

PATIENTS AGAINST LYMPHOMA



Patients Helping Patients

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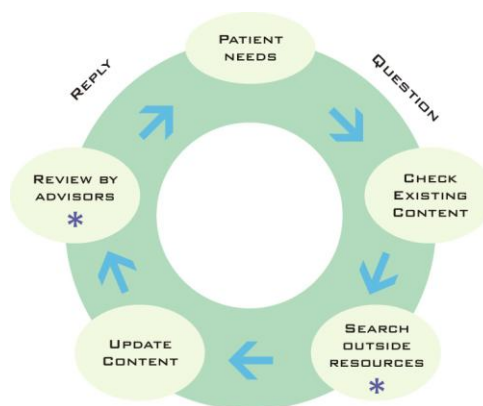
Founders

President: Karl Schwartz, Patient Consultant to FDA
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Patients Against Lymphoma

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a non-profit 501 (c) (3) organization



Impressive website statistics

| Month | Unique visitors | Number of visits | Pages | Hits |
|--------|-----------------|------------------|---------|-----------|
| Jan-10 | 94,639 | 118,985 | 163,092 | 1,249,970 |
| Feb-10 | 97,414 | 121,963 | 166,820 | 1,285,245 |
| Mar-10 | 111,020 | 142,214 | 200,907 | 1,519,082 |
| Apr-10 | 98,140 | 127,924 | 180,110 | 1,431,222 |
| May-10 | 99,218 | 129,093 | 177,388 | 1,445,643 |

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 and for patients

FOSTERING:

- Evidence-based, patient/physician shared decision making
- Consideration of the full range of appropriate therapies, including investigational
- Identification of best practice and the many case-based factors that inform clinical decision making
- Awareness of investigational therapies and clinical trials
- Consults with independent lymphoma experts, 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 lymphoma information:

www.Lymphomation.org
Online support forums

Available 24 hours

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

- Requiring no fees, subscriptions, or registration
- Asking for no identifying information
- Providing **INFORMATION RELEVANT TO NEEDS:**

Our focus is on providing **EVIDENCE-BASED** information – guided by our advisors:

We are experienced patient navigators guided by our scientific advisors, among them survivors and caregivers.

We help patients to critically evaluate the strengths and weaknesses of medical information. 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

- Driven by patient 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 credible resources on a given subject.
- Providing Ask Question Service, often responding in real time.
- Providing Trial Search tools and direct help locating clinical trials to consider.
- Find Doctor service
- Find Research Centers
- And much more

RESEARCH ADVOCACY

Patients are the primary stakeholders in clinical research (not the scientists, not Medicare, not the companies),

... and enrollment in trials is a critical obstacle to progress against lymphomas.

Thus, informed patients must become active partners in the design and implementation of clinical research.

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

- Ethical design of clinical trials
- Obstacles to enrollment in clinical trials

including our published survey on patient attitudes (ASCO 2009)

- Unencumbered access to all approved treatment options - such as radioimmunotherapy, an underutilized and potent targeted therapy for lymphomas

Helping scientists to think more like patients

Here our **FINANCIAL INDEPENDENCE** from health care sponsors is of vital importance ... so that our content and perspectives cannot be perceived as influenced by our sponsors.

Increasing participation in clinical trials **is essential** to making progress against lymphoma - to answering vital clinical questions, such as how to treat more effectively with less toxicity. However, the studies must combine good science with good medicine – the investigational protocol must compare well with all other choices.

... That is, we represent the interests of patients, present and future - reminding that we are all future patients.