



# Hemophilia Center

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**Peter Kouides, MD**  
Director of Research  
**Prad Phatak, MD**  
Associate Medical Director

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You are cordially  
Invited to  
Visit  
Our New Website  
Anytime  
Day or Night  
at  
[www.hemocenter.org](http://www.hemocenter.org)  
No R SVPs but Feedback Welcome  
at: [rona.wyner@viahealth.org](mailto:rona.wyner@viahealth.org)



**PARTICIPATE  
VOLUNTEER  
SUPPORT  
ATTEND  
TRAIN**

**FOR**

**The Finger  
Lakes  
Triathlon  
Sept. 18, 2005**

### QUOTE OF THE QUARTER

The worst thing you can do for those you love is the things they could and should do for themselves.

-- Abraham Lincoln

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**SUMMER 2005**

## ANNUAL MEETING 2005 - EXPANDING OUR CIRCLE OF FRIENDS

**O**ur Circle of Friends definitely expanded when Alan Kinniburgh came to Rochester for our Annual Meeting. Appointed as CEO of the National Hemophilia Foundation (NHF) in January of this year, Dr. Kinniburgh came to NHF with vast experience and impressive credentials. Armed with a PhD in biology from the University of Illinois at Chicago, Dr. Kinniburgh rose to Professor of Cellular and Molecular Biology at SUNY Buffalo and was founding director of Roswell Park Cancer Institute Laboratory of Molecular Diagnostics. His research led to discoveries on the normal cellular control of genes that regulate growth. He also discovered ways in which these controls can be altered in cancer - particularly leukemia. In addition to his role in NHF, Dr. Kinniburgh also sits on the Dept. of Defense's Chronic Myelogenous Leukemia Integration Panel.



Under Dr. Kinniburgh's leadership, two major thrusts for NHF will be in research and fund raising - both of which promise to propel NHF and the entire Hemophilia community to new heights.

In his spare time, Dr. Kinniburgh grows bonsai and orchid plants outdoors and in his basement. He loves Oriental gardens, so his visit to the Gooleys fabulous garden must have been one of the highlights of his visit to Rochester.

At the Annual Meeting, a truly exceptional young woman, Amanda Bingham, was honored. At only 12 years of age, Amanda placed first in her age category in the Sprint Distance of our Finger Lakes Triathlon last year and raised over \$1,000 for our Center on behalf of her tribuddy, Michael, in our Train for Treatment program. Amanda is also involved in cross country and swims competitively in the Camilus Swim Club.



Amanda loves science, and at the meeting was engrossed in a conversation about specialized microscopes (oil immersion) with Martin Scott.



At the meeting, Lucinda Lapoff, Esq. was also honored for her service to the hemophilia community as Board Chairman for 3 years, member of the board for a total of 7 years and the founder of our Finger Lakes Triathlon. Patrick Pullano was also praised for serving the Board with distinction for 5 years.

New Board members joining the board for the first time are: Laura Bills, Wanda Dukes, Dan Mikel, Yuk Seidman and Michael Smith. Congratulations go to our new Board Chairman, Vicky Orto, RN and Vice-Chairman Yvonne Ace-Wagoner.

At the meeting Dennis Conolly was presented with a \$1,000 scholarship for his college studies from our Hemophilia Center's special Scholarship Fund. Dick Blum, an active board member did the award presentation honors.



### VERN LOVELESS, DDS RETIRES

For several years, Dr. Loveless has served as a consultant to our Center and has looked after the dental needs of many of our patients. His kind and gentle manner has endeared him to both staff and patients.

He is well versed in genetic bleeding disorders and has been a tremendous asset to all of us. We thank him for his prompt follow-up of our patients and we will miss his visits to our Center to facilitate patient care.

We understand he and his wife are moving to the Boston area to be closer to their children and grandchildren and that they plan to do more travel in their retirement. The board, staff and patients of the Hemophilia Center wish them a long, healthy and fulfilling retirement.



## PRESIDENT'S MESSAGE

**ROBERT W. FOX**  
**PRESIDENT/CEO**

### THE WHOLE 9 YARDS... AND MORE

What does the "comprehensive" in "Comprehensive Care" mean? Complete, broadly inclusive. If you attend a comprehensive clinic, depending on you and the nature of your disorder, you may be seen by a hematologist, a hemophilia nurse, a pediatrician, an orthopedic specialist, a physical therapist, a social worker, a dentist, a genetic counselor and a research specialist. The team meets before clinic to discuss your case and after clinic to reach consensus on your care plan. If we deliver those services well, including all of the administrative rigmarole healthcare demands, we're meeting expectations.

To make a difference, to have a positive impact on

someone's life, to help a family in need, we have to do more. Typically, doing a little extra is unscripted. But we can't do just what we're supposed to do and expect different results. For every improvement, there are inputs - things people do to make someone else's healthcare experience a little better, to lend the unexpected hand or a listening ear, to do a favor, to make someone's life easier.

At the Center we pride ourselves on our caring spirit, on going that extra mile for people we serve. Chances to make a difference in someone's life come and go, and when we have the opportunity, we must seize it and give our best. Tomorrow the chance may be gone.

Bend over backwards, show flexibility, be pleasant, recognize people's needs, go out on a limb, be helpful. Everyone on the planet should follow such advice. At the Center it's how we operate. Caring is in our blood.

## EXERCISE HAS ITS OWN REWARDS ...

Regular physical activity will help you to feel better and be healthier because it:

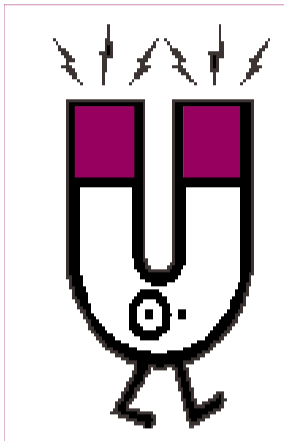
- 🚴 helps you protect your joints
- 🚴 helps to build stronger muscles & bones
- 🚴 Leads to fewer bleeds due to stronger muscles
- 🚴 helps your heart & lungs function better
- 🚴 lowers your stress level
- 🚴 increases your strength
- 🚴 helps you to burn calories
- 🚴 helps to control your blood sugar
- 🚴 aids in controlling blood pressure
- 🚴 improves how you feel
- 🚴 helps to enhance your self-esteem

### Do It!



## JULY IS NATIONAL HEMOCHROMATOSIS AWARENESS MONTH

If you or someone you know is experiencing several of the following symptoms, it may indicate that the body is storing too much dietary iron. The results could be devastating. Be smart and get tested for Hereditary Hemochromatosis (HH) before the iron does damage to your body.

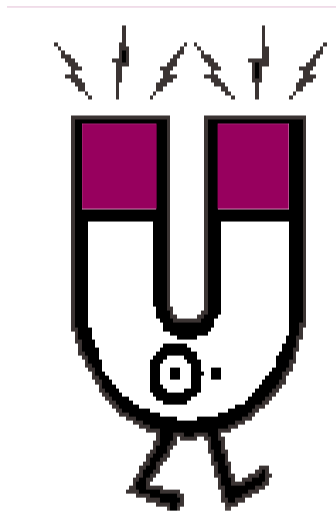


### Symptoms

- weakness or chronic fatigue
- loss of libido (sex drive) or impotence
- arthritis in joints
- abdominal pain
- bronze or gray discoloration of the skin

### Diagnosis

- Hemochromatosis can be diagnosed through an Iron Panel which includes transferrin iron saturation percentage and serum ferritin tests.
- When Iron Panel tests indicate HH, doctors sometimes follow up with a liver biopsy to determine the extent of damage to the liver.

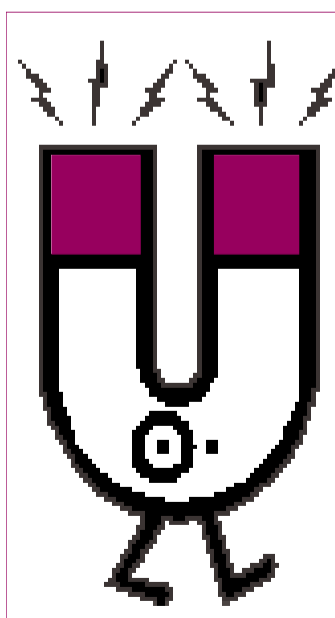


### Treatment

- Weekly phlebotomies (removal of blood) until iron levels are normal.
- Maintenance phlebotomies several times a year as needed.

### What Can Result if Iron Accumulates in Body Organs

- diabetes
- heart disease
- liver disease
- arthritis
- neurological problems
- depression
- impotence
- cancer
- infertility



### People Most at Risk for Getting HH

- Males of Scots-Irish, British, Dutch, German, French, Spanish, Italian, (Northern Western European), or Mediterranean descent.
- People with a family history of premature death by heart attack, liver disease, diabetes, arthritis, impotence, neurological disorders or cancer.
- Women who no longer have a period due to menopause, premature discontinuation of period or hysterectomy and who have the same ancestry and family history listed above.
- Blood relatives of these men and women.

**FOR MORE INFORMATION CALL THE CENTER - (585) 922-5700**

## BOARD PROFILES

### VICTORIA ORTO, RN, MS

**V**icky is the Director of Medical Nursing at Rochester General Hospital and prior to this position was Director of Medical Nursing at Genesee Hospital until it closed in 2001. She received her BS in Nursing at Nazareth College and her MS in Nursing Administration from St. John Fisher College. She is the Region 2 Representative to the American Organization of Nurse Executives and Treasurer and Board Member of the New York Organization of Nurse Executives. She also finds time to serve on the Finance Committee of the Genesee Valley Nurses Association. Vicky has been Vice-Chairman of our Center's Board as well as a very dedicated Board member for several years. She was recently elected Chairman of our Board and we are delighted to have her!



### RONALD SHAM, MD

**D**r. Sham is the Center's Medical Director and has provided hematology services to patients for over 16 years. He graduated from Pennsylvania State University with a degree in biophysics and from Pennsylvania State University College of Medicine. He practices hematology in the Lipson Cancer and Blood Disorders Center at Rochester General Hospital. Ron has been intimately involved with hereditary hemochromatosis outreach and research at the Center. He is a regular speaker at conferences around the world and was honored in 2004 by Gilda's Club in Rochester as their Physician of the Year for "taking time with patients and for delicately combining the wonders of high-tech medicine with the healing kindness of the human spirit."



### YVONNE ACE-WAGONER

**Y**vonne's father and two uncles were patients of the Center until the early 1990's. Her son has severe hemophilia A and is also a patient at the Center. Yvonne assists our social worker, Tricia Oppelt, with parent meetings and has volunteered in other various capacities. During and after completing her bachelor's degree in Psychology, she worked at the Mt. Hope Family Center as a research assistant on various NIMH grants including the summer camp program, after-school program and Project Hope. After three years, Yvonne pursued a new position at Harris Interactive on their Healthcare team. Specifically, she manages clinical recruitment and protocol feasibility projects from conception to finish. In the fall of 2003, Yvonne also began classes toward her MBA at the University of Rochester, Simon School of Business. We are fortunate to have her as Vice-Chairman of our Board of Directors.



### DAN KELLY

**D**an has a diverse career in scientific instrument development. He has worked at the University of Rochester's Nuclear Structures Research Lab, at Xerox Corporation helping to develop mammography products for clinical testing. He worked for Hampshire Instruments and Milton Roy Company (formerly B & L's Instrument Division) working on production improvements in optics and instruments. He also owned and operated the Grey Iron Foundry Company in Ohio. He is currently a consultant specializing in information systems solutions. Dan is the Treasurer of our Board of Directors and has been active on the Board for many years. He works closely with Bob Fox and Linda Magliocco on budgets, audits and the general financial affairs of the Center.



Save the Date!

# CENTER LAUNCHES NEW WEB SITE CENTER LAUNCHES NEW WEB SITE CENTER LAUNCHES NEW WEB SITE



I am delighted to announce the launch of our brand new Center Web Site. It has a new, modern look and is chock-full of valuable information. It is designed for both adults and children - for the veteran who has lived with a bleeding disorder and for the novice wanting to learn more. It is for patients and for the general public. There is even a glossary of terms to make your learning experience more enjoyable.

Read about the history and philosophy of our Center or go directly to the medical section to learn more about the disorders we treat. We've even provided you with a host of other websites to explore in order to broaden your knowledge base. Want to read a back article in one of our CenterUpdates or a media release -- they're posted on the web site too!

Meet our Board and staff - click on their photos and you'll find a short bio for each person.

Patients - we have included a special section just for you where you can report your Home Infusions or any changes in your Medical Insurance. We've also provided information for you about the pros and cons of ports, some information about home infusions and our mentor program.

A comprehensive calendar will remind everyone when and where meetings, special programs and events will be held. And of course we have provided you with emergency contact numbers -- just in case!

Want to make a donation to the Center via the website? Modern technology makes it simple. Just click on the "donations" button and you can use your credit card safely and securely through PayPal to make a contribution and we'll be informed immediately!

Spend some time surfing the site - use the scroll bars and get to know the website. You may even see yourself or your child (if you've signed a consent form of course). And please send me your feedback. I'm open to new ideas, suggestions and of course corrections. Once you are on any page except the 'home page', click on the 'contact' button at the top of the page and under 'subject' click on 'website'. The email will go directly to me. Hope you find the new site easy to navigate, informative and enjoyable to browse.

*Rona Wyner - Director of Development & Communications aka Webmaster*



## WHEN YOU HEAR HEMOPHILIA CENTER YOU PROBABLY THINK OF MEN AND BOYS BUT DID YOU KNOW THAT WOMEN CAN HAVE BLEEDING DISORDERS TOO?

Indeed women can and do have bleeding disorders too! The common symptom in women is heavy menstruation. The causes of heavy menstruation are being researched presently and the Mary M. Gooley Hemophilia Center is an active research site for this. The Center for Disease Control in Atlanta is sponsoring a study to see how many women with heavy periods have an underlying bleeding disorder that could be the cause of the menorrhagia. Women are given a blood test to see if they are deficient in any of the factors that help blood clot. If the testing shows a bleeding disorder such as von Willebrand's deficiency, platelet disorders, or other coagulation deficiencies, then women are eligible to try some treatment options. We have multiple treatments we are studying to see if they decrease menstrual flow including: Stimate nasal spray and tranexamic acid. All testing, physician consultations, and treatments are free of charge and a \$25 stipend is offered for completion of each phase of the study. If you would like more information concerning this study or others please call 922-5041.

### VOLUNTEER TO MAKE A DIFFERENCE

"Be the change you wish to see in the world." -  
*Mahatma Gandhi*

**H**ow does the Center impact your life? If you are a patient, there are the obvious ways - it may be the first number you call if your health is impacted in a negative way. You are probably confident in knowing that you can call the Center if you have upcoming surgery, are preparing to travel or you run out of Factor, and the Center will respond accordingly.

The Center coordinates comprehensive care clinics where you are given access to medical professionals in multiple specialties. Our staff schedules you to come in once a year for these clinics, which are an important piece of comprehensive care. The Center staff disentangles insurance issues and advocates on your behalf - things you may not see directly, but can have a big impact. If you are a family member of a patient, the Center may provide security. You know that it provides a level of caring and expertise that will see your family member through whatever health issue they face. The Center gives home infusion training and counseling that provides a level of freedom not known to families a mere 30 years ago.

You may be aware that there is a social worker at the Center who will listen, provide empathy and counsel when there is no one else to whom you can vent. You may know that, through the social network that the

Center provides, you can interact with other people like you, who also live with the emotional impact of seeing a loved one live with a chronic health issue.

Many of our patients and their families give back. They donate money. They participate in the Triathlon Train for Treatment program. They sell raffle tickets. They already volunteer for the triathlon in September. They serve as board or committee members. This is the kind of support the Center needs in order to keep having an impact on the lives of its patients and their families.

Please consider volunteering for the 2005 Finger Lakes Triathlon. This one day of the year contributes greatly to the services provided to you and your loved ones and helps ensure that those services will be there in the long run. If you haven't already, please call Abby Wade at (585) 922-4168 or send an email to [abby.wade@viahealth.org](mailto:abby.wade@viahealth.org) to sign up. Signup sheets or raffle tickets are also available in the lobby of the Center.

- Abby Wade, Director, Special Events



## ANNUAL APPEAL 2005 PLEASE HELP US TO REACH OUR GOAL

**YES** I WISH TO BECOME A MEMBER OF THE PILLARS OF SUPPORT SOCIETY.

MY GIFT WILL BE AT THE FOLLOWING LEVEL:

- \$ 500-\$ 999 PER YEAR FOR EACH OF THE NEXT 2 YEARS.
- \$1,000-\$2,999 PER YEAR FOR EACH OF THE NEXT 2 YEARS.
- \$3,000-\$4,999 PER YEAR FOR EACH OF THE NEXT 3 YEARS.
- \$ \_\_\_\_\_ PER YEAR FOR EACH OF THE NEXT \_\_\_\_ YEARS.



**YES** I WOULD LIKE TO CONTRIBUTE TO THE CENTER'S ANNUAL APPEAL

- \$250-\$499 PER YEAR FOR EACH OF THE NEXT 5 YEARS.
- \$100-\$249 PER YEAR FOR EACH OF THE NEXT 5 YEARS.
- \$ 50-\$99 PER YEAR FOR EACH OF THE NEXT 5 YEARS.
- \$ \_\_\_\_\_ PER YEAR FOR EACH OF THE NEXT \_\_\_\_ YEARS.



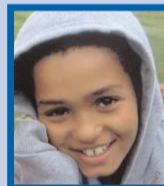
### PAYMENT METHOD

NAME \_\_\_\_\_ PHONE \_\_\_\_\_

ADDRESS \_\_\_\_\_

EMAIL \_\_\_\_\_

- MY CHECK IS ENCLOSED WITH FULL PAYMENT FOR 2005
- OTHER METHOD (QUARTERLY CHECKS, STOCK ETC.- CALL US)
- PLEASE CHARGE MY VISA OR MC WITH \_\_\_\_ EQUAL PAYMENTS BETWEEN NOW AND DECEMBER 31, 2005.



CARD # \_\_\_\_\_ EXP. \_\_\_\_\_

LAST 3 DIGITS ON BACK OF CARD \_\_\_\_\_

SIGNATURE \_\_\_\_\_



Fridays are dress-down days at our Center ... but for a very good reason. In order to wear jeans, each staff member must donate \$1 every Friday, and this goes to the NHF Jeans for Genes Research Fund. It's truly a win-win situation - so smile when you see the staff in jeans. Who knows, it could help lead to a cure for hemophilia.

**STAFF PARTICIPATES IN NHF'S JEANS FOR GENES PROGRAM**

## THE TOP 10 REASONS PEOPLE LOVE OUR PARENT GROUP

10. IT'S A GREAT OPPORTUNITY TO LEARN.
9. IT'S A SAFE PLACE TO SHARE.
8. IT'S A WONDERFUL PLACE TO MEET 'PEOPLE IN THE SAME BOAT'.
7. THE BABYSITTING IS AWESOME.
6. THE OTHER PARENTS ARE SUPER!
5. THE SPEAKERS ARE HELPFUL.
4. THE PEER SUPPORT IS PHENOMENAL.
3. THE KIDS HAVE A GREAT TIME.
2. WHERE ELSE CAN YOU GET A FREE DINNER, SOCIALIZE & HAVE FUN.
1. TRICIA TRICIA TRICIA!

**DON'T MISS OUR NEXT MEETING - AUGUST 24TH**

**PARENTS: MANAGING STRESS - KIDS: ICE CREAM SOCIAL & MOVIE**

