



## **Hemophilia Center**

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Nurse Coordinator

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**Patty Seiler, RN**  
Nurse Coordinator

**Jan Stolte**  
Billing Coordinator

**Rona Wyner**  
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Communications

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**Peter Kouides, MD**  
Director of Research

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## SOME IMPORTANT DATES FOR 2006

- APRIL 7 - PILLARS DINNER
- JUNE 16 - ANNUAL MEETING
- SEPT. 10 - FINGER LAKES TRIATHLON
- DEC 5 - HOLIDAY PARTY

## QUOTE OF THE QUARTER

*A candle throws its light into the darkness. In a nasty world, so shines a good deed.*

*- Ben Harper*

# HIGHLIGHTS FROM



## IN THIS ISSUE:

2005 HIGHLIGHTS	1
PRESIDENT'S MESSAGE	2
CONGRATS DR. KOUIDES	2
FLOWERS	2
JOINT PROJECT WITH NCJW	3
GAUCHER'S SYMPTOMS	3
NEW YEAR'S WISH	3
FROM OUR SOCIAL WORKER	4
NOTES FROM ABBY	4
2005 DONORS	5
2005 DONORS CONT'D	6
NHF - A PARENT'S VIEW	6
IMPORTANT MESSAGE #2	7
'T WAS THE NIGHT BEFORE...	7
POWER TOOLS PROGRAM	7
WHO'S WHO AT THE CENTER	8

**WINTER 2005**



## PRESIDENT'S MESSAGE

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ROBERT W. FOX  
PRESIDENT/CEO

### **2006: Change & Opportunity**

I'm go

*Bob Fox*

## ESPECIALLY FOR PATIENTS

### IMPORTANT MESSAGE #2 FOR PEOPLE WITH HEMOPHILIA

ATTEND AN ANNUAL COMP.  
CLINIC EXAM. IT'S IMPORTANT  
FOR YOUR LONG-TERM HEALTH!

#### Comprehensive Care Clinic Dates for 2006



Feb. 17th  
April 7th  
June 30th  
July 21st  
Aug. 18th  
Nov. 17th

Please call in your preferred  
date if you haven't already  
done so.

(585) 922-5700

## COMING SOON



For more  
information,  
please contact  
Tricia Oppelt at  
585-922-5700

Programs will take  
place in the greater  
Rochester area.  
Program details to  
follow.

A free interactive, educational series for you  
and your family to learn more about

healthy eating / exercise  
stress management

Give-aways for participants - it's free, it's fun, and will provide  
you with the tools to live your healthiest life!

Supported by  
The Mary M. Gooley Hemophilia Center

and  Bayer HealthCare  
Biological Products Division



## NHF ANNUAL MEETING: A PARENT'S PERSPECTIVE

Going to the NHF conference in San Diego was a great opportunity for my husband and me. Our son has severe Type A Hemophilia and is 2 1/2 years old. The greatest part was meeting and talking with other parents from all over the country about their children with hemophilia. Sitting in on a "Rap Session" with parents of babies and toddlers with bleeding disorders was also very interesting. We learned how differently Hemophilia Treatment Centers across the country treat their patients. Some Centers put their little patients on prophylaxis at about 6 months of age while others just treat the child when he has a bleed.

Ports were another big topic with brought out a wide range of feelings. Some parents were very opposed to them and others thought they are great and have had them in their children for years and don't see a need to give factor through venipuncture.

A lot of tips were shared - one practical tip I learned was that hydrogen peroxide will take out blood stains.

During one of the symposiums we heard a man in his 50's speak about his life with severe Type A Hemophilia. He didn't receive treatment for any of his bleeds until he was 7 years old. When he finally started getting treatments of plasma, he contracted the HIV virus. We also talked to another man who was 47. He was zooming around in his wheelchair, and is waiting for his second knee replacement. It was really sobering to hear these stories. It made us realize how lucky our son is to have hemophilia now compared to years ago. Treatments have come so far. Our children have the great opportunity to be put on prophylaxis. It may not always be pleasant or convenient, but our boys are actually very lucky to have that option.

During most of the educational and informational sessions about hemophilia, my husband and I realized we knew quite a bit. I want to thank the Hemophilia Center for this. As parents, we are so fortunate to have our children treated by such wonderful, knowledgeable people. The staff at the Mary Gooley Hemophilia Center make sure we the parents know how to take care of our children. Whether it's teaching us how to spot a bleed or giving us confidence and encouragement in doing prophylaxis at home, they really treat the whole family. They are great. They have given us knowledge as parents thus giving us power over the bleeding disorders that our children have. Thank you!

The NHF was great! My husband and I are so very happy that we were able to attend.

- Kelly Wilkes

**NCJW & HEMOPHILIA CENTER  
EMBARK ON A GAUCHER'S DISEASE OUTREACH PROJECT**

**From**

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