

# What we do

- **Patient services:**

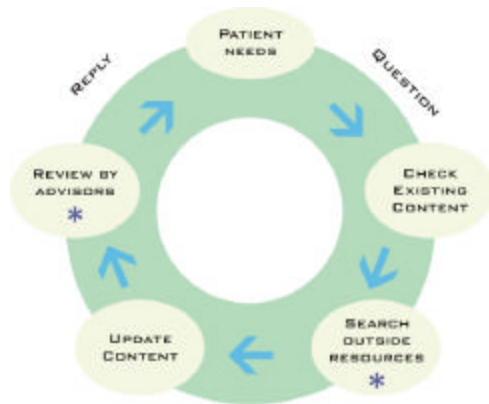
Providing support and evidence-based information on lymphomas and its treatments, independent of health industry funding.

TOPIC SEARCH: [ASCO](#) | [ASH](#) | [Cancer.gov](#)  
[ClinicalTrials.gov](#) | [Medscape](#) | [PubMed](#)

Our focus is on information: helping patients to become more informed partners in their care.

Guided by our scientific advisors and the published literature, we continuously update [lymphomation.org](#) as we respond promptly to visitor questions.

We also help patients to evaluate the strength of data and medical claims – to recognize sources of bias.



- **Research advocacy:**

Providing informed patient perspectives on clinical trial design, access to standard of care, and research directions.

# Who we are

## Board of Directors

Jama Beasley  
Betsy de Parry

Linda Gerstley, PhD.  
Dennis McComb  
Andrew Michael, Ph.D.

## Scientific Advisory Board

Maurizio, Bendandi, PhD, MD  
Susan B. Spector, MS, RD, CDN  
Susan Olender, M.D.  
John Densmore, MD, Ph.D.  
Lurdes Queimado, MD, Ph.D.

Andrew Croaker, MD  
Lynda Olender, R.N. A.N.P., C.N.A.A.  
Dimitris Placantonakis, MD, Ph.D.  
Allen Cohen, MD, Ph.D.  
Andrew Michael, Ph.D.

And numerous anonymous advisors.

## Advisors & Patient Navigators

Betsy de Parry  
Carol Lee  
Nancy Lowis

Toby Hollander  
Tony Hines  
Kathy Fry

## Founders

President: Karl Schwartz, MFA, Patient Consultant to FDA  
Honorary Advisor: Allan Marson, Esq.

## In Remembrance

Charles Brennan and Page Irby, founding directors  
lost to us in 2008, but *never* forgotten

## Measuring our Impact

- **Page views: 3 million** in past year
- **Website ranking ~246,000** of all websites in world (Alexa 8/2007)
- **Support lists: 1,900 subscribers** in six moderated online support forums
- **Visitor comments: See** [www.Lymphomation.org/testimonials.html](http://www.Lymphomation.org/testimonials.html)

# PATIENTS AGAINST LYMPHOMA

~ Education ~ Support ~ Advocacy ~

*Providing evidence-based resources on lymphoma and its treatments and informed patient perspectives on clinical trial design – independent of health industry funding*



## Patients Against Lymphoma

3774 Buckwampum Road  
Riegelsville, PA 18077

Phone: 610-346-8419 | Fax: 801-409-5736  
[Support@Lymphomation.org](mailto:Support@Lymphomation.org)

PAL is a 501 (c) (3) non-profit organization  
founded in 2002

## Lymphomation.org

[About Lymphoma](#) | [Advocacy & Art](#) | [CAM](#) | [Clinical trials](#)  
[Doctors](#) | [Guidelines at diagnosis](#) | [How to Help](#) | [Research](#)  
[Side Effects](#) | [Support](#) | [Symptoms](#) | [Tests](#) | [Treatments](#) | [WebCasts](#)

## MISSION

✦ Providing comprehensive, evidence-based information on lymphomas and its treatments through [www.lymphomation.org](http://www.lymphomation.org), available 24 hours a day, 7 days a week.

✦ Providing online forums for patients to ask questions, receive support, share experiences and evidence-based information.

✦ Advocating for standardized, cooperative, biospecimen-based clinical research.

*A reason that even well-controlled studies can fail to provide definitive answers is they are unable to account for underlying biological differences in the tumors and the patients – disease and patient heterogeneity.*

✦ Advocating for clinical trial design that's in harmony with meeting the clinical needs and treatment objectives of patients.

*~ Identify and validate biomarkers that can predict the disease course, and the toxicity and activity of new agents.*

✦ Advocating for a patient-centered, healthcare and clinical research systems.

✦ Increasing awareness of lymphoma and research opportunities.

✦ To Researchers/sponsors:

It's evident that we need each other, and that we need to communicate better. Delays in trial enrollment are costly to drug sponsors, and to patients. Indeed, the urgency of our situation requires that the drug discovery and evaluation system become as efficient as it can be. I think it's well-accepted by the industry that patient enrollment is THE issue, because without it the assessment of the protocol will not be made no matter how well it's designed from the point of view of regulators and investigators.

Presentation:

[http://www.lymphomation.org/adaptive\\_1.pdf](http://www.lymphomation.org/adaptive_1.pdf)

## SERVICE HIGHLIGHTS

✦ **Evaluating Medical Claims and Data**  
Guidance on how weigh evidence and to recognize conflicts of interest and sources of bias among patients, alternative practitioners, drug sponsors, physicians, and scientists.

✦ **Locating Clinical Trials for Lymphoma**  
Providing single-click access to trials by:  
Lymphoma **subtype**  
Treatment **type**  
Treatment **setting** - first line, refractory...  
Geographic **location**

✦ **ClinicalTrials of interest for lymphoma**  
Perhaps the sheer number of trials for lymphoma is an obstacle to enrollment? That, and the complexity of evaluating each and how it could address one's clinical circumstance and treatment goals:

Reasonable options to watchful waiting  
First primary treatment  
Overcoming refractory lymphoma  
Meeting special needs

✦ **Preparing for Doctor Visits**  
Guidance to help patients prepare for visits.

✦ **The Problem with Testimonials**  
We provide reasons testimonials cannot be relied upon as evidence, and list red flags for untrustworthy information on cancer.

✦ **Online Support Groups** We moderate several online support groups.

✦ **Ask Question** We respond to questions posted to our website or support forums in a timely manner, and link patients to reputable sources of information, such as peer-reviewed medical literature.

## ADVOCACY HIGHLIGHTS

**2007! PA L Spearheaded a successful grassroots initiative to require full payments by CMS to hospitals for radioimmunotherapies – to ensure continued patient access to these vital drugs (Bexxar and Zevalin)**

✦ **Presentation:** Harmonizing Research and Treatment Goals: Patient Perspectives on the Design of Clinical Trials ~ Cancer Vaccines Conference ~ Boston, MA 2003.

✦ **Presentation:** Patient's Perspective: the Demand for Innovation vs. Safety ~ Leigh Thompson Renaissance Conference, Charleston, SC 2005

✦ **Participant** in the FDA ODAC Patient Consultant program

✦ **Participant** in the Progress Review Group for Blood Cancers, NCI, 2001

✦ **Participant** in the "Chronic GvHD: The Next Frontier in Transplantation Medicine", NCI 2005

✦ **Participant** in the SEER workshop, NCI, 2005.

✦ **Participant** in the NCI National Biospecimen Network Workshop, NCI, 2005

✦ **ASCO exhibitor:**  
(1) Increasing Participation in Clinical Trials; (2) Optimizing Patient-Physician Consults; (3) Locating Clinical Trials for Lymphoma; (4) Preparing for Doctor Visits

✦ **Speaker:** National Press Club, Dec 13, 2005 ~ Announcing The Cancer Genome Atlas Project - Patient Perspectives.

✦ **Presentation:** Harmonizing Research Goals with Meeting Clinical Needs of Participants – Adaptive Trial Design Conference 2006.

✦ **Advocacy Letters and White Papers:**  
[www.lymphomation.org/advocacy-issues.htm](http://www.lymphomation.org/advocacy-issues.htm)