



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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Support the Hemophilia Advisory Committee Bill

In January 2009, state Senator Richard T. Moore, Chair of the Committee on Health Care Financing, together with 15 other state senators and representatives, introduce Senate Bill 567, the Hemophilia Advisory Committee bill. NEHA is hard at work on the passage of the bill. Support from the bleeding disorders community continues and there is still time to get involved and help pass the bill. This month NEHA's advocacy committee approved a proposed amended version of the bill provided by Sen. Moore's office. According to Sen. Moore's office, the final version of the bill, as amended, will shortly come up for a vote on the Senate floor. The expectation is that the bill will pass the Senate and move to the House. Supporters of the bill believe its passage will ensure that the voice of the bleeding disorders community will be heard on public decisions that stand to profoundly affect their

lives and the lives of their children and grandchildren. As importantly, it will revive a forum in which the perspectives and expertise of clinicians, patients, and insurers can combine to furnish the Department of Public Health and the



Division of Insurance with intelligent and rational advice.

The bill seeks to establish an 11 person hemophilia advisory committee to review administrative actions and the impact of legislation relative to the treatment and care of persons with hemophilia or other inherited bleeding and clotting disorders. The Hemophilia

Advisory Committee would make recommendations to the Commissioner of Public Health and the Commissioner of Insurance on legislation and the establishment of programs for public awareness, reporting and treatment of hemophilia and other inherited bleeding and clotting disorders. In addition, the legislation underscores the very similar needs of people who suffer from von Willebrand disease.

The Hemophilia Advisory Committee will bring together all types of expertise to forge policies affecting hemophilia care. Both the Commissioner of Public Health and the Commissioner of Insurance would be non-voting members of the Committee. The remaining Committee members would be appointed by the Governor. These members would include a registered nurse treating indi-

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Get Out and Vote!

The American president John Quincy Adams once said, "Always vote for principle, though you may vote alone, and you may cherish the sweetest reflection that your vote is never lost."

So get out and vote but before you do learn about the principles of the candidates in your state. Visit vote411.org and build "your ballot" with their online voters' guide. The site is easy to use. Just type in your



address to see the races on your ballot. Candidates' positions can be compared side-by-side. You can print a "ballot" indicating your preferences as a reminder and take it with you to the polls on Election Day.

Want to know more about the electoral process in your state? Visit the "Voting in Your State" section of vote411.org

to find out about the electoral process in your state.

For example, you will find the voter registration deadline, ID requirements for voting, and the types of voting machines used by your state. In addition you can register to vote online, find polling places, and use links to many state voting resources. The vote411.org site is sponsored by the League of Women Voters® Education Fund.



Vermont State House,
Montpelier, Vermont

Get Involved!

Connecticut

The CT legislature has adjourned until January 2011 but you can join the CT task force on the Bleeding Disorders bill. Contact [Wendy Owens](#) to learn how you can get involved and help support this important piece of legislation in Connecticut.

Maine

The ME legislature has adjourned until January 2011. Until then you can learn more about how to make healthcare in ME affordable from [Consumers for Affordable Healthcare](#).

Massachusetts

Support the *Hemophilia Advisory Committee* bill (SB567). See the article on page 1 for more information on how you can get involved and make a difference for the Massachusetts bleeding disorders community.

In 2010, at the request of NEHA, Rep. Anne Gobi introduced a *Standards of Care* bill in the MA legislature. Following a public hearing in March 2010, the bill was

referred to the committee on Joint Committee on Health Care Financing where it went into study, blocked by one of the committee's co-chairs from passage due to fiscal concerns.

The *Standards of Care* bill will be re-introduced at the beginning of the 2011 session. Contact [Wendy Owens](#) to learn how you can get involved and help support this important piece of legislation in MA.

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.

New Hampshire

New Hampshire residents can find information on voting in their state as well as general election information at www.sos.nh.gov. The NH legislature has adjourned until January 2011 when newly elected officials will begin their duties.

Rhode Island

Voters in Rhode Island can learn more about the election process, view sample ballots, and learn about the candidates at <https://sos.ri.gov/vic>.

The Rhode Island legislature has adjourned until January 2011.

Vermont

The Vermont Chronic Care Initiative (VCCI) was honored by the Care Continuum Alliance (CCA) as the winner of the "Outstanding Government Program" award at the organization's annual meeting in Washington D.C. To learn more about the CCA, visit www.carecontinuum.org.

Vermont voters can now "vote-by-phone" on election day. This is a particularly good option for people who have trouble filling out paper forms. To learn more, visit <http://www.vermont.gov/portal/government/article.php?news=2101>

The VT legislature has adjourned until January 2011.

"Everyone's support is needed to pass this bill."

Support the Hemophilia Advisory Committee Bill in MA

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viduals with bleeding and clotting disorders, a social worker treating individuals with bleeding or clotting disorders, a representative of a commonwealth-based, federally funded hemophilia treatment center, a representative of a commonwealth provider of health insurance, a representative of a voluntary health organization that services persons with hemophilia or

other bleeding and clotting disorders, a person with hemophilia or a caregiver thereof, a person with a bleeding disorder other than hemophilia or a caregiver thereof, a person with a clotting disorder or a caregiver, and a board certified physician treating persons with bleeding and clotting disorders.

Because the bill is considered "non-controversial" it can be passed during the informal ses-

sion of the MA legislature. Everyone's support is needed to pass this bill. NEHA will send "Calls to Action" to its members and others in the Massachusetts bleeding disorders community via email.

Those who receive the Call to Action should send it to friends and relatives in Massachusetts so that legislators hear from as many people as possible encouraging passage of this bill.

NH Insurance Dept. Acts to Preserve Child-Only Policies



At the same time that many health carriers have announced the discontinuation of their child-only policies, the New Hampshire Insurance Department is notifying insurers that offer indi-

vidual policies that they must continue to offer child-only poli-

New Hampshire State House

cies. The Department recently issued a bulletin informing insurers that New Hampshire state insurance law and the Affordable Care Act taken together require that individual market plans be made available to children under 19, including those with a pre-existing condition.

The Affordable Care Act makes it illegal for insurance companies to deny coverage to children with pre-existing conditions and makes discrimination against all individuals with pre-existing conditions illegal in 2014—a trend that was rising at exceedingly high rates in recent years.

In fact, a recent report from the House Energy and Commerce Committee found that more than 651,000 people were denied coverage because of a pre-existing medical condition between 2007 and 2009.

House Passes Improving Access to Clinical Trials Act

In a victory for rare disease patients and families, the U.S. House of Representatives on Sept. 23 passed the Improving Access to Clinical Trials Act (I-ACT), a bipartisan piece of legislation championed by over 120 other health advocacy organizations. The legislation, which had been passed a few weeks earlier by the Senate, now goes to the White House where President Obama is expected to sign it.

The legislation enables patients with rare diseases to participate in clinical trials without losing eligibility for public healthcare benefits. Specifically, it changes the eligibility requirements for Social Security Supplemental

Income (SSI) and Medicaid so that compensation of up to \$2,000 for participating in clinical trials will not be considered income in SSI and Medicaid determinations. The legislation was introduced by Senator Ron Wy-



den, D-Ore., with Senators Chris Dodd, D-Conn., James Inhofe, R-Okla., Richard Shelby, R-Ala., Dick Durbin, D-Ill. as original co-sponsors and an additional 14 co-sponsors also signed on.

Current law prevents many people who receive Supplemental Security Income (SSI) from accepting research compensation because it makes them ineligible to receive government medical benefits. This penalty has stopped significant numbers of people with rare diseases from participating in clinical studies.

Passage of this legislation is particularly important for people with bleeding disorders. A limited patient population makes it challenging to find enough people to participate in research studies evaluating the effectiveness of promising new drugs.

“Passage of this legislation is particularly important for people with bleeding disorders.”

“Genetic information helps you know and understand health conditions that run in your family, as well as your risk for developing certain health conditions or having a child with certain conditions.”

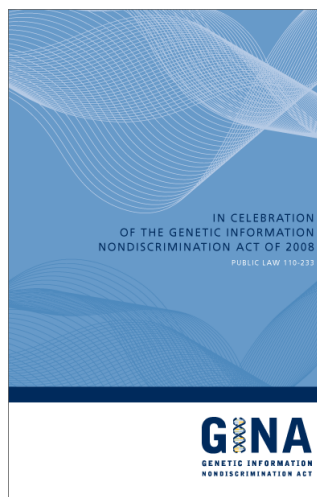
411 on Genetic Information Non-discrimination Act

For those participating in or considering participation in genetic research, the Genetic Information Nondiscrimination Act (GINA) of 2008 is a must understand. Also referred to as GINA, this Federal law prohibits discrimination in health coverage and employment based on genetic information. The genetic information protected by the law includes family health history, the results of genetic tests, the use of genetic counseling and other genetic services, and participation in genetic research.

Genetic information helps you know and understand health conditions that run in your family, as well as your risk for developing certain health conditions or having a child with certain conditions. This information can help you make healthy lifestyle choices and important life and medical decisions. It also helps your doctor in providing you the best care possible. With GINA’s protections, you can feel more comfortable talking about family health history with your family and healthcare providers. You may choose to use genetic testing and other services to learn about health risks without fear of genetic discrimination.

GINA makes it against the law for health insurers to request, require, or use genetic information to make

decisions about: 1) your eligibility for health insurance and 2) your health insurance premium, contribution amounts, or coverage terms. This means it is against the law for your health insurer to use a genetic test result or family health history as a reason to deny you health insurance, or decide how much you pay for your health insurance. In addition,



GINA makes it against the law for your health insurer to: 1) consider family history or a genetic test result a pre-existing condition; 2) ask or require that you have a genetic test; and 3) use any genetic information they do have to discriminate against you, even if they did not mean to collect it.

GINA was signed into law on May 21, 2008 by President George W. Bush. It is now in effect. The Department of Labor, the Depart-

ment of the Treasury, and the Department of Health and Human Services all have specific responsibilities in enforcing the health insurance protections of GINA. The Equal Employment Opportunity Commission (EEOC) is responsible for enforcing the employment protections of GINA. Remedies for individuals who feel they have been discriminated against in either health insurance or employment include corrective action and monetary penalties. Under Title II of GINA, individuals may also have the right to pursue private litigation.

GINA provides a “floor” or minimum level of protection against genetic discrimination. If a state has a law against discrimination that is stronger than GINA, the state law applies. For example, some states don’t allow health insurers to make decisions about whether or not a person qualifies for health insurance or how much they should pay for health insurance based upon current health status. Check with your state health insurance commissioner to learn about your state’s protections against health insurance discrimination.

GINA requires that state health insurance regulations match GINA’s protections

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as of May 21, 2009. If states do not offer GINA's level of protections, the federal government can step in and enforce GINA. GINA protects you from genetic discrimination in employment and health insurance regardless of when you had a genetic test done, when you received the results, or when you used genetic counseling or other genetic services. However, GINA is not retroactive. This means that GINA does not apply to acts of discrimination that occurred before GINA went into effect. GINA's protections apply to most health insurers. GINA applies to the health insur-

ance plan you receive through your employer (a group plan) as well as health insurance you purchase on your own (an individual plan) for you and your family. GINA also applies to Medicare supplemental policies for individuals who have insurance through Medicare. The health insurance protections of GINA do not apply to members of the US military who receive their care through the Tricare military health system, the Indian Health Service, and federal employees who get care through the Federal Employees Health Benefits Plans. These groups have policies in place that provide protec-

tions similar to GINA. GINA makes it against the law for employers to use your genetic information in the following ways:

- ◆ To make decisions about hiring, firing, promotion, pay, privileges or terms
- ◆ To limit, segregate, classify, or otherwise mistreat an employee.

This means it is against the law for your employer to use family health history and genetic test results in making decisions about your employment. It is also against the law for an employer to request, require, or purchase the genetic information of a

potential or current employee, or his or her family members. There are a few exceptions to when an employer can legally have your genetic information. If an employer does have the genetic information of an employee, the employer must keep it confidential and in a separate medical file.

For more information on GINA, please visit GINAhelp.org.

This resource provides an introduction to GINA and its protections in health insurance and employment. It includes answers to common questions about GINA and examples to help you learn. .



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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.