

We are **Patients Against Lymphoma (PAL)**,

a non-profit organization founded in 2002 by caregivers and survivors of lymphoma, a blood cancer that afflicts about 700,000 American citizens and many more individuals worldwide. Here we describe the services we provide to thousands of affected families.

Our mission is to first help to meet the **Support** Needs of patients in recognition of the considerable psychosocial impacts of the disease and treatments on the patient and his or her family: The emotional stress of a diagnosis, the overwhelming sense of isolation and loss of control over one's life.

Guided by our scientific advisors, we also provide evidence-based information on lymphoma and its treatments for the purpose of helping patients to become better informed partners in their care.

Importantly, the **Education** we provide on lymphomation.org, and the resources we link to, is determined by patient questions, which likely explains the very high usage of our website:

Lymphomation.org, website server statistics:
50,000 to 128,000 unique visitors per month,
2010-2011

Because our focus is on providing information, including information about clinical trials, we have chosen to be independent of health-industry funding in order to avoid even the appearance that our content is influenced by a financial conflict of interest.



Our objective is to help patients to achieve a high level of informed consent when consulting with their doctors, who often have very limited time to provide complex background information about the disease and how it's treated.

For example, we teach that informed choice is a process, which requires an objective understanding of the clinical context:

- 1) the natural history – or anticipated clinical course for their type of lymphoma,
- 2) the potential benefits and risks of the current standards of care,
- 3) and an appreciation of the unique and sometimes changing individual risk factors – such as one's age and performance, the changing behavior of the lymphoma, or responsiveness to prior therapies.

The clinical context can influence how much risk is appropriate to take when treating the lymphoma and also how appropriate it might be to ask about and consider clinical trials.

A second aspect of our mission we call **Research Advocacy**, where we act as liaisons between the patient and research communities – helping patients to critically evaluate clinical reports, and helping clinical scientists to better understand and think like patients – in particular how clinical trial design can influence the feasibility of achieving full enrollment.

We engage investigators, drug sponsors, and the major research organizations by letter and with presentations, and also by direct participation at professional conferences and organizations.

We enjoy a high standing in both communities, citing here as an example, our

study that was published in a prestigious medical journal.¹ Our core objective is to harmonize research goals with meeting the clinical needs of the participants, and to foster the routine and informed consideration of clinical trials.

... Many of our tools and much of our content is aimed at addressing a very real crisis in clinical research – particularly for lymphoma: the very low percentage of available patients who participate in clinical trials, which require completion in order to make additional progress against the disease.²

We provide our information and tools as:

- 1) Website pages
- 2) Notices to support group members with links to our web pages
- 3) Printed brochures
- 4) Checklists
- 5) Letters and published reports

Please note that we are very careful to avoid recommending that individuals participate in any specific clinical trial. We remind that we are not doctors and that even trained physicians would require first-hand clinical information before advising any person about a treatment for a life-threatening medical condition.

We encourage instead that patients carefully review consent documents, review outcome

¹ Schwartz, advisors, JCO / ASCO 2009, Interest, attitudes, and participation in clinical trials among lymphoma patients with online access

² NEJM, 2010, Young, M.D., Cancer Clinical Trials – A Chronic but Curable Crisis

reports critically, consult and rely on their doctor's judgment, and when feasible that they consult independent experts prior to making treatment decisions.

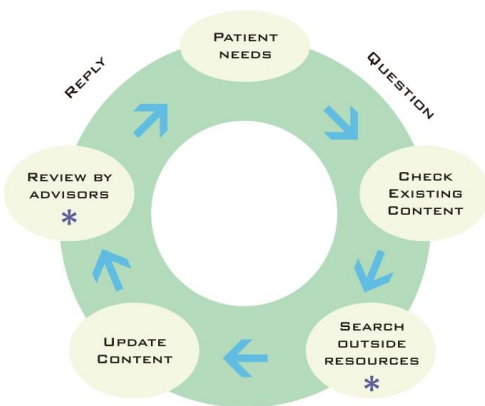
The impact of PAL is much larger than the size of our organization. We direct stakeholders to our well-known lymphomation website by email, by letter, or by posting notifications to our many support forums, which includes thousands of subscribers – this to ensure that the appropriate audience is aware of the information and tools we provide and how to make use of it.

In closing, we thank you for taking time to read about PAL. We would be happy to answer any questions that you may have and to provide details of the services we provide to patients and how we measure the effects of our work. We ask that you please also consider making a financial contribution in support of our mission by visiting: www.lymphomation.org/how-to-help.htm

Sincerely,

Karl Schwartz
President, Patients Against Lymphoma

Lymphomation.org



Founded in 2002

President:

Karl Schwartz, Participant:
Alliance Cooperative Group,
Lymphoma Committee
FDA Advisory Committee,
NCI Progress Review Group
NCI Biospecimen Best
Practice Workshops
Patient Advocate Faculty
ASCO/AACR Workshop:
Methods in Clinical Cancer
Research

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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*



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

Lymphomation.org

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