

# HEMOPHILIA OUTLOOK



A Newsletter of

**The Hemophilia Association of New York, Inc.**

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## **HANY SCHOLARSHIPS AWARDED**

Fourteen candidates are sharing \$52,500 in HANY scholarship awards this academic year. Six are first-time recipients and eight are repeat grantees.

Their fields of study cover acupuncture, marketing, accounting, business, criminal justice, computer science, biology, geology, music, social work, pre-dental, pre-law, and nursing.

Among the stipends given are the 'Isabel K. Brach Award' (this year for social work) and the "Dr. Margaret Hilgartner Memorial Award" (this year for nursing).

Since 2001 the Association has awarded 79 competitive scholarships for higher education totaling \$260,000. The program provided up to \$2,000 stipends to persons with bleeding disorders during their freshman year — it has expanded to consider annual grants up to \$7,000 each for study at accredited academic institutions, including under-graduate and graduate schools, and certified trade and vocational facilities.

**Si usted necesita traducción or interpretación en español de algún artículo en este letras de noticias por favor de llamar a Ann Pérez o Gabriela Blum al (212)682-5510.**

Eligibility now extends from persons with certain diagnosed bleeding disorders to carriers and unaffected children of parents with qualified bleeding disorders. *June 1, 2012 is the deadline for applying. Call HANY for an application at 212-682-5510.*

## **OTHER SCHOLARSHIPS AVAILABLE...**

Pfizer pharmaceutical is offering Soozie Courter hemophilia scholarships to undergraduate, graduate and vocational school students. For more information, visit [www.hemophiliavillage.com](http://www.hemophiliavillage.com).

For a full list for the various scholarship programs look at the website of LA Kelley Communication ([www.kelleycom.com](http://www.kelleycom.com)) or call HANY.

## **CONGRATULATIONS**

Congratulations to Newlyweds Theresa and Mark Centeno. This generous couple, in lieu of customary favors for their wedding guests, has made a donation to support the programs and services of HANY.

*If you are planning a celebration such as a Wedding, Bar or Bat Mitzvah, Christening or even a birthday please consider a donation in lieu of flowers or favors. HANY will provide you with recognition scrolls for the day of your event.*

## **PREPARE AHEAD FOR SCHOOL**

Preparation for the school year is best done before the first day of school. Contact the principal, school nurse and your child's teachers (including gym instructors) to explain his or her special needs. Give them the name of his doctor and hospital and a telephone number at which you can be reached at any time.

Your child should be able to participate in all of his classes, including physical education. However, if he experiences frequent bleeds during gym class, your doctor or the physical therapist at the HTC can work with the school to arrange a modified exercise program.

- Remind them that he/she will not bleed any faster than other children.
- Explain the indications of a bleed (e.g., favoring an arm or leg) and the events — such as a hit on the head — that require immediate attention.
- Tell them to believe him/her and respond whenever he/she indicates that he/she might be bleeding.
- Be clear about what he/she can't do and insist he/she be permitted to do everything else.
- Let them know how your child wants information about his/her condition to be treated. Does he/she want it not to be mentioned? Does he/she want to tell the class about it?
- Assure them that you know he/she could get a bleed in school through no fault of the staff.

HANY can provide you with free pamphlets for educators and school nurses, to explain hemophilia. Call us for copies. Your treatment center is also available as a resource for starting the school year right.

## **FAMILY CAMP**

This 3 day - 2 night retreat is open to families and couples with bleeding disorders, October 8<sup>th</sup>-10<sup>th</sup> (Columbus Day weekend) at the Aldersgate Camp & Retreat Center in Brantingham, NY.

The retreat is free to attend. HANY is providing bus transportation to and from the camp site. For more information, call HANY at 212-682-5510.

You'll be staying in furnished, heated cabins at a beautiful, fully accessible facility. The program mixes fun with learning, and this year features: making easy & healthy meals, demystifying care choices, and legislative advocacy.

You can find out more about the retreat, get an online or mail in application, and see photos of Aldersgate at [www.bdaninc.org](http://www.bdaninc.org). Space is limited, so contact Bob Graham at (315)396-2944.

## **NATIONAL HEMOPHILIA FOUNDATION'S ANNUAL MEETING**

National Hemophilia Foundation's 63<sup>rd</sup> Annual Meeting, from November 10<sup>th</sup> to 12<sup>th</sup>, 2011 in Chicago, Illinois. To register, visit [www.hemophilia.org](http://www.hemophilia.org) or call toll-free 800-424-2634.

## **MEN'S GROUP**

HANY has hosted three successful Men's Group meetings this year! If you are interested in participating at the next event, contact HANY at 212-682-5510.

## **LINDA'S CORNER**

Linda's Corner is focusing on **Advocacy Issues**. HANY will be looking for volunteers to go to Albany (April) and/or Washington, DC (March). Below are two of the advocacy issues we anticipate bringing up to our representatives. If you have a story to share or would like to lend your support (expenses are paid) please contact Annie at the office.

- **Child Health Plus Insurance does not cover outpatient factor.** If a child with a bleeding disorder has CHIP insurance, they will not have access to factor in a home setting. Their condition cannot be managed comfortably in home. Imagine how difficult prophylaxis would be if a visit to the hospital were required for each dose. We are trying to change this program.
- **Aging Issues:** Input from Hemophilia Treatment Center Social Workers has put a spotlight on an area of concern. This regards our clients who will need temporary or permanent care in a nursing or rehabilitative facility. Historically these facilities will try very hard (often succeeding) not to admit a person with a bleeding disorder. They desire to avoid the high cost of clotting factor. These facilities are reimbursed for their care as a 'bundled payment' meaning that expensive medications or care cannot be billed separately. Unless changes are made regarding how factor is reimbursed, there is a fear that some persons with bleeding disorders will spend time in hospitals when a facility would be the better provider. And then there could be those who are sent home who would benefit from rehabilitation

and care from a facility. We are seeking shared stories in relation to this issue.

## **SPECIAL THANKS:**

To the committees and volunteers who helped to make our fundraising events this past Spring and Summer successes. Special Thanks goes to Kathy Hornreich, chief organizer for "The Day at The Races" held in May and the "Nick Salerno Memorial Golf Tournament" held in July, and to Bob Greer, chief organizer of the "Matthew Lee Greer Golf Classic" held in June. These were my first events as Executive Director of HANY. It was especially rewarding for me to participate.

Thank you to our program's sponsors, their generosity helps us achieve our Mission.

*Bayer Healthcare; Baxter Healthcare;  
CSL Behring; Grifols, USA; Inspiration  
Biopharmaceuticals; Novo Nordisk;  
and Pfizer.*

## **GRIFOLS OVERVIEW**

On June 1, 2011, Grifols acquired Talecris Biotherapeutics Inc., a merger designed to expand patient access to life-saving protein therapies and to enhance Grifols' position as a leading global producer of plasma-derived therapies.

The merger joins two organizations that share a commitment to integrity, safety and quality as well as 70-year legacies of scientific discovery and innovation in the plasma therapeutics industry.

**FEDERAL GRANTS AWARDED FOR  
HEALTH INSURANCE  
EXCHANGES**

*(latimes.com, August 12, 2011)*

Over \$185 million goes to 13 states and the District of Columbia to establish 'marketplaces' as part of the healthcare overhaul.

The Obama administration has awarded more than \$185 million in grants to 13 states and the District of Columbia to help establish new state-based health insurance marketplaces where consumers can shop for insurance starting in 2014, a key benefit of the new healthcare law.

These Internet-based exchanges, designed to help Americans who don't receive health benefits through their employer, are intended to make buying health insurance akin to comparison shopping online for an airline ticket or a hotel room.

The exchanges will provide basic information about health plans, including premiums and covered benefits.

By 2019, the exchanges are expected to provide insurance for an estimated 24 million Americans, most of whom will receive subsidies to help them buy a health plan because they are expected to earn too little to bear the full cost.

Employers with fewer than 100 workers will also be able to use the exchanges, which will have to offer plans with a minimum level of coverage. No plans will be able to deny coverage to people with preexisting conditions.

Obama administration officials and many insurance experts have urged states to

develop their own exchanges rather than have the federal government operate one overseen by officials in Washington who will be less familiar with the local insurance market. And in a letter to governors, Secretary of Health and Human Services Kathleen Sebelius again urged them to take advantage of the grants.

That means a family of four making as much as \$89,400 could be eligible for aid. Subsidies, which will vary depending on income, are expected to average about \$5,000 a year.

Americans making less than the poverty line will be eligible for the government Medicaid program.

New York State was awarded \$10,774,898 which will be administered by the New York State Department of Health.

New York has made significant progress under its exchange planning grant, early innovator grant, and consumer assistance program grant.

This funding will: support background research; seek stakeholder input through a series of policy discussions focused on Exchange design and operation options; fund IT Systems; expand the capacity of its consumer assistance to serve the needs of small businesses, to expand assistance to individuals in regions of the State that currently have limited in-person access and expand consumer assistance with commercial insurance issues.

The proposal also requests funding for key staff to begin the process of implementing the Exchange around governance.

**ADVISORY: NEW YORK MEDICAID AND FAMILY HEALTH PLUS (FHP) BENEFICIARIES**

*The following information pertains to anyone who receives healthcare benefits from New York State Medicaid or Family Health Plus.*

If you are covered by one of these programs, you should have received a letter by now from the New York State Department of Health (NYS DOH), which highlighted changes in Medicaid pharmacy services beginning October 1, 2011. **Please be aware that these changes do not affect hemophilia clotting factor therapies.** You can continue to receive your factor from your current specialty pharmacy provider (i.e., Hemophilia Treatment Center 340B program or other specialty pharmacy or home care company). These will continue to be covered as a Medicaid fee-for-service benefit. New York State is considering making changes to the way Medicaid and FHP cover factor in the future, but as of now factor is exempt from these changes.

**Please note this does not replace previous advisories from the NYS DOH requiring you to select a Medicaid Managed Care (MMC) plan for your basic health care coverage.** The MMC plan you chose will provide coverage for all Medicaid benefits except factor products. Examples of some of the services that will be covered by the MMC plan are preventive health and dental services, hospital inpatient and outpatient services, laboratory and x-ray services, and other prescriptions drugs.

If you have any questions, you may contact the New York State Department of Health Medicaid Helpline at 866-976-3526. You can also contact your Hemophilia Treatment Center or the Hemophilia Association of New York at 212-682-5510.

**FOUNDATION FOR WOMEN & GIRLS WITH BLOOD DISORDERS**

*Vision: "All women and adolescent girls with blood disorders are correctly diagnosed and optimally treated and managed at every life stage."*

The Foundation for Women & Girls with Blood Disorders (FWGBD) was launched in 2010 to serve as a single site, single source where physicians and healthcare providers can obtain information and education.

The natural life events of menstruation, pregnancy, childbirth, and menopause present unique challenges in women and girls with blood disorders. Undiagnosed, untreated blood disorders in women and adolescent girls have medical consequences and unique issues at every life stage, creating the need for a foundation dedicated to provider education and awareness. The need to educate healthcare providers was very evident to three internationally renowned physicians, Drs. Andra James, Roshni Kulkarni and Barbara Konkle, who founded the organization. The intention of FWGBD is to fill this need not currently met by other professional or advocacy organizations.

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**FOUNDATION FOR WOMEN & GIRLS WITH BLOOD DISORDERS**

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FWGBD's mission is to ensure that all women and adolescent girls with blood disorders are correctly diagnosed and optimally treated and managed at every life stage. The Foundation works to achieve this goal through:

- Raising awareness and educating the key healthcare providers for each particular life stage, including but not limited to, family practice providers, pediatricians, internal medicine physicians, obstetricians, gynecologists, hematologists/oncologists, geriatricians, nurses and social workers
- Translating and disseminating provider information and research

The Foundation is dedicated to achieving correct diagnosis and treatment of blood disorders and accompanying reproductive problems in women and girls with von Willebrand Disease (VWD), other factor deficiencies, hemoglobinopathies, thrombophilias, sickle cell disease (SCD) and sickle cell trait (SCT), immune thrombocytopenic purpura (ITP) and anemias. FWGBD is an innovative organization that will build the education resource base in these important areas.

Using a multidisciplinary approach, FWGBD will educate providers across specialties. Its core tactics include: educational presentations, symposia, and interactive exhibit booths at medical society meetings; recommendations for medical curricula; a state-of-the-art Web site; and accredited Webinars. FWGBD's Web site is in development and will launch in the fall.

The FWGBD is building partnerships with established national organizations, including HTRS (Hemostasis & Thrombosis Research Society), ASPHO (American Society of Pediatric Hematology/Oncology), ASH (American Society of Hematology), NASPAG (North American Society for Pediatric and Adolescent Gynecology), PDSA (Platelet Disorder Society of America) and SCDA (Sickle Cell Disease Association of America), and with regional and state organizations, such as, the Hemophilia Center of Western Pennsylvania (HCWP) and THE Hemophilia Association of New York (HANY).

The Foundation's address and contact information is:

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

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**KEDRION ACQUIRED KOATE®-DVI**

Kedron S.p.A., a global leader in biotherapeutics, announced on June 10<sup>th</sup>, 2011 that it has acquired Koate®-DVI (antihemophilic factor, human) franchise effective June 2, 2011. Kedron acquired Koate-DVI following Grifols' acquisition of Talecris. Under the agreement Grifols will contract-manufacture Koate-DVI for seven years and thereafter Kedron shall have an option to transfer manufacturing to one of Kedron's state of the art facilities.