



## JOIN NEHA'S RAPID RESPONSE NETWORK

To become a member of the Rapid Response Network, email [Wendy Owens](mailto:Wendy.Owens@neha.org), NEHA's Advocacy Coordinator

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## Join NEHA at NHF's Washington Days

Join NEHA in Washington, DC in February! The National Hemophilia Foundation will hold its annual Washington Days lobby days in Washington, DC from February 16-18, 2011. NEHA members are invited to attend. Last year we took 21 NEHA community members to the event and had a great time as well as made a difference for the bleeding disorders community in the six New England states. Washington Day attendees do not need experience or a degree in political science to get involved. All you need is your story, your personal experience, and your commitment to improving the quality of life for persons with bleeding disorders and their families.

NHF will provide attendees with federal and state advocacy training. NEHA staff will be available to attend meetings with Congressmen and women with attendees who feel they need support during their meetings.



NHF has published a preliminary Washington Days agenda that describes the schedule of activities. Activities begin in the evening on Wednesday, February 16, with Washington Day training followed by a regional

break-out training session and a reception. On Thursday, attendees will meet with their Congressional lawmakers on Capitol Hill. Thursday evening NHF will host a dinner and special presentation on "The Importance of Clinical Trials." For those who wish to stay, on Friday morning breakfast will be offered and NHF will run state advocacy training. Training and meals will take place at the Crystal Gateway Marriott hotel in Arlington, VA. Wheelchair accessible buses will be provided to and from the Hill visits for those who need them. NEHA will offer those who need them the following travel subsidies to attend Washington Days:

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## Watch out for Limits on Number of Doctor Visits & Prescriptions

When examining your health benefits for the new year, you'll probably notice that your plan has eliminated lifetime and most annual dollar limits on coverage. That was mandated by the federal health-care overhaul. But for some consumers, coverage may still be restricted: Limits on the number of doctor visits or prescriptions or other services continue to be permitted and can stymie patients' efforts to get necessary care. So far, most companies do not seem to be adding new numerical limits on services to compensate for the elimination of lifetime and annual benefits,

says Mike Thompson, a human resource services principal with benefits consultants PwC. But it could be a problem in the future. The health law requires that plans sold on the state-based insurance exchanges that will start up in 2014 cover certain "essential health benefits," including hospitalization, prescription drugs and rehabilitative care, such as physical therapy. The secretary of Health and Human Services is charged with defining exactly what the coverage will be for these essential benefits, but those details aren't expected until next year. Some policy experts say

they hope that the coverage requirements will steer clear of arbitrary numerical limits and instead emphasize evidence-based research on the most cost-effective treatments. That approach would permit physical therapy to the extent that it was medically necessary, no more and no less. Whatever HHS decides about "essential" coverage will only be required of plans sold on the state-based exchanges, primarily to individuals and companies with fewer than 100 workers, and of small-group and individual policies sold on the private market. Source: Kaiser Health News.



Maine State House,  
Augusta, Maine

## Get Involved!

### Connecticut

NEHA is forming a coalition of voluntary health organizations to pursue legislation to preclude the use of specialty prescription drug tier pricing by insurers. For prescription drugs at tiers I-III, patients generally pay a co-pay. Should an insurer add a tier IV to their prescription drug pricing formulary, a patient may have to pay a co-insurance payment of 20-33% of the cost of a specialty drug for which patients currently pay a co-pay. For example, if your medication costs \$400,000 annually and the tier IV co-insurance payment is 20%, then your annual out-of-pocket cost would be \$80,000. The coalition would draft and introduce legislation to preclude the possibility that the cost of prescription drugs will be so high as to be unaffordable and put life saving medication out of reach. Contact [Wendy Owens](#) to learn how you can get involved and help support the coalition's efforts in CT.

### Maine

To learn about the impact the federal Affordable Care Act is having on Maine's health care system, click [here](#). Hemophilia is on Maine's list of pre-existing conditions. The Pre-Existing Condition Plan is a federal program for individuals who have been uninsured for at least six months and who have been previously diagnosed with a serious medical condition. To learn more, click [here](#).

### Massachusetts

NEHA is re-introducing the Hemophilia Advisory Bill during the 2011 legislative session. Please contact your MA legislators by **February 2** and ask that they sponsor this bill.

HIV Project ABLE's Annual Lobby Day will be on Thursday, January 27, 2011 at the Grand Staircase in the State House, from 10-12 noon. For more information, contact Mary Ann Hart [HIVProjectABLE@aol.com](mailto:HIVProjectABLE@aol.com).

NEHA is forming a coalition of voluntary health organizations to pursue legislation to preclude the use of specialty prescription drug tier pricing by insurers. For details, see "Connecticut" above. For more info, contact [Wendy Owens](#) to get involved.

### New Hampshire

[HealthCost](#) provides information on the price of medical care in New Hampshire by insurance plan and by procedure. This site gives patients information about the price of health care services and serves as a resource to help you make informed decisions about purchasing health care services and insurance.

### Rhode Island

To learn about the impact the federal Affordable Care Act is having on Rhode Island's health care system, click [here](#).

### Vermont

For the latest on health care reform in Vermont, visit [Vermont's Health Care Reform](#).

## Join NEHA at NHF's Washington Days

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- A travel reimbursement of up to \$150/person for air or train fare. Costs over this subsidy will be assumed by the attendee. This reimbursement is payable after the event with submission of a copy of air or train ticket receipt;
- \$0.44/mile/vehicle plus tolls for those who drive (mileage will be calculate based on a round trip from

your home address to the Crystal Gateway Marriott in Arlington, VA; limit one vehicle per family); and

- One room for up to two-nights at the Crystal Gateway Marriott, where all NHF events will take place. You are not required to stay both nights in order to attend the event.

The number of travel subsidies is limited. Priority for travel subsidies will be given to NEHA members who have not

attended Washington Days before. Attendees will pay for their own miscellaneous expenses. NEHA will register all New England based attendees for the event.

If you would like to attend Washington Days, please contact Wendy Owens, NEHA's Advocacy Coordinator, [wowens@newenglandhemophilia.org](mailto:wowens@newenglandhemophilia.org) or 781-326-7645, as soon as possible so that NEHA can register you for the event. Hope to see you in DC!

*"If you would like to attend Washington Days, please let Wendy Owens, NEHA's Advocacy Coordinator, 781-326-7645"*

# Pre-Existing Condition Insurance Plans Options

The US Department of Health and Human Services announced new plan choices for people enrolling in the Pre-Existing Condition Insurance Plan (PCIP) for 2011. These options will give current and future enrollees a greater number of coverage choices and allow people to select the plan that best meets their needs.

The new options will be offered in a three-tiered structure beginning January 1, 2011, and will be available in States where the program is federally administered through the Office of Personnel Management. These choices build on the current single plan option: experience with the program has provided valuable information that has allowed for the creation of new and improved options.

The federally administered program is available in 23 States and the District of Columbia.

PCIP provides Americans living with such conditions as cancer, diabetes, or heart disease the opportunity to obtain insurance coverage. The program covers a broad range of health benefits and is designed as a bridge for people with pre-existing conditions who cannot obtain health insurance coverage in today's private insurance market.

In 2014, all Americans – regardless of their health status – will have access to affordable coverage either through their employer or through a new competitive marketplace, and insurers will be prohibited from denying coverage to anyone based on the state of their health.

In 2010, people enrolled in the federally-administered PCIP program were offered one plan. Beginning in 2011, such enrollees in

the federally administered PCIP program will be able to choose between three plan options: the Standard Plan, the Extended Plan and the Health Savings Account eligible plan. In addition, families will be able to enroll their eligible children in PCIP at child-only rates. These options will allow enrollees to select a plan that best meets their needs.

The existing option in PCIP has



been improved. The 2010 Standard Plan had a single, combined medical and pharmacy deductible of \$2,500. The 2011 Standard Plan now has two separate deductibles -- a \$2,000 medical deductible and \$500 drug deductible, while also offering premiums that are almost 20% lower than the 2010 premiums.

The reduced pharmacy deductible is particularly beneficial for people who take one or more maintenance medications. The lower premiums result from experience and are expected to be more affordable for the eligible population with pre-existing conditions.

A new plan option, called the Extended Plan, has a \$1,000 medical deductible and \$250 drug deductible plan. The premiums for the 2011 Extended Plan will be slightly higher than 2010 premium levels.

Just as with the Standard Plan,

separating the drug and medical deductibles makes this plan option more valuable for those enrollees who take one or more maintenance medications.

The Health Savings Account (HSA) Option will carry a \$2,500 deductible but with premiums that are 16% less than 2010 premiums. As with the current plan, this option is eligible to receive favorable tax treatment by the federal government when used with a Health Savings Account (HSA).

To ensure that children have more affordable access to coverage, HHS has established premiums targeted for covering children under PCIP, creating a child-only rate for PCIP enrollees between 0-18 years of age.

For more information, visit [www.healthcare.gov/law/provisions/preexisting/](http://www.healthcare.gov/law/provisions/preexisting/) and [www.pcip.gov](http://www.pcip.gov). Source: Kaiser Health News.

*“PCIP provides Americans living with such conditions as cancer, diabetes, or heart disease the opportunity to obtain insurance coverage.”*

## New Regs Could Equal Rebates for Consumers

Millions of Americans might be eligible for rebates starting in 2012 under regulations released in November detailing the health care law's requirement that insurers spend at least 80 percent of their revenue on direct medical care. The regulations closely follow recommendations sent to the U.S. Department of Health and Human Services by the National Association of Insurance Commissioners (NAIC) after months of meetings and debate involving industry and consumer representatives. The government estimates that 45 percent of people who buy their own coverage are in plans that currently don't meet the standard. If the law were in effect now, about 9 million would get rebates, either directly, if they buy their own coverage, or through their employers if they are in job-based coverage. Source: Kaiser Health News.

## New England State-by-State News

### Connecticut

#### **Challenge to Law Denying Legal Immigrants Health Benefits:**

The Connecticut Supreme Court will decide whether or not to strike down a state law that takes away Medicaid benefits from 4,800 legal immigrants. Last year, Connecticut approved a law to deny Medicaid coverage to immigrants who have been in the country for less than five years – an attempt to save the state about \$9 million. However, a Hartford Superior Court judge ruled that this violated the immigrants' constitutional rights. The state appealed this ruling. A final Supreme Court decision could take months.

*“The Connecticut Supreme Court will decide whether or not to strike down a state law that takes away Medicaid benefits from 4,800 legal immigrants.”*

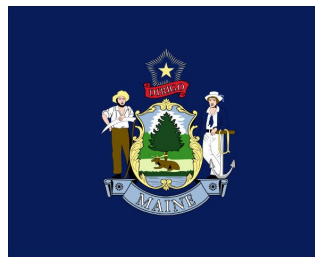
### Maine

#### **People With Pre-existing Conditions Qualify for a New Health Insurance Option!**

The Dirigo Health Agency (DHA) administers the PCIP to residents of Maine who have a qualifying pre-existing condition, which includes bleeding disorders. To be eligible for the program, the individual must meet the following criteria:

- Uninsured for the previous 6 months before applying for assistance and provide a signed statement. (Note: if you have a pre-existing condition, but have had coverage within the past six months, you still may qualify for enrollment in another DHA program).

- Have at least one of the 37 listed medical conditions, of which hemophilia is one, and provide supporting documentation from a medical provider.
- Be 1) a citizen or national of the US and able to provide a copy of a US public birth certificate or passport **or** 2) lawfully present with permanent resident status in the US and able to provide a copy of a permanent resident card



Subsidies are available on a sliding scale to enrollees with household incomes under 300% of the Federal Poverty Level (\$32,490 for a single, \$66,150 for a family of four) and assets under \$60,000 for a single and under \$120,000 for a household of 2 or more.

This program was made possible by the passage of the Affordable Care Act last March. For more information about Dirigo coverage options, visit the [Dirigo-Health website](#) or call DHA at 1-877-892-8391.

### Massachusetts

#### **New Online Resource Dedicated to Massachusetts Health Reform:**

The Blue Cross Blue Shield Foundation of Massachusetts launched a [new online resource](#) dedicated to Massachusetts health reform. The website includes links to a wide variety of resources on Massachusetts health reform, including legislation, reports, data sources and analyses. It also includes resources on how national health reform will affect Massachusetts, including a report entitled [“Re-Forming Reform: What the Patient Protection and Affordable Care Act Means for Massachusetts.”](#)

### New Hampshire

**State Ranked First in Health Care Quality:** The Agency for Healthcare Research and Quality ranked New Hampshire first in their [annual Health Care Quality Report](#).

Maine finished 4<sup>th</sup> (and was the most improved state overall, moving up from 12<sup>th</sup> place the previous year) and Rhode Island came in 5<sup>th</sup>.

The annual rankings are based on a list of measures, including those pertaining to maternal and child health. Click on the [State Selection Map](#) to explore the quality of your state's health care.

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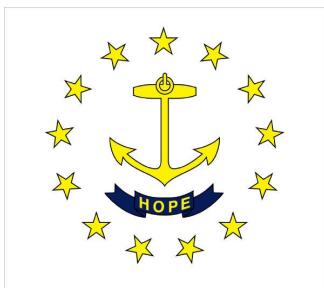
**Rhode Island**

**Plan Proposed to Cover Uninsured Residents Until 2014:**

At a [recent health reform implementation forum](#), Neighborhood Health Plan of Rhode Island, in collaboration with the Rhode Island Health Center Association, proposed a new program called [Center Care](#) to cover approximately 35,000 uninsured Rhode Islanders before national health care reform's coverage expansions take effect in 2014.

Center Care would be a temporary, limited benefit pro-

gram for Rhode Islanders without children who earn less than 133 percent of the [federal poverty level](#). Enrollees would be able to choose a primary care doctor at one of the 27 community health centers in the state; they would become eligible for Medicaid in 2014 as a result of the Affordable Care Act's Medicaid expansion.



**Vermont**

**Sugar-Sweetened Beverage Tax Campaign**

[The Alliance for a Healthier Vermont unveiled its plans to support a state sugar-sweetened beverage \(SSB\) tax](#) campaign at a press event last month. The group is made up of 17 organizations, including health care providers, consumer groups, senior

citizen groups and organized labor. It is supporting a penny-per-ounce excise tax on sugary drinks, proposed by the Vermont Attorney General in November.

State legislators plan to bring up the tax, which could cut Vermonters' consumption of SSBs by 20 percent and raise \$30 million annually, when their legislative session begins in January.



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The New England Hemophilia Association is dedicated to improving the quality of life for persons with bleeding disorders and their families through education, support, and advocacy.

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**Advocacy in Action** is a publication of the New England Hemophilia Association. Corrections, submissions, suggestions, and volunteers to help with production are gratefully accepted. Please address all correspondence to the NEHA office, or to [info@newenglandhemophilia.org](mailto:info@newenglandhemophilia.org).