

# Patients Against Lymphoma



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Patients Against Lymphoma is a non-profit organization, independent of health industry funding.  
Here we are representing the concerns of many lymphoma survivors and their loved ones regarding proposed CMS payment policies for radioimmunotherapy ("RIT") agents (Bexxar and Zevalin), administration, and supply.

November 5, 2007

Chairman Senator Edward M. Kennedy  
Majority House Policy Office  
527 Hart Senate Office Building  
Washington, Dc 20520-6300

Re: **CMS-1392-FC** – “*Use of inadequate and inaccurate claims data by CMS to set reimbursements rates*”<sup>1</sup> for highly effective radioimmunotherapies against lymphomas: Bexxar (I131 tositumomab) and Zevalin (Y90 ibritumomab)

Dear Senator Kennedy:

As the Chairman of the Committee on Health, Education, Labor and Pensions, your attention is needed to an issue of extreme consequence to patients and caregivers of those suffering with non-Hodgkin's lymphomas, the most common type of blood cancer.

Specifically, CMS has proposed (*and now has approved*) payment cuts for radioimmunotherapies ("RIT"), namely Bexxar and Zevalin, that are crucial to the survival and quality of life of patients suffering from these diseases.

As detailed in the enclosed letter to CMS ("PAL CMS Letter"), hospitals struggle to provide these therapies due to very low reimbursement levels for radiopharmaceuticals. It is our shared belief and reasoned fear that the improperly calculated rates will lead to reduced or eliminated patient access to these life-saving therapies.

In our letter to CMS we show that RIT is highly effective yet underutilized; and that it can lead to *durable complete responses* in a sizable percentage of patients resistant to standard chemotherapies.

Notably, the alternative to RIT will many times be death, or rescue via more toxic, less effective or higher-risk therapy and more expensive in-patient treatments, such as stem cell transplantation, which is contraindicated in older patients – the population most dependent on Medicare.

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<sup>1</sup> GlaxoSmithKline letter to CMS: Use of inadequate and inaccurate claims data by CMS to set reimbursement rates: <http://www.cms.hhs.gov/eRulemaking/downloads/CMS1392PPC177-195.pdf>

Lymphomas are more common than leukemias<sup>2</sup>, reflected in the number of famous and notable individuals who have been touched by the disease, including the late Senator Paul E. Tsongas, and more recently, Senator Fred Thompson. We also respectfully note your personal connection to this group of diseases through Jacqueline Kennedy Onassis.

On a personal note, I have reason to doubt that my spouse, Joanne, would be alive today, and, more certainly, that she would be living normally and apparently free of disease – eleven years following her diagnosis of follicular lymphoma – if not for RIT.

In summary, we believe that CMS very low reimbursement rates for RIT:

- (1) will increase pain, suffering, and *unnecessary loss of life* for patients with lymphomas;**
- (2) will limit a physician's ability to prescribe a highly effective therapy today;**
- (3) will lead to the termination of radioimmunotherapy in the near future; and**
- (4) will be a *disincentive* to develop urgently needed innovative drugs for *all cancers*.**

Please note that the public outcry against the proposed cuts is further evidenced by the fact that the PAL CMS Letter was signed by more than 1,500 citizens representing every region of the United States in the very short time period of approximately 14 days since we learned about this issue (Sept 2007). ...

... Among the names are *physicians* who specialize in treating lymphoma patients, which validates and reinforces our concerns. (*We ask that you try to keep this list CONFIDENTIAL to protect the privacy of the many patients who have signed.*)

Please help us to ensure that CMS amends the CY2008 reimbursement rates for Zevalin and Bexxar so that hospitals can be adequately paid for providing radioimmunotherapy, which in turn will allow patients to continue to benefit from these targeted and highly effective new cancer therapies, which have been described by experts as the *most potent and effective therapeutic agents ever invented for lymphoma, and arguably for any cancer*.

Sincerely yours,

Karl Schwartz (caregiver)

President, Patients Against Lymphoma  
Patient Consultant to the FDA/Oncologic Drug Advisory Committee (ODAC)  
Participant: NCI Progress Review Group for Blood Cancers (LMPRG)  
Participant: Biospecimen Access and Ethical, Legal, and Policy Issues Workshop (ELP)  
Participant: NCI Custodianship and Ownership Issues in Biospecimen Research Workshop

Encl. PAL CMS Letter | Endorsements

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<sup>2</sup> "It is estimated that **71,380 men** and women (38,670 men and 32,710 women) will be diagnosed with and 19,730 men and women will die of lymphoma in 2007" SEER:

\* [http://seer.cancer.gov/statfacts/html/leuks.html?statfacts\\_page=leuks.html&x=9&y=19](http://seer.cancer.gov/statfacts/html/leuks.html?statfacts_page=leuks.html&x=9&y=19)

\*\* [http://seer.cancer.gov/statfacts/html/lymph.html?statfacts\\_page=lymph.html&x=16&y=17](http://seer.cancer.gov/statfacts/html/lymph.html?statfacts_page=lymph.html&x=16&y=17)