

## A Global Perspective of Hemophilia with excerpts from the World Federation of Hemophilia

Maria del Carmen de Agurcia discovered her mission about 20 years ago when she first took her baby son, Carlos Humberto, who has Hemophilia A, to an insensitive doctor in Honduras who told her, "it's not worth caring for people with hemophilia because they will all die like chickens."

"I decided then that fighting for people with hemophilia was going to be my life's work."

Maria's son is now a young man and he is alive today largely because of his mother's public efforts to improve government supplies of factor concentrate, patient care and knowledge of hemophilia treatment.

Maria del Carmen attributes much of her success to advocacy training and other support provided by the World Federation of Hemophilia (WFH) to 113 of its member organizations.

While people with bleeding disorders in developed countries are living longer, fuller lives, only about 25% of patients in the developing world receive adequate treatment. The others die young or face a life of pain and disability.

The World Federation of Hemophilia is a global not-for-profit organization working to improve and sustain treatment of people with hemophilia and other inherited bleeding disorders and has been doing so for a half-century.

With **Treatment for All** as its vision, the Montreal-based organization builds sustainable hemophilia care in cooperation with governments, medical practitioners, industry, and associations such as Maria del Carmen's Honduras Society.

For example, the Honduran association has been partnered with Hemophilia of Georgia as part of the WFH Twinning Program, which links hemophilia organizations and treatment centers in developing and developed countries.

"Exchange visits, training programs, and other activities forge friendships around the world and strengthen the global hemophilia community," says WFH president Mark Skinner.

Our Hemophilia Center is currently engaged in an effort to form a twinning relationship with Bishkek, Kyrgyzstan (see photos on right.) Here, Dr. Peter Kouides and physical therapist Marilyn Passer visit Biskek and see hemophilia patients.

Thousands of people are also helped each year by the WFH's Humanitarian Aid program, which distributes

donated treatment products to hemophilia patients in developing countries. More than 80 million units of factor have been channeled through the WFH to 65 countries for emergency cases of life-threatening bleeds or patients undergoing surgery.

"Donated factor saved my leg," says Parimal Chandra Debnath from the Hemophilia Society of Bangladesh. Hit by a car on his way home from work, Debnath suffered a broken knee. Complications from severe hemophilia A threatened his future ability to walk and earn a living. However, a WFH emergency supply of factor enabled him to recover and devote his life to helping other people with hemophilia. "We need to reach out to them," he says.

To promote such outreach, the WFH annually organizes World Hemophilia Day on April 17<sup>th</sup>. This year's theme focuses on the different types of bleeding disorders. Hemophilia and lesser known bleeding disorders impact hundreds of thousands of people of all ethnicities, education levels and incomes, their families and their communities. The focus for this year's World Hemophilia Day is on dispelling myths about inherited bleeding disorders.

### FACTS

- ❖ **bleeding disorders can affect both men and women;**
- ❖ **von Willebrand disease is the most common bleeding disorder;**
- ❖ **carriers of hemophilia can also experience bleeding complications;**
- ❖ **women might not know they have a bleeding disorder until they experience complications with childbirth; &**
- ❖ **most people with bleeding disorders around the world do not have access to adequate diagnosis and treatment.**





## President's Message

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

### Health, not Care, Should Drive Healthcare

**M**any people live with chronic disorders related to blood – various bleeding disorders, iron overload disorders, thrombophilia (clotting disorders) and sickle cell disease, to name just a few (and to lump them together in a jumble).

In our lifetimes, healthcare services in the developed world have been grouped and organized based on care that is delivered and how that care is financed. Imagine an ideal healthcare system built from scratch, one that groups services not by medical specialty but by disability, by the affect disorders have on people. That healthcare system would likely look quite different from the system we now have.

Professionals, volunteers and affected families throughout such an imaginary system for blood disorders would work proactively to promote the health of and improve outcomes among people at risk for or affected by blood disorders. They would collaborate across many diagnoses, in many areas including advocacy, financing, delivery of services, research, outreach, education. Disease prevention and prevention of complications from blood disorders would take center stage. That new system is ours to envision and to realize.

In this time of change, we have opportunities to think and act in new ways around our own health and the health services we use and provide. If you are a patient, exercise, eat right, be a compliant partner with your caregivers and assume more responsibility for your health. If you are a provider, be open to collaboration and to new views about what you do and how you do it. Moving beyond the status quo is never easy but together we can create positive change.

## Annual Campaign

**Our annual campaign continues to be extremely important to us. Please respond to our request with as much haste and generosity as you are able. It makes a world of difference in terms of the programs and services we are able to provide to our patients and their families.**

## STAFF PROFILE

### Thomas Wilmarth



**T**he Center is pleased to welcome Tom Wilmarth to its staff as Vice President, Public Policy.

Tom will be tasked with communicating and advocating for critical issues facing people with bleeding disorders to both the public and private sectors. He will also be in charge of raising the profile of the Center to further enhance support of its mission, care model and goals. He will also play a critical role in fund development for The Center with a major component being Director of the Finger Lakes Triathlon which is the biggest annual fund raiser that the Center holds every September on Canandaigua Lake.

Although Tom is the newest employee, he is no stranger to the Center. He is the proud father of two children, one of whom has been a patient of the Center since infancy, when he was diagnosed with Hemophilia. Tom has also served as an active board member, fundraiser and triathlete!

Tom graduated from SUNY Geneseo in 1996 with a B.A. in English. His career has provided him with extensive experience in marketing, business development and program management.

He is an extremely high-energy individual and prides himself on his ability to multi-task, team build and problem solve.

His skills, enthusiasm and personal commitment to the realm of bleeding disorders make him an ideal person to handle the diverse aspects of his new position.

# Planning for Summer Camp

Dear Parents and Guardians,

It's time to begin planning your child's summer camp. The Mary M. Gooley Hemophilia Center offers 3 camps this summer. At summer camp children interact with peers who have bleeding disorders or other chronic health conditions. Sending your child off to camp for the first time can bring mixed emotions for a parent, however it is important for you to know you are giving your child a chance to grow in a comfortable and nurturing environment outside of the home. There are many positive things children gain by going to camp. Some of these include:

- **Boosting a Child's Self-Esteem** - Children learn more about themselves which allows them to gain confidence in their abilities and believe in themselves.
- **Learning to have Greater Respect for Others** - Children find ways to work together and respect everyone's surroundings.
- **Learning to Respect Yourself** - At camp children gain confidence to believe in themselves by participating in activities for the first time.
- **Encouraging Kids to Be Themselves** - Camp provides children with the opportunity to be themselves and not be judged by anyone.

Children who are affected by a chronic health condition such as a bleeding disorder benefit from a place they can go and meet other children with the same or similar conditions and experience similar challenges in their daily life. Camps allow children to feel special without focusing solely on their medical condition. And camps empower children to learn more about their bleeding disorder and provides them the opportunity to learn to self infuse if they are interested in learning. Please read about the camps the Hemophilia Center is participating in this summer. If you have questions or interest in sending your child to camp the summer of 2010 please contact me at the center 585-922-5700.

Tricia Oppelt, LMSW

## Double H Ranch Hole in the Wall Camp

Dates: Sunday July 11th  
Friday July 16th

Location: 97 Hidden Valley Rd.  
Lake Luzern, NY  
12846-3318

Eligibility: Children with  
Hemophilia or von  
Willebrand Disease  
Ages 6-16

Transportation will be provided  
and funded by Camp Double H.

## Camp High Hopes

Dates: Sunday August 15th  
Saturday, August 21st

Location: Camp Aldersgate  
Camp Grounds in  
Adirondack region  
of New York.

Eligibility: Boys ages 7-17 who  
have Hemophilia or von  
Willebrand Disease.

Parents/Guardians will be  
responsible transporting  
children to and from camp.

## Camp Little Oak

Dates: Sunday August 8th -  
Saturday August 14th

Location: Camp Aldersgate Camp  
Grounds located in the  
Adirondack region of NY.

Eligibility: Girls ages 7-17 who  
either have or are carriers  
of a bleeding disorder.

Parents/Guardians will be responsi-  
ble for transporting children to and  
from camp.

## Rona Wyner Retires

The end of an era has arrived at the Hemophilia Center. Rona Wyner retired from our staff at the end of 2009.

Rona joined the Center in 2001 and with her considerable skill and determination made indelible marks on all of us. Spurred by Rona's single-mindedness for our cause, thousands of people pitched in to donate and to raise funds to support the Center. She was never afraid to ask others to join her and to share the passion she has for helping the families we serve.



Her day-to-day impact was powerful and far reaching. She often took the lead and gave activities and products her own touch. Rona's creativity brought about big changes in the Center's look and feel – our colors, our letterhead, even the interior of our beautiful facility. She was instrumental in numerous Center publications – books, brochures, pamphlets, mailings and our newsletters.

People who know her well know that Rona has spent time on every continent, save Antarctica. When she returned from an African safari several years ago she donated her own wildlife photographs for display in the Center's waiting room. Much of her newfound spare time will be spent visiting her grandchildren in Atlanta and Boston. We wish her the very best.

CAMPAIGN  
FOR OUR FUTURE

PHASE II:

*Research is our future*

Visionary Partner and Lead Benefactor



In 1965, Dr. Judith Graham Pool discovered a method of extracting clotting factor from human plasma. This opened the door to a series of rapid developments that revolutionized hemophilia treatment.

Phase II of NHF's Campaign for Our Future targets research to support and stimulate new treatment breakthroughs and ultimately, cures for bleeding disorders.

In the fall of 2010, the Center will ask for your support for these incredibly important endeavors, because research really is our future and it's our children's future. The Center supports national research efforts. You can too.

To learn more or to donate today, visit <http://www.active.com/donate/campaignforourfuture>



# The Voice of Advocacy

For over 50 years the Mary M. Gooley Hemophilia Center has been a voice for people with bleeding disorders in both private and public arenas. We feel that patient advocacy and support can be as important as medical treatment. In this spirit, The Center has been active in presenting our cause and needs to state and federal officials as well as private and corporate foundations and the media. Reaching out to all empowered institutions and letting them know our direct challenges and needs gives the bleeding disorders community a much needed voice.



The week of February 22nd, our CEO Bob Fox, board member Chuck Skopinsky and I flew down to Washington D.C. to participate in Washington Days, organized by the National Hemophilia Foundation. This is an annual event attended by hemophilia advocates from across the country to have dedicated time to state our case and needs with elected officials. It is also a wonderful opportunity for the national hemophilia community to come together and network and connect on best practices, advocacy updates and inspirational stories. Unfortunately our trip was cut short this year due to bad weather, but we were able to make some great connections. Bob and I will be meeting locally with federal officials to keep the message forefront and strong.

On the State front, a contingent of advocates from across New York participated in "Hemophilia Day in Albany" on March 21-23rd. From Rochester were Bob Fox, Tricia Oppelt, Chuck Skopinsky, Julie Wright, Leslie Vecchiotti, Tony Vecchiotti and me. Beyond the general goal of educating public officials about the needs of people with bleeding disorders, we also had two specific pieces of legislation that we were advocating for which are critical to New York State residents with expensive medical conditions such as Hemophilia. The first was Assembly Bill A8278 (Senate version S5000) which would ban insurance companies from instituting a new "cost sharing" tier for expensive prescription drugs in New York State. Such a policy would be financially devastating to people who need the prescription drugs that would fall under this new tier. The second was making sure that an item in The Executive Budget restoring control to the New York State Insurance Department over health insurance premium increases is kept in the final budget. This would be a critical check to protect New York State residents from unreasonable premium increases as have been seen recently in other states.

I encourage anyone who wants to help advocate for these issues to call your respective Assembly Member and State Senator. Feel free to contact me if you would like some guidance or more detail. We are always looking for more voices to contribute to our advocacy efforts!"

One last note - an exciting and important one! I am proud to announce the formation of the Hemophilia Foundation of Upstate New York (HFUNY). This new organization was created by a small group of volunteers in response to external pressures on funding and due to the Center's inability to provide financial assistance to patients. To fully support and advocate for the bleeding disorders community in our region, it became clear that a separate foundation independent of the Center was needed. After a great deal of strategic planning and legal consultation the new foundation was established with a volunteer board of directors, office space and a pending tax ID number. The board has begun to articulate its vision and a mission and goals for the organization. I will share much more information on this exciting milestone in coming months. Please call the Center with your questions and ideas.

-- Tom Wilmarth



## Wearing a Medic Alert Bracelet could Save Your Life



1. In an emergency, first responders look for the "Medic Alert" ID and read the engraved information.
2. First responders can call the MedicAlert 24-hour Emergency Response Center for additional critical medical information.
3. The MedicAlert Emergency Response Center calls your designated contact so you and your loved one are not alone in an emergency.
4. MedicAlert 24-hour emergency response service is always there for you and may save your life.

When ordering your medic alert bracelet, the engraving on the back should be as informative as possible. It should include your diagnosis, medications, allergies and emergency contact. The Hemophilia Center recommends patients obtain their bracelet through the Medic Alert Foundation. This is a national 24-hour emergency medical information and identification service. Enrollment into MedicAlert includes:

- \*MedicAlert 24-hour emergency response service
- \*MedicAlert 24-hour family/caregiver notification
- \*Personalized MedicAlert ID
- \*Personalized MedicAlert wallet card
- \*Emergency Medical Information Record (EMIR)



Contact Tricia Oppelt (585-922-4177) for assistance or information regarding obtaining a MedicAlert ID.

# SWIM • BIKE • RUN

Finger Lakes Triathlon - Sunday, September 19, 2010

On Sunday September 19th over 1,200 athletes will gather on the shores of beautiful Canandaigua Lake for the 8th annual Finger Lakes Triathlon. The Triathlon is an exciting event which is the biggest fundraiser of the year supporting the work of the Mary M. Gooley Hemophilia Center. It is a premier regional event in the world of competitive triathlon and the largest in Upstate NY.

Each year we make gains both in our fundraising and athlete participation. Last year we had athletes from over 16 states compete in the event and the race was sold out by July with a waiting list of almost 200! So, we strongly encourage anyone who is interested to get more information at [www.fingerlakestriathlon.com](http://www.fingerlakestriathlon.com) and to register now at [www.active.com](http://www.active.com).

Another major component of this event is our Train For Treatment Program. This is a wonderful program that enables an athlete to raise money during their training on behalf of a patient of the Hemophilia Center. You can choose or be assigned a child to represent and you will have an opportunity to learn a little about the child and meet the child before the event to make a personal connection. To make the process easy, a personal fundraising web page will be created for you to send to potential donors. Having done Train For Treatment myself the last 3 years, I can attest that having that having a patient's family cheering you on sporting huge signs throughout the race gives you a whole different level of accomplishment and gratification. Every dollar that you raise goes directly to the Center to help provide better care for those affected by bleeding disorders. As an extra incentive, if you raise at least \$200 your race fee will be refunded. Train For Treatment raised just under \$60,000 last year and we are looking forward to beating that number by a substantial amount this year!

Another event to note is the Kids Triathlon that we run on the same day which is designed for 4-15 year olds (including some of our Hemophilia patients). A healthy lifestyle is strongly encouraged for all children and exercise in particular, strengthens joints of those affected by Hemophilia. This is a great way to inspire, encourage and build confidence in our youth while keeping them healthy at the same time.

Please contact Tom Wilmarth with any questions or offers to volunteer at the event: [thomas.wilmarth@rochestergeneral.org](mailto:thomas.wilmarth@rochestergeneral.org) or 585.662.4120.

## **Benefits of Prophylaxis in Children with Hemophilia B**

The results of a study published last month in the journal *Haemophilia* demonstrated the benefits of a prophylactic (preventive) treatment regimen for children with severe hemophilia B using a recombinant factor IX (rFIX) product. The lead author of the study was Paul Monahan, MD, Gene Therapy Center, University of North Carolina at Chapel Hill. Monahan is also a member of the National Hemophilia Foundation's Medical and Scientific Advisory Council (MASAC).

The use of prophylaxis to treat children with hemophilia A is well documented. But there is limited data for such use in children with hemophilia B. The study included 25 children, six years- old or younger, with severe hemophilia B. In all, 22 of 25 (88%) of the children received routine prophylactic therapy (one to two infusions per week) with BeneFIX®, a rFIX product manufactured by Wyeth (a part of Pfizer), which also sponsored the study.

The therapy typically lasted more than six months. Investigators reported an average of less than one bleed per year and a "near complete prevention of spontaneous breakthrough hemorrhages."

The majority (77%) of the children exhibited no spontaneous breakthrough bleeds, while approximately a third (32%) experienced no bleeding. Breakthrough



bleeds that did occur were resolved with 1 or 2 infusions of rFIX in 89% of episodes. Though the patient group included children who had previously experienced multiple joint bleeds, 68% of the study subjects experienced no joint hemorrhaging. Investigators also reported that safety had been established "by the low incidence of treatment-related adverse events." Further, the authors reported that the therapy was well tolerated by patients with central venous access devices.

The study, "Safety and Efficacy of Investigator-Prescribed BeneFIX® Prophylaxis in Children Less Than 6 Years of Age with Severe Haemophilia B," was published online January 4, 2010, in the journal *Haemophilia*.



You're Invited  
to the  
Mary M. Gooley  
Hemophilia Center's

## **ANNUAL MEETING**

on  
June 18, 2010  
12:00 pm - 2:00 pm

Mario's via Abruzzi  
2740 Monroe Ave.  
Rochester, NY

\$15 per person  
\$50 per patron

Special Guest Speaker  
NY State Senator Joseph E. Robach  
56 Senate District

RSVP  
by June 10th to  
[andrea.lester@rochestergeneral.org](mailto:andrea.lester@rochestergeneral.org) or  
585.922.5700



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**LEGACY**

**A legacy is that which someone is remembered for or what they have left behind that is remembered or revered.**

**Philanthropic legacies are often made by means of a bequest in a will. These gifts can be life changing for the recipients since they enable vital research or support needed programs.**

**We ask that you help change the lives of future generations of families with bleeding disorders and iron overload by remembering the Center in your will. CARING IS IN YOUR BLOOD **