

PATIENTS AGAINST LYMPHOMA



Patients Helping Patients

Patients partnering with scientists to make progress against lymphoma

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Non-profit 501 (c) (3) organization

Schema Lymphomation.org content cycle



Website statistics for 2015

	<u>Unique</u> visitors per mo.	Number of visits	Pages	Hits
January	64,265	82,739	108,212	726,708
February	64,330	81,536	107,223	726,690

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

- Helping patients to become informed partners in their care by providing education, decision tools, and checklists on how to optimize doctor consults.
- Linking patients to evidence-based Best Practice Guidelines on the different types of lymphoma.
- Increasing awareness and understanding of investigational therapies and the importance of clinical research.
- Providing tools to find trials based on ones treatment status, the type of drug, and trials of interest.
- Helping patients to locate lymphoma experts and specialty centers -- encouraging expert second opinions.

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

- Providing, safe, patient-friendly support forums:

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.

Newly diagnosed patients are vulnerable to misinformation and false claims. We help patients to critically evaluate claims. 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 **Finding trials** for lymphoma based on the type of lymphoma, our treatment status, type of agent, and more

- 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
(2009-2015)

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 2011 - 2014

Stand Up to Cancer, Joint
Scientific Advisory Committee