

Patients Against Lymphoma



Non-Profit | Independent | Evidence-based

Founded in 2002

Thursday, April 24, 2008

President:

Karl Schwartz, MFA,
Patient Consultant to FDA

Founding Members

Page Irby, RN
Allan Marson, Esq.

Board of Directors

Jama Beasley
Charles Brennan, CPA
Linda Gerstley, PhD.
Dennis McComb
Andrew Michael, Ph.D.

Scientific Advisors

Andrew Croaker, MD
Lucien Joubert MD
Susan B. Spector, MS, RD, CDN
Lynda Olender, R.N. A.N.P.,
C.N.A.A.
Susan Olender, M.D.
Dimitris Placantonakis, MD, Ph.D.
John Densmore, MD, Ph.D.
Allen Cohen, MD, Ph.D.
Lurdes Queimado, MD, Ph.D.

Public Policy Advisors

Betsy de Parry
Tobby Holinder, Esq.
Leonard Rosen, Esq.

Patient Navigators

Carol Lee
Nancy Lewis
Kathy Fry

Cancer Statistics Branch
Surveillance Research Program
Division of Cancer Control and Population Sciences
National Cancer Institute
Suite 504, MSC 8316
6116 Executive Boulevard
Bethesda, MD 20892-8316

Dear Sir or Madam:

The SEER website has improved, but the utility of the statistics for non-Hodgkin's lymphomas continue to suffer because subtypes of the disease are not yet provided. For comparison purposes SEER provides the following useful categories for Leukemias:

Lymphocytic Leukemia

Acute Lymphocytic Leukemia
Chronic Lymphocytic Leukemia
Myeloid and Monocytic Leukemia
Acute Myeloid Leukemia
Chronic Myeloid Leukemia

Non-Hodgkin's Lymphoma:

none

As you know, incidence, prevalence and survival vary significantly based on subtypes of lymphoma. Trends in survival also vary significantly based on the clinical tempo of the disease - aggressive versus indolent, as does, presumably, conditional survival.

We do not know yet what NHL entities are available to SEER (in the raw data sets), but we ask that you provide subtype specific information on NHL, perhaps as outlined on the next page, and a timetable for achieving this important goal.

Proposed categories for lymphomas, perhaps as a subset of blood cancers:

Lymphomas

Non-Hodgkin's lymphoma

Aggressive

DLBCL

T-cell

MCL

Other (Aggressive - defined entities)

Indolent

Follicular

MALT

T-cell

Other (Indolent - defined entities)

Hodgkin's Lymphoma

Subtypes?

Note: As you know, CLL is b-lymphocyte cancer. Presumably, it's classified as a leukemia based on where it presents and other factors, but many experts considered it a lymphoma, based on the cell of origin: b-lymphocyte.

Thank you for your attention to our proposal and comments. We look forward to your reply.

Sincerely,

Karl Schwartz

President and co-founder, 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: Custodianship and Ownership Issues in Biospecimen Research Symposium