

Hemophilia OUTLOOK

A Newsletter of

The Hemophilia Association of New York, Inc.

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✿ SPRING 2011 ✿

JUNE 3rd, DEADLINE FOR HANY SCHOLARSHIP APPLICATIONS

HANY is offering scholarships of up to \$7,000 to qualified individuals who are planning full-time study at a college, university, graduate or vocational school in the academic year 2011-2012.

Applicants must have, or be the child of a person who has, a genetic bleeding disorder and is registered with HANY. They must live within the 14 southeastern counties of New York state.

If you are interested, call us for an application at 212-682-5510. Remember... we must receive completed applications by June 3, 2011.

HANY GOLF 2011

4th Annual Matthew Lee Greer Golf Classic – June 20th

18th Annual Nick Salerno Memorial Golf Tournament – July 11th

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.

HANY SUPPORT GIVES A FIRM FOUNDATION FOR RESEARCHER

In the December 23 issue of the prestigious journal, BLOOD, Dr. Victor Arruda, senior author of the paper on the “Eradication of Neutralizing Antibodies to Factor VIII in Canine Hemophilia after Liver Gene Therapy”, acknowledges support for the project from the Hemophilia Association of New York and the National Institutes of Health (NIH).

According to Dr. Margaret Karpatkin, recently retired chairperson of our Medical Advisory Council, “This implies that Dr. Arruda was able to obtain funding from NIH presumably because of preliminary data which he was able to generate with a grant from HANY. I find this very gratifying as the Association has helped to launch a new young investigator.”

Our focus has been on solving the problem of “INHIBITORS”, with \$2.76 million committed in ten grants since 2005. In our fiscal year which ended June 30, 2010, we paid grants to four projects, totaling \$525,844. During the current fiscal year ending this June 30, we expect to disburse \$868,740.

Over the past 45 years the Association has delivered \$4.1 million in direct grants to scores of researchers for their promising work.

While committed to Help Today for people with bleeding disorders, our support of research is the Hope for Tomorrow.

HOW THE NEW HEALTH CARE LAW CAN HELP YOU

(Hemaware, Fall 2010)

Much of the federal healthcare reform that passed in March 2010 will not take effect until 2014. However, key parts of the legislation began this fall, offering expanded insurance benefits and protections to members of the bleeding disorders community now and during the next year.

End of Lifetime Limits

September 23, 2010, as individual and group health plan policies are issued or renewed during the next year, they will no longer have lifetime limits. By September 22, 2011, no health plan will have a lifetime limit.

Annual Limit Minimums

Until January 1, 2014, when annual limits for all insurance plans will be abolished, the law sets a minimum annual limit dollar amount for all group policies and new individual policies. (However, the law does not apply to existing individual policies.) For a plan or policy year beginning between September 23, 2010, and September 22, 2011, the minimum annual limit can be no less than \$750,000. That amount will increase in subsequent years.

Addressing Pre-Existing Condition Exclusions

Individual and group health plan policies issued or renewed on or after September 23, 2010, will no longer be permitted to exclude or restrict coverage for an individual younger than age 19 with a pre-existing condition. By September 22, 2011, no policy will be able to exclude this group.

End of Insurance Plan Cancellations

As of September 23, 2010, individual and group health plans cannot cancel an

insurance policy because an individual had high-cost medical claims.

Medicare Drug Benefit Savings

This year, Medicare will provide a one-time \$250 rebate to help pay for prescriptions in the “donut hole,” a gap in Medicare Part D coverage that occurs when drug costs exceed the initial coverage limit, but do not reach the catastrophic coverage threshold. In 2011, there will be a 50% discount on covered brand-name prescription drugs for those in the donut hole.

Coverage for Children

All children younger than 19, regardless of medical condition, must be accepted by individual plans for an individual policy (for the child) or as a dependent under an approved family policy.

New Dependent Coverage Limit

The law requires all insurance plans that offer dependent coverage under a parent’s policy to provide it until an adult child turns 26, whether single or married. The only exception is if the parent has an employer-based plan and the child is eligible for his or her own employer-based coverage. By September 22, 2011, all eligible adult children should be enrolled.

New Pre-Existing Condition Insurance Plans

If you have a pre-existing condition and have been without insurance for six months or more and have no insurance options, the law has created a pre-existing condition insurance plan in each state. Often referred to as temporary high-risk pools, these plans will serve as a bridge until 2014, when all individuals, including those with pre-existing conditions, will be able to purchase qualified individual plan coverage through state-based American Health Benefit Exchanges.

Linda's Corner: More than 25 years ago, the Hemophilia Association of New York realized the long term importance of keeping costs of clotting factor down. Lower cost factor helps people avoid lifetime caps, and keeps us off the radar screen for hospitals and insurers who are afraid of losing money by providing hemophilia care. Towards that goal, we organized a consortium of treatment centers, hospitals, The New York Blood Center, and the Hemophilia Association of New York to purchase and distribute clotting factor at the lowest possible cost while maintaining the greatest amount of patient choice. This system has worked very well all this time. (Among insurers the NY consortium members had the reputation of having the lowest cost for factor in the country.) But now we see the real long term payoff. Other parts of the country that don't have such systems and rely on very expensive homecare companies for factor are now seeing insurers mandate the use of specific -- often lowest price -- clotting factors. There are even concerns about treatment options being limited. Recently I had a conversation with a physician who had attended a meeting where other physicians were lamenting how insurance companies were starting to limit their patients' choice of factor. We realized that this scenario (loss of

factor choice) had not been a threat in this area. Hopefully our system will continue to keep this from happening in New York.

INHIBITOR MEETING

On Thursday, March 31, 2011 at 7:00P.M., Dr. Acharya and Dr. Lipton will be hosting a meeting to provide you with information regarding Inhibitors and to answer any questions you might have. The meeting will take place in the Long Island Jewish Hospital Teaching Center, Room # 1. Please respond by calling the main Hemophilia number at (718) 470-7380.

FDA CONFIRMS ORPHAN DRUG EXCLUSIVITY FOR WILATE®

(Letter to Octapharma from Timothy R. Cote, Director, Food and Drug Administration, Office of Orphan Products Development, June 24, 2010)

Octapharma USA has received confirmation of orphan drug exclusivity from the U.S. Food and Drug Administration (FDA) for wilate® (von Willebrand Factor/Factor VIII Concentrate, Human) the replacement therapy developed specifically for von Willebrand disease (VWD). The approval comes from the FDA office of Orphan Products Development, which helps to advance the development of products that demonstrate promise for the treatment of rare diseases. The FDA has approved wilate® for the treatment of spontaneous or trauma-induced bleeding episodes in patients with severe VWD as well as in patients with mild or moderate forms of the illness in whom the use of desmopressin is known or suspected to be ineffective

According to the National Institutes of Health, VWD is the most common inherited bleeding disorder and occurs in about 1 out of every 100 to 1,000 people.

HEALTH INSURERS TO BE REQUIRED TO JUSTIFY RATE INCREASES OVER 10 PERCENT

(NY Times, 12/21/2010, By Robert Pear)

In a move to protect consumers, the Obama administration said Tuesday, December 21st that it would require health insurance companies to disclose and justify any rate increases of 10 percent or more this year.

State or federal officials will review such increases to determine if they are unreasonable, the administration said in proposing a regulation to enforce the requirement. The proposed rule represents a major expansion of federal authority in an area long regulated by states.

Kathleen Sebelius, the secretary of health and human services, said the reviews would “help rein in the kind of excessive and unreasonable rate increases that have made insurance unaffordable for many families.” The new health care law, signed in March by President Obama, calls for the annual review of “unreasonable increases in premiums for health insurance coverage.”

The law did not define unreasonable — a gap the administration is now trying to fill. Under the rule issued December 21st, insurers seeking increases of 10 percent or more in the individual or small-group market this year must publicly disclose the planned increases and the justifications for them.

In recent years, individual and small-group premiums have been rising more than 10 percent a year, on average, and many increases far exceed national measures of medical cost inflation, federal officials said. The 10 percent threshold may change in later years. Starting in 2012, the federal government will set a threshold for each state, reflecting trends in its insurance and medical costs.

Consumer advocates welcomed the rules as a way to hold insurers accountable for skyrocketing premiums.

Karen M. Ignagni, president of America’s Health Insurance Plans, a trade group, said that in their zeal to review premiums, “the administration and Congress have largely ignored factors driving up the cost of coverage.” These factors, Ms. Ignagni said, include the power of doctors and hospitals to negotiate higher reimbursement rates, new benefit mandates and the tendency of younger, healthier people to drop coverage, leaving sicker people in the insurance pool.

Under the proposed regulation, the federal government will assess each state’s procedures for reviewing insurance rates. If it finds that a state has an “effective rate review system,” the state would conduct the annual reviews of premium increases. But, the administration said, “if a state lacks the resources or authority to do thorough actuarial reviews, the Department of Health and Human Services would do them.” Thus, it said, “all rate increases that meet or exceed the 10 percent threshold would be reviewed.”

The department will post information about the results of all rate reviews on its Web site, and insurers must post the data prominently on their Web sites. States are beefing up their ability to review rates, with the help of \$46 million in federal grants — the first installment of \$250 million that will be distributed over five years. Under the new federal law, insurers that show “a pattern or practice of excessive or unjustified premium increases” can be excluded from the centralized insurance market, or exchange, to be set up in each state by 2014. Ms. Sebelius, a former Kansas insurance commissioner, said that shining a spotlight on rates would discourage exorbitant increases.

(Continued on Page 6)

HIV AND DISCLOSURE

(thewellproject.org, August 2010)

Preparing for Disclosure

Disclosure means telling someone that you are HIV+. Sharing your HIV status can help with the stresses of living with HIV. But who to tell and how to tell can be complicated and difficult decisions.

There is no one best way to tell someone, just as there is no sure way to know how they will react to your news or whom they may choose to tell. To prepare, it may help to ask yourself a few questions:

Who do I want to tell and why do I want them to know?

How much am I ready to share or are they ready to hear?

How will disclosing my HIV status affect me and how will it affect the people I tell?

Consider where you want the disclosure to take place. It could be at home, at a friend's house, or in a health care setting so that support is readily available. The important thing is that you choose a place that is comfortable for you.

Who Needs to Know... You do not have to tell everyone that you are HIV+. However, it is important that you tell your current and past sexual partners and anyone you have shared needles with to inject drugs. This way they can be tested and seek medical attention if required. If you are afraid or embarrassed to tell them yourself, the health department in your area can notify your sexual or needle-sharing partners without even using your name.

You also need to tell your health care providers to ensure you receive appropriate care. Your health care provider may ask how you were infected to determine if are at risk for other diseases, such as hepatitis C for injection drug users and other sexually

transmitted diseases (STDs) for women infected through sex.

Disclosure and Relationships

Serious Relationship

If you are in a serious relationship, telling your partner is one of the first things you will probably think about. Many turn to their partners for comfort and support. However, some people may worry that they will lose their partner's love when they disclose. It's normal to feel nervous, embarrassed, or even fearful of your partner's reaction.

Since you and your partner most likely have a sexually relationship, you do need to let them know that they may have been exposed to HIV and should get tested. Also, you now need to think about practicing safer sex.

Disclosing your HIV status can put a strain on the best of relationships. It's important for you to think about when and how to disclose, but keeping the information to yourself for too long is probably not a good idea. It may be helpful to getting some professional counseling.

Be aware that women are at risk for violence when disclosing their HIV status. If you are worried that your partner may become violent, think about having the discussion with another person you trust present: a therapist, an HIV advocate, or a health care professional.

Dating

Women who are dating have to face the question of disclosure with each new relationship. Some women prefer to get the issue out into the open immediately. Others prefer to wait and see if the relationship is going to develop beyond casual dating.

Although many people know about safer sex and how HIV is transmitted, fear and stigma are still a reality. Your HIV status will prevent some from wanting to see you,

(Continued on Page 6)

HEALTH INSURERS TO BE REQUIRED TO JUSTIFY RATE INCREASES OVER 10 PERCENT

(Continued from Page 4)

State officials have repeatedly said that premiums must be not only affordable to consumers, but also adequate to guarantee the solvency of insurance companies.

“From a consumer protection standpoint, the most important thing we do is ensure the solvency of companies,” said Sandy Praeger, the Kansas insurance commissioner and chairwoman of the health committee of the National Association of Insurance Commissioners. “Closer scrutiny can help hold down rates,” Ms. Praeger said, “but it will not control costs resulting from the overuse or inappropriate use of health care.”

Jay Angoff, the director of the federal Office of Consumer Information and Insurance Oversight, said, “We are not setting an absolute numerical standard for whether a rate is unreasonable.” Instead, the proposed rule lays out factors to be considered.

Under the proposal, a rate increase will be considered unreasonable if it is excessive, unjustified or “unfairly discriminatory.” A rate increase is defined as excessive if it “causes the premium charged for the health insurance coverage to be unreasonably high in relation to the benefits provided.” The rule envisions a two-step review process. An insurer must file a “preliminary justification” for an increase of 10 percent or more in the rates for any products sold to individuals or small groups. If state or federal officials find the increase unreasonable, the carrier must then file a final justification. To justify rate increases, insurers will have to submit data on claims experience, projected medical costs, executive compensation and many other factors.

“The statute does not give us authority to disapprove rates,” Mr. Angoff said. “We do not have that authority. The regulation leaves state laws intact. It does not interfere with state law.”

In some states, rates cannot be put into effect unless the state affirmatively approves them. In other states, insurers must file rates with a state agency before using them, but the state does not approve or disapprove them. Whether an insurer can carry out a particular rate increase “is entirely a matter of state law,” the rule says.

HIV AND DISCLOSURE

(Continued from Page 5)

while others will not be put off by the information.

In most cases, sharing your HIV status is a personal choice, but in the case of sexual relationships, it can be a legal requirement. It is best if you disclose your status prior to having sex with anyone new.

Non disclosure of HIV status in a sexual relationship can lead to criminal charges whether or not your partner becomes infected with HIV. In most states, the law requires that you disclose your HIV status before knowingly exposing or transmitting HIV to someone else. Penalties vary from state to state. In many states, you can be found guilty of a felony for not telling a sexual partner you are HIV+ before having intimate contact.

Dealing with HIV can be hard, but you don't have to do it alone. There are many resources you can turn to for information and support. New York State Department of Health telephone hotline, 1-800-541-AIDS. You can ask them anything, and you do not have to give your name. New York State Department of Health Web site: www.health.state.ny.us.