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## NEHA Says "No" to Specialty Tiers in New England

Legislation to preclude the creation of specialty tiers in private insurers' prescription drug formularies is before the Rhode Island, Connecticut, Vermont, and Massachusetts legislatures. This legislation will prevent members of the bleeding disorders communities from potentially paying **20% to 33%+** of the annual cost of their medication out of their own pockets. Many health insurance plans are implementing new cost sharing mechanism in their drug plans, including establishing specialty tiers in their drug formularies. Most often new and high cost treatments, "specialty drugs," are placed on these specialty tiers. Most often specialty drugs treat or slow the progression of life threatening diseases and chronic conditions such as HIV/AIDS, cancer, heart disease, hemophilia, and multiple sclerosis and their costs are

very high. The rising cost of specialty drugs is especially alarming given that there often are no generic alternatives to higher cost specialty drugs.



As a cost sharing strategy, specialty tiers are problematic for a number of reasons.

1. Specialty tiers violate the basic principal of insurance whereby individuals and employers purchase health insurance plans to preclude the risk of needing to pay for highly expensive medical treatments.
2. Insurers can change specialty tier coinsurance rates unpredictably. This makes it im-

possible for patients to anticipate and budget for health care costs. It also impedes them from having informed discussions with their doctors about containing the cost of their treatment.

3. In locations where the practice of specialty tiering is allowed, researchers find that the out-of-pocket costs for medications are high enough to prohibit people from complying with the treatment prescribed by their doctors. Severely ill people are four to five times as likely to delay or avoid medical care when faced with financial problems because of their medical bills. Numerous studies demonstrate that high out-of-pocket costs lead to decreases in compliance to medical treatment, especially for lower-income

*(Continued on page 2)*

## Personal Advocacy & Health Care Reform Webinars from NEHA

All NEHA members are invited to participate in NEHA's first Personal Health Care Advocacy Webinar presented online on **April 13 at 7 PM**. Learn about personal health care advocacy from the comfort of your home. The webinar presenter is Daniel Riley, president of Comprehensive Health Education Services. Daniel will focus on educating members of the bleeding disorders community how to be their own advocates when it comes to their healthcare needs. The presentation will be 45 minutes with 15 minutes of

questions and answers following the formal presentation. Topics to be discussed will include, but are not limited to: dealing with insurance companies, advocating for you and your family's needs to health-care providers, making informed health care decisions, and how to educate yourself about your chronic health condition so you can be a more effective self-advocate. You can learn more about Daniel from his company's [web site](http://www.comprehensivehealtheducation.com). Participants will access the webinar via their computer. Details for accessing the webi-

nar will be provided in a registration confirmation email. In addition, NEHA is offering a webinar on the impact of national health care reform on the bleeding disorders community. This webinar will take place on **May 18 from 7 to 8 PM**. The presentation will answer the who, what, and when of national health care reform and why it is so significant to NEHA members. RSVP for both webinars by contacting NEHA's Advocacy Coordinator, [Wendy Owens](mailto:Wendy.Owens@neha.org), or 781-326-7645. Space is limited so please register early.



New Hampshire State House, Concord, New Hampshire

## Get Involved!

### All New England States

Personal Health Care Advocacy Webinar: All NEHA members are invited to participate in NEHA's first Personal Health Care Advocacy Webinar presented online on **April 13 from 7 to 8 PM**. Learn about personal health care advocacy from the comfort of your home.

The Impact of National Health Care Reform Webinar: NEHA is offering a webinar on the impact of national health care reform on the bleeding disorders community. This webinar will take place on **May 18 from 7 to 8 PM**.

Please see the article on page 1 to learn how to sign-up for both webinars.

### Connecticut

NEHA invites all of its CT members to join us for Connecticut Connect. This is an opportunity for CT members to meet with their state lawmakers to discuss issues important to the CT bleeding disorders community. Contact NEHA's Advocacy Coordinator, Wendy Owens, via [email](#) or 781-326-7645 to schedule a time to meet with your CT state lawmakers.

### Maine

Interested in testifying at a public hearing in Maine? You can find notice of public hearings for bills before the state legislature at the Senate's hearing [web page](#) or the House's hearing [web page](#) which lists the schedules of committees.

### Massachusetts

Save the Date! On May 25 from 9 AM to noon the New England Hemophilia Association will host its Massachusetts Legislative Day at the Massachusetts State House in Boston. For details, see page 3.

### New Hampshire

Receive free flag status alerts by signing up on the State of New Hampshire [web site](#).

### Rhode Island

Stay current on RI Legislative news, visit the [Weekly Round Up page](#).

### Vermont

Stream live broadcasts of VT State House and Senate proceedings courtesy of [Vermont Public Radio](#).

## NEHA Says "No" to Specialty Tiers in New England

(Continued from page 1)

*"For a person with hemophilia without inhibitors, for example, the patient out-of-pocket cost of medication could range between \$80,000 and \$120,000 per year should the patient have to pay specialty tier co-insurance rates."*

groups who are more likely to experience chronic illness. Decreased compliance with medical treatments leads to increased medical costs for employers and insurers as patients need emergency care and other high cost treatments due to non-compliance.

Unlike most pharmaceutical drugs that are dispensed with set dollar amount co-payments, drugs on specialty tiers are assigned co-insurance rates where the patient pays a percentage of the drug's cost. From a patient perspective the difference between paying a co-payment and paying a co-insurance rate for medication could be hundreds or thousands of dollars per

month. Specialty tier co-insurance rates range from 20% to 33%+ of the cost of the medication. For a person with hemophilia without inhibitors, for example, the patient out-of-pocket cost of medication could range between **\$80,000** and **\$120,000** per year should the patient have to pay specialty tier co-insurance rates. Currently, most insurers in New England have not implemented specialty tiers, though there is a possibility for them to do so as it is not illegal in any state to add specialty tiers to drug formularies. Specialty tiers are NEHA's most urgent priority. NEHA is making a concerted effort to preclude the establishment of specialty prescription drug tiers by insurance companies in New England states. Together with the coalition, NECAPD (see

article on page 4), NEHA is supporting the specialty tier legislation before the Rhode Island, Connecticut, Vermont, and Massachusetts legislatures. This is a critical issue for the New England bleeding disorders community. NEHA hopes that all of its members will get involved to make their state lawmakers aware of the threat specialty tiers poses. If you are in a state in which there is specialty tier legislation before the state legislature and you want to help NEHA support this legislation, please contact your state senator and representative. For help with contacting your state lawmakers, please contact NEHA's Advocacy Coordinator, Wendy Owens, via email at [wowens@newenglandhemophilia.org](mailto:wowens@newenglandhemophilia.org) or 781-326-7645.

## NEHA Members Go to Washington, DC

On February 17, 24 NEHA members, including kids and entire families, spent the day on Capitol Hill in Washington, DC meeting with their federal lawmakers as part of the National Hemophilia Foundation's (NHF) Washington Days. Individuals with bleeding disorders and their families met with the senators and representatives from their respective states to advocate for issues important to them and the bleeding disorders community. Participants focused on two main issues when speaking with their US lawmakers: (1) the maintenance of the Affordable Care Act provisions that allow individuals with high-cost conditions, such as hemophilia, access to adequate and affordable coverage; and (2) maintenance of funding for the hemophilia programs at the Centers for Disease Control (CDC)

and Health Resources and Services Administration (HRSA). NEHA members reported that these received very positive response to these requests from lawmakers and their aides.

Some of the representatives and senators with whom the NEHA participants met included Senator Olympia Snow of Maine, Senator Joseph Lieberman of Connecticut, and Representative Barney Frank of Massachusetts. Some NEHA members ran into other notable lawmakers include Senator John McCain whom they met on an elevator ride.

In addition to meeting with US lawmakers, NEHA participants took part in advocacy training for both the federal and state levels on the day prior to and the day after their day on Capitol Hill. For those who had attended Washington Days in the past, it

was an excellent opportunity to catch-up with friends from non-New England states who they knew from past events.

Planning is already under way for NHF's 2012 Washington Days to be held next winter. All members of the bleeding disorders community are welcome to attend Washington Days. NEHA will keep members posted on the 2012 Washington Days dates.

This year NEHA offered substantial travel subsidies to Washington Days attendees that included paying for hotel stays and a travel stipend for air, car, or rail travel. NEHA hopes to continue to offer these subsidies next year.

If you are interested in attending NHF's 2012 Washington Days, please contact Wendy Owens, NEHA's Advocacy Coordinator, via [email](#) or 781-326-7645.

*“Individuals with bleeding disorders and their families met with the senators and representatives from their respective states to advocate for issues important to them and the bleeding disorders community.”*

## Go to DC with Children's Hospital

Children's Hospital Boston is committed to advocating for public policies that improve health care for children at the federal, state and city levels. The Office of Government Relations is looking for patient families from the New England region to assist it in its federal advocacy efforts this summer. Each year, Children's Hospital Boston selects several families to participate in the National Association of Children's Hospital's Family Advocacy Day event in Washington, DC. This is a unique event that offers families with children who have been treated at Children's Hospital Boston the opportunity to visit DC and advocate on behalf of the hospital. This year, the two day event will be held on July 25 and 26. In selecting families to represent

Children's Hospital, they identify families who have a child that has been treated at Children's and are willing to speak to their elected officials about the important role the hospital plays or has played in the care of their child. In particular, they would like to identify families who reside in New Hampshire, Maine,



Vermont, Rhode Island, and Massachusetts. If you or a family that you know might be interested in participating, please contact Amy DeLong, Manager of Federal Government Relations, 617-919-3070 or [email](#).

### SAVE THE DATE MASSACHUSETTS!

Save the Date! On May 25 from 9 AM to noon the New England Hemophilia Association (NEHA) will host its Massachusetts Legislative Day at the Massachusetts State House in Boston. All NEHA members are invited to attend. A light breakfast will be served. Together NEHA volunteers will:

- ◆ acquaint legislators and their staff with bleeding disorders and make them aware of the community's general needs and interests; and
- ◆ advocate for support for the Hemophilia Advisory Committee bill before the Massachusetts legislature.

NEHA members will have the opportunity to meet one-on-one with their state lawmakers following the event. If you would like to participate in the MA Legislative Day and meet with you MA state lawmaker, please contact , NEHA's Advocacy Coordinator, Wendy Owens, via [email](#) or at 781-326-7645.

*“NECAPD’s mission is to promote and protect New England residents’ access to safe and affordable prescription drugs.”*

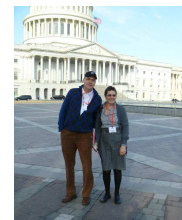
## NEHA Launches NECAPD to Protect Members

To better meet the advocacy needs of the New England bleeding disorders community, NEHA’s Advocacy Coordinator, Wendy Owens has organized the New England Coalition for Affordable Prescription Drugs (NECAPD). NECAPD is an alliance of non-profit organizations concerned about the high and rising cost of prescription drugs. NECAPD is dedicated to promoting and protecting New England residents’ access to safe and affordable prescription drugs through education and advocacy. Its mission is to promote and protect New England residents’ access to safe and affordable prescription drugs. NECAPD will raise awareness of the rising cost of prescription drug and promote workable solutions for how to keep prescription drug costs down and assure access to affordable prescription drugs by New England residents. NECAPD will do this through educational outreach, advocacy, and

open dialog with elected officials, government agencies, the insurance industry, and other major stakeholders. NECAPD’s goal is to preclude a situation when a patient is forced to choose between paying for basic living expenses and paying for their prescription medications. In 2009, the price for brand-name prescription drugs rose 9.1%, the biggest increase in a decade. According to Express Scripts, in the same year, the price of specialty drugs, those used to treat or slow the progression of life threatening diseases and chronic conditions, rose 11.5%. This raised alarm bells for NEHA since the cost of medication is a critical issue to the bleeding disorders community. In order to effectively respond to the rising cost of prescription medication, NECAPD believes that communication, information sharing, and transparency are the key to finding workable solutions to keep drug costs down. Cur-

rent NECAPD members include the New England Hemophilia Association, the Arthritis Foundation - New England Region, Advocacy for Patients with Chronic Illness, Inc., US Pain Foundation Inc., and NeedyMeds, Inc. Many other organizations are seeking permission from their boards to join the Coalition. Member recruitment is ongoing. One of NECAPD’s most pressing issues is that of the addition of specialty tiers to prescription drug formularies. To learn more about this issue, see “NEHA Says No to Specialty Tiers in New England” on page 1. With a coalition, there is power in numbers and the ability to leverage each member’s resources for the benefit of all people in New England who take any type of prescription drug. If you know an organization that might be interested in joining NECAPD, contact [Wendy Owens](#), NEHA’s Advocacy Coordinator & NECAPD leader.

## Pictures from NHF Washington Days 2011



**Clockwise from top left:** NEHA CT members meet with Rep. Chris Murphy; mother and son, Kate & Ian Muir; Jon & Christine Pineo; father and son, Ron & Tyler Ricchiuto meet with Sen. Olympia Snow; Alan & Mary Hurley; and US Capitol Building February 17.

## Congratulations to Leland Smith for Outstanding Youth Award

*Advocacy in Action* would like to congratulate one of NEHA's top advocates, Leland Smith. Smith is one of four Shrewsbury High School seniors who were honored with the Outstanding Youth of Shrewsbury Award for their achievements, resiliency and volunteerism at the Shrewsbury Youth and Family Services' Annual Gala.

An article in the Shrewsbury Chronicle said of Smith: "One of only 800 people suffering from Severe Hemophilia A, a medical condi-



**Taylor & Leland Smith meeting with Rep. Stephen Lynch (D) of Massachusetts at NHF's Washington Days 2010**

tion resulting in painful bleeding within joints, Smith has become an advocate for hemophilia treatment and

research. He has spoken at Harvard Medical School and MIT Health Sciences Tech about hemophilia research and treatment and has participated in several fundraisers for hemophilia treatment. Although he has had to miss a significant amount of time at school because of the rare disease, Smith has performed in the top half of his class." Congratulations, Leland!

Click [here](#) to learn more about the gala. To learn more about Shrewsbury Youth and Family Services, visit their [web site](#).

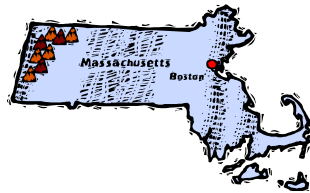
*"Although he has had to miss a significant amount of time at school because of the rare disease, Smith has performed in the top half of his class."*

## Hemophilia Advisory Committee Bill Before MA Legislature

In January, as lead sponsor Representative Jeffrey Sanchez filed a revised version of the Hemophilia Advisory Committee bill, HB1526. Rep. Sanchez is the chair of the Joint Committee on Public Health. Passage of the bill would authorize the creation and maintenance of the Hemophilia Advisory Committee. The Committee would, among other things:

1. Advise both the Commissioner of Public Health and the Commissioner of Insurance on a broad array of issues, including access to care, insurance coverage, standards of treatment, public education, and other matters that affect the interests of the MA bleeding and clotting disorders communities; and
2. Support the Common-

wealth in addressing the needs of a large number of people of all ages affected by bleeding and clotting disorders in Massachusetts.



Currently, the Hemophilia Advisory Committee is part of the Massachusetts General Laws (Chapter 111, Section 6a-c), but subsequent to the original law's passage in 1973, the legislation was not enacted for unknown reasons. If passed, the new bill would update the current law and allow the Committee to aid the Commonwealth in its efforts to support the bleeding and clotting disorders

communities in the best ways possible. A public hearing on the Hemophilia Advisory Committee bill is scheduled for **May 10 from 10 AM to 1 PM** at the Massachusetts State House. The date is subject to change. All Massachusetts residents, whether NEHA members or not, are welcome to testify at the hearing. Should you be unable to testify, please consider submitting written testimony in support of the bill. NEHA's Advocacy Coordinator can provide sample text for written testimony in support of the bill that anyone can use to aid them in preparing written testimony. In addition, to testify in-person or via a written statement, Massachusetts residents can support NEHA's efforts to have the Hemophilia Advisory Committee bill passed by contact-

ing their state senator and representative whose contact information can be found at [Find Your MA Elected Official](#). The Hemophilia Advisory Committee bill is currently before the Joint Committee on Public Health. To see a list of members, click [here](#). If one of your lawmakers is on the Committee, please contact them directly and ask them to vote favorably on the bill. In addition, on **May 25 from 9 AM to noon** the New England Hemophilia Association will host its Massachusetts Legislative Day at the Massachusetts State House in Boston. All NEHA members are invited to attend and it is a great way to meet your state legislators face-to-face and advise them of the issues facing the Massachusetts bleeding disorders community.



## New England State-by-State News

### Connecticut

#### **HUSKY Program to Shift out of Managed Care**

The Malloy administration has announced plans to [move the HUSKY and Charter Oak health programs out of managed care](#) and into a self-insured system managed by an Administrative Services Organization (ASO). Under this new structure, the state would pay all medical claims and the ASO would provide a range of administrative services. A request for proposals will likely be issued next month and the new system is expected to be in place in 2012. Proponents say this change could save costs, facilitate delivery system reforms, and better coordinate patient care.

### Maine

#### **Proposed Cuts to MaineCare**

The Governor's budget proposes a number of harmful cuts to MaineCare, the state's Medicaid/CHIP program. The Governor's proposal would reduce MaineCare eligibility for parents from 200% FPL to 133% FPL and apply new premiums equal to 4% of household income for all people with income over 150% FPL. The Governor also seeks to eliminate eligibility for MaineCare and other state programs for legal immigrants during their first five years of residency in Maine, place a lifetime cap on the length of time families can receive TANF assistance (5 years), and make harmful changes to eligibility rules for the General Assistance program. [Maine Equal](#)

[Justice Partners](#) testified against these cuts at a recent hearing. Click [here](#) for more information.

#### **Medical Loss Ratio Adjustment Approved**

Maine is the first state to be granted an [adjustment](#) to a rule under the Affordable Care Act that requires individual health insurance plans to spend at least 80% of premiums on medical care or quality improvements. Maine will be allowed to use a lower standard of 65 percent for the next three years. The Center for Consumer Information and Insurance Oversight approved Maine's [requested adjustment](#) because of their belief that an 80% medical loss ratio standard in Maine has a reasonable likelihood of destabilizing the Maine individual health insurance market.

### Massachusetts

#### **Massachusetts Ranked Number One for Children's Health**

The Commonwealth Fund's 2011 [State Scorecard on Child Health System Performance](#) ranked Massachusetts as the best state in the country for children's health (tied with Iowa). The Scorecard package – which includes interactive maps, charts, and more – examined 20 dimensions of care for kids, including health care access, affordability of care, prevention and treatment, the potential to lead healthy lives, and health system equity. The other five New England states all ranked in the top 10.

### The Governor's Budget

#### **Governor Patrick's FY 2012 budget**

holds spending for many state health care programs at FY 2011 levels and proposes steps to avoid more than \$1 billion in estimated new costs. Small budget cuts were made to the Healthy Start Program, the Children's Medical Security Plan, and School-based Health care programs. More substantive cuts include:

- ◆ An \$8 million cut to Early Intervention (EI) services. This is a 27% reduction from current FY2011 funding and includes alterations that could remove parents' rights to services (to view a statement from the Massachusetts Early Intervention Consortium, click [here](#)).
- ◆ \$6.6 million cut from group care services provided by the Department of Children and Families.
- ◆ A \$14 million cut to family respite services.

#### **Improvements to Student Health Plans**

The state recently released a [report](#) that documents the improvements made to student health plans. Improvements to the community college student plans are especially dramatic, and include:

- ◆ Eliminating the \$50,000 annual benefit maximum
- ◆ Eliminating the 6-month pre-existing condition limitation
- ◆ Eliminating the \$1,500 cap on all outpatient

services for each illness or injury

- ◆ Eliminating the \$150 cap on ambulance coverage
- ◆ Lowering co-payments for most office visits
- ◆ Improving access to preventive care and disease management

**New Hampshire Governor’s Budget**

Governor Lynch released his [FY 2012-13 budget](#), which makes hundreds of changes across state government. Some notable health-related budget items include:

- ◆ Shifting to a managed care system for Medicaid
- ◆ Imposing a moratorium on hospital expansions
- ◆ Eliminating payments to hospitals to subsidize the education of medical residents
- ◆ Merging the administration of the NH Healthy Kids Children’s Health Insurance Program into

the Medicaid program

- ◆ Limiting patients’ access to Children’s Hospital Boston



**Medical Loss Ratio Adjustment Requested**

The individual market MLR standards in the new health law require insurance companies to spend at least 80% of premium dollars on health care expenses, as opposed to administrative costs and profits. New Hampshire has requested to adjust the MLR standard to 70% until 2014, contending that a requirement for insurers in the individual market to meet the 80% MLR could destabilize the market and result in fewer consumer choices. The

public comment period regarding NH’s request will be open until Thursday, March 24th.

**Rhode Island**  
**The Nation’s Only Health Insurance Commissioner**

The [February issue of Governing Magazine](#) features an article about Rhode Island Health Insurance Commissioner Christopher Koller – the only person in the country to hold that title. [The article](#) speaks about how Commissioner Koller and the Rhode Island Office of the Health Insurance Commissioner have worked to tackle the issue of rising health care costs in their quest to improve the state’s health care system.

**Vermont**  
**Vermont Gov. Proposes Single-Payer Health Plan**

Governor Shumlin unveiled a bill ([H 202](#)) that would create a single payer health care system in the state. The bill enables the state to create

an exchange infrastructure and set up the Vermont Health Reform Board to help control health care costs. It does not address how the state will pay for the new system; a financing plan will be unveiled in 2013. Click [here](#) to read Ezra Klein’s recent interview with Governor Shumlin.

**Medical Professionals Protest Provider Tax Increases**

Over [200 medical professionals gathered at the Vermont Statehouse](#) this week to rally against a proposed tax hike on insurers, hospitals, and dentists. They argued that these tax increases could undermine the quality of health care in the state, resulting in longer waiting times, cuts in services, and difficulty attracting new physicians. The governor has proposed increasing the provider taxes from 5.5 percent to 6 percent of net revenues in his 2012 budget – which is estimated to bring in about \$30 million.



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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).