



Join NEHA's Rapid Response Network

- ◆ Make your voice heard, join NEHA's *Rapid Response Network*.
- ◆ To become a member of the Rapid Response Network, email [Wendy Owens](mailto:Wendy.Owens@newenglandhemophilia.org), NEHA's Advocacy Coordinator

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NEHA Launches the *Rapid Response Network*

The New England Hemophilia Association (NEHA) launched its *Rapid Response Network* of volunteers to participate in its advocacy activities in Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island and Vermont.

Political decisions play a major role in the treatment of bleeding disorders. We have the power to impact these decisions, but it takes *action*. Policy makers need to hear from us; we can have a significant impact on the legislative process by making our elected officials aware of our community's needs.

You 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. NEHA has formed the *Rapid Response Network* so that it has

volunteers ready and willing to call or visit legislators' offices, write letters or emails in support of (or opposition to) a particular bill or issue, and provide testimony at hearings. We need you to join the *Rapid Response Network*.



New Hampshire, Vermont, Maine, Massachusetts, Connecticut, Rhode Island State Houses

To help our *Rapid Response Network* volunteers feel confident, knowledgeable, and *ready*, NEHA will provide regular advocacy training sessions at special events and at a location near you. These training sessions will give our volunteers (1) the basics of advocating for public policy initiatives that aid the bleeding disorders community and (2) the resources to

help you get involved in NEHA's advocacy activities in whatever way you can. NEHA will also create online resources and tools for volunteers to access whenever they need them.

To keep the community informed of advocacy issues in each of the New England states and at the federal level, NEHA will send out a bi-monthly email newsletter, *Advocacy in Action*, and post this information online. Should immediate action be needed, NEHA will send out "Call to Action" alerts asking for the support of volunteers. These alerts will also appear online.

All *Rapid Response Network* communications will be sent via email. If you would like to become a member of the *Rapid Response Network*, please contact Wendy Owens, NEHA Advocacy Coordinator, wowens@newenglandhemophilia.org.

NEHA Legislative Days

NEHA held its third annual Massachusetts Legislative Day at the State House on May 12. The event was a success with NEHA members, Massachusetts legislators, and legislative staff in attendance. NEHA held an advocacy training session for NEHA members prior to the briefing portion of the event. Members learned what a lobbyist is, received tips on educating their elected officials,

and were briefed on the bleeding disorder bills before the Massachusetts legislature. During the briefing, NEHA members acquainted legislators and their staff with bleeding disorders and made them aware of the community's needs and interests. In addition, members advocated support for the two bleeding disorder bills before the MA legislature ([HB 4590](#) and [SB 567](#)). Representative

Anne Gobi, sponsor of HB 4590, spoke at the event in support of her bill and the community. NEHA is recognized at the New England state capitols as a major voice of progress and change for the region's bleeding disorders community. Join us in the fall of 2010 for Connecticut Legislative Day. Look for details in the next bi-monthly issue of *Advocacy in Action*.

Get Involved!



NEHA members at the Capitol Building in Washington, DC, in February 2010

“Much of lobbying is listening, looking for indications of the elected official's views, and finding opportunities to provide good information.”

- Common Cause, 1989

Federal

On March 15, Congresswoman Carolyn McCarthy (D-NY) introduced H.R. 4846, the *Bleeding Disorder Screening, Awareness, and Further Education (SAFE) Act* of 2010. This legislation will improve the quality of life for Americans with bleeding disorders by promoting screening of adolescents and young adults, raising awareness among health professionals, and by augmenting and expanding research. To get involved, click [here](#).

Connecticut

Join NEHA members and others on the Connecticut task force of the Standards of Care for Bleeding Disorders bill. Contact [Wendy Owens](#) to learn how you can get involved and help support this important piece of legislation in Connecticut.

Maine

Learn more about how to make healthcare in Maine affordable from the non-profit [Consumers for Affordable Healthcare](#).

Massachusetts

Contact your legislators and urge them to support [House Bill 4590](#) (An Act Relative to Coverage and Standards of Treatment of Persons with Bleeding Disorders) and [Senate Bill 567](#) (An Act Relative to the Hemophilia Advisory Committee).

Vermont

Just passed: a [healthcare bill](#) that includes designing new healthcare models for the state and expanding the Blueprint for Health program.

6 Tips on Lobbying Your Elected Official

Speaking to your elected officials should be a positive experience. Follow these 6 steps for a good meeting:

Step 1: Establish your agenda and goals. Know what subject you are going to address. Don't overload with issues -- stick to no more than 2 or 3. Decide what you would like to get out of the visit, i.e., a commitment to vote for your issue, leadership on the issue, or you may decide the visit is simply informational. Allow time for small talk at the outset, but not too much. Remember, it's your visit. If it is a group visit, decide who will start the discussion and put your agenda on the table.

Step 2: Listen well. Much of lobbying is listening, looking for indications of the elected official's views, and finding opportunities to provide good information. If you are meeting with a silent type, draw her/him out by asking questions. If you are confronted with a long-winded type, look for open-

ings to bring her/him back to the point.

Step 3: Be prepared, but don't feel that you need to be an expert. Most elected officials are generalists, like many of us. Do your homework, but don't feel that you need to know every little detail of an issue. Air personal feelings and experiences where appropriate. Relate the concerns of your friends and members of the community. Know when to admit "I don't know," and offer to follow up with the information. Be open to counter-arguments, but don't get stuck on them. Don't be argumentative or confrontational.

Step 4: Don't stay too long. Try to get closure on your issue. If you hear what you had hoped for, express your thanks and leave. If you reach an impasse, thank her/him, even if disappointed, and say so. Leave room to continue the discussion another time.

Step 5: Remember you are there to build a relationship. If the elected official is in favor of an issue you've been involved in or has supported your position in the past, be sure to acknowledge your appreciation during the course of the visit. If the opposite is true, think of the phrase, "No permanent friends, no permanent enemies." Someday, on some issue of importance to you, s/he may come through. In the meantime, your visit may prevent the official from being an active opponent. In other words, you may help to turn down the heat on the other side.

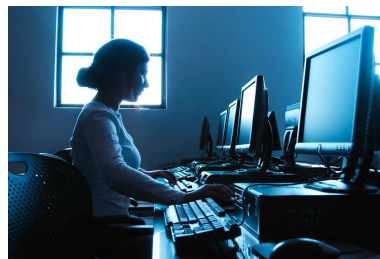
Step 6: Follow-up is important. Be sure to send a thank-you note after the visit. If commitments were made in the meeting, repeat your understanding of them. If staff members were present, write to them too. They can often be important allies.

- Common Cause 1989

Sign-up to Receive Your Copy of *Advocacy in Action*!

NEHA will send out to the *Advocacy in Action* newsletter on a bi-monthly basis to NEHA members and members of the bleeding disorders community who wish to receive it.

If you would like to receive this newsletter, please email Wendy Owens at wowens@newenglandhemophilia.org. The newsletter will only be available in electronic format. Should you have any questions, please do not hesitate to contact the NEHA office. Thank you for your interest.



Stay up-to-date on what is going on with advocacy that effects you and your family, sign-up to receive NEHA's *Advocacy in Action* newsletter.



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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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