

HEMOPHILIA OUTLOOK



A Newsletter of

The Hemophilia Association of New York, Inc.

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❄️ **WINTER 2011/2012** ❄️

SUPPORT THE ANNUAL APPEAL

Last year there was an increase of 16% in the number of persons with bleeding disorders we served. We saved people many thousands of dollars through our problem resolution service. We provided \$47,706 in direct financial aid for problems that only cash would solve. Almost half of this cash assistance was funded by the annual appeal.

More and more of our families will struggle and need help in the coming year. You can help us to continue our mission by making a donation at our Web site, www.hemophilia-newyork.org.

NYCharities.org will be processing donations made to the Hemophilia Association of New York (HANY). Your credit card statement will indicate "NYCharities.org".

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.

THE RIGHT FIT

Hemaware, Fall 2011

Finding a Gym to Achieve Your Fitness Goals

Knowing what you want out of a gym is an essential first step in picking the right one for you, says physical therapist Debra Voss, PT, ATC, CSCS, of the Hemophilia Center of Western Pennsylvania in Pittsburgh.

Your physical therapist or other healthcare provider can help you review your goals and develop an appropriate exercise plan based on your individual joint and muscle limitations. "Whether those goals include general wellness, weight loss or building strength, you should first decide what you are willing to commit to", says Voss.

Once you define your goals, it's time to start shopping around. For people with advanced joint problems, Voss advises finding a gym with a pool. "Pools offer a comfortable and gentle environment," she says. Exercising in a pool relieves pressure on the joints and works well for most people.

(Continued on page 5)

WOMEN WITH BLEEDING DISORDERS

(The Source, Fall 2011)

In the Fall, the European Haemophilia Consortium (EHC) held a roundtable on woman with bleeding disorders. The event featured presentations from patients and physicians and was moderated by Professor Paul Giangrande from the Oxford Haemophilia & Thrombosis Center and Nuffield Departments of Clinical Medicine, University of Oxford, United Kingdom.

Although bleeding disorders in men are widely recognized, diagnosed and treated, the same cannot be said for bleeding disorders in women. The conditions are rarer in women than in men and are frequently overlooked and remain untreated, often until patients reach middle age. This can be attributed to several factors. First of all, even among the patient community there is a lack of awareness that female carriers can be affected by lower levels of clotting factors; and, therefore, they tend to ignore symptoms such as menorrhagia (heavy menstrual periods), nose bleeds or easy bruising.

Another factor in the under diagnosis of women with bleeding disorders is the fact that even among physicians there is a misconception that bleeding disorder occur exclusively in male patients. This may cause physicians to overrule the diagnosis in women. For instance, Dorothee Pradines, one of the attendees of the EHC roundtable and a French patient with severe hemophilia A, described a situation that she faced as a child when she was on vacation in the French countryside.

After she had cut her hand and needed treatment for heavy bleeding, she went to the local hospital. The hospital's physician proceeded to tell her that women do not suffer from hemophilia and denied her the treatment necessary for her condition. This lack of awareness led to her having to go through an extended healing period instead of being treated effectively.

It is essential that more awareness is raised among general practitioners, gynecologists and obstetricians who, due to the rarity of the disorders, might never come across women with bleeding disorders. These practitioners need to be aware of the symptoms of these disorders and pick up on them when they encounter a patient who actually has these symptoms.

During the event, several female patients were present and they expressed the need for education beyond the medical professionals. They stressed the importance of efforts to educate women on bleeding disorders in women, including symptoms and implications for these disorders. Patient communities have started to organize events and campaigns to raise awareness among women, which have had varied success so far.

Following a series of factual, interesting presentations the participants discussed what needed to happen next and several recommendations were made on how to raise awareness among women regarding bleeding disorders.

Bleeding disorders in women, like in men, not only occur but have a detrimental impact on the patients' lives and more work is needed to ensure that these patients receive the care they need.

HANY SCHOLARSHIP PROGRAM

For the 2012-2013, academic year the maximum award set by the Board of Trustees will be \$7,000, although lesser amounts may be awarded.

The program is for qualifying full-time study at an accredited college, university, graduate school, or certified trade or vocational school for the coming school year. Applicants will be judged on their achievements and financial need.

HANY scholarships are available to persons with inherited genetic bleeding disorders (as diagnosed by a board-certified hematologist) and their children. Considerations will also be given to females who are carriers attested to by a board-certified hematologist.

Applicants must be registered with HANY and live within the fourteen counties of southeastern New York (the five boros of New York City, Long Island, Dutchess, Orange, Putnam, Rockland, Sullivan, Ulster and Westchester counties).

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.

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

TAX DEDUCTION REMINDER

If you itemize your tax return remember that medical and many healthcare-related expenses that cumulatively exceed 7.5% of your adjusted gross income are deductible. There is a long list of items which are deductible (check Internal Revenue Service publications or visit www.irs.gov), including your out-of-pocket cost for prescriptions, health insurance premiums and health-related transportation.

If you used your personal auto to get to doctors, a pharmacy, therapist or other medical destination, you may deduct 19¢ (.19) per mile driven from January to December 2011. If you traveled by taxi, bus or other transport, that verifiable cost is also deductible.

WOMEN'S GROUP COMING SOON

Women with bleeding disorder events coming in 2012. If you are interested in participating in the group meetings, contact HANY at 212-682-5510.

MEN'S GROUP WITH BLEEDING DISORDER

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

***Our Best Wishes
for a Happy
and Healthy
New Year!***

NEW YORK GETS \$2 MILLION PLUS IN HEALTH CARE GRANTS

New York Able Newsletter, October 2011

Department of Health and Human Services (HHS) Secretary Kathleen Sebelius recently announced that \$2,243,662 in grant funding is available, partly supported by the Affordable Care Act (ACA), to enhance New York's public health infrastructure and strengthen its public health workforce.

Awarded in nearly every state, this funding will improve the delivery of public health services across the country. Approximately \$1,593,000 in grants, supported through the Centers for Disease Control and Prevention (CDC), will fund key state and local public health programs in the New York City Department of Health and Mental Hygiene and the New York state Department of Health.

An additional award of \$650,000 will support the development of a public health training center at Columbia University in New York City. The Public Health Training Center Program provides education and training to the nation's public health workforce in areas such as environmental health, public health leadership and nutrition.

"These funds will help departments around the country maximize the impact of the essential services they provide every day and build the public health workforce to ensure we're ready to meet the public health challenges of tomorrow," said Sebelius. "Strengthening our nation's public health system is critical to protecting the health of all Americans."

This is the second year of CDC's five-year program, known as the National Public Health Improvement Initiative Strengthening Public Health Infrastructure for Improved Health Outcomes Grant Program. More than 100 people across the country have already been hired through the initiative, and additional positions are expected to be filled through current awards.

"A strong efficient and effective public health system is critical for building a healthy society," said Thomas Frieden, CDC director. "Investing in preventive services, system improvement and comprehensive interventions is essential to reducing the burden of health care costs in the future."

"In a challenging economy, public health training and education are vital in our efforts to ensure access to affordable, high quality health care," said Mary Wakefield, administrator of HHS Health Resources and Services Administration. "These grants provide learning opportunities that enhance technical, scientific, managerial and leadership skills of public health workers and help build a strong, well-rounded public health workforce for the future."

PATIENT NOTIFICATION SYSTEM

Please sign up for the Patient Notification System (PNS) for direct notifications about the latest recall or withdrawal of recombinant and plasma products. It's free, confidential, time sensitive and a 24-hour communication system.

To enroll in PNS, please visit its Web site: www.patientnotificationsystem.org or call 888-873-2838.

THE RIGHT FIT

Hemaware, Fall 2011

(Continued from page 1)

A good gym will have a wide range of weights and cardio equipment to help build muscle and burn fat. However, before you get started, you need to be schooled on how to use the equipment properly.

Most gyms have personal trainers on staff. Voss recommends checking out their credentials before you join. Ideally, they should be certified by either the National Strength and Conditioning Association or the American College of Sports Medicine.

Even if the gym you choose has personal trainers, talk to your physical therapist about exercising safely. “You should be evaluated prior to deciding what to do in the gym, especially if you have a lot of joint issues,” says physical therapist Anita Davie, PT, of the Tulane Hemophilia Treatment Center in New Orleans.

A personal trainer should show you how to properly and safely use the weight machines, treadmills and other equipment in the gym, while also offering advice and encouragement.

Gym Alternatives

Local community centers or other nonprofit fitness centers like the YMCA can provide a wider range of options. “Community centers often offer a more holistic approach to getting in shape,” Davie says. “They frequently have a nutritionist on staff, as well as classes on healthy eating.” Eating well will complement your exercise regimen and help you improve your overall health. Other classes may focus on stress management, diabetes prevention and smoking cessation.

Taking a class will add a social aspect to your routine. “Community centers are usually more family-oriented and offer more social support,” Voss says. “This is life-changing behavior. You are more likely to have success if you have a family member or friend on board”.

Subsidizing Fitness

There is a growing trend for health insurance companies to reimburse their policyholders for a portion of the cost of a gym membership. One is United Healthcare policy, for example, covers up to \$300 every six months for policyholders who go to the gym at least twice a week. Check your own policy to see what it covers.

Your employer might also help share cost of joining gym. An increasing number of companies offer wellness programs to improve their employees’ health. Ask your supervisor or human resources department about these programs.

Whatever gets you to the gym, remember that it may take time before it becomes a habit.

Learn More...

- Tips from WebMD on choosing and using a gym: webmd.com/video/how-to-pick-a-gym.
- Locate personal trainers certified by the American College of Sports Medicine in your area: forms.acsm.org/_frm/crt/online_locator.asp.
- National Strength and Conditioning Association: nsca-lift.org.
- Find exercise tips and videos for people with arthritic joints at arthritistoday.org/fitness.

CSL BEHRING RECEIVES FDA APPROVAL OF CORIFACT™ FOR TREATMENT OF CONGENITAL FACTOR XIII DEFICIENCY

(Press Release, February 2011)

CSL Behring announced February 2011 that the U.S. Food and Drug Administration (FDA) has granted marketing approval for Corifact™, Factor XIII Concentrate (Human), for the routine prophylactic treatment of congenital factor XIII (FXIII) deficiency. Corifact, already available for use in 12 countries throughout the world under the trade name Fibrogammin®- P, is the first and only FXIII concentrate approved in the U.S.

Congenital FXIII deficiency, also known as fibrin-stabilizing factor deficiency, is a rare and potentially life-threatening bleeding disorder in which blood clots normally, but the clots formed are unstable, leading to recurrent bleeding. It is estimated that the condition affects one person in two million, with an incidence in the U.S. of approximately 150 people.

"FDA approval of *Corifact* is a very special opportunity to make a positive difference in the lives of people who need our safe, high-quality therapies, while continuing to enhance our extensive portfolio of products for people with bleeding disorders," said Lynne Powell, CSL Behring Senior Vice President, North America Commercial Operations. "*Corifact* is the fourth new product that CSL Behring has brought to the U.S. market in the past two years. This represents our ongoing commitment to developing products for the treatment of rare and serious diseases."

Symptoms of congenital FXIII deficiency include bleeding from the umbilical cord after birth, poor wound healing, miscarriages, subcutaneous bleeding, and excessive bleeding in joints and muscles following trauma. Patients lacking the FXIII protein are also at high-risk for intracranial hemorrhage (ICH), bleeding inside the skull that can be life-threatening. Studies have shown that between 25 and 60 percent of FXIII-deficient patients will experience an ICH at least once during their lifetime. For a doctor to accurately diagnose FXIII deficiency, specific blood testing and detailed family history are necessary.

Corifact, an intravenous (IV) infusion given approximately every 28 days, is indicated for routine prophylactic treatment of congenital FXIII deficiency. There are no controlled trials demonstrating a direct benefit on treatment of bleeding episodes with *Corifact*. *Corifact* is a fibrin-stabilizing factor concentrate that provides both A- and B-subunits to protect against FXIII deficiency. Clinical studies have shown that *Corifact* immediately increases FXIII levels in the blood. The concentrated formula is dosed, depending on the patient's weight, to maintain trough FXIII levels between 5 and 20 percent of normal.

This information is provided for your general information only. HANY does not give medical advice or engage in the practice of medicine. HANY under no circumstances recommends treatment for specific individuals and in all cases recommend that you consult your physician or local hemophilia treatment center before pursuing any course of treatment.