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June 19, 2015

The Honorable Orrin Hatch  
Chairman  
Committee on Finance  
United States Senate  
Washington, DC 20510

The Honorable Ron Wyden  
Ranking Member  
Committee on Finance  
United States Senate  
Washington, DC 20510

The Honorable Johnny Isakson  
Committee on Finance  
United States Senate  
Washington, DC 20510

The Honorable Mark R. Warner  
Committee on Finance  
United States Senate  
Washington, DC 20510

Dear Chairman Hatch, Ranking Member Wyden, Senator Isakson, and Senator Warner:

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

We applaud the efforts of the Committee on Finance to improve the delivery of care to those with chronic diseases, an effort that is in the best interest of those with chronic conditions and that will contribute to the long-term sustainability of the Medicare program. For this generation and those to come, this effort is of the utmost importance.

We recommend the establishment of a Medicare cancer care planning service, which would provide beneficiaries with cancer access to care planning and coordination across the continuum of care. Such a service is a critical element of any health system that strives to accomplish the delivery of personalized, or precision, therapies. Because treatment for lymphoma is increasingly targeted according to the individual patient's profile, care planning is a core element of quality care delivery for them. We describe in some detail below how lymphoma care might be improved through planning and coordination, as well as how Medicare resources might be more effectively used through care planning and coordination.

## **The Status of Lymphoma Research and Care**

Patients with lymphoma are significant beneficiaries of advances in the basic understanding of cancer and the development of promising new approaches to cancer treatment. Decades ago, lymphoma was typically categorized as Hodgkin lymphoma and non-Hodgkin lymphoma, and treatments were tailored to these diseases. Now, we know that there are six types of Hodgkin lymphoma and 61 types of non-Hodgkin lymphoma.

Knowledge of the subtypes of lymphoma has informed research and development of new therapies and has also guided the delivery of care according to the individual's specific disease profile. The lymphoma subtypes include diseases that are considered indolent and others that are aggressive in presentation.

Treatment options may include radiation, chemotherapy, or biologic therapy, or combinations of these approaches, or stem cell or bone marrow transplantation. For certain patients with indolent forms of lymphoma, a decision to "wait and watch" could be a viable part of the treatment equation.

Decisions regarding treatment options are based on the individual patient's lymphoma subtype, and many lymphoma treatments clearly meet the definition of a "targeted therapy." In fact, lymphoma is at the forefront of precision medicine. We expect that immunotherapies, which harness the patient's immune system in a treatment response, will in the future be an important lymphoma treatment option. Immunotherapies may be accompanied by side effects that are different from those that accompany traditional chemotherapy. As a result, these treatments require significant discussion for review of risks and benefits.

In summary, planning and coordination of lymphoma care will help to ensure that patients receive adequate information to assess treatment options and choose the treatment that is right for them, benefit from coordination of all of the elements of active treatment and symptom management, and receive information and training to manage the side effects of therapies. Planning of care also eases the transition to long-term survivorship during which lymphoma patients may experience serious late effects, including second cancers.

### **Implications of the Lymphoma Treatment Revolution for Medicare**

The challenge of delivering the right treatment to the right lymphoma patient at the right time is great, and LRF has tailored its educational materials, meetings, direct patient services, and outreach to educate patients about their own disease subtype and the treatment options that might be appropriate for them. This educational and decision-making process must also address the order in which a patient might undergo specific treatments, the possible side effects of therapies and how to manage them.

Many lymphoma subtypes are chronic diseases, with patients undergoing treatment over a long period of time, survivors managing the late and long-term effects of cancer and cancer treatment, and some dealing with recurrences and second cancers. The success of lymphoma treatment has resulted in a large population of patients who are addressing concerns related to treatment sequencing and managing long-term side effects of treatment.

Because lymphoma treatment is often multi-modality treatment, it creates serious obstacles to coordination of care among specialists and across health systems. There is also the need to balance active treatment and symptom management.

The success or failure in delivering the right treatment to the right patient at the right time has substantial implications for the Medicare program. Inappropriate treatment choices have financial ramifications for Medicare, as they do for the patients who suffer them. In addition, poor coordination of care can affect the utilization of cancer care resources and increase the overall cost of care.

It is clear that efforts must be directed to improving the education of patients about treatment choices and treatment management, enhancing the coordination of active treatment and symptom management, and easing the transition from active treatment to monitoring and management of long-term and late effects of cancer and cancer treatment.

### **Recommendation for Improving Care for Lymphoma Patients**

The 1999 Institute of Medicine (IOM) report, "Ensuring Quality Cancer Care," identified access to an agreed-upon care plan as a key marker of cancer care quality.<sup>1</sup> The 1999 report recommended that cancer patients be provided a plan that outlines the goals of care, access to the full complement of resources necessary to implement the care plan,

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<sup>1</sup> Institute of Medicine, Ensuring Quality Cancer Care, 1999. See recommendation 4.

availability of information about treatment options, a mechanism or system to coordinate health care services, and access to psychosocial services.

In subsequent IOM reports (the products of the National Cancer Policy Board and its successor National Cancer Policy Forum), progress toward this quality standard has been monitored. In the most recent report on the cancer care system, the 2013 “Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis,” IOM noted limited progress toward well-planned and well-coordinated cancer care and once again urged widespread adoption of cancer care planning.

LRF believes that lymphoma patients and the Medicare program would benefit significantly if Medicare beneficiaries had routine access to cancer care planning services. We endorse the standards for cancer care planning articulated by IOM:

- Patient information
- Diagnosis, including specific tissue information, relevant biomarkers, and stage
- Prognosis
- Treatment goals (curative, life-prolonging, symptom control, palliative care)
- Initial plan for treatment and duration (including chemotherapy, radiation, and surgery)
- Expected response to treatment
- Treatment benefits and harms, including how to manage toxicities
- Information on patient’s likely experience with treatment
- Who will take responsibility for various elements of care and how the various teams will be coordinated
- Advance care plans
- Estimated total and out-of-pocket costs of cancer treatment
- A plan for addressing a patient’s psychosocial care<sup>2</sup>

Because a patient’s disease and treatment needs may change over the continuum of his or her disease, we recommend that patients have access to a cancer care planning service at several specific times. First, a treatment plan should be developed and provided in writing to the patient after diagnosis and before treatment begins. This plan will guide treatment choices, encourage appropriate symptom management, and facilitate the coordination of care. Access should also be ensured if there is a significant change in a patient’s prognosis that would necessitate major changes in treatment and symptom management. Finally, a plan should be provided to the patient at the point of transition from active treatment to monitoring and management of late and long-term treatment effects.

As the development of cancer care plans becomes a more widespread practice, we anticipate that the treatment plan will inform the plan for long-term survivorship management.

### **Benefits of Cancer Care Planning**

A cancer care planning process as defined above will facilitate a shared decision-making process necessary for the delivery of precision medicine. By providing beneficiaries with cancer access to a patient-centered process for consideration of prognosis, goals of treatment, and all treatment options, the Medicare program can increase the likelihood that the right treatment will be delivered to the right patient at the right time, that patient outcomes are optimized, and that cancer care resources are efficiently utilized.

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<sup>2</sup> Adapted from the definition of a cancer care plan in IOM, Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis, 2013. See Box3-3, Information in a Cancer Care Plan.

We urge the Committee on Finance to consider the addition of a cancer care planning service to the Medicare program. Such a service would be consistent with the transitional cancer management service and complex chronic care management service that have been recently incorporated into Medicare by action of the Centers for Medicare & Medicaid Services. We applaud the addition of those planning and management services but do not think that they are adequate to address the complexity of cancer care treatment decision-making and planning, as well as cancer care coordination.

Representatives Lois Capps and Charles Boustany are planning the reintroduction of the Planning Actively for Cancer Treatment (PACT) Act, a bill to establish a Medicare cancer care planning service, by the end of June 2015. We hope that you will consider a parallel Senate effort to incorporate this service in the Medicare program.

We note that the Oncology Care Model, a demonstration project to test an episode of care system and its impact on oncology practice transformation, incorporates a cancer care planning service as one of the standards that oncology practices must meet. We anticipate that this payment reform pilot project will have a positive impact on adoption of cancer care planning, but not all oncology practices will participate in the demonstration project. We hope that the cancer planning service might improve the quality of care for those who will receive their cancer care for those whose oncologists are not participating in the payment demonstration.

We look forward to discussion with you regarding this important Medicare reform to foster higher quality cancer care.

Sincerely,



Meghan Gutierrez  
Chief Executive Officer