USCLC Cutaneous Lymphoma Patient Registry:
Potential Use by Outside Agencies

I. Background

The USCLC is a nonprofit agency charged with the goal of enhancing the prognosis and quality of life of patients with cutaneous lymphoma. One of the primary means of accomplishing this is through our USCLC cutaneous lymphoma registry. The USCLC will, from time to time, query the data gathered in the registry for answers to specific questions that it generates and in line with federal directives as well as our mission, this data will be published for public dissemination. The USCLC also realizes that other agencies, companies, societies or individuals may also have specific questions on cutaneous lymphoma that they would like to see if the USCLC registry can answer. The following are guidelines for the use of the USCLC data by outside companies.

II. Proposal:

The company, agency, society or individual seeking use of the USCLC data should submit a study proposal to the USCLC Secretary-Treasurer that includes the following:

1. Hypothesis: this must relate to the care of patients with cutaneous lymphoma or to the advancement of the understanding of cutaneous lymphoma.
2. Supporting data: references and background information that give credence to the hypothesis
3. Specific set of data needed to address hypothesis: the particular set of patient criteria , including years encompassing study data
4. Methods: details on the plans for using the data
5. Statistical analysis: no proposal will be considered without a firm plan for statistical analysis of data
6. Personnel involved: specifics of who will have access to the data
7. Plans for publication: the data in the USCLC registry must be used for the public good and therefore publication of results is required.
8. Timeline: expectation on when data needed and when publication expected to be submitted. All publications are required to acknowledge that the USCLC registry is the source of the data

III. USCLC Action

1. The USCLC BOD or designee Committee will review all study proposals for scientific validity and rigor. If the USCLC feels that the study has scientific merit, the USCLC will provide the following to the petitioner within 30 days of receipt:
   a) Any suggested modifications to the study proposal
   b) A proposed budget including IRB costs
   c) A timeline for providing the data
   d) An opportunity for meeting in person or by teleconference to discuss the study proposal
2. Upon mutual acceptance of the proposal, budget and timeline, the USCLC would send a contract to the petitioner.
3. Once the contract is signed, the work on the study proposal will begin.
4. A.30 day period for review by the USCLC of any potential paper or abstract coming out of the registry use is required prior to submission for publication.