

2012 Public Policy Agenda

The Lymphoma Research Foundation (LRF) is the nation's largest non-profit organization devoted to funding innovative research and providing people with lymphoma and healthcare professionals with up-to-date information about this type of cancer. The LRF mission is to eradicate lymphoma and serve those touched by this disease.

LRF is committed to advocating on behalf of the entire lymphoma community in support of this mission, working collaboratively with policymakers, the medical community, patient advocates and other stakeholders at the state and federal levels to advance legislative, regulatory and programmatic efforts that will improve the lives of lymphoma patients and survivors. The Foundation and its network of more than 5,000 grassroots advocates support policy measures which will increase federal funding for lymphoma research and education and ensure access to high quality lymphoma care for every patient. As an extension of these efforts, LRF seeks the integration of the lymphoma community's perspective throughout the policymaking process and urges that lymphoma patients, survivors and their loved ones be appointed to relevant federal panels, committees and commissions. Below is a summary of LRF's public policy goals and priorities for 2012.

Federal Investment in Lymphoma Research and Education

Greater federal support for biomedical research at the National Institutes of Health (NIH), including growth in funding for the National Cancer Institute (NCI), is necessary to provide investigators with the resources they require to accelerate the progress of research that will ultimately lead to new and innovative treatments for lymphoma and other cancer types. In addition to increasing the amount of federal monies dedicated to lymphoma research through NIH and NCI, supporting new opportunities for investment in lymphoma research is vital. The federal government is also in a position to support the creation and distribution of education and support materials related to lymphoma, the most common form of blood cancer. Supporting the development of more effective education methods and tools for patients, scientists, healthcare professionals, and other care providers are essential to reducing cancer incidence and mortality and improving the quality of life for cancer survivors. Toward the objective of strengthening federal commitment to lymphoma research and education, LRF calls upon Congress to:

- Provide increased funding for NIH in FY 2013 (increasing the NCI budget commensurate with increases in the overall NIH budget) to improve the nation's health, advance the U.S. medical research enterprise, and support groundbreaking advances in the treatment of cancer and other life-threatening illnesses.
- Support increased investment and support for the development of new therapies for rare diseases.
- Expand blood cancer research opportunities within the Department of Defense, specifically within the Peer Reviewed Cancer Research Program.
- Support federal investment in a national blood cancer education program.

Access to Quality and Comprehensive Lymphoma Treatment and Survivorship Care

Since numerous factors influence a patient's access to healthcare, LRF supports public policies which ensure equal access to cancer treatment for people with lymphoma and the development of tools to assist physicians and investigators improve the quality of cancer care in the United States. Toward this end, the Foundation recommends that:

- Every lymphoma patient and survivor receives adequate information about their disease, possible interventions and the known benefits and risks of specific treatment options.
- Congress dedicates federal funding for comprehensive, medically-accurate cancer survivor education, including funding for survivorship health services research.
- Congress, the President and his administration work to ensure that all individuals, including lymphoma patients and survivors, have affordable access to qualified physicians and medical staff, quality healthcare facilities, cancer treatment and prescription medications.
- Congress ensures that cancer patients have equality of access (and equality of insurance coverage) to all approved anticancer regimens including, but not limited to oral and intravenous drugs, injections, surgery, radiation and transplantation.

- Congress and the Food and Drug Administration (FDA) identify solutions for the current drug shortage problems facing U.S. cancer patients.
- The federal government and its relevant agencies support access for cancer patients to clinical research studies and that NIH, NCI and FDA increase lymphoma patient access to clinical trials by implementing policies which support trials for rare diseases.