



August 17, 2012

Donna Frescatore
Executive Director
New York State Health Exchange
Executive Chamber
State Capitol
Albany, NY 12224

Danielle Holahan
Project Director
New York State Health Exchange
Corning Tower
Empire State Plaza
Albany, NY 12237

RE: Recommendations on New York's Essential Health Benefits Package (EHB)

Dear Ms. Frescatore and Ms. Holahan:

The Leukemia & Lymphoma Society (LLS) appreciates the opportunity to submit our recommendations on New York's selection of an Essential Health Benefits (EHB) benchmark plan for use in the individual and small group insurance markets. LLS is the world's largest voluntary health agency dedicated to blood cancer. LLS funds lifesaving blood cancer research around the world and provides free information and support services. The mission of LLS is to cure leukemia, lymphoma, Hodgkin's disease and myeloma and improve the quality of life of patients and their families.

The health care needs of blood cancer patients are the needs of those with serious and life-threatening illnesses, as well as chronic health care issues. Treating blood cancers like Chronic Myelogenous Leukemia (CML) and Non-Hodgkin's Lymphoma involves accessing a complex and exhaustive set of health care services including chemo and radiation therapy, surgery, diagnostic, prescription drugs, and cancer treatment planning, among others. These long-term treatment plans often put patients at great financial risk due to the cost sharing burdens associated with care, even if they are insured.

New York blood cancer patients and survivors who are currently uninsured and underinsured, are among those who stand to benefit greatly from the establishment of the state's Health Exchange. We commend Governor Cuomo for his Executive Order, released on April 12th, to establish the state's health exchange, as well as to confirm New York's commitment to meeting federal deadlines for implementation of health reform.

One of the most important next steps for the state is to establish a comprehensive essential health benefits (EHB) package of health care services for the exchange; the EHB will also serve as a

benchmark for the state's Medicaid program and other insurance coverage available to New Yorkers.

As you are aware, to determine what services will be included in the EHB, New York must choose from 10 benchmark plans, established by the U.S. Department of Health and Human Services (HHS). Unless New York follows its rich tradition of providing affordable access to comprehensive care, the promise of meaningful access to quality, coordinated cancer care will not become reality for patients or survivors. If the state's EHB package leans too heavily toward maximizing payer discretion at the expense of ensuring patient access to comprehensive and quality cancer care, blood cancer patients may find themselves with insurance that is inadequate and unable to meet their health care needs, while being saddled with crippling financial responsibilities.

LLS believes that New York must take a comprehensive approach when setting the standard for the state's EHB package. To that end, attached please find a set of recommendations that we have developed with the goal of ensuring access, quality and affordability for blood cancer patients in New York's EHB package. These recommendations focus on three key principles:

1. A meaningful prescription drug benefit that is comprehensive, affordable and enables access to the most effective drug therapies tailored to the patient's needs
2. Access to specialists, procedures and technologies for needed diagnostic and treatment services
3. Coverage for comprehensive cancer planning as well as palliative and end of life care

We greatly appreciate your consideration of our recommendations. We would welcome the opportunity to meet with you to discuss our recommendations further, as they relate to the benchmark plan options that are currently under review. I will contact your office shortly to inquire about scheduling a meeting.

Sincerely,

A handwritten signature in black ink, appearing to read "Brian M. Rosen", with a stylized, flowing script.

Brian M. Rosen
Vice President, Legislative & Regulatory Affairs
The Leukemia & Lymphoma Society

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The Leukemia & Lymphoma Society (LLS) strongly urges that New York's benchmark plan include the following:

1. Prescription drug benefit with full coverage of the six protected classes, inclusion of multiple drugs in a range of therapeutic categories, as defined in the Medicare Part D program and a patient appeals process.
2. Independent Pharmacy and Therapeutic (P&T) Committees that review the drugs included on a Plan's formularies, as well as the utilization management requirements for such drugs, and consideration of newly approved treatments and indications for inclusion in formularies within certain timeframes such as those required under Part D.
3. A mechanism for incorporating new therapeutic categories or classes in order to protect patients' access to innovative therapies as they become available.
4. Equal treatment of out-of-pocket expense to patients receiving intravenous, injectable, and/or orally administered anti-cancer therapies.
5. Drugs and biologics, both physician & self-administered and off-label uses, according to the evidence-based standards utilized in the Medicare program.
6. Affordable access to procedures standard to the treatment of blood cancers including bone marrow & cord blood transplants and radiation therapy.
7. Allows cancer patients to seek treatment at National Cancer Institute (NCI) Cancer Centers or any other out of network provider.
8. Maintain New York's current external appeals process for cancer patients denied coverage of "routine patient care" in cancer clinical trials until the federal requirement for coverage of routine patient care in clinical trials takes effect in 2014.
9. Diagnostic services using all available evidence-based technologies.
10. Individual, comprehensive cancer planning that is communicated by health care professionals both orally & in written form.
11. Palliative & hospice care.

For more information, please contact Brian Rosen, Vice President, Legislative & Regulatory Affairs for LLS at brian.rosen@lls.org