



2010 Public Policy Agenda

The Lymphoma Research Foundation (LRF) is the nation's largest voluntary health organization devoted exclusively to funding lymphoma research and providing patients and health care professionals with critical information on the disease. LRF's mission is to eradicate lymphoma and serve those touched by this disease; the organization's national public policy and advocacy priorities reflect these objectives. Specifically, LRF supports policy measures that will increase federal funding for lymphoma research and education and ensure access to high quality lymphoma care.

LRF is committed to advocating on behalf of the entire lymphoma community, 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. As part 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, commissions and boards.

Below is a summary of LRF policy goals and priorities for 2010.

Federal Investment in Lymphoma Research and Education

Greater federal support for biomedical research at the National Institutes of Health (NIH), including significant 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, health care 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 the federal commitment to lymphoma research and education, LRF calls upon Congress to:

- Continue the momentum for medical progress by providing increased funding to NIH in FY 2011 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.
- Increase the NCI budget commensurate with increases in the overall NIH budget, providing special investment for especially innovative and groundbreaking research.
- Expand blood cancer research opportunities within the Department of Defense Congressionally Directed Medical Research Programs and Peer-Reviewed Cancer Research Program.

- Increase federal support for the Geraldine Ferraro Blood Cancer Education Program, currently located at the Centers for Disease Control and Prevention (CDC).
- Encourage and support comparative effectiveness research (CER) with respect to lymphoma, including randomized trials as well as registry development and analysis, while ensuring that the expertise of research agencies such as NIH, CDC and the Food and Drug Administration (FDA) is fully utilized in the development of a federal CER program.

Access to Quality and Comprehensive Lymphoma Treatment and Survivorship Care

Lymphoma patients across the United States do not have equal access to quality cancer care. Because numerous factors influence access to cancer care, LRF supports public policies which ensure equal access to treatment for lymphoma patients and survivors and the development tools to help physicians and researchers improve the quality of cancer care in America.

To address barriers to access to quality cancer care, LRF recommends that:

- Every lymphoma patient should receive adequate information about their disease, possible interventions and the known benefits and risks of specific treatment options.
- Congress, the President and his administration work ensure that all individuals, including lymphoma patients and survivors, have affordable access to qualified physicians and medical staff, quality health care facilities, cancer treatment and prescription medications.
- Relevant federal agencies such as NIC, NCI, CDC and the Agency for Healthcare Research and Quality (AHRQ) develop and support patient-centered programs, including but not limited to patient navigation and education programs, to assist individuals with lymphoma access comprehensive cancer treatment.
- Congress establish Medicare payment for the development of cancer care plans for beneficiaries and the communication of the plan to patients, including the development of treatment summaries that would also outline follow-up care for survivors.
- The federal government and its relevant agencies support access for cancer patients to investigational therapies offered in clinical research studies and that NIH and NCI increase lymphoma patient access to clinical trials by implementing policies which support trials for rare diseases.
- Congress create a dedicated funding stream for comprehensive, medically-accurate cancer survivor education, including funding for survivorship health services research.