

## *2016 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. LRF recognizes that public policy change, through both the legislative and regulatory process, is critical to achieving its mission, 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 to advance those efforts that will improve the lives of people with lymphoma. The Foundation and its network of more than 5,000 grassroots advocates across the United States support policy measures which will increase federal funding for lymphoma research and education and ensure patient access to high quality cancer care. 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.

The LRF 2016 Public Policy Agenda is approved by the Board of Directors, highlights the Foundation's top legislative and regulatory priorities and guides the activities of the LRF Advocacy Program. For additional information, visit [lymphoma.org/advocacy](http://lymphoma.org/advocacy).

LRF supports the following policy initiatives, which would increase federal investment in lymphoma research:

- Increased funding for the National Institutes of Health (NIH) in FY 2017 and an increase in the National Cancer Institute budget commensurate with increases in the overall NIH budget.
- Greater support for the nation's clinical trials enterprise and improvements to infrastructure, including efficiencies to the trial development process, maximization of secure data sharing and focus on patient-centered outcomes.
- Increased support for research and infrastructure for the development of new therapies for rare diseases.
- Enhanced support for young investigators whose innovative research has the potential to make noteworthy advancements in cancer research.
- Expansion of blood cancer research opportunities within the Department of Defense, specifically within the Peer Reviewed Cancer Research Program.

LRF endorses legislation and regulations which seek to increase access to comprehensive lymphoma treatment and cancer survivorship care, including:

- 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.
- Federal policies and regulations which monitor and protect against potential discriminatory benefit designs in the implementation of the Affordable Care Act., including establishment of a system in which violations can be easily reported by consumers if needed.
- Legislation and regulations which outline a responsible process for moving the Medicare program away from a system that emphasizes volume of service to one that focuses on quality of care.
- Legislation and regulations which ensures 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.
- Legislation which provides education and provider reimbursement for cancer care planning and which would facilitates care planning services for all lymphoma patients.
- Implementation of policies which support the development of new therapies and clinical trials for rare diseases and policies which assist and encourage patient participation.
- Legislation and policies which ensure that the Prescription Drug User Fee Act (PDUFA) VI includes: 1) a process for incorporating the patient reported outcomes in the regulatory process; 2) a process for quantifying benefit-risk and incorporating that data into the drug development process; and 3) increase regulatory clarity on issues of diagnostics and laboratory developed tests (LDTs).
- Legislation which seeks to create new systems of care and research funding streams to benefit adolescents and young adults diagnosed with cancer.