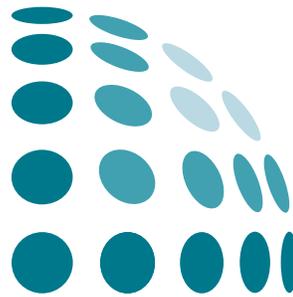


# 2012 LeIP REPORT CARD

Lymphoma eInformation Project (LeIP)

**LYMPHOMA  
COALITION**

Worldwide Network of  
Lymphoma Patient Groups



## Lymphoma Report Card on

Clinical Trials  
Standard of Care  
Demographics  
Treatment Access

*Lymphoma patients everywhere have the right to an understanding of and access to the latest evidence-based therapies and diagnostic protocol information. Any constraints in providing this type of information should not serve as a barrier to the flow of information that could possibly result in best practice saving patient lives.*

## 2012 LeIP REPORT CARD

### Lymphoma eInformation Project

**SPECIAL THANKS** to all the lymphoma patients and the LC member organisations who offered their insight and support for this publication. In particular those who participated in the 2012 LC Global Patient Survey, the 2012 LC Member Clinical Trials Survey and the many other organisations and individuals who generously shared their ideas with us, especially the LeIP committee members.

Thank you to the editorial committee for making time to review the initial goals and the outcomes.

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**Founding Sponsors:** Celgene Corporation, Michael Crowthers, Chad Saward; Millennium: The Takeda Oncology Group, Kip Cross.

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Thank you to the following committee members for taking the time to offer perspective into each lymphoma subtype.

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Thank you to Celgene Corporation and Millennium: The Takeda Oncology Group for your support of LeIP.

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**DISCLAIMER:** Lymphoma Coalition (LC) provides the 2012 LeIP Report Card for general information related to topics relevant to lymphoma worldwide. While LC makes best efforts to ensure accuracy, the information contained in the 2012 LeIP Report Card is taken from various public and private sources so that no responsibility can be assumed by LC for the accuracy or timeliness of this information.

**WARNING:** LC's 2012 LeIP Report Card should not be used for the purpose of self-diagnosis, self-treatment or as an alternative to medical care. If you have any concerns arising out of the information contained in LC's 2012 LeIP Report Card, you should consult your own physician or medical advisor. If you suspect you have lymphoma, seek professional treatment immediately.

## ABOUT LYMPHOMA COALITION

The Lymphoma Coalition (LC) is a global network of 54 lymphoma patient organisations from 40 countries with a Vision to free the world of lymphomas.

LC supports its member organisations through its Mission activities by raising the awareness, improving the understanding, ensuring best practice management of lymphomas, and encouraging the creation of new lymphoma patient groups in countries where one does not presently exist. Our goal is to encourage the best patient care around the world with the end goal of saving more lives.

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**Karen Van Rassel**  
Executive Director  
Lymphoma Coalition

## A MESSAGE FROM THE EXECUTIVE DIRECTOR

Lymphoma Coalition's (LC) strength as a global coalition lies in its network of 54 member patient organisations with a unique ability to develop a synergy among members to build an effective platform for the sharing of information among its local community, as well as advocate for change.

LC is endeavoring to accomplish its mandate within a rapidly changing environment for which information about topics such as standard of care, clinical trials, treatment availability and demographics on both a global scale and at the local level is essential to understanding best practices with the end goal of saving patient lives. Thus the establishment of the Lymphoma eInformation Project (LeIP).

Thank you to Lucy Krucko for your hundreds of internet research hours and to Perception Insight for the compiling and analysis of all three components of the research, the Global Patient Survey, the LC Member Clinical Trial Survey along with the LeIP research resulting in the following 2012 LeIP Report Card.

The report is supported by four separate summary reports, the 2012 Global Patient Survey, Standard of Care, Clinical Trials and Demographic and Treatment Access summaries as well as many information charts that will provide ongoing up-to-date local information. Please visit the LC website to view this information.

LC is privileged to partner with the INTERLYMPH Consortium, and their latest findings of risk factors and causes of lymphoma is included. Thank you to the members of the consortium for bringing together all the global research in this area to compare results and expand on the excellent work being done in centres all over the world.

Over the next two phases of LeIP, LC will develop the 2012 LeIP report recommendations, evaluate the role of biosimilars in patient care and continue to research issues and needs while bringing up-to-date information to our membership and the global lymphoma community. There is work to be done to ensure equality among all patients and to ensure that lymphoma healthcare is protected, especially during tough economic times.

## A MESSAGE FROM THE CHAIR OF THE LC MEDICAL ADVISORY BOARD



**Dr. Laurie Sehn, MD, MPH**  
Chair, BC Cancer Agency Lymphoma Tumor Group  
Clinical Associate Professor at the University of British Columbia, Vancouver, Canada  
Chair, LC Medical Advisory Board

Lymphoma is a complex malignancy. There are varied clinical presentations, multiple diagnostic subtypes, and a multitude of treatment options. Worldwide, there are regional variations in incidence of lymphoma subtypes, disparities in access to therapies and differences in management approaches. Despite these challenges, the Lymphoma Coalition (LC) and its member organisations have a common goal, to ensure that all patients with lymphoma have access to comprehensive and reliable information regarding diagnostic standards, therapeutic options, best practice approaches and novel therapeutics in development within the context of clinical trials. This initial report provided by LC highlights the lack of such a resource in the majority of countries reviewed, demonstrating the significant need for a centralized source of information such as LeIP.

Once fully developed, LeIP will serve as a global resource for patients, patient support organisations, advocacy groups and physicians. Using a structured framework and standardized process, it will aim to provide relevant and updated information that will empower patients with the knowledge required to become an active participant in the treatment process. It will also serve to facilitate interactions between patients and support groups, to provide valuable information on regional disparities that can be helpful to advocacy organisations, and to foster a culture of enthusiasm in clinical trials, which may improve enrollment and thereby promote drug development. The initial steps taken by LC have enabled the development of a strategic plan to create a resource with the potential to universally impact the quality of lymphoma care.

## A MESSAGE FROM THE CHAIR OF THE LC BOARD OF DIRECTORS



**Anna Williamson, PhD**  
General Manager Research and Advocacy,  
Leukaemia Foundation of Australia  
Chair, LC Board of Directors.

We understand from psychosocial research into the needs of newly diagnosed cancer patients that their greatest need at diagnosis is to have access to accurate and comprehensible information about their lymphoma, how their lymphoma will be managed and what they can expect to experience in both the short and longer term.

LeIP is LC's first major attempt to document and report on the status of lymphoma and its management in the 40 member countries around the globe. The collation and analysis of the data and information presented in LeIP 2012 clearly demonstrates that lymphoma patients and the member organisations that support them in different parts of the world have varying experiences of diagnosis and differing access to the most appropriate therapy for their sub form of lymphoma. Even in parts of the world where care can be regarded as "good or excellent", there appears to be plenty of room to improve. For patients in some countries access to comprehensive diagnostic services, malignant haematology expertise, good hospital services and drug supply schemes as well as infrastructure to support research-based medicine remain elusive.

The Lymphoma Coalition hopes to track measurable improvements in lymphoma experiences of patients in member countries over time. We envisage that with this annual "report card" for lymphoma, members and the patients will have evidence to advocate for improvement in their own organisations and countries. We hope that in time LeIP will provide the impetus to seriously address patient needs leading to better survival and quality of life for every person in the world living with lymphoma.

**LYMPHOMA  
COALITION**

Worldwide Network of  
Lymphoma Patient Groups



# 2012 LeIP REPORT CARD

Lymphoma eInformation Project (LeIP)

## BACKGROUND

The Lymphoma Coalition (LC) is a global network of 54 lymphoma patient organisations with a vision to free the world of lymphomas.

LC supports its member organisations to affect change by raising the awareness, improving the understanding, and ensuring best practice management of lymphomas, leading to best patient care around the world with the end goal of saving more lives.

LC is endeavoring to accomplish its mandate within the context of a rapidly changing environment for which information about topics such as standard of care, treatment availability, clinical trials and demographics on both a global scale and at the local level are available for all member countries. This is essential to understanding best practice with the end goal of saving more patient lives.

For example, consider the following:

- The continually evolving complexities of lymphoma including the identification of subtypes;
- The availability of more treatment options resulting in the trend toward individualized patient care, complicated by the lack of a formal or optional education process for healthcare professionals;
- The inequality of treatment access caused by huge disparities in healthcare prioritization amongst member countries;
- The difficulties in developing cost effective therapies for less common subtypes, made more difficult by smaller demographic populations and patient availability for clinical trials;
- The global healthcare community's lack of understanding about lymphomas as evidenced by the high rates of misdiagnosis and inappropriate management<sup>(1)</sup>; and
- The barriers to treatment for patients in countries struggling with financial constraints imposed by the world's economic woes as well as the lack of access to healthcare professionals, therapies, pathology services and supportive care.

Despite these circumstances, it is LC's position that:

- Lymphoma communities have the right to access the most current information by subtype, so that trends can be monitored in the progression of various lymphoma subtype definitions and the effectiveness of new therapies;
- Lymphoma patients everywhere have the right to an understanding of and access to the latest evidence-based therapies and diagnostic protocol information;
- Any constraints in providing this type of information should not serve as a barrier to the flow of information that could possibly result in best practice saving patient lives and that;

- Consideration must be given within the context of economic conditions around the world, to ensure that all lymphoma patients regardless of their personal situations are informed and treated equally.

The Lymphoma Coalition recognises the value and the potential power behind a centralized global resource for lymphoma communities everywhere that would provide them with the information they need to understand:

- The growth of less common subtype populations that may require more global collaboration to gain a critical mass of patients so that the best diagnostic process and therapies can be developed thereby reducing the cost and timing to bring them to market;
- The effectiveness of new therapies by subtype population;
- A 'best practice evidence-based' versus the 'best available' standard of care and diagnostic protocol resource; and
- Information about standard of care and the availability of clinical trials in a language appropriate to different countries and communities.

LeIP was established to facilitate a process for the gathering and dissemination of credible, reliable and current information about lymphoma to:

1. Channel information worldwide to raise lymphoma awareness, improve understanding and ensure best practice management of lymphomas;
2. Create a situation analysis of lymphoma demographics to highlight the differences in reporting by country as well as the lack of subtype reporting;
3. Determine reasons for the importance of clinical trials and the puzzling lack of patient enrolment around the world from the member organisation perspective;
4. Provide clarity around how the term 'standard of care' is being interpreted, and an overview of what resources are currently available that might fit the definition of 'best practice' based on the latest evidence-based protocols, versus that which is 'best available';
5. Provide resource information for both evidence-based research for 'best practice' standard of care as well as clinical trials by member country;
6. Provide information about the approval status of various treatments for the five lymphomas that were the focus of Phase I of LeIP, Follicular (FL), T Cell, Diffuse Large B Cell Lymphoma (DLBCL), Hodgkin Lymphoma (HL) and Chronic Lymphocytic Leukemia (CLL).

## METHODOLOGY

The goals of Phase I of LeIP were accomplished through:

- The establishment of and meetings with five subtype advisory committees and an editorial committee, made up of hematologists, patient groups and a nursing representative to provide both guidance and direction;
- Consideration of findings within the context of results of the Lymphoma Coalition 2012 Global Patient Survey (1700 respondents globally);
- Completion of a survey with 29 patient leaders in 19 patient organisations around the world in an effort to better understand enrolment rates in clinical trials, barriers to enrolment, and potential opportunities to connect with and educate newly diagnosed patients; as well as
- Searches for country and subtype specific, reputable websites providing:
  - Demographic information;
  - List of available clinical trials;
  - 'Best practice' and 'best available' standards of care, and;
  - The approval status of 31 lymphoma drug therapies.

Due to the overwhelming volume of information anticipated from searches of over 3,800 websites, this information was concisely captured in charts detailing any existing information and practices that will be regularly updated and maintained on the LC website.

Readers are also encouraged to visit this site to review separate, more detailed summary reports for each of the following topics: LC Global Patient Survey<sup>(2)</sup>, Demographics and Access to Treatment<sup>(3)</sup>, Clinical Trials<sup>(5)</sup>, Standard of Care<sup>(7)</sup> and summary charts for each LC member country<sup>(8)</sup>.

This phase of LeIP was conducted with LC member countries only, as it is within these countries the Coalition is able to affect real change, and for CLL, HL, DLBCL, T Cell and FL, the intent being the eventual inclusion of all subtypes and countries in later phases of the project.

## KEY FINDINGS & DISCUSSION

As anticipated, during our research for Phase I of LeIP, available information sources about demographics, treatment approvals, clinical trials, and standards of care were found to be inadequate, confusing and inconsistent across LC member countries as illustrated in the tables that follow. These tables are presented along with other key findings from the research conducted.

### LC 2012 Global Patient Survey

Along with Phase I of LeIP, a worldwide survey of 1700 lymphoma patients was conducted among LC member countries<sup>(2)</sup>.

Key findings from that survey are as follows:

- Although awareness about lymphomas amongst the general public has shown an increase over the last two years, this understanding is still relatively poor as evidenced by the fundamental lack of awareness as to basic symptoms of the disease;
- Understanding about lymphomas is also low within the healthcare community as shown by the rate of misdiagnosis, inappropriate treatment, and the time taken for an accurate diagnosis;
- Although lymphoma patients were willing to learn more about and participate in clinical trials, their lack of understanding and the inadequacy of information was the most significant barrier to enrolment;
- The earlier a patient understands their treatment options, i.e. at the initial diagnosis stage, the greater the opportunity they can make an informed treatment decision;
- Despite the increasing need for information and support for how patients might enhance the quality of their lives as they live longer with a more chronic disease, there are significant gaps in what the healthcare profession, treatment centers and patient support organisations are able to do in terms of making patients aware of and delivering the support resources available to help them improve their quality of life; and
- In this respect, patient organisations are essentially an untapped resource for newly diagnosed patients.

### Demographics & Treatment Access

As shown in Table 1, current, country specific or global information that would provide a demographic picture of lymphoma by subtype trends over time proved to be difficult to access, and was either very limited or non-existent.

In fact, to complicate matters, the demographic information about lymphomas was available only for 'leukemia' (which included CLL), 'Hodgkin lymphoma', and 'non-Hodgkin lymphoma'.

**Table 1 - Most Recent Demographic Data Available by LC Member Country**

DATA	2012	2008
Population	X	X
Lymphoma Incidence	(X) Canada & US only (Canada: HL & NHL only; USA: HL, NHL, CLL)	X
Lymphoma Mortality	(X) US only (HL, NHL, CLL)	X
5 year Prevalence		X
GDP (US\$)		X
Healthcare System	X	
Lymphoma Treatment Approval Status	X	
Standard of Care	X	
Clinical Trials	X	

The benefit of this demographic information, should it become available, can be illustrated by the U.S. and Canada, the only countries providing recent information for which a trend analysis could occur<sup>(4)</sup>.

As shown in Table 2, information about access to lymphoma therapies is not recorded in a global database nor is it easily accessible, complete or consistently or formally available in many countries.

**Table 2 - Rating on Availability of Information on Approval Status for Lymphoma Treatment by LC Member Country**

RATING (% for which information was available on the internet about treatment approval status )	LC MEMBER COUNTRIES		
	# of Countries	% of Countries	Country
<b>GOOD</b> (94% - 100%)	23	58%	Canada, U.S.A., Bulgaria, Czech Republic, Denmark, France, Germany, Hungary, Ireland, Italy, Latvia, Lithuania, Macedonia, Netherlands, Poland, Slovakia, Slovenia, Spain, Sweden, U.K., Belgium, Australia, New Zealand
<b>AVERAGE</b> (79% - 85%)	8	20%	Mexico, Barbados, Colombia, Uruguay, Switzerland, India, Japan, Singapore
<b>POOR</b> (0% - 18%)	9	22%	Argentina, Brazil, Venezuela, Croatia, Serbia, Turkey, Ukraine, China, Russia
<b>TOTAL</b>	<b>40</b>	<b>100%</b>	

Specifically, 78% of LC's member countries have 'good to average' information available on the internet about the approval status of lymphoma treatments. This means that information was only available for 79% of the therapies researched.

### Clinical Trials

During our research it was determined that only 30% of member countries had easily accessible, country specific websites about the availability of clinical trials in their own countries, while 70% did not, nor was there a centrally available, multi-lingual global resource for such information. (See Table 3)

Furthermore, as determined in the 2012 LC Patient Organisation survey<sup>(6)</sup>:

- While patient organisations were just as willing to provide clinical trial information to newly diagnosed patients as patients were to enrol in them, their sources for procuring this information and the approaches used have varied across member organisations;

- Patient organisations may be unable to assist newly diagnosed patients about clinical trials as an important treatment option insofar as they lack access to these patients as well as information about clinical trials themselves, but given the appropriate information and patient access, this situation could change; and
- There is a lot of missed opportunity for patient organisations to not only connect with, but also to strengthen relationships with newly diagnosed patients to offer support and information alongside the healthcare community.

**Table 3 - Availability of Country-Specific Clinical Trial Websites by LC Member Country**

Country-specific website available?	No. (%)	LC MEMBER COUNTRIES
YES	12 (30%)	<b>NORTH AMERICA:</b> Canada, U.S. <b>SOUTH AMERICA:</b> Brazil <b>EUROPE:</b> Switzerland <b>EUROPEAN UNION:</b> Ireland, Italy, Netherlands, U.K. <b>ASIA PACIFIC:</b> India, Japan, Australia, New Zealand
NO	28 (70%)	<b>NORTH AMERICA:</b> Mexico, Barbados <b>SOUTH AMERICA:</b> Argentina, Colombia, Uruguay, Venezuela <b>EUROPE:</b> Croatia, Serbia, Turkey, Ukraine <b>EUROPEAN UNION:</b> Belgium, Bulgaria, Czech Republic, Denmark, France, Germany, Hungary, Latvia, Lithuania, Macedonia, Poland, Slovakia, Slovenia, Spain, Sweden <b>ASIA PACIFIC:</b> China, Russia, Singapore
<b>TOTAL</b>	<b>40</b> <b>(100%)</b>	

### Standard of Care

The term 'standard of care' is used rather loosely around the world, where the 'standards' used in one country are not necessarily the same as those used in others, and so typically are based on the 'best available care,' rather than on the most current evidence-based or 'best practice' standard of care.

Specifically, only four sites were found in three countries (Canada, UK and Germany) providing the latest evidence-based diagnostic and therapeutic protocols.

This is detailed in Table 4, which shows that only 8% of LC member countries had a 'best practice' standard of care, none had guidelines, 15% had informational resources only, and as many as 77% had incomplete information.

**Table 4: - Member Countries by Standard of Care Categories**

CATEGORY	DEFINITION	LC MEMBER COUNTRIES	
		No. (%)	BY CONTINENT
Standard of Care	'Best practice' or providing the latest evidence-based protocols, including full treatment algorithms and dosage information.	3 (8%)	NORTH AMERICA (2 of 4): Canada, USA EUROPEAN UNION ( 1 of 19): Germany
Guidelines	Resources not providing full treatment algorithm or dosage information, yet providing detailed information about care.	0 (0%)	
Informational	Resources providing general treatment information and may break out by subtype.	6 (15%)	SOUTH AMERICA (2 of 5): Uruguay, Venezuela EUROPEAN UNION (3 of 19): Bulgaria, France, Ireland ASIA PACIFIC (1 of 7): Australia
Incomplete	Information is general in nature, i.e. no reference to lymphoma specifically.	31 (77%)	NORTH AMERICA (2 of 4): Mexico, Barbados SOUTH AMERICA (3 of 5): Argentina, Brazil, Colombia EUROPE (5 of 5): Croatia, Serbia, Switzerland, Turkey, Ukraine EUROPEAN UNION (15 of 19): Belgium, Czech Republic, Denmark, Hungary, Italy, Latvia, Lithuania, Macedonia, Netherlands, Poland, Slovakia, Slovenia, Spain, Sweden, United Kingdom ASIA PACIFIC (6 of 7): China, Russia, Singapore, Japan, India, New Zealand
<b>TOTAL</b>		<b>40 (100%)</b>	

## CONCLUSIONS

After searches of over a thousand internet sources, it was concluded that both country and lymphoma subtype specific published information about latest evidence-based standard of care, including diagnostics, the access of lymphoma therapies and clinical trial information was difficult to access, inadequate, and/or inconsistent across LC member countries. This results in confusion and missed opportunities across global lymphoma communities for example including:

- The inability to track the effectiveness of new therapies and trends by subtype to determine those requiring more attention;
- A lack of empowering information for member countries to advocate for changes in treatment options in their own countries;
- The inability of patient organisations to assist newly diagnosed patients willing to explore clinical trials as an important treatment option;
- Enrolment in clinical trials, negatively affecting the development of therapies for increasing numbers of smaller subtype populations such as T Cell lymphomas for example, that may require more global collaboration to gain a critical mass of available patient subjects;
- Lack of treatment choices caused by the gap in understanding between what is the 'best available' versus 'best practice' standard of care;
- High rates of lymphoma misdiagnosis by the medical profession based on the Global Patient Survey.

On the flip side, LC believes that the creation and provision of credible sources of published, consistent and current

information on both a global scale and at the local LC member level should take place yielding the following potential benefits:

- The bi-annual gathering of demographic information by lymphoma subtype would allow for a better demographic trend and treatment success analysis, as well as aid global collaboration for less costly and more timely development of the best diagnostic process and therapies;
- The ongoing collection of treatment availability data by country would provide member organisations, healthcare professionals and patients with empowering information about the latest clinically proven therapies by which they could advocate for change in their own countries;
- Information about clinical trials would give patient organisations the ability to strengthen relationships with patients to offer support and information alongside the healthcare community at the newly diagnosed stage;
- Information for 'best practice' standard of care therapies and protocol versus what is the 'best available' treatment by country would provide better clarity around correct diagnosis and treatment options for patients as well as allowing for the option of a better informed patient journey; and
- Further inferring that all patients have a right to this understanding, thereby putting the onus on and providing the healthcare profession with the responsibility of educating both themselves and the patient about 'best practice' standard of care therapies and protocols.

- It is Lymphoma Coalition's belief that its member organisations are perfectly positioned to act as enablers in facilitating a consistent flow of information to lymphoma communities. By highlighting best practice, it provides the opportunity to have the most informed patient.

## RECOMMENDATIONS

This report is a call for the lymphoma community to come together to ensure that a consistent, accurate and current flow of information be developed so all parties involved will be informed.

With this in mind, it is recommended that:

1. A bi-annual gathering of demographic information by country and by lymphoma subtype be undertaken to provide a better understanding of how each cancer is tracking, act as an enabler to benchmark trends so to plan for, and provide more leverage for awareness and advocate for what is needed;
2. LC develop a protocol for information gathering and dissemination for any treatment altering clinical trials;
3. LC determine how best to ensure that members and their local communities have easy access to clinical trial and standard of care websites in a language they understand;
4. A structured, formal process and communication plan be developed that would keep Lymphoma Coalition up to date on the newest developments particularly for 'best practice' standard of care and available treatments;
5. LC work with the healthcare community through education of member organisations to address the misdiagnosis issues focusing on signs and symptoms of lymphoma and lymphoma subtypes;
6. The barriers to treatment be reviewed in countries that struggle with basic issues of access to healthcare professionals, therapies and pathology services;
7. LC determine how the term 'standard of care' is being defined and used by local medical communities, enabling effective education about any differences;
8. A formal process be developed to assist in connecting the newly diagnosed patient and the local patient organisation with the primary objective of ongoing support and information dissemination. Achievement of this goal will require:
  - a. The education of patient organisations so they fully understand not only the implications of clinical trials, but also the importance of their role in proactively providing information to inform patients;
  - b. The development of a global toolbox that would provide patient organisations with an understanding

of how to support and educate newly diagnosed patients, including information about clinical trial access, barriers to enrolment and treatment access, as well as ongoing psycho-social support; and

c. An exploration of how patient organisations could become better connected with their own healthcare communities so they are able to work with and build relationships with the newly diagnosed patient, resulting in the development of a standardized, global mechanism for patient organisations to work alongside healthcare professionals to foster a connection with their local patient organisations.

9. LC take the treatment access chart one step further and review and gather information on reimbursement.
10. LeIP information will be housed on the LC website, and regularly updated and maintained.

In Phase II & III of LeIP, LC will evaluate and work towards the recommendations listed above and continue to strive to meet its objective of providing patient organisations with accessible information about 'best practice' standard of care by creating a global resource while remaining diligent to the education process that not all therapies are the best option for every patient.

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## CAUSES & RISK FACTORS OF LYMPHOMA LATEST FINDINGS FROM INTERLYMPH CONSORTIUM 2012



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Epidemiology (InterLymph) Consortium.

### What is InterLymph?

The International Lymphoma Epidemiology Consortium (InterLymph,) is an open international consortium of research groups and individuals who have conducted large-scale epidemiology studies of non-Hodgkin lymphoma (NHL) aetiological and prognostic risk factors. In 2000, epidemiologists at the United States National Cancer Institute (NCI) were instrumental in the formation of the Consortium and the NCI continues to host a web portal for use by InterLymph members. Although the main emphasis of the collaboration is epidemiology, InterLymph has expanded to include geneticists, pathologists, immunologists, clinicians and other scientists and now includes more than 100 members. InterLymph consists of four specialist working groups (Immunology and Infection, lifestyle and environment, pathology and survival, genetics), and has evolved to include multiple large scale projects that operate across working groups. <http://epi.grants.cancer.gov/InterLymph/>

### What are the goals of InterLymph?

The overarching goal of InterLymph is to identify patterns of commonality and heterogeneity in the etiology of NHL subtypes which may assist in illustrating mechanisms of lymphomagenesis. This knowledge has implications for understanding biology, etiology, prevention and control of these malignancies. The Consortium aims to achieve this by addressing research questions that are difficult to answer in individual studies, by sharing data and biological samples. The Consortium has established a central data coordinating centre that is a repository of pooled, harmonised data from all recently completed international case-control studies of NHL. It has also facilitated the creation of secondary data as well as new, second-generation studies that are currently in the field. To-date 22 peer-reviewed manuscripts describing pooled InterLymph Consortium studies have been accepted for publication.

### Latest findings from InterLymph

A pooled analysis of 17 InterLymph case-control studies (Becker N et al, International Journal of Cancer, in press 2012) including more than 12,000 NHL patients and 15,000 controls, observed a modest excess risk of NHL associated with a self-reported history of infectious mononucleosis. The strongest association was found for the CLL and T-cell NHL subtypes. Infectious mononucleosis is caused by infection with Epstein-Barr virus in adolescence or later life. Unexpectedly, a self-reported history of measles or whooping cough was associated with a small (15%) reduction in NHL risk. However, this finding was considered to have occurred due to chance or systematic bias in reporting. A range of other infections were examined and showed no association with NHL risk. It was concluded that there was little clear evidence of an association between NHL risk and self-reported history of infection as a child or adult.

A pooled analysis of 18 InterLymph case-control studies with 4263 NHL patients and 5971 controls (Kane et al, Annals of Oncology 2012;23:2362-74) found little evidence of an association between reproductive factors and risk of NHL overall or of diffuse large B-cell lymphoma. However, the risk of follicular lymphoma decreased with increasing number of pregnancies, and increased with use of hormonal contraception. Menstrual factors were also examined and were not associated with NHL risk.

A pooled analysis of 9 InterLymph case-control studies with close to 5000 participating subjects (Kane et al, Annals of Oncology, in press 2012) observed a 20% reduction in risk of NHL in postmenopausal women who used hormone therapy, in particular in women who started hormone therapy when they were 50 years of age or older. However, there was no clear trend with increasing number of years of use. Current users were at decreased risk while those who had stopped using the therapy more than 2 years ago were not. Risk reductions were observed for the two most common NHL subtypes, diffuse large B-cell lymphoma and follicular lymphoma. Risk of NHL was not associated with history of hysterectomy.

# [www.lymphomacoalition.org](http://www.lymphomacoalition.org)

*Consideration must be given within the context of economic conditions around the world, to ensure that all lymphoma patients regardless of their personal situations are informed and treated equally.*



**Recognize World Lymphoma Awareness Day on September 15th**

Contact us if you are a patient organisation that focuses on lymphoma, including CLL, or if you are interested in starting a patient organisation.

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