



Hemophilia OUTLOOK

A Newsletter of

The Hemophilia Association of New York, Inc.

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☀ **SUMMER 2011** ☀

HANY IS ON FACEBOOK



HANY'S WEBSITE

HANY's website has been redesigned! Visit us at www.hemophilia-newyork.org.

The website is designed primarily for people looking for a connection to the hemophilia community. The site includes information on what services the Association offers.

HANY SCHOLARSHIP

Look for the announcement of our 2012-2013 scholarship program in the Fall issue of OUTLOOK.

THANK YOU

We would like to express our appreciation to *Grifols, USA, LLC and Talecris Biotherapeutics* for their support of our newsletter and other patient services.

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.

TURNING MEDICAID INTO A FEDERAL BLOCK GRANT IS A BAD IDEA

(Medicaid Matters New York, March/April 2011)

To anyone who is unfamiliar with the idea of converting Medicaid into a block grant program, it may seem like a streamlined, more flexible way for states to receive Federal funding to administer the program. However, there are many reasons why block grant would be detrimental to state Medicaid programs, particularly New York's.

Changes will force New York to eliminate some existing categories of coverage and/or set up waiting lists for Medicaid coverage. People with disabilities could lose coverage without being able to afford private coverage.

New York could shift individuals into private coverage plans with less coverage. Health plan packages are less comprehensive in their coverage of prescription drugs, rehabilitation, durable medical equipment and home care.

New York could eliminate benefits relied on to maintain health and prevent secondary chronic conditions. It could eliminate community-based home care services, prescription drugs, rehabilitation and more.

(Continued on Page 3)

COMMUNITY HEALTH ADVOCATES

(www.communityhealthadvocates.org)

Community Health Advocates (CHA), a program of the Community Service Society, has provided one-on-one counseling and community trainings to New Yorkers for over 10 years. Consumers can seek help regardless of whether they are privately insured, publicly insured, or uninsured.

Through funding provided by the New York State Office for the Aging, CHA partners with five community based organizations across the city to provide specialized assistance to Medicare consumers. Some of these services include: assistance with selecting and changing Medicare Part D plans; helping to understand how Medicaid and Medicare work together; assisting in applying for low-income subsidy programs such as Elderly Pharmaceutical Insurance Program (EPIC), Low-Income Subsidy (LIS), and Medicare Savings Program (MSP); assisting with appeals, prior-authorization, reconsiderations, billing and coverage denials; and providing advice and resources to help with problems around Medicare Part D coverage. Assistance to consumers is provided in Spanish, English, Polish, Russian, Yiddish, Chinese, Korean and American Sign Language.

Community Health Advocates (CHA) is a network of organizations from around New York State that helps New Yorkers:

- get health care,
- get health insurance,
- get the most out of it,
- give you information and individual assistance,
- can help you in any language,
- keep your information confidential, and
- provide free services.

If you have any of these questions, Community Health Advocates can help.

- What's in health care reform for me?
- How can I get health care with a limited budget?
- How can I get health insurance?
- How does my insurance work?
- What are my rights?
- How do I deal with medical bills?
- How can I resolve a dispute with my insurance?
- How can I reduce my insurance costs?

The new federal health care law is called the Affordable Care Act.

- Affordable Care Act makes health care less expensive and more accessible for many people.
- Affordable Care Act provides discounts for people in Medicare Part D who hit the donut hole.
- Affordable Care Act gives tax credits to small businesses so they can provide health insurance to their employees.
- Affordable Care Act prevents insurance companies from denying services to their members for a pre-existing condition.
- Affordable Care Act makes health insurance companies spend more in actual health care.

Community Health Advocates has 25 agencies located all over the five boroughs of NYC - there may be one just around the corner. You can visit a Community Health Advocates agency during their walk-in hours, or you can call the Community Health Advocates agency of your choice with any questions you may have.

To contact Community Health Advocates:

- Call: 1-888-614-5400
- Email: cha@cssny.org
- Visit website:
www.communityhealthadvocates.org

LINDA'S CORNER:

Thank You, Senator Chuck Schumer and Senator Kirsten Gillebrand for signing onto the letter to President Obama opposing Medicaid Block granting. Our concern is that if Medicaid was turned into a block grant for each state then some who are eligible now will not be eligible and enrollment would be limited. There are many people with bleeding disorders who depend on Medicaid to cover their comprehensive care and factor. The 2012 Federal Budget is being worked on, so there exists the opportunity to have your voice heard. Please contact the Hemophilia Association of New York (HANY) and we will help you advocate for yourself and your community.

Imagine this: **HEMOPHILIA TREATMENT CENTERS TO CLOSE!** There are Federal funding cuts coming! Our Hemophilia Treatment Centers (HTCs) have been doing a great job in keeping you and your loved ones healthy. Our concern is: What will happen if the hospitals that house your "Medical Home" cannot support the nurses, physical therapists, social workers, and HTC operations without the level of Federal funding that has been so critical for many years? Here is another opportunity for your voice to be heard.

In closing this Summer's "Corner", I'd like to ask a question for pondering: "If a person with a bleeding disorder needed to spend time in a nursing home or a rehabilitation facility to recover from illness, accident or surgery would they be able to find a facility to admit them?" I promise to have more information on this topic in the Fall "Corner", although there may not be a black and white answer.

MIKE TOUTS Rx CARD PROGRAM

(AM New York, May 23, 2011)

On May 22, 2011, Mayor Michael Bloomberg reminded New Yorkers to take advantage of the city's newly issued Big Apple Rx card.

"Prescription medications are not something anyone should have to cut out of the household budget when money gets tight," Bloomberg said on May 22 in his weekly radio address. "And the discounts provided by the Big Apple Rx card will help more New Yorkers avoid that terrible choice."

Launched the week of May 16th, the free card is available to everyone living, working or visiting New York City; regardless of age, income, citizenship, or health insurance status. The city said it offers discounts on prescription drugs, an average discount of 47 percent. It can't be used in conjunction with prescription insurance coverage.

For more information, visit www.bigapplerx.com or call 800-697-6974.

TURNING MEDICAID INTO A FEDERAL BLOCK GRANT IS A BAD IDEA *(Continued from Page 1)*

Out-of-pocket health costs are covered or non-covered health services will rise. Block grant shift costs to beneficiaries.

Capped funding will not grow to respond to the aging of the population, epidemics or disasters.

Block granting Medicaid would lock in the current Federal share of funding, meaning New York would not be able to negotiate a rate higher than the current 50% (the lowest in the nation).

TRAVEL TIPS: PREPARING FOR SECURITY SCREENING

(TSA, www.tsa.gov)

Increased travel security measures may cause some difficulty for people with bleeding disorders and their families.

- Notify your airline or travel agent in advance if you need assistance at the airport. TSA can only help with the screening process; your airline will help you through the airport facility and the screening line.
- The limit of one carry-on and one personal item (purse, briefcase or computer case) does not apply to medical supplies, equipment, mobility aids or assistive devices.
- Pack your medications in a separate pouch/bag to simplify the inspection process. Do not fill medication containers too full, and make sure that all your medication is clearly identified. If you have medications you don't want exposed to X-rays, don't pack them in your checked baggage. Instead, send larger quantities of medications to your destination by FedEx or similar services.
- If you have documentation about your medical condition or disability, present it to the security officer. (TSA does not require this documentation, and it will not exempt you from the security screening process.)

When traveling with your clotting factor, it is advised that you bring a prescription from your physician that includes contact information, as well as a letter from your physician/Hemophilia Treatment Center providing a brief explanation of your condition and the need for this medication.

In addition, if you bring needles onto an airplane in your hand luggage you must also have the clotting factor with you.

Check with your airline at least two days prior to departure to learn their specific regulations regarding the transport of medications. Each airline is developing regulations that are subject to change.

Following is a link to the Transportation Safety Administration of the U.S. Department of Homeland Security. Please check this link for regular updates: <http://www.tsa.gov/travelers/index.shtm>.

NATIONAL HEMOPHILIA FOUNDATION'S ANNUAL MEETING

“Inspiration in the Windy City” is this year's theme for the National Hemophilia Foundation 63rd Annual Meeting, November 10-12, 2011 conference, which offers educational sessions, networking opportunities and social events for all ages. Individuals and families come with questions and concerns, but leave with answers, encouragement and hope.

Educational Participant Grants Available for NHF's 63rd Annual Meeting

NHF is pleased to offer *Educational Participant Grants* for **first-time attendees** to its 63rd Annual Meeting. The Annual Meeting enables our community to come together and exchange information on a wide variety of topics, from the basics of diagnosis to the most recent and relevant developments in treatment and technology. It is the premier opportunity for networking and support for individuals and families affected by bleeding disorders. NHF currently provide \$30,000 annually to families who wish to attend the meeting and take advantage of the wealth of information and educational opportunities during the annual meeting.

For more information on the meeting go to www.hemophilia.org.

SUMMER REMINDER

Every summer OUTLOOK carries a reminder of ways to avoid injuries while enjoying summer activities.

Most people are aware that running on a wet pool deck, wearing flip-flops during active play, and using a baseball rather than a softball can cause accidents. Everyone should wear helmets when using skateboards, skates, scooters and bicycles.

But it is easy to forget that amusement park rides can cause serious, even fatal, injuries. The greatest hazard on these rides is to the brain. The sharp turns common not only on roller coasters but on many rides have been known to result in bleeding beneath the brain's outer membrane ("subdural hematoma"). This must be of particular concern to people with hemophilia. Prophylaxis is a good precaution before a day at the amusement park or any strenuous activity. But it isn't a replacement for observing safety precautions.

The most recommended sports for people with bleeding disorders are those that put less impact on joints but still do a lot for muscle strength and flexibility. Swimming, walking, golf and bike riding are good suggestions. However, with proper safeguards, it's possible for people with bleeding disorders to enjoy a wide variety of outdoor activities.

You and your child can experiment together to find out which activities work the best for him and for your family. Talk to the HTC staff, especially the physical therapist, about appropriate activities. Other parents of boys with hemophilia can be helpful, especially if their sons are older than yours.

SUMMER CAMPS FILL UP EARLY

OUTLOOK readers know how enthusiastic we and the parents of former campers are about the developmental benefits camp offers to children with chronic disorders. Campers have had wonderful experiences at the three specialty camps nearest to our area, listed below. All three provide on-site medical care and supervision.

Transportation and travel arrangements to camp are the responsibility of the camper's family. *HANY offers help with "camperships" and the cost of transportation for those who require it.*

Camp High Hopes

Where: Aldersgate Camp, Brantingham, N.Y.

Ages: 7-17

Tuition: free

Sessions are available for boys and girls in August 2011.

Siblings and carriers are welcome if space is available.

For more information about attending or volunteering at camp, call 315-463-5354.

Double "H" Ranch

Where: Lake Luzerne, N.Y.

Ages: 6-16, co-ed.

Tuition: Free.

Call 518-696-5676 for applications or information on volunteering.

The Hole in the Wall Gang Camp

Where: Ashford, CT.

Ages: 7-15, co-ed.

Tuition: Free

For application or volunteering at camp, call 860-429-3444.

NEW YORK STATE'S HEALTH INSURANCE PLAN FOR PEOPLE WITH PRE-EXISTING MEDICAL CONDITIONS IS NOW AVAILABLE

March 2010, Congress passed the health care reform law, the Patient Protection and Affordable Care Act. The law created a temporary program until January 1, 2014 that makes coverage available for individuals who have a pre-existing medical condition, have not had insurance for six months, and who are legal US residents.

This new program is called the Pre-Existing Condition Insurance Plan (PCIP) and will be available throughout the country. In New York State, the PCIP plan is the NY Bridge Plan, administered by GHI, an EmblemHealth company.

PCIP plans will operate until the year 2014. At that time other provisions of health care reform will go into effect and state health benefit exchanges will be available for individuals to purchase coverage.

Highlights of the NY Bridge Plan Covered Services:

- No Deductibles
- Preventive Care
- \$20 Office Visit Co-pay
- \$500 Inpatient Per Occurrence Co-pay
- \$100 Emergency Room Co-pay
- Pharmacy Benefits
- Vision Care

For Eligible New Yorkers, you must:

- Be a legal US resident
- Be a resident of New York State
- Have one or more pre-existing medical condition(s), and
- Not have had health care coverage for the last six months.

There is no minimum age to qualify — even newborns may be enrolled if they meet the eligibility requirements. However, once you turn 65 years of age and have Medicare coverage, you will no longer be eligible for the NY Bridge Plan. Applicants who transfer from another state's PCIP program will be eligible if they are a resident of New York and have less than a 63 day lapse in coverage from their prior PCIP coverage.

With the NY Bridge Plan, your eligibility is not based on income. The NY Bridge Plan offers premium rates that are significantly lower than other individual coverage, plus low copayments and no deductibles.

Premium rates are standardized depending on where you live. These rates are for individuals only, as there is no family or dependent coverage offered with the NY Bridge Plan. If other family members qualify, they may also apply for coverage separately. Accepted members will be billed individually and be fully responsible for paying the monthly premium.

For those who live in downstate New York, the premium rate is \$421.00 per month and for those who live in upstate New York, the premium rate is \$362.00 per month.

Information about hemophilia won't be found anywhere on the NY Bridge program's website. Hemophilia is a qualifying condition. GHI/Emblem Health will cover factor products, both inpatient and outpatient, as well as other necessary services (nursing, etc).

For more information on the NY Bridge Plan, call from 8:30 am to 5:30 pm, Monday through Friday at 1-866-693-9277 or go to www.ghi.com/nybridgeplan/index.html. For information on factor coverage call GHI at 877-444-9622.