part of this program, the first Georgian Hemophilia Treatment Center (HTC) was established. This is the story of how Dr. Levani Makhaldiani became Medical Director of the Georgian HTC and his long journey to Minnesota to discover better ways to treat patients with bleeding and clotting disorders.

MEDICAL TRAINING: The most important period of Dr. Makhaldiani's medical training began in 2004, when he started his hematology residency at the Institute of Hematology and Transfusiology (IHT) in Tbilisi. Being chosen to do a residency at this prestigious Institute was a top honor, because of its long and distinguished tradition of excellence in patient care, research and training. He describes his time at IHT as a truly profound learning experience because he had the rare opportunity to work with the nation's most imminently qualified hematologists. After completing his residency in 2008, he was named the head of the Department of Clinical Transfusiology. If that wasn't a big enough challenge, Dr. Makhaldiani also decided to pursue his PhD. His dissertation research on hereditary thrombophilia resulted in being awarded a grant from the Georgian National Science Foundation to identify the prevalence of hereditary thrombophilia in the Georgian population.

INFLUENCE OF DR. NIGEL KEY: Dr. Nigel Key's association with Georgia can be traced back to his involvement with the World Federation of Hemophilia's Twinning Program. This program, established over 15 years ago, aims to improve hemophilia care in emerging countries through a formal, two-way partnership between two hemophilia organizations or treatment centers for a period of four years. Twinned organizations or hemophilia treatment centers work together and share information, resulting in a mutually beneficial partnership. It is a great way to transfer expertise, experience, skills, and resources. According to Dr. Key, "Frequently the impetus for change in many countries does not come from physicians but the patients. Physicians may often, knowingly or unknowingly, support the status quo." Patient power was dramatically demonstrated a decade ago, when he first visited the newly independent Republic of Georgia. At that time there was little or no access to factor concentrates, few hemophilia patients were diagnosed and the government lacked serious commitment to improving hemophilia treatment.

Shortly after Dr. Makhaldiani learned about the Novo Nordisk Hemophilia Foundation Fellowship (NNHF), he consulted with his colleague and mentor, Romanoz Khomasuridze, President of the Georgian Association of Hemophilia & Donorship. Mr. Khomasuridze recommended that he reach out to Dr. Key, who, in turn suggested that he contact the Center for Bleeding & Clotting Disorders in Minnesota. Dr. Makhaldiani was subsequently

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"Anything is Possible" – HFMD 2012 Annual Member Meeting

With a theme of hope and unlimited potential, our Annual Meeting kicked-off on the evening of Friday, April 20th with a state fair style carnival and dinner buffet. Half of the ballroom was sectioned off for dining, while the other half featured games of skill, chance, and just plain old fun. There were ring tosses, throwing games, a fishing pond, and even a simulated roller-coaster ride created by HFMD Event Coordinator Carrie Kissoon.

With another big turnout of nearly 250 attendees, guests indulged in corn-dogs, 47 pounds of cheese curds, and a build-your-own burger buffet. Balloon animals by Fritz, and face-painting led by Jocelyn Gorlin and a troop of Girl-Scouts, it was a busy night for all of the kids. Volunteers at each games station kept a good flow throughout the event.
On the quieter side of the ballroom, there was bingo with prizes and mingling for the adults. The excitement in the air wound down after a busy fun-filled night.

Saturday morning started with breakfast and time to visit 14 company exhibitors. Child Life Programming (child-care) was led by Vicki Nies who runs this program at Children's Hospital and Clinics of Minneapolis. The kids are not only cared for, but are also participating in fun activities which are hemophilia related education based. They play games and have fun while learning more about bleeding disorders. This was followed by an HFMD opening address led by Jim Paist and announcements from Committee Co-Chair Vicky Hannemann. Then it was time for our very special keynote speaker Dr. Glenn Pierce. With an amazing back ground in the hemophilia community having worn many different hats, Dr. Pierce was born with hemophilia, is a physician, and has been deeply involved with clinical research of blood-factor products.

Having previously worked in this area with a number of other pharmaceutical companies, Dr. Pierce is the Vice President of Product Development with Biogen Idec. Part of Dr. Pierce's presentation included a look at what is down the pipeline in blood-factor product development. In a very balanced and thoughtful manner, he profiled several published products currently under development by a variety of pharmaceutical companies. Our attendees were on the edge of their seats listening to what types of new and longer lasting therapies will likely be available in the future to treat those affected by hemophilia. Guests applauded emphatically after Dr. Pierce finished his presentation sponsored by Biogen Idec.

After a 30 minute break and time to visit exhibit tables, our morning breakout sessions and teen programming opened. Teen programming was very special this year featuring fencing lessons from the U of MN fencing club, and a craft session with T-shirt design.
Breakouts included New Families/New Beginnings – Susan Kearney, MD, Aging in Hemophilia – Mark Reding, MD. Afternoon Breakouts featured Home Infusion – Kirstin Schmidt, RN, and Joni Osip, RN, MS, Carriers of Hemophilia – Matt Bower, Genetic Counselor, and Skye Peltier, PA, Blood Brotherhood Program - Stress Management - Nancy Saslow, Integrative Therapist.

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BAYER HEALTHCARE AND THE HEMOPHILIA COMMUNITY:

Commitment, Leadership *and* Innovation

Bayer HealthCare

Office News

After nine years of working as the HFMD Office Manager and after a very successful career prior to coming here, Pam Cella announced her retirement in May. Pam has been a very important part of HFMD operations during her distinguished tenure here doing a terrific job in keeping things organized in the office and at our big events.

In addition to her many office skills, Pam also brought a high level of professionalism and consistently positive demeanor to the position. She is well liked by so many involved with the HFMD, and will be missed here in the office and in this bleeding disorders community. Thank you Pam Cella for all of your hard work and dedication to this organization!

With some big shoes to fill, Lisa Carlson has been hired as HFMD's Administrative Assistant. Leaving a similar position with a local business to work for the HFMD, Lisa began her employment here on June 25th.

HFMD Emergency Assistance Program

When you donate to the HFMD, your dollars help to support a number of our programs and services including our amazing Summer Camp for Kids, Group Fitness Program, Educational Seminars, and our emergency financial assistance program.

Our emergency assistance program is designed to help members who are facing an unexpected financial crisis relating to medical issues. For example, we help to cover the costs of lodging for parents experiencing financial hardship when a child affected by hemophilia needs an emergency visit to the hospital or has to have surgery. Our program guidelines are designed to have all requests come from the Social Workers of our affiliated Hemophilia Treatment Centers (HTC's) who review the request to see if it may fit. If a patient or family is experiencing an unexpected one-time financial crisis, they can approach the Social Worker with the situation to see if they may be eligible for some type of support through a county or state agency first, before deciding if a request to the HFMD program qualifies for our guidelines.

Occasionally our program can help with a very unique situation. For example, a teenage boy with severe hemophilia from Nepal recently came to the Mayo Clinic in Rochester with his father to have a corrective surgery on his knee due to severe hemophilic arthropathy and joint destruction that had left him unable to bear full weight on his leg. The deteriorating condition of the boy's knee was a result of not having access to proper blood-factor treatment in the part of the country he and his family live.

After a long, but successful surgery and recovery in Rochester, he was ready to be fitted with a custom leg brace that would support his knee and help ensure proper healing. While there were immediate resources to cover the cost of the surgery, no funds were available to pay for the leg-brace. A request was made to our Emergency Assistance Program to see if HFMD could pay for the cost of a medical leg-brace. We were glad to help in this special situation. This father and son were very grateful to the Mayo Clinic Hemophilia Treatment Center for taking such wonderful care of him before and after this corrective surgery. They were also thankful to the HFMD for helping with the brace.

Makhaldiani continued from page 5...

awarded the fellowship and in January 2012 traveled to Minneapolis to become a visiting scholar for the next twelve months.

FELLOWSHIP GOALS: To obtain the maximum value from this NNHF fellowship, Dr. Makhaldiani created the following educational goals for himself to improve the treatment of patients with bleeding and clotting disorders in Georgia: 1) Gain knowledge of the laboratory tests used in clinic to diagnose and/or monitor patients, especially cutting-edge diagnostic approaches; 2) Comprehend the many different treatment approaches for patients with hemophilia and other bleeding and clotting disorders; 3) Understand and gain experience in the management of inhibitors patients with hemophilia; 4) Establish and maintain long-term professional relationships with James Paist, Executive Director of the Hemophilia Foundation of Minnesota/Dakotas and the Center for Bleeding & Clotting Disorders team: Mark Reding, MD; Joni Osip, RN, MS, NP-C; Ricky Chan, PA-C; Kim Baumann, MPT; Stephen Calvit, MSW; Sue Curoe, RN, MS; Vicky Hannemann, RN, BS; and Kerry Hansen, RN, BS.

THE REAL WINNERS: If you were to ask Dr. Makhaldiani who will benefit the most from his NNHF fellowship, he would not hesitate to tell you that the patients of the Georgian Hemophilia Treatment Center are the real winners, followed by his colleagues and his beloved country, Georgia. Under the tutelage Dr. Mark Reding, he is learning leading-edge treatment, testing and diagnostic approaches to providing better patient care. Equally important is recognizing the value of an interdisciplinary team approach for treating patients. Moreover, he's impressed by how social work services are utilized to help patients connect with community resources, deal with psychosocial stressors and sort out complicated insurance matters. It is this holistic model of patient care that Dr. Makhaldiani hopes to implement at the Georgian Hemophilia Treatment Center upon his return.

Thank you to the Novo Nordisk Hemophilia Foundation Fellowship for helping to make all of this possible.

National Hemophilia Foundation 2012 Annual Meeting

November 8-10, 2012 Orlando World Center Marriott
Orlando, Florida

Join NHF for three full days of programs, workshops, networking and fun social activities! There is something for everyone – individuals, families and healthcare providers. And be sure to join us for our closing party at Universal Studios.

Accommodations: Make Your Reservation Now!
To receive the discounted room rate at the Orlando World Center Marriott hotel, go to: https://resweb.passkey.com/go/NHFattendee or call 888-789-3090 and ask for the NHF group rate. The access code is NHFATT1112. Rooms are limited, so book yours today.

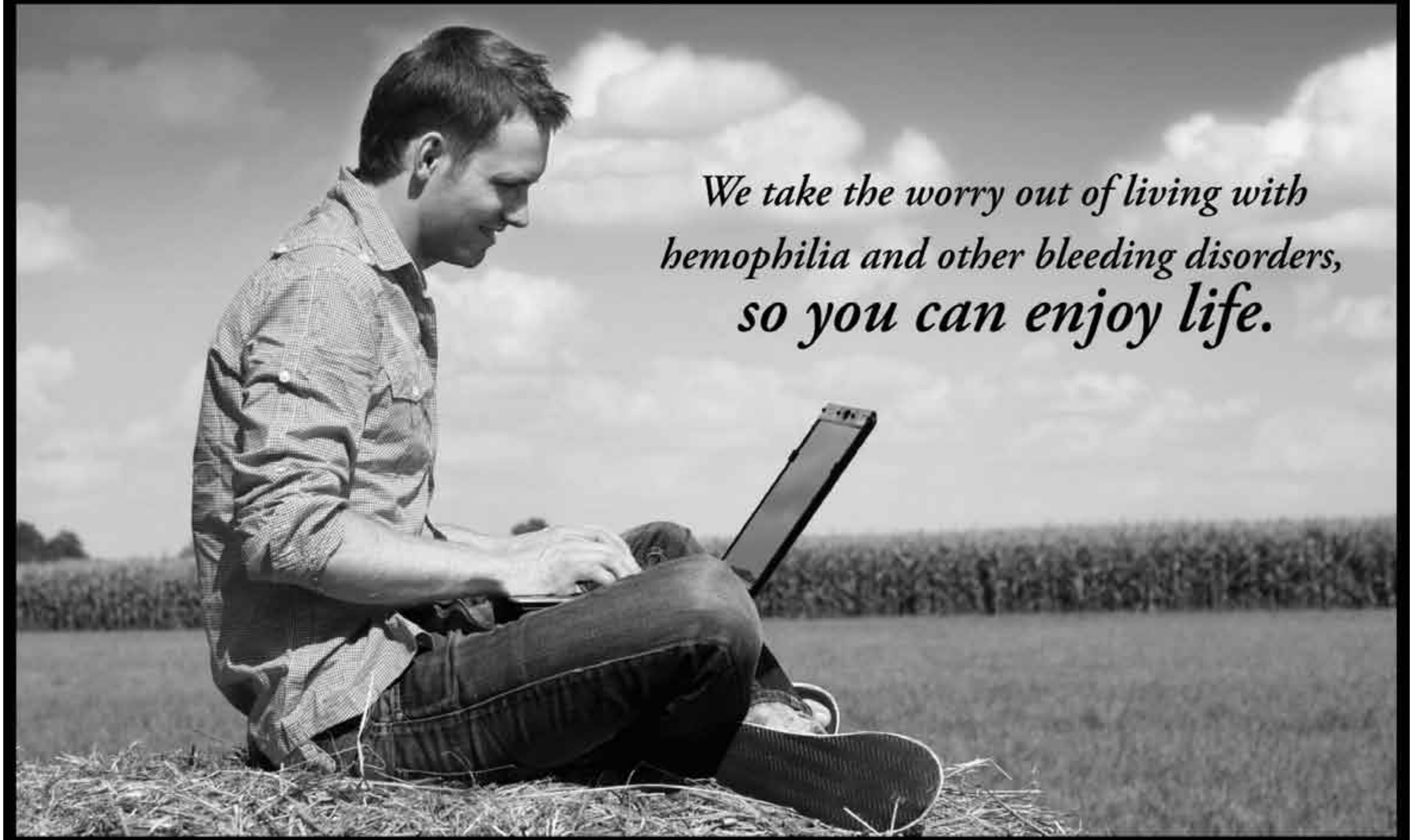
Babycare/Activity Program for Kids & Teens: Register Now!
Space for these popular programs is limited so reserve your spot by registering now!

Registration Deadline: Monday, September 3, 2012

HFMD Community Member Travel Scholarship

The HFMD is accepting letters from individuals or from parents of those affected by hemophilia or a chronic bleeding disorder to apply for our annual community member travel scholarship. One application will be selected by a review committee before August 30th. Letters should explain why you wish to attend the conference, how you and another family member could benefit from the education seminars, and please indicate if you have previously attended an NHF conference. Priority is given to those who have never attended. Please include the name of your Hemophilia Treatment Center (HTC). Letters of recommendation from your HTC can be considered in addition to your letter.

Our travel scholarship can reimburse an individual for travel and lodging expenses for the NHF conference up to $1,000 maximum. Or, can reimburse one or more community members of a family up to a $1,500 maximum. Selected applicant will need to make all travel arrangements. Please send or email your letter to the HFMD.



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2012

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Event Coordinator

Board News

After serving nearly ten years on the HFMD Board, Dan Tinklenberg has decided to take some time away from the Board. Dan has led the Board as President since 2008 and also volunteered his time on our Fitness Committee and at many of our events. He has been instrumental in helping to shape the way the Foundation operates during this time. The HFMD extends a heartfelt thanks to Dan for all of his efforts!

On April 21st, the Board voted in John Schulte as the new Board President. Mike Neubert was elected Vice- President, while Steph Miller was re-elected as Treasurer and Liz Myers re-elected as Secretary. The Board also welcomed in two new members: Mike Johnson and Ignacio Ramos.

member of Community Health Charities
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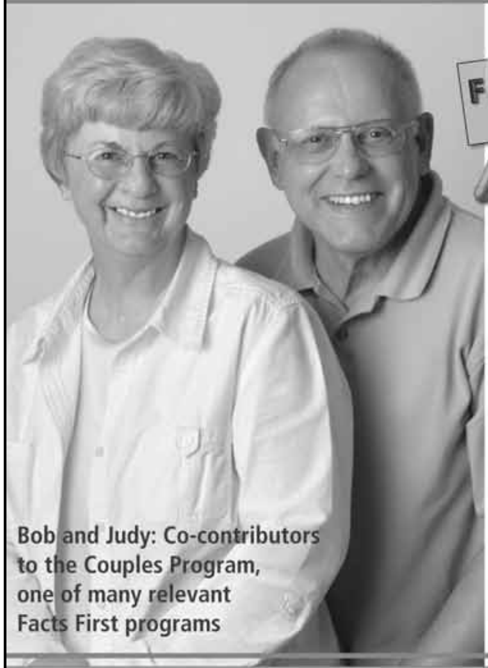

COMMUNITY PROGRAMS

Bob and Judy: Co-contributors to the Couples Program, one of many relevant Facts First programs

FACTS FIRST

Interactive and educational programs presented by community experts

Offering a variety of programs created for you, including:

- Hemophilia Basics
- Power of Choices: Taking Control of Your Health
- Partnering With Your School
- Couples Program
- Balancing Sports and Exercise
- Healthcare Reform
- Emergencies Happen

Contact your Baxter representative to learn more about attending a Facts First program:
Stacie Cowen
(612) 701-5880
stacie_cowen@baxter.com

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The HFMD gratefully acknowledges our donors who have given so generously. Below are donations received from January 1, 2012 through June 30, 2012.
Please note the donations from the Walk website will be included in the next issue of the veinline.

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Annual Meeting continued from page 2...

Our 2012 Annual Meeting was truly a reflection of this bleeding disorders community with many our families, individuals with bleeding disorders, HTC staff, sponsors and exhibitors. There were terrific speakers sharing important information, networking and families reconnecting, and a fun time had by all.

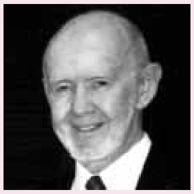
The HFMD extends our deepest appreciation to our event sponsors:
Baxter BioScience, Novo Nordisk, University of Minnesota Medical Center – Fairview and Sanford Health.

A special thanks to the event planning committee: Vicky Hannemann & Kirstin Schmidt (committee Co-chairs), Angie Boyd, Vicki Neis, Carrie Kissoon, Steph Miller, Deb Starling, and Nancy Golden.

We also thank company exhibitors: Accredo, AxelaCare, Baxter BioScience, Bayer Health Care, Biogen Idec, Bio Rx, Coram, CSL Behring, CVS Caremark, Grifols, Kedrion, Mid-West Cornerstone, Novo Nordisk, Pfizer, & Walgreens Infusion Services.

by James Paist

Memorial



Watson, William H. (Bill) 84, of St. Louis Park, MN went to be with his Lord and Savior, Jesus Christ on May 18, 2012.
Born on June 2, 1927 in Arlington, MA to Samuel and Eva Watson.
Preceded in death by parents, 4 brothers and 1 sister. Survived by his loving wife of 59 years, Peggy; daughters, Joan (Nathan) Boyer, Debra Watson, and Karen (Gerard) Page; grandchildren, Geoffrey (Emily), Amanda, and Missy; great-grandson, Logan; and sister-in-law, Patsy Harmon. Bill was a veteran, having served in the U.S. Navy during World War II and the Korean Conflict.

The HFMD extends our deepest sympathies to the Watson family. We thank the Watson family for all of the generous donations in memory of William.

HFMD Awards Post-Secondary Scholarships

Knowing that an education is usually necessary for people to attain the kind of work they dream of, the Hemophilia Foundation was delighted to receive 13 completed applications for post-secondary school this year from members within our bleeding disorders community. During the month of July, the Scholarship Committee reviewed all applications, the recipients were named, and the applicants were notified by mail. Scholarship checks will be awarded to the recipients and mailed to the school of their choice at the end of July.

Scholarship eligibility requirements for applicants include (1) having an inherited bleeding disorder, (2) being a resident of Minnesota, North Dakota or South Dakota, or be a patient of one of the Hemophilia Treatment Centers in these states, and be a participant in HFMD programs and services, and (3) and being accepted into a post-secondary educational program.

Hemophilia Treatment Centers (Tri-State Area)

Hemophilia and Thrombosis Center
Children's Hospital and Clinics of Minnesota (CHCMN)
2525 Chicago Avenue, CSC-175
Minneapolis, MN 55404
612-813-5940
angela.boyd@childrensmn.org

Margaret Heisel Kurth, MD
Susan Kearney, MD
Steve Nelson, MD
Michael Sprehe, MD, MPH
Skye Peltier, PA-C
Kim Jacobson, RN, CPNP
Jocelyn Gorlin, RN, CPNP
Jane Hennessy, RN, CPNP
Kristen Appert, RN, CPNP
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Janice Baker, Genetics Counselor
Angie Boyd, HTC Coordinator

Sanford Health, Sioux Falls, SD Region
1600 West 22nd Street
P. O. Box 5039
Sioux Falls, SD 57117
605-312-1000

Mustafa Barbour, MD
KayeLyn Wagner, MD
Jerilyn Moore, RN
Grant Boltjes, PT
Wendy Jensen, CCLS
Amy Woltanski, Genetics Counselor
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Center for Bleeding and Clotting Disorders
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B549 Mayo Building
Minneapolis, MN 55455
612-626-6455
htc@fairview.org

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Lisa Baumann-Kreuziger, MD
Ricky Chan, PA-C
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Chelsea Antilla, Genetics Counselor
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Mayo Comprehensive Hemophilia Center
Mayo Clinic
Mayo 10-75E
200 First Street SW
Rochester, MN 55905
507-284-8634 or 1-800-344-7726
schmidt.kirstin@mayo.edu
eckerman.amy@mayo.edu

Rajiv Pruthi, MBBS
Vilmarie Rodriguez, MD
Kirstin Schmidt, RN
Amy Eckerman, RN
Melinda Otto, SW

Sanford Health, Fargo, ND Region
820 Fourth Street North
Fargo, ND 58122
701-234-2757

Nathan Kobrinsky, MD
Courtenay Misheski, RN
Jana Suder, NP
Linda Thorseth, PT
Diane Sjolander, CCRP
Kate Syverson, LCSW
Mark Plencner, RPh

MEMORY OF ANNA DESIMONE

Anna DeSimone, founding Board member and Treasurer for FWGBD, died on Saturday, April 21, 2012, after a long, valiant struggle with myelofibrosis. The Foundation for Women & Girls with Blood Disorders and the entire blood disorders community suffered a significant loss.

We remember Anna as a woman of singular stamina, selfless service and integrity. She was not someone who quietly or passively accepted life challenges. Anna's approach to life was best characterized as: get educated, get involved, then educate and take action that yields positive outcomes for the community. Anna had a thoughtful, insightful way of making sense of things for others--forcefully changing things that should.

In the late 1980's as the mother of an infant son with hemophilia A-new for her family-she reached out to her state association, the Hemophilia Association of New Jersey (HANJ). In the arena of HANJ, Anna started coming to meetings, then she became a Trustee and, eventually, President of the Board. She was an important force against discrimination and for truth, and recognition, treatment and compensation for individuals and families with HIV.

Anna always understood that women have bleeding disorders too. She herself was a hemophilia carrier, had thalassemia minor and was later diagnosed with a myeloproliferative disorder, then myelofibrosis. During her tenure at HANJ, the task force on women became a Committee of the Board. When the Governor of NJ established a commission on women's bleeding disorders, Anna was appointed to serve. The outcome: state department of health recognizes the need for screening women with menorrhagia and other symptoms for underlying bleeding disorders.

A top event in the history of the National Hemophilia Foundation US, was Anna joining the staff, in 2003, as Coordinator of Project Red Flag (PRF)-real talk about women's bleeding disorders, the national awareness campaign about von Willebrand Disease and other bleeding disorders with dire consequences for women and girls. She soon became Director of PRF. Among her achievements were: the checklist for school nurses, created to help them recognize the signs of bleeding disorders in girls; a pre-conference symposium devoted to the issues of women with bleeding disorders at each annual meeting; and an Ask-the-Experts session, with hematologist and Ob/Gyn, featured at each meeting.

And yet the best story is the individual lives Anna touched. Meeting her own challenges of raising a son with hemophilia and finding a course of treatment for her own aggressive disorder--a regimen that would sustain a quality life, Anna instinctively understood the lives of women in the blood disorders community. Her connection was direct.

While Anna stepped back from working on a daily basis, ever true to herself and what she believed in, she became a founding Board member and Treasurer of the Foundation for Women & Girls with Blood Disorders. With the Foundation, Anna's focus was on education of healthcare providers-across disciplines-about all blood disorders affecting women and adolescent girls. It was Anna's insightful, solid guidance that helped FWGBD achieve its growth and progress in such a short time.

The Foundation for Women & Girls with Blood Dis orders (FWGBD) pays tribute to Anna's indomitable spirit, dedication and tireless work in advancing the mission of this Foundation. To sustain and enhance Anna's work in educating healthcare providers about the needs of women and girls with blood disorders-including those with myeloproliferative disorders, bone marrow failure and hemophilia carriers, the Foundation will dedicate a healthcare symposium to be held in 2012 in Anna's memory and honor. Contributions can be made to the Foundation in Anna's name which will be applied to this major educational symposium. Any additional contributions will be used to continue Anna's work in promoting the mission of this Foundation.

Anna's family requests that contributions be made to the Foundation for Women & Girls with Blood Disorders in her name to educate healthcare providers and advance Anna's work to change women's lives.

Mailing Address:
Foundation for Women & Girls with Blood Disorders
11 Cloverhill Place
Montclair, NJ 07042-4818

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NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

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Mendota Heights, MN 55120

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1-800-994-4363
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Calendar

August 5-10, 2012	**HFMD Summer Camp** Camp Courage Maple Lake, MN
August 12, 2012	**Blood Brothers Event** Education and Twins Baseball Game Target Field
August 18, 2012	**Group Fitness Event** Canoeing at Lake Calhoun 10:00 a.m. Call HFMD to R.S.V.P.
September 21-23, 2012	**Dakota's Family Retreat** Smokey Hills Wilderness Retreat Osage, MN
October 6-7, 2012	**Women's Education Day** Oakridge Conference Center Chaska, MN
October 26-28, 2012	**Minnesota Family Retreat** Arrowwood Resort & Conference Center Alexandria, MN
February 9, 2013	**Heart of Hope Gala** Embassy Suites - Airport Bloomington, MN