LEUKEMIA & LYMPHOMA SOCIETY
fighting blood cancers

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**Testimony Re: Implementation of the *New York State of Health* Insurance Exchange**
**NYS State Senate Standing Committees on Insurance and Health**
**Public Hearing – January 13, 2013**

Chairmen Seward and Hannon, and Members of the Insurance and Health Committees:

On behalf of the Leukemia & Lymphoma Society (LLS) and the thousands of blood cancer patients we serve throughout the state of New York, we thank you for the opportunity to comment on the *New York State of Health* (NYSOH) insurance exchange and the coverage it offers for plan year 2014.

New York has created one of the nation's most patient-friendly exchanges, thanks largely to the standard benefit design developed under NYSOH leadership and the State Department of Health and Department of Financial Services. Not only will this standardization empower our patients to understand their coverage; it also provides robust options for them at the silver level and above.

Further, LLS strongly commends the NYSOH exchange for the levels of drug coverage built into the standard benefit design for all metal tiers, in particular the $70 limit on specialty drugs. This contrasts dramatically with the levels of specialty drug cost-sharing that have emerged in several other states, especially where exchange plans have made common use of high coinsurances. Taken together, these aspects of NYSOH coverage mark a profound improvement in what our patients typically encounter in the insurance marketplace.

However, LLS is deeply concerned about certain aspects of NYSOH coverage which threaten to *diminish* access to affordable health care for those who most need it. This includes:

- The heavy **cost-sharing burden imposed upon any patient with bronze coverage**, many of whom will be lower-income and thus unable to afford plans on other metal tiers
- **Networks that include few, if any, of New York's National Cancer Institute (NCI)-designated cancer treatment and transplant centers**, which is compounded by the lack of an out-of-network benefit
- Consumers having to make plan selections using **incomplete and/or inaccurate information on provider networks**

These issues are detailed below and in the attached report produced for LLS by actuarial firm Milliman, based on publicly available data for exchange plans being sold in New York and three other states.

**Cost-Sharing**
As mentioned above, the NYSOH exchange offers good coverage options – for those patients who can afford it – at the silver, gold, and platinum levels. That said, LLS is concerned that the cost-sharing for bronze plans will force lower-income patients to delay or forego care, leading to disease progression and diminished chances for survival. Of particular concern:

- **Deductibles:** Coverage will not be applied to nearly any benefit or service until a patient with bronze coverage has satisfied a $3,000 deductible. While this deductible is more manageable than many others noted in the report, the simple fact is such high upfront demand will have a chilling

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effect on utilization of care, especially for those patients who have already endured sustained periods of high medical need over multiple years.

- **Cost-share for individual benefits and services:** Bronze coverage also requires patients to cover 50% of the cost of nearly every benefit and service, including the specialist visits that – for cancer patients – are absolutely necessary to survival. With a 50% coinsurance, these critical episodes of care will be out of reach for many cancer patients with bronze plans, further limiting the usefulness of their coverage. Note that, of the plans studied in all four states, the vast majority do not impose such high coinsurance on specialist visits.

**Network Adequacy**

Many blood cancer patients rely upon specialized facilities—namely, NCI-designated cancer centers and transplant centers. In New York, this includes fifteen facilities located in seven different counties: five NCI centers and ten transplant centers.

Of the sixteen NYSOH plans profiled in the report, one plan network includes only one of these fifteen facilities. In three plans, the networks include only two facilities each. Even more restricted are the networks for two plans that do not include a single one of New York's NCI centers or transplant centers. Ordinarily, consumers could enhance these networks by utilizing an out-of-network benefit, but extremely few plans in New York provide the option. From a cancer perspective, these networks are problematic for a number of reasons:

- **Access to appropriate care:** These centers provide cutting-edge treatment; have experts well-versed in these less-common diseases; and can often provide access to treatments not yet available outside of a clinical trial. This level of innovation is generally unavailable in a community setting.
- **Accurate diagnosis:** Even when a blood cancer patient can be appropriately treated in a community setting, many of them must first visit a specialized facility to receive or confirm their diagnosis. The blood cancers include diseases that are aggressive, rare, and sometimes difficult to distinguish from other blood cancers or disorders. Correct diagnosis is the lynchpin to effective treatment.
- **Urgency of acute care needs:** While consumers may request access to out-of-network coverage, these processes are often difficult and time-consuming for patients to navigate. For an acute care patient, the risk of disease progression is increased any time treatment or diagnosis is delayed.
- **Increased risk of medical debt:** If forced to seek care out-of-network, a cancer patient could rack up thousands of dollars of medical debt, as these costs are unlikely to fall under the protection of the out-of-pocket maximums established by the Affordable Care Act.

**Transparency in Exchange Plan Details**

Though transparency is not addressed in detail in Milliman's research, LLS is concerned about the numerous reports of inaccuracies in the data published by Exchange health plans related to their provider networks. Without thorough and accurate information, patients will be forced to take a gamble on which plans will in fact suit their medical and financial situation. It is imperative that these inaccuracies be resolved.

LLS is conducting further research to assess the patient experience of enrolling in and utilizing the coverage provided by exchange plans, with results anticipated in early spring. LLS looks forward to sharing these results with you and to working together on solutions to the access issues described above.

With questions, please contact Marialanna Lee, Director, State Government Affairs, Northeast Region, Leukemia & Lymphoma Society, at marialanna.lee@lls.org or (215) 232-2763.