

# PATIENTS AGAINST LYMPHOMA



## Patients Helping Patients

*Patients partnering with scientists to make progress against lymphoma*

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University of California, Davis

And numerous anonymous lay advisors.

#### Patient Navigators /Advisors

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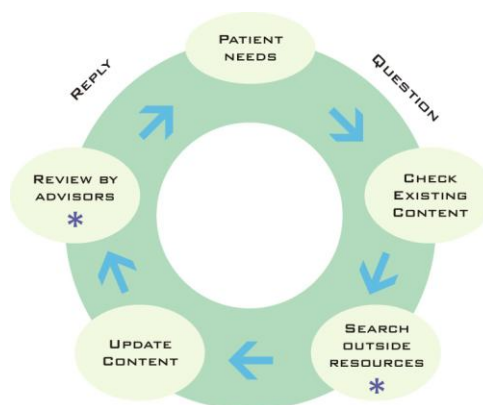
### Founders

President: Karl Schwartz,  
Founding Member: Allan Marson, Esq.

## Patients Against Lymphoma

3774 Buckwampum Road,  
Riegelsville, PA 18077  
Phone: 610-346-8419 | Fax: 801-409-5736  
[Support@Lymphomation.org](mailto:Support@Lymphomation.org)

non-profit 501 (c) (3) organization



### 2012 Website statistics lymphomation.org

|                        | Unique visitors | Number of visits | Pages     | Hits       |
|------------------------|-----------------|------------------|-----------|------------|
| <b>Total</b>           | 584,409         | 789,569          | 1,736,800 | 10,997,756 |
| <b>Monthly Average</b> | 48,701          | 65,797           | 144,733   | 916,480    |

## Lymphomation.org

About Lymphoma | Advocacy & Art | CAM & Life Style  
Clinical trials | Docs & Centers | Guidelines at Diagnosis | How to Help | Side Effects | Support | Symptoms | Tests  
Treatments | Types of Lymphoma

## About Patients Against Lymphoma

**Founded in 2002**  
**by patients for patients**

- Fostering patient-physician shared decision-making by providing decision tools and checklists.
- Linking patients to evidence-based Best Practice Guidelines for their type of lymphoma.
- Increasing awareness of investigational therapies and the importance of clinical research.
- Providing tools to easily locate studies that may be appropriate based on our clinical circumstances.
- Helping patients to locate lymphoma experts and specialty centers, and encouraging expert second opinions, particularly prior to treatment.

*Recognizing that only trained medical professionals with DIRECT contact with the patient should provide medical advice.*

- Providing patient-friendly access to evidence-based information on a wide range of topics:

**[www.Lymphomation.org](http://www.Lymphomation.org)**  
**Online support forums**

Our information and support venues are available 24 hours. We require no fees, subscriptions, or registration, and we ask for no identifying information.

***Day or night, and without leaving home, patients can find answers in total privacy, without concern about asking a "dumb" question.***

We are experienced patient navigators, guided by our scientific advisors.

Our focus is on providing science- and EVIDENCE-BASED information in response to patient and caregiver questions.

We help patients to critically evaluate the strengths and weaknesses of medical claims and reports. Reminding that being open-minded includes being skeptical about opinion and testimonials.

***Helping patients to think more like scientists***

## **PROVIDING A COMPREHENSIVE RANGE OF TOPICS**

- Our topics are determined by patient and caregiver questions.

Ranging from Financial Help to Primers on the Biology of Lymphoma ... and how drugs work

- Providing Topic Searches to help visitors easily locate additional information on a given subject, from the most credible sources.
- Providing an Ask a Question Service, often responding to visitor and support forum questions in real time.

- Helping patients to find expert oncologists and research centers by region of the country
- And much more

## **RESEARCH ADVOCACY**

We remind scientists that patients are the primary stakeholders in clinical research – that we suffer the most when trials do not achieve full enrollment, which is a common and tragic event.

We engage scientists, investigators, the FDA, the Cooperative groups, CMS etc, depending on the issue – providing patient perspectives on:

- Ethical design of clinical trials
- Obstacles to enrollment in clinical trials, such as eligibility criteria, or the appeal of the study protocol as a therapeutic decision.

***Helping scientists to think more like patients***

Our FINANCIAL INDEPENDENCE is of vital importance ... so that our content and perspectives cannot be perceived as influenced by any financial conflict of interest.

Our sole purpose is to represent the interests of patients, present and future - reminding that we are all future patients.

***Advancing the routine and informed consideration of clinical trials***

***Supporting clinical research that is good science -- answering important clinical questions -- and good medicine -- appropriate to the participants as a treatment decision***

Thank you for your support!

Yours truly,

Karl Schwartz  
President and co-founder,  
Patients Against Lymphoma

Patient representative:

Alliance Cooperative Group,  
Lymphoma Committee

NCI:

- Progress Review Group,
- Biospecimen Best Practice,
- Lymphoma Steering committee
- Patient Advocate Steering Committee (co-chair)
- Centralized Review Board
- National Cancer Advisory Board (NCAB) Evolving Clinical Trials System (Biospecimen banks)

Patient Advocate Faculty  
ASCO/AACR Workshop:  
Methods in Clinical Cancer  
Research

Stand Up to Cancer, Joint  
Scientific Advisory Committee