

# Patients Against Lymphoma (PAL) – 2015

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## Mission statement

PAL provides evidence-based online support and information for patients and caregivers. Our focus is on fostering the routine and informed consideration of clinical trials --- this in to **accelerate progress against lymphoma** – for current and future patient, which is needed to make therapies more effective and less toxic.

**PAL is an independent resource for evidence-based information on lymphoma and related topics. Our non-profit group relies entirely on public funding.**

We thank you for, need, and encourage your continuing support! [How to Help](#)

## Lymphomation.org

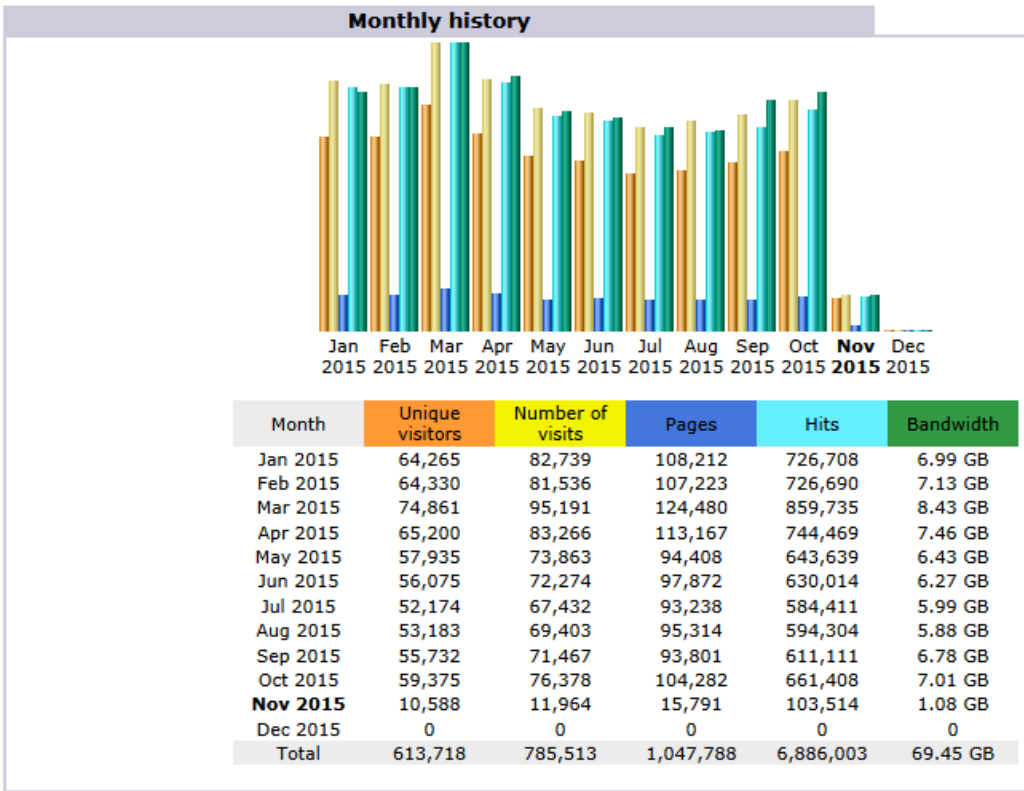
Lymphomation.org is our primary resource – the place we put useful information so that present and future patients can find it easily. Lymphomation.org contains no distracting signs, splashing graphics, or commercial ads. We provide open access to lymphomation ... with no login required; with no need to disclose identifying information.

The screenshot shows the Lymphomation.org website in a browser window. The address bar displays 'http://www.lymphomation.org/'. The page features a navigation menu with links such as 'About Lymphoma', 'Advocacy', 'Art', 'CAM', 'Clinical trials', 'Doctors - Experts - Centers', 'Guidelines at Diagnosis', 'News', 'Risk Factors', 'Side Effects', 'Statistics', 'Support', 'Symptoms', 'Tests', and 'Treatments'. A search bar is located below the navigation menu. The main content area includes a 'Patients Against Lymphoma' banner, a 'Menu A to Z' section with a grid of letters, and several sidebar sections: 'A' (with sub-sections like 'Adrenoleukodystrophy', 'Abit-199', etc.), 'Ask a Question | Comment | See Comments | How to Help!', 'What's New' (listing new trials and abstracts), 'Getting Started' (evidenced-based topics), and 'Just Diagnosed?' (guidelines and patient stories). The website is designed to be user-friendly and accessible, with a focus on providing evidence-based information and support for patients and caregivers.

See [www.lymphomation.org](http://www.lymphomation.org)

## Lymphomation.org statistics:

The chart below is a screen capture from our web server, showing public use of lymphomation.org – anywhere from 64,000 to 52,000 unique visitors per month.



## Recent Projects

- **Trial Talk** – to encourage and facilitate consults with experts for second opinions and discussion of clinical trials. More than 100 specialists in both name and location order. 27 persons have clicked the Trial Talk button to tell us they used the list.

See Trial Talk experts in name order [www.lymphomation.org/trial-talk.htm#name](http://www.lymphomation.org/trial-talk.htm#name)

- **Patient Survey** – to understand patient needs and concerns and to guide the content we provide.

See Lymphoma Patient Community Survey <http://bit.ly/1EnaYY3> & Results <http://bit.ly/1NzzWpH>

- **Fostering the Informed and Routine Consideration of Clinical Trials**

We provide a comprehensive list of related tools and information

- Just one example: **Find Trials by type of agent** – to help patients and treating physicians keep up with the rapidly changing opportunities to test new agents in lymphoma.

See Find Lymphoma and CLL trials by type of Study Drug <http://bit.ly/LxKoeR>

- **Agents that Target Disease Pathways**
  - an index of study drugs in alphabetical order for lymphoma and CLL

Format:

**Study drug name** / alternate name <sup>1</sup> (short name for target or mechanism) <sup>2</sup>  
Find Trials <sup>3</sup> [Sometimes with]: Report / Trial of Interest

<sup>1</sup> - with link to Google scholar search for background information

<sup>2</sup> - with short name for target/mechanism of action  
(sometimes linked to a related PAL topic)

<sup>3</sup> - Shows clinical trials for study drug on ClinicalTrial.gov

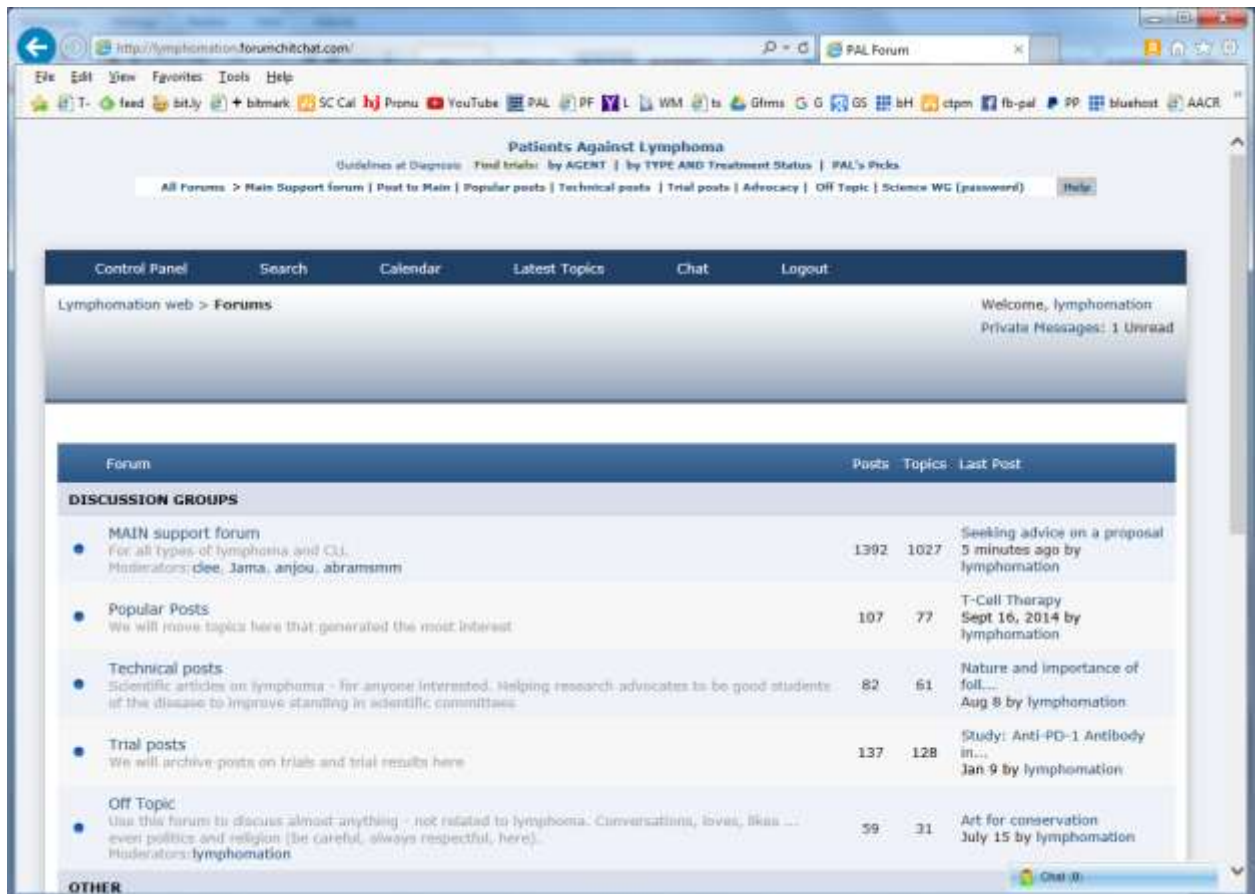
See <http://www.lymphomation.org/agents.htm>

### Overview of PAL's Support

- **PAL forum** - a moderated web-based forum where we distribute information directly to the lymphoma community. Subscribers can ask or respond to posts, and have off-topic discussions if desired in sub-forums set up for this purpose.

To protect the privacy of the subscribers our forum is not open to web site searches and subscribers must register and create a password.

There are 365 subscribers as of this date.



See <http://lymphomation.forumchitchat.com/>

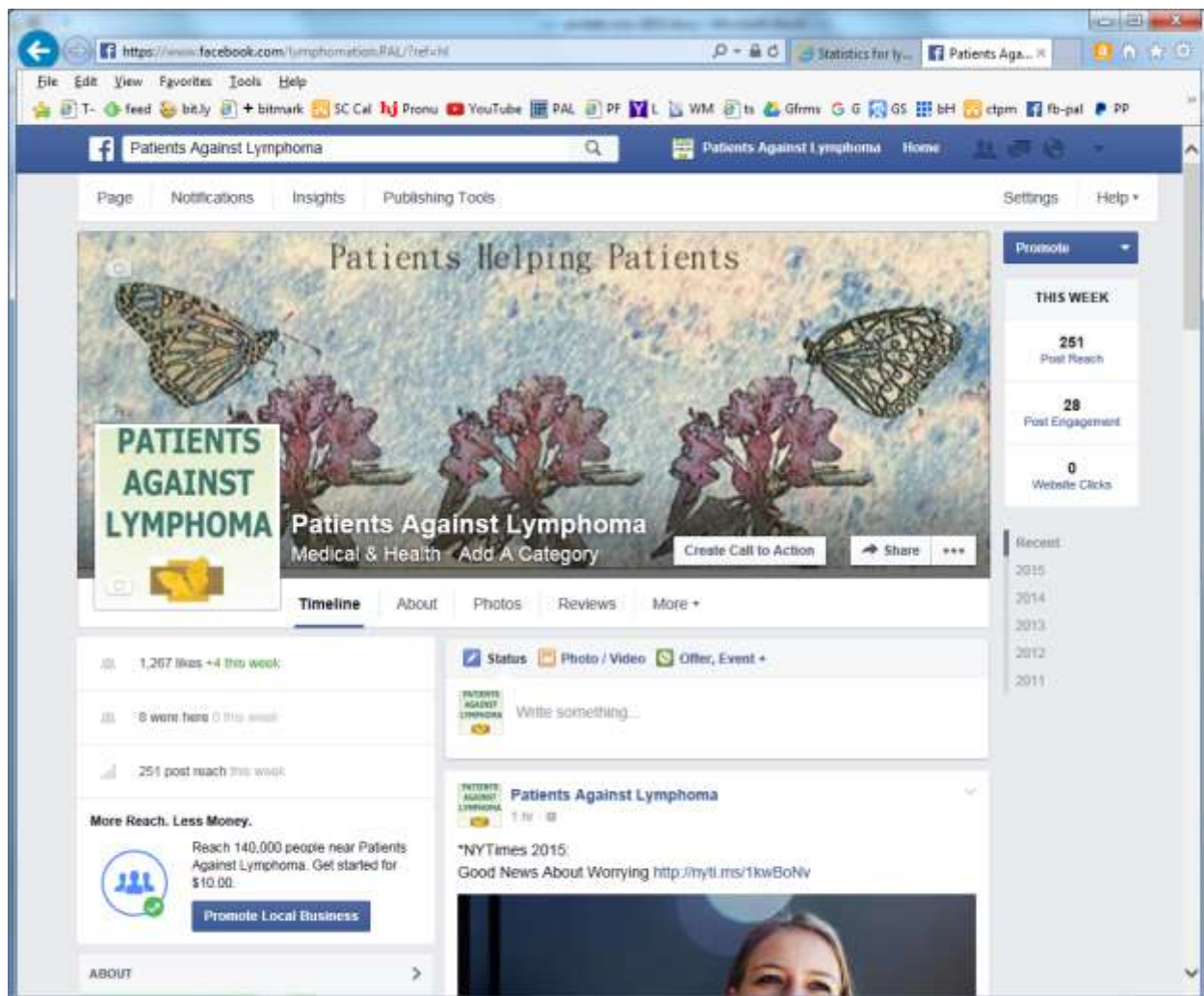
- **Lymphomation on Yahoo groups** – a moderated email-based forum where we distribute information directly to the lymphoma community. Subscribers can ask or respond to posts. To protect the privacy of subscribers the forum is not open to web site searches and subscribers must register and create a password.

There are 249 subscribers as of this date.

To subscribe to either support venue: <http://www.lymphomation.org/support-groups.htm>

## Patients Against Lymphoma on Facebook

We also provide a facebook resource in order to provide useful and encouraging support information.



See [www.facebook.com/lymphomation.PAL](http://www.facebook.com/lymphomation.PAL)

## Lymphomation on Twitter

Our twitter account allows PAL to communicate with a wider audience – in particular medical professionals involved in lymphoma research, and other advocates. Here we share perspectives, notify about new topics and research news.



See <https://twitter.com/lymphomation>

We have 2,228 followers. Hash tags: [#lymsm](#) | [#Follic](#) [#CLL](#)

## Research Advocacy

We are partners with scientists and researchers – helping to make clinical research more efficient and patient centered. Karl Schwartz participates in the following:

- **NCI cIRB** (centralized Institutional Review Board)
- **NCI CTPM** (clinical trials planning meeting) for lymphoma
- **NCI Lymphoma Steering Committee**
- **Patient Advocate Committee (co-chair)**

We have proposed a hybrid trial design that is gaining traction among some researchers and statisticians. It's called the **Observation-Enriched Randomized Clinical Trial (OE-RCT)**, which allows participants to choose to be randomized or to choose the preferred study arm when the patient has a preference. See *for the OE-RCT at a glance – [a schema](#)*.

## On the OE-RCT, an influential patient advocate wrote:

*Of interest to all of you might be my continuing efforts to "advocate" OE-RCTs. I talk about this design both formally and informally whenever I have a chance. For example, both last November and last week I had the privilege to be on FOCR (Friends of Cancer Research) panels and mentioned the design. Last year, in response to a question, I got Rich Simon to publicly "sort of" endorse the design. This year on a panel about "Blurring the Distinction between Phase 1, 2 and 3" I mentioned it publicly, and also sat next to Lisa LaVange (who is head of Bio-stat for all of FDA) and was pleased to learn that she is actually a big advocate of OE-RCT and believe SMART (Sequentially multiple assignment randomized trials, which we are proposing for I-SPY 2+)' unfortunately Raji (FDA's biostatistician for Cancer) is not as enthusiastic. I also wrote about OE-RCT in a commentary that will be published next month.*

## Goals Moving Forward

With the help of our scientific advisors we will continue to develop **evidence-based** content and tools to support patients and to help advance progress against lymphoma ... based on the **questions we receive from patients and caregivers.**

**Since 2001**, we rely on individual donations from the patient community as PAL does not accept donations from pharmaceutical or vitamin companies.

See How to help: <http://www.lymphomation.org/how-to-help.htm>



### How to Help

**Again, we thank you for, need, and encourage your continuing support!**