

LYMPHOMA

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MAKING MY VOICE
HEARD

Guide to Advocacy



Becoming an LRF Advocate

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The Lymphoma Research Foundation's (LRF) mission is to eradicate lymphoma and serve those touched by this disease. One of the ways LRF seeks to fulfill this mission is by supporting public policies that increase federal funding for lymphoma research and ensure access to high quality cancer care for every patient. The LRF Advocacy Program provides volunteers with the tools necessary to garner attention and support for those public policies most important to the lymphoma community.

You can make your voice heard by becoming an LRF advocate today – it is easy. Simply register at www.lymphoma.org/advocacy or sign up during a local LRF event. Once registered, you will begin to receive regular advocacy updates from the Foundation. These Advocacy Alerts enable you to make a meaningful difference in just minutes. You have the ability to influence lawmakers and make others in your community aware of the impact lymphoma has in your state and around the country.

"After I was diagnosed with non-Hodgkin lymphoma in 2005, I recognized that supporting lymphoma research was the most important thing I could do. That's why I joined the LRF Advocacy Program."

–Sandy Haddad, Minneapolis, MN



Communicating with Lawmakers

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Communicating directly with your elected representatives is the best way to keep them informed about the issues that are important to you. As an LRF advocate, you will have the opportunity to communicate with your elected officials in support of policies and legislation that will impact the lives of people affected by lymphoma.

LRF Advocacy Alerts

Many people think that they must travel to Washington, DC to make their voices heard, but in reality, lawmakers are more concerned about what you are saying than where you are saying it. That is why LRF Advocacy Alerts make it simple for you to send an email message to the people who set policy and make laws – all from the comfort of your home or office.

When you receive an Advocacy Alert, LRF will describe a policy issue and the way in which it affects people with lymphoma. This email alert will prompt you to visit the LRF website for additional information, and provide you with a standard email message that you can personalize and send to your representatives in Congress. Participating in an LRF Advocacy Alert takes just minutes, but is a critically important part of the Foundation's efforts to ensure that the needs of the lymphoma community are addressed by federal lawmakers.

Meeting with Lawmakers

If you wish to take your message directly to your members of Congress, LRF also arranges face-to-face meetings with federal lawmakers for interested advocates. Through the LRF chapter network, meetings are arranged with legislators and their staff in their offices near your home.

These legislative visits are led by your local LRF chapter's designated Advocacy Chair and are an effective way to educate members of Congress on high-priority policy issues. LRF provides advocates with a specialized training session before each legislative visit via teleconference. If you wish to participate in a legislative visit or to learn more about meeting with your local lawmakers, please contact your local chapter's Advocacy Chair or LRF staff at advocacy@lymphoma.org.



Advocacy at the Local Level

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“Our legislative visits have been extremely worthwhile. The legislators have been impressed with our grassroots efforts to raise funds for research through our Lymphomathons and with the Foundation’s educational programming. They are interested in our experiences as survivors and advocates. We look forward to future meetings and renewing these contacts.”

–Paul Majkowski, New York, NY

Becoming an LRF advocate will help you to educate not only lawmakers about lymphoma, but other members of your community as well. By engaging people outside of your network, your message will be noticed by elected officials, community members and other people whose lives have been affected by a lymphoma diagnosis. All of these people can help prioritize policies that are important to LRF advocates and people with lymphoma.

Attending a Town Hall Meeting

When members of Congress return to their home states, they often hold town hall-style meetings. These public forums provide an opportunity for legislators to share an update on the work they are doing in Washington and for constituents to share issues of concern. These meetings also offer the chance to discuss important lymphoma-specific policy initiatives, and to show legislators that they have constituents who care about these issues. Even if only one person representing the lymphoma community gets the opportunity to speak or ask a question, it will make an impact: the lawmaker and his or her staff will respond to the question and everyone else in the room will have the opportunity to learn more about lymphoma.

LRF organizes opportunities for groups of local advocates to attend these public meetings. To learn more about upcoming town hall meetings in your area, visit lymphoma.org/advocacy for additional information and to sign-up for updates.



Advocating Through the Media

Using the media for advocacy outreach allows you to educate your community on issues of importance to LRF and its supporters. Many people in your community may be unaware of the policy issues important to people with lymphoma. A letter to the editor (LTE) in your local daily newspaper is a great way to bring these issues to other people's attention.

An effective LTE is written in response to a recent article in your local paper. While your local newspaper may not publish many lymphoma-specific stories, issues like the federal budget and health care system are regularly covered. In responding to an article on either of these topics, advocates can use template LTEs that are provided on the LRF website or use language taken from an LRF Advocacy Alert to write a persuasive LTE.

To identify the way(s) in which you can submit a LTE to your local newspaper, look for tips in the Opinion section of the newspaper or on the publication's website, or contact LRF at advocacy@lymphoma.org.



National Leadership Opportunities

For advocates who wish to dedicate more of their time and talents to advance the Foundation's public policy and advocacy goals, a variety of leadership opportunities exist. There are numerous ways in which you can either lead LRF advocacy efforts on the local level, or represent the lymphoma community on the national stage.

Local Leadership Opportunities

LRF Advocacy Chairs are volunteers with an interest in advocacy who are responsible for overseeing the implementation of advocacy-related activities for LRF chapters and their members. This leadership position is critical to the success of the chapter's advocacy efforts at the local level. Advocacy Chairs receive one-on-one training and assistance from LRF staff. In addition, Advocacy Chairs are encouraged to form an advocacy committee comprised of local advocates to help them organize specific advocacy activities. If you would like to learn more about the role and responsibilities of local Advocacy Chairs or advocacy committee members, contact LRF staff at advocacy@lymphoma.org.

National Leadership Opportunities

On a regular basis, LRF is notified of a variety of opportunities for advocates to represent the lymphoma community before federal and state agencies, committees, and commissions. These volunteer advocate positions usually do not require a specific skill set beyond the desire and commitment to express your opinions and experiences as a patient, survivor or caregiver. Nomination and election to these unique advocate positions help to raise awareness about lymphoma and ensure that the voice of the lymphoma committee is being heard by people at the highest levels of government. Since these opportunities often require that an organization like LRF nominate individuals for these roles, advocates are encouraged to contact LRF staff or their local Advocacy Chair to express interest in learning more.

"By serving as a Patient Representative within the Food and Drug Administration, I get the opportunity to represent the lymphoma community at the highest level, and draw upon my experience as a lymphoma survivor and a healthcare professional."

—James Fratzke, Portland, OR



LRF Advocacy Alerts

“Sending an email to my Congressman takes me five minutes, and it lets them know that lymphoma research is important to me.”

–Elizabeth Naylor, Boston, MA

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