About Lymphoma Coalition

The Lymphoma Coalition (LC), a non-profit organisation, was formed in 2002 and incorporated in 2010 with the express purpose of facilitating lymphoma patient organisations around the world to form a community that could support one another’s efforts in helping patients with lymphoma receive the best care and support. LC is made up of 71 patient organisations from 48 countries. The need for a global coalition was recognised as a way to bring together members to share resources and best practices; collect global information and provide an online platform for information dissemination; and build a network of Lymphoma Opinion Leaders. The goal of the coalition is to transform the lymphoma landscape ensuring patient centricity is defined by people affected by lymphoma in order to improve patient outcomes across all health system decisions.

Special Thanks
Special thanks to all patients and the LC member organisations who offered their insight and support as well as to the many other organisations, government agencies, pharmaceutical companies, medical professionals, pharmacists and individuals who generously shared their knowledge, resources and understanding for this report. Thank you to the editorial committee for making time to review the report: Dr. Laurie Sehn, Pru Etcheverry, Lorna Warwick and Shawn Sajkowski. Thank you to those who provided an unrestricted grant to support this project: Celgene Corporation, Pfizer, Inc., and Takeda Oncology.

LeIP Team
Karen Van Rassel, Leonie Bedford, Shawn Sajkowski and Shafia Abdulhusein

Disclaimer
Lymphoma Coalition (LC) provides the 2017 Report Card on Lymphomas for general information related to topics relevant to lymphoma worldwide. While LC makes every effort to ensure accuracy, the information contained in the report is taken from various public and private sources. No responsibility can be assumed by LC for the accuracy or timeliness of this information.

Warning
LC’s 2017 Report Card on Lymphomas 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 this report, you should consult your own physician or medical advisor. If you suspect you have lymphoma, seek professional attention immediately.
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Message from the Chair of the LC Medical Advisory Board

Laurie H. Sehn, MD, MPH
Chair, BC Cancer Agency Lymphoma Tumour Group
Clinical Professor, University of British Columbia, Vancouver, Canada

Supporting patients with such a complex cancer like lymphoma does not stop in our offices or clinics. The 2017 Report Card on Lymphomas discusses the findings from the 2016 Lymphoma Global Patient Survey that showed many patients and their caregivers were not receiving the supportive care they required.

The 2017 Report Card on Lymphomas also demonstrates that patients deal with psychological as well as medical issues not only during treatment, but also long after treatment is completed. When patients seek help, 80% view their doctor as their primary source of information. Unfortunately, only 30% of them find that their doctor is able to help. While we, as a physician community, cannot provide all the help patients need, we can ensure they know about credible resources. We can do this by providing patients with support tools and information on supportive care and patient organisations so they do not feel alone.

I urge each of you to take the healthcare support challenge (Figure 5, p. 18). It is a short quiz to help you determine if you know what patients truly need. By answering the questions honestly, you will be making a positive contribution to ensure patients receive the best care possible.
Message from the Chair of the LC Board of Directors

Pru Etcheverry
CEO, Leukaemia & Blood Cancer New Zealand

With a strong focus on patient centricity, the Lymphoma Coalition has defined it to ensure that all patients with lymphomas and chronic lymphocytic leukaemia are offered the best care and those working in this field encompass this into their daily activities.

- Engaging individuals with lymphoma, and their caregivers in all aspects of their care, tailoring support with the understanding that every patient is unique with a different set of complex needs that may change over time.

- Giving the lymphoma patient, and those close to them, a voice so that the focus of their care and needs are included throughout the decision-making process.

- Listening to and hearing the person affected by lymphoma respecting their culture, input, dignity, intelligence and capacity to make informed decisions about the impact on their lives and their care.

- Including patient organisations as active partners representing a patient’s emotional and psychosocial needs at every stage of care including; treatment, protocol development and by informing research throughout the clinical and treatment development continuum.

We understand so much about patient needs by walking alongside them daily as well as through specific learnings from our 2016 Lymphoma Global Patient Survey. It is important to give patients with lymphoma the voice they require to ensure they feel emotionally supported and empowered to receive the care they seek and need.

As a global lymphoma patient coalition, we need to ensure that input from patients, their caregivers and patient organisations is a fundamental part of all stages of the patient experience, from diagnosis and throughout survivorship. This approach ensures improved quality of life for patients and fosters patient confidence in knowing they will be supported regardless of their experience.
Message from the

Chief
Executive Officer

Karen Van Rassel

For the 2017 Report Card on Lymphomas, the Lymphoma Coalition (LC) focused on the impediments that prevent patients from receiving optimal care. These impediments – unequal access to clinical trials, no or limited funding/reimbursement of therapies, limited supportive care and limited access to specialists and treatment centres – must be diminished or, ideally, removed altogether. In spite of our best efforts, patients continue to struggle to receive the care they need. While this is somewhat disheartening, our members continue to make sterling efforts to improve access to care.

This year, we have included two case studies that demonstrate what members have done to improve access to care. These case studies – from Oncohaematological Patients’ Association of Blood, (OHLB) Kraujas, Lithuania, and Udruženje Obolelih od Limfoma (LIPA), Serbia – show that by all stakeholders working together, patients’ lives can be improved.

It’s time to see access as true access for the patient. Defining it as regulatory approval for a product is not enough. When we are pricing a product, designing a clinical trial or protocol, or setting our training plans for doctors worldwide, we need to ask ourselves: are we ensuring that real access and real outcomes are manageable and achievable for all patients regardless of where they live?

Thank you for being part of the solution.

Many thanks to our financial supporters. It is through their support that we are able to undertake the advocacy work that supports patients while, at the same time, identifies the gaps in patient care. As in previous years, heartfelt thanks to the editorial committee for reviewing this report as well as all the LC member organisations whose input has been most valuable.
Overview

The Lymphoma Coalition (LC) continues its quest to improve access to therapy, including clinical trials, in a timely and cost-effective manner for all patients with lymphoma. However, through discussions with LC member countries and findings from the 2016 Lymphoma Global Patient Survey (GPS), LC has identified four impediments that need to be addressed to improve therapy access.

Four impediments that need to be addressed to improve therapy access are:

1. Unequal access to clinical trials;
2. No or limited funding/reimbursement of therapies, in particular innovative therapies;
3. Limited supportive care;
4. Limited access to specialists and treatment centres.

Based on these impediments, it is clear that the patient is not at the centre of care. Given the increased focus on patient centricity, LC defines it as:

• Engaging individuals with lymphoma, and their caregivers in all aspects of their care, tailoring support with the understanding that every patient is unique with a different set of complex needs that may change over time.

• Giving the lymphoma patient, and those close to them, a voice so that the focus of their care and needs are included throughout the decision-making process.

• Listening to and hearing the person affected by lymphoma respecting their culture, input, dignity, intelligence and capacity to make informed decisions about the impact on their lives and their care.

• Including patient organisations as active partners representing a patient’s emotional and psychosocial needs at every stage of care including: treatment, protocol development and by informing research throughout the clinical and treatment development continuum.

To read the full patient charter visit the LC website.

While healthcare professionals/providers (HCPs) may be the experts about a particular lymphoma subtype, the expert on the individual is the patient.

The 2017 Report Card on Lymphomas will demonstrate how the impediments in providing timely and cost-effective care have a negative effect on the well-being of patients. The report card will also review, through case studies, what initiatives member countries have undertaken to improve or remove these impediments.

Objectives

The objectives of LC’s analysis were to:

- Review availability, by LC member country, of phase II and III clinical trials as well as the availability of clinical trials being undertaken in new therapy protocols, i.e., therapy protocols approved in the last five years;
- Determine, by LC member country, the degree to which novel therapies with regulatory approval also had funding or reimbursement approval;
- Determine the extent to which patients and their caregivers received needed supportive care during the course of their diagnosis, treatment and post-treatment;
- Investigate the effect of limited access to specialists and treatment centres;
- Identify initiatives undertaken by member countries to assist patients in receiving timely and cost-effective care.

To address the objectives of this review, LC:

- Analysed, by member country, the availability of clinical trials and therapies;
- Reviewed the findings from the 2016 Lymphoma GPS to determine the level of supportive care patients and caregivers received, as well as the degree of access patients had to treatment centres and specialists;
- Interviewed LC members about their initiatives to improve access to care.

Methodology

To achieve these objectives, LC undertook a review of the availability of phase II and III clinical trials for all lymphoma subtypes. This information was obtained from clinicaltrials.gov, the European Union Clinical Trials Register, the Australian Cancer Trials, the German Hodgkin Study Group and the World Health Organization websites. Compiled information can be found in LC’s global database by country and subtype.

To determine how many of the novel therapies were available in LC member countries, LC obtained information from a quarterly review of member country regulatory and reimbursement websites, medical journals and general media press releases. Information on therapy availability, compiled by country and subtype, can be found in LC’s global database.

To assess to what degree patients received supportive care and had issues accessing specialists and treatment centres, LC used information from the 2016 Lymphoma GPS in which 4,154 individuals from 72 countries, including 44 LC member countries, participated.

LC consulted with OHLB Kraujas, Lithuania, and LIPA, Serbia, to learn about their initiatives to improve access to therapy. Both OHLB Kraujas and LIPA are members of LC.
Key Findings and Discussion

Clinical Trial Availability

Clinical trials are a way in which patients can access both standard and novel therapies. Yet, they are not available to the same degree in all countries with a few countries not having any clinical trials available (see Figure 1). Phase I trials assess safety, phase II trials test efficacy, and phase III trials test on a larger patient population to increase understanding of the effectiveness, benefits and possible side effects of the new therapy over time. While it is encouraging that many phase II and III clinical trials were underway (n = 739) of which 567 were studying novel therapies, most of these trials were phase II (n = 473) and only 94 were phase III. Estimates suggest a mere one-third of molecules studied in a phase II clinical trial are studied in a phase III clinical trial.¹

Contributing to fewer molecules being studied in a phase III clinical trial is the growing trend for molecules to be approved based on phase I and II data.² Both the Food and Drug Administration (FDA) in the USA and the European Medicines Agency have processes in place to allow for faster evaluations using surrogate end points and less stringent data. These tools include adaptive pathways and breakthrough therapy designations.² Consequently, therapies approved based on phase I or II data must be followed up with a phase III study as well as surveillance to ensure the true impact of a therapy is well understood. Greater efforts are needed in ensuring that outcomes are not only for the short term, but also for the long term so patients can achieve both an enduring remission and optimal quality of life.

While research into new treatment options is crucial, are investments into research being used wisely given the challenges with patient enrolment in clinical trials? Approximately two-thirds of clinical trial investigative sites fail to meet patient enrolment requirements leading to delays and higher costs.³ Factors affecting enrolment in clinical trials include a lack of referral by physicians and nurses, and changes to protocols of clinical trials already underway resulting in patients no longer being eligible to participate.⁴,⁵ As pressure mounts to approve new therapies faster, efforts are being made to increase patient enrolment through the analysis of data to better identify and understand patient populations, engaging patients in the trial design and using new technologies and social media.⁶
Involving patients is of even greater importance when contemplating a new treatment protocol for study. It is not fair to ask patient organisations to support a clinical trial that does not meet the real-world needs of patients and is not readily available in all countries. As shown in the 2017 Chronic Lymphocytic Leukaemia Global Subtype Report, too many countries do not have access to a clinical trial for that subtype. LC asks that clinical trial groups include representatives from patient groups at the start of the planning process to ensure that patient needs are understood and factored into the outcomes to be assessed in the clinical trial.

Figure 1. Availability of All Phase II and III Trials vs. Availability of Novel Therapy Phase II and III Trials


When studying a new therapy protocol, efficacy is key but efforts are also needed to reduce the short- and long-term side effects experienced by patients. Findings from the 2016 Lymphoma GPS showed that 65% of respondents experienced medical issues such as numbness (30%) and tingling (27%) and physical issues such as fatigue (77%) long after treatment. Consequently, greater efforts are needed to incorporate long-term quality of life into the planning of clinical trials.
Access to Innovative Therapies

As demonstrated in previous LC report cards, gaining access to therapies is an ongoing challenge for most LC member countries. While therapies, including innovative ones, may receive regulatory approval, approvals for funding or reimbursement often lag considerably so patients, in reality, continue to lack access. For some countries, the situation is even more dire as they do not have any novel therapies available with either regulatory or funding/reimbursement approval (see Figure 2).

**Figure 2. Novel Therapies with Regulatory Approval vs. Funded/Reimbursed Therapies**


*The novel therapies LC tracks are: belinostat, bendamustine, bendamustine-rituximab, bendamustine-ofatumumab, bortezomib, bortezomib-rituximab, brentuximab vedotin, CAP-VcR (cyclophosphamide, doxorubicin, bortezomib, prednisone, rituximab), ibritinib, idelalisib, idelalisib-rituximab, idelalisib-ofatumumab, IBR (ibrutinib, bendamustine, rituximab), lenalidomide, lenalidomide-rituximab, nivolumab, obinutuzumab-bendamustine, obinutuzumab-chlorambucil, obinutuzumab maintenance, ofatumumab, ofatumumab-chlorambucil, pembrolizumab, pixantrone, venetoclax. †In the USA, therapies are covered by insurance plans. The level of coverage depends on individual plans but usually requires co-payment from the patient.
Lenalidomide is one of the novel therapies that continues to be studied in clinical trials. While lenalidomide has been available since 2005 for use in blood disorders such as myelodysplastic syndrome, it has only recently been approved for use in the treatment of different subtypes of lymphomas hence its classification as a novel therapy.

As of June 15, 2017, lenalidomide was involved in 83 phase II or phase III clinical trials. What is concerning is that some of these trials were underway in countries that do not provide funding/reimbursement for lenalidomide. Only 11 countries provided funding/reimbursement for lenalidomide (see Figure 3). Ibrutinib, another therapy that has regulatory approval, was involved in 88 clinical trials. Yet, only 25 countries provided funding/reimbursement.

If the clinical trials have positive results, how will patients benefit in those countries where either ibrutinib or lenalidomide is not funded/reimbursed? Putting novel therapies out of reach only adds more stress to patients’ lives.

Figure 3. Novel Therapy Clinical Trials vs. Funding/Reimbursement of Novel Therapy


CAP-VcR = cyclophosphamide, doxorubicin, bortezomib, prednisone, rituximab; CT = clinical trial; IBR = ibrutinib, bendamustine, rituximab

*Information based on 45 member countries.
Supportive Care

While there are a number of definitions for supportive care as defined by the National Cancer Institute Dictionary of Cancer Terms (USA), Cancer Australia and the National Council for Palliative Care (UK), they all have a similar approach in that the goal is to support the patient and their families from the time they are diagnosed to when they are no longer dealing with any residual disease, side effects, psychosocial issues or any other issues relating to their cancer. Yet findings from the 2016 Lymphoma GPS showed that many patients and their caregivers were not receiving the supportive care they needed (see Figure 4). In addition, 17% of respondents indicated that their psychosocial issues had lasted six years or longer following treatment.
Psychosocial issues have a huge impact on patients, as evidenced from the findings of the 2016 Lymphoma GPS. The majority of respondents (83%) had experienced psychosocial effects with the fear of relapse being of greatest concern (63%). Other issues were concerns about body image/physical appearance (33%) and depression (33%). While 25% of respondents indicated that their psychosocial issues only lasted a year, for 17% they lasted for six or more years.

What Tables 1 and 2 demonstrate is that the adverse consequences of treatment last well beyond treatment completion or the conclusion of clinical trials.

Most clinical trials only examine issues for a short period of time and findings do not reflect what happens after the clinical trial is over. Tables 1 and 2 also show that it is not only medical issues that are ongoing long after treatment is completed but also psychosocial issues. These effects need to be captured in the clinic and clinicians need to adapt their care to ensure these issues are addressed.

So, where do patients turn for support? Results from the 2016 Lymphoma GPS showed that 80% of respondents viewed their doctor as their primary source of information yet only 30% indicated that their doctor had been able to help. Consequently, two-thirds of respondents were not receiving the support they needed.

### Table 1. Significant Differences in Psychosocial Impacts During & After Treatment

<table>
<thead>
<tr>
<th>Psychosocial Impact</th>
<th>% Affected</th>
<th>Significant Differences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of relapse</td>
<td>44%</td>
<td>87%</td>
</tr>
<tr>
<td>Problems getting life or health insurance</td>
<td>49%</td>
<td>70%</td>
</tr>
<tr>
<td>Depression</td>
<td>61%</td>
<td>58%</td>
</tr>
<tr>
<td>Difficulty on the job or in school</td>
<td>63%</td>
<td>59%</td>
</tr>
<tr>
<td>Isolation</td>
<td>76%</td>
<td>48%</td>
</tr>
<tr>
<td>Difficulty working through the healthcare system</td>
<td>76%</td>
<td>50%</td>
</tr>
<tr>
<td>Concerns about body image/physical appearance</td>
<td>77%</td>
<td>54%</td>
</tr>
<tr>
<td>Stress related to finances</td>
<td>77%</td>
<td>56%</td>
</tr>
<tr>
<td>Changes in relationships</td>
<td>74%</td>
<td>59%</td>
</tr>
<tr>
<td>Loss of self esteem</td>
<td>72%</td>
<td>57%</td>
</tr>
<tr>
<td>Loss/reduction in employment</td>
<td>65%</td>
<td>59%</td>
</tr>
</tbody>
</table>

Legend: ■ Highest Increase ■ Lowest Decrease

©Lymphoma Coalition 2017. Source: 2016 Lymphoma Global Patient Survey

### Table 2. Medical Issues based on Year of Diagnosis

<table>
<thead>
<tr>
<th>Medical issue</th>
<th>Year of diagnosis</th>
<th>Total % Affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>No medical issues</td>
<td>Prior to 2003</td>
<td>30%</td>
</tr>
<tr>
<td></td>
<td>2003 - 2014</td>
<td>34%</td>
</tr>
<tr>
<td></td>
<td>2015 - 2016</td>
<td>45%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>35%</td>
</tr>
<tr>
<td>Numbness</td>
<td>Prior to 2003</td>
<td>22%</td>
</tr>
<tr>
<td></td>
<td>2003 - 2014</td>
<td>30%</td>
</tr>
<tr>
<td></td>
<td>2015 - 2016</td>
<td>33%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>30%</td>
</tr>
<tr>
<td>Tingling</td>
<td>Prior to 2003</td>
<td>21%</td>
</tr>
<tr>
<td></td>
<td>2003 - 2014</td>
<td>27%</td>
</tr>
<tr>
<td></td>
<td>2015 - 2016</td>
<td>31%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>27%</td>
</tr>
<tr>
<td>Other</td>
<td>Prior to 2003</td>
<td>28%</td>
</tr>
<tr>
<td></td>
<td>2003 - 2014</td>
<td>28%</td>
</tr>
<tr>
<td></td>
<td>2015 - 2016</td>
<td>20%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>27%</td>
</tr>
<tr>
<td>Stomach related issues</td>
<td>Prior to 2003</td>
<td>24%</td>
</tr>
<tr>
<td></td>
<td>2003 - 2014</td>
<td>24%</td>
</tr>
<tr>
<td></td>
<td>2015 - 2016</td>
<td>24%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>24%</td>
</tr>
<tr>
<td>Eyesight issues</td>
<td>Prior to 2003</td>
<td>17%</td>
</tr>
<tr>
<td></td>
<td>2003 - 2014</td>
<td>21%</td>
</tr>
<tr>
<td></td>
<td>2015 - 2016</td>
<td>18%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>20%</td>
</tr>
<tr>
<td>Heart related issues</td>
<td>Prior to 2003</td>
<td>24%</td>
</tr>
<tr>
<td></td>
<td>2003 - 2014</td>
<td>13%</td>
</tr>
<tr>
<td></td>
<td>2015 - 2016</td>
<td>11%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>14%</td>
</tr>
<tr>
<td>Issues with other organs</td>
<td>Prior to 2003</td>
<td>20%</td>
</tr>
<tr>
<td></td>
<td>2003 - 2014</td>
<td>14%</td>
</tr>
<tr>
<td></td>
<td>2015 - 2016</td>
<td>11%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>14%</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>Prior to 2003</td>
<td>12%</td>
</tr>
<tr>
<td></td>
<td>2003 - 2014</td>
<td>13%</td>
</tr>
<tr>
<td></td>
<td>2015 - 2016</td>
<td>16%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>13%</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>Prior to 2003</td>
<td>18%</td>
</tr>
<tr>
<td></td>
<td>2003 - 2014</td>
<td>10%</td>
</tr>
<tr>
<td></td>
<td>2015 - 2016</td>
<td>5%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>10%</td>
</tr>
<tr>
<td>Secondary cancer</td>
<td>Prior to 2003</td>
<td>10%</td>
</tr>
<tr>
<td></td>
<td>2003 - 2014</td>
<td>7%</td>
</tr>
<tr>
<td></td>
<td>2015 - 2016</td>
<td>9%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>8%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>Prior to 2003</td>
<td>6%</td>
</tr>
<tr>
<td></td>
<td>2003 - 2014</td>
<td>5%</td>
</tr>
<tr>
<td></td>
<td>2015 - 2016</td>
<td>5%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>6%</td>
</tr>
</tbody>
</table>

Legend: ■ Most Prevalent ■ Least Prevalent

*Responses filtered by year of diagnosis
Table 3. Therapy Classes Used in Treatment of Lymphoma
(Approved therapies as of July 2017)

<table>
<thead>
<tr>
<th>Radiation Therapy</th>
<th>Targeted Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>External radiation</td>
<td>Unlabelled MOABs</td>
</tr>
<tr>
<td>• Gamma knife</td>
<td>• Anti-CD25</td>
</tr>
<tr>
<td></td>
<td>• Anti-CD20</td>
</tr>
<tr>
<td>Internal radiation</td>
<td>• Obinutuzumab (IV)</td>
</tr>
<tr>
<td>• Radiolabelled MOABs</td>
<td>• Ofatumumab (IV)</td>
</tr>
<tr>
<td>• Yttrium-90-ibritumomab tiuxetan</td>
<td>• Rituximab (IV, sc)</td>
</tr>
</tbody>
</table>

**Chemotherapy**

- **Alkylating agents**
  - Nitrogen mustards
    - Bendamustine (IV)
  - Chlorambucil (oral)
  - Cyclophosphamide (IV/oral)
  - Ifosfamide (IV)
  - Mechlorethamine (IV)
  - Melphalan (oral)
  - Nitrosoureas
    - Carmustine (IV)
  - Platinum agents
    - Carboplatin (IV)
  - Cisplatin (IV)
  - Nonclassical alkylating agents
    - Dacarbazine (IV)
    - Procarbazine (oral)
    - Temozolomide (oral)

- **Antimetabolites**
  - Cytarabine (IV)
  - Gemcitabine (IV)
  - Purine analogues
    - Fludarabine (IV/oral)
  - Pentostatin (IV)
  - Folate analogues
    - Methotrexate (oral)
    - Pralatrexate (IV)

- **Antitumour antibiotics**
  - Anthracyclines
    - Doxorubicin (IV)
  - Nonanthracycline antibiotics
    - Bleomycin (IV)
  - Mitoxantrone (IV)
  - Plicamycin (IV)
  - Etoposide (oral)

- **Topoisomerase inhibitors**
  - Etoposide (oral)
  - Antitumour antibiotics
    - Doxorubicin (IV)
  - Mitoxantrone (IV)
  - Plicamycin (IV)

- **Mitotic inhibitors**
  - Vinca alkaloids
    - Vinblastine (IV)
  - Vinorelbine (IV)
  - Vinorelbine (IV)
  - Brentuximab vedotin (combined with CD30 MOAB) (IV)

- **Corticosteroids**
  - Dexamethasone (oral/IV)
  - Methylprednisolone (oral)
  - Prednisolone (oral)
  - Prednisone (oral)

**Surgery**

- **Local excision**
- **Splenectomy**
- **Plasmapheresis**
- **Watchful Waiting**

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Akt = protein kinase B; BTK = Bruton tyrosine kinase; HDAC = histone deacetylase; HSCT = hematopoietic stem cell transplant; IV = intravenous; MOAB = monoclonal antibody; mTOR = mammalian target of rapamycin; PD-1:PD-L1/2 = programmed death-1:programmed death-ligand 1/2; sc = subcutaneous
The need for patient support is likely to grow, especially as treatment options increase and some become more complex, likely resulting in the need for a different level of understanding for patients. Table 3 outlines the different classes of therapies that are available today for the treatment of lymphoma. These classes are often combined to get a longer remission as each one targets the cancer in different ways. However, when combining therapies, there will likely be more side effects as patients are now being exposed to the side effects of each drug. In addition, sometimes when drugs are combined, there may be new side effects that were not seen when the drug was used alone. These are issues that the patient needs to understand. In the 2016 Lymphoma GPS, while 70% of respondents reported understanding the potential side effects associated with their treatment plan, only 61% reported that they understood how their side effects would be managed.

Given that doctors may not be aware that their patients likely need more than medical advice but also psychosocial support or, if aware, they cannot provide it, it would be helpful if referrals were made to other sources of help such as a patient organisation.

Findings from the 2016 Lymphoma GPS showed that 77% of respondents found the patient organisation helpful.

Referring a patient to a patient organisation provides them with the benefit of having someone to walk alongside them throughout their whole experience. Greater efforts are needed on the part of all those involved in the care and treatment of patients to ensure patients receive the support they need and that they know where to find it.

As many doctors may not be aware of the support needed by patients, LC proposes that HCPs take the healthcare support challenge by answering the questions shown in Figure 5.
Figure 5. Do You Know What Patients Need?
Rate Yourself Based on the Last 10 Patients You Saw Who Had Lymphoma

**STATEMENT:**
In my clinic, patients feel they get a timely investigation and an accurate diagnosis.

- A. In all cases
- B. Most of the time
- C. Rarely

**STATEMENT:**
I ensure patients are referred for a second opinion if requested.

- A. In all cases
- B. Most of the time
- C. Rarely

**STATEMENT:**
I tell patients about all treatment options regardless of their financial status and I seek the patient’s input in the treatment decision.

- A. In all cases
- B. Most of the time
- C. Rarely

**STATEMENT:**
I give patients detailed information about their lymphoma subtype, treatment options, side effects associated with treatment options and clinical trial opportunities.

- A. In all cases
- B. Most of the time
- C. Rarely

**STATEMENT:**
I tell the patient what subtype they have and do not use the term non-Hodgkin lymphoma.

- A. In all cases
- B. Most of the time
- C. Rarely

**STATEMENT:**
I give patients support tools and information on patient organisations.

- A. In all cases
- B. Most of the time
- C. Rarely

**STATEMENT:**
I ensure that patients know what their long-term care plan is and who will be part of their healthcare team, both in and out of the clinic.

- A. In all cases
- B. Most of the time
- C. Rarely

**STATEMENT:**
I make the time in clinic to encourage patients and their families to ask questions not only about their diagnosis and treatment, but also about other issues that may be affecting them such as emotional issues.

- A. In all cases
- B. Most of the time
- C. Rarely

If mainly A responses chosen, you are providing your patients with the best care possible.

If mainly B responses selected, you may consider making more time for your patients and if you can’t then provide patients with additional support through referral to a patient organisation or support group.

If you selected mainly C responses, LC suggests that you consider providing patients with additional support through referral to a patient organisation or support group.

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Access to Specialists and Treatment Centres

Part of ensuring patients receive care in a timely and cost-effective manner entails patients being able to see a physician(s) as needed and having easy access to the treatment centre. Yet, findings from the 2016 Lymphoma GPS demonstrated that these were challenges for some patients. In the USA where there are just under 15,000 medical oncologists and/or haematologists, 41% of respondents reported having challenges in seeing a specialist. Respondents in Lithuania also reported challenges in seeing a specialist (see Figure 6). While availability of specialists will vary from country to country, LC wonders if in those countries where it is not reported as an issue if it is because patients are not aware that there are doctors who have specialised knowledge in the treatment of lymphoma.

Not having easy access to the treatment centre was primarily an issue for respondents in Serbia (32%) although it was somewhat of an issue for those living in Lithuania (26%) and Japan (24%).

Based on findings from the 2016 Lymphoma GPS, it would appear that respondents who had challenges in accessing either a treatment centre or specialty physician had more medical issues compared with those who did not. Among those who had challenges accessing a specialty physician, 76% reported medical issues and 75% of those who had issues getting to a treatment centre reported medical issues.

Regardless of the degree of challenge with either seeing a specialist or getting to a treatment centre, patients should not have to deal with these issues as they will only add more stress to what is already a difficult time.

Figure 6. Access to Specialty Physicians and Treatment Centres

What barriers, if any, have you experienced in receiving adequate lymphoma treatment (select all that apply)?

©Lymphoma Coalition 2017. Source: 2016 Lymphoma Global Patient Survey
Case Studies: How Members Have Improved Care for Patients with Lymphoma

To determine how members have helped remove impediments to accessing care in a timely and cost-effective manner as well as improve supportive care, LC conducted interviews with member countries to determine how they influenced change.

The 2017 Report Card on Lymphomas presents two case studies:

- Creating Partnerships with Health Authorities, Lithuania
- Improving Access to Innovative Therapies, Serbia

Case Study Report 1: Creating Partnerships with Health Authorities, Lithuania

The Issue

In 2006, there was a general lack of awareness about blood cancers including treatment options among all Lithuanians. Many thought having a blood cancer was a death sentence and were unaware that there were therapies available that could prolong survival as well as improve quality of life. While education of the public was needed, it was also important to make politicians aware of the need to have these therapies available.

Background

OHLB Kraujas was formed in 2002 with the goal of improving the availability of new therapies in Lithuania. In 2006, rituximab, a therapy that had shown great benefit to many patients, was not available in Lithuania. Rituximab was approved by the FDA, USA, in November 1997 and the European Agency for the Evaluation of Medicinal Products in June 1998. Another challenge was that cancer was viewed as a stigma resulting in people not talking about it. Kraujas, a young and unknown organisation, needed to find a way to raise awareness among politicians about the benefits of treatment options, such as rituximab, for those with a blood cancer.

The Approach

To raise awareness among politicians about the benefits of rituximab, Kraujas started by sending a letter to politicians involved in healthcare, as well as other influential politicians who could talk to members of parliament letting them know that there was now an organisation in place that would be speaking out for patients with a blood cancer. This letter included Kraujas’s opinion, arguments supporting the issue, changes that could be made and why the changes were necessary. Next, Kraujas set about arranging a meeting between the politicians and a representative from Kraujas. Kraujas found that meetings at the Ministry of Health or at parliament were an effective way to meet politicians to express concerns and explain problems relating to the patient experience.

To combat the stigma associated with cancer, Kraujas initiated an education programme directed towards both the public and politicians. A variety of tactics were used to educate politicians. They included:

- Articles in the media (online, television, etc.). Kraujas would prepare patient success stories that included input from haematologists or other specialists. These success stories demonstrated that innovative therapies could save lives, prolong survival and improve quality of life. In addition, Kraujas would also put out press releases with relevant facts and figures where the information was available, arguments regarding the issue and adjustments to legislation that could be implemented.
• Meetings with politicians to share knowledge, concerns and interests. In some cases, these meetings took place after the publication of an article to remind politicians about the issue. The key to making the meetings a success was to be well prepared which entailed gathering information relating to the issue to be discussed, to get input from haematologists, prepare arguments and steps as to how the situation could be changed.

• Annual conference – Blood Day – and other roundtable discussions. Health politicians were invited to these meetings to discuss treatment access, possibilities in Lithuania and how everyone – politicians, patient organisations, society, volunteers, patients and families – could work together to ensure better treatment access, improved conditions for patients in hospital, better psychological help, etc.

What helped the organisation's initiative was that a well-known local actor got involved and told the public that he had cancer. In addition, he spoke to politicians. He also had influential relatives involved in politics who helped.

Results

After some publicity, official letters and meetings with politicians and members of parliament, rituximab was reimbursed. While Kraujas was an unknown entity in 2006, today politicians seek input from Kraujas on health policy issues relating to patients, new therapies have become available, treatment protocols have changed and more clinical trials are available. The overall result is that lymphoma is now one of the most successfully treated blood diseases in Lithuania.

Kraujas’s approach to issues has also changed, the result of more than 10 years’ experience in the field. In the beginning, Kraujas did not know the best way to communicate with politicians so took a demanding approach that did not bring results. Kraujas then started to think about what a patient organisation could do with politicians to make changes. Kraujas started to explain that cancer is not a death sentence and that people who receive treatment get better and can live a normal life. Today, Kraujas works as a partner in the healthcare system by looking for solutions and making suggestions on how access to treatment can be improved. The types of issues Kraujas discusses with health authorities include:

• Drug policy and reimbursement schemes in general, government budget for drugs, priorities for all blood disorders, better treatment access, other issues related to drug policy;
• Financial insurance for personal healthcare services/hospital services;
• Better and faster access to treatment centres and specialists through the use of “green corridors”. This is a system that allows a patient who is diagnosed for the first time, or has a suspected blood cancer, to get an appointment with a specialist within seven days and to start receiving treatment within three weeks;
• Evaluation of hospitals services’ quality indicators. Patients do not have any way of evaluating the quality of hospital services, but hospitals and treatment centres often boast about how good they are. A formalised, consistent assessment provides inclusive feedback;
• Other issues that are important for patients: at-home nursing care, hospice services, social guarantees for patients, fertility preservation and related matters, rehabilitation possibilities as patients with a blood cancer do not receive any rehabilitation following treatment;
• Biomedicine ethic laws and biobanks.

Key Learnings/Take Home Messages

• Look for success stories to show possibilities.

• Work as a team with all parties involved in healthcare, e.g., health politicians, patients, caregivers, medical staff and other members of society.

• Work with politicians who understand the issues and seek their help.

• Talk to other patient organisations with the same interests and seek their support.

• Find out what organisations are doing in other countries.

• Publish all evidence that demonstrates the patient experience and how it can be improved.

• Ensure politicians are made aware of the patient experience.
Case Study Report 2: Improving Access to Innovative Therapies, Serbia

The Issue

Between 2007 and 2016 only 12 new therapies were approved for reimbursement by Serbia’s Health Insurance Fund, the agency responsible for placing treatments on the reimbursement list. This was a result of the Serbian government requiring the Health Insurance Fund to decrease the number of therapies eligible for reimbursement. In comparison, 148 new therapies were approved in Slovenia and 83 in Bulgaria. LIPA, the patient organisation in Serbia that helps patients with lymphoma, decided that this situation was untenable and took action. LIPA’s initial approach was to talk to Serbia’s Minister of Health. While sympathetic, the Minister told LIPA: “Do not bring a problem, bring a solution!” The Minister also said if LIPA provided a solution, he would help them.

Realising that they would not be successful on their own, LIPA joined forces with three other organisations that were experiencing similar challenges: CML Association Serbia, Rare Cancer Patients’ Association (UPRT) and Blue Circle (diabetes). By joining forces, 700,000 patients were represented. While diabetes is not closely associated with blood diseases and rare cancers, by including this group, a wide range of therapies could be covered. In addition, it meant the group could apply to more companies for grants to be used to create a plan for improving access to innovative therapies.

Background

In addition to the lack of access to new therapies, Serbia is faced with other issues such as poor-quality hospital facilities, long waiting lists for tests, analysis and surgeries, and old equipment that is often broken resulting in patients having to stop their radiation treatment after only a few treatment cycles. Compounding these challenges, are corruption within the healthcare system and a shortage of specialists such as oncologists, radiologists and nurses in general.

While Serbia has the highest spending on health as a percentage of gross domestic product compared with four other Eastern European countries, it only ranks fourth in terms of total health spending per capita (see Figures 7 and 8).

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**Figure 7. Total Expenditure on Health as a Percentage of GDP, 2014**

![Chart showing GDP percentages for different countries](image1)

Adapted from Modernising the Serbian health system. The need for a reliable decision-making compass. The Economist Intelligence Unit. 2016. GDP = gross domestic product

**Figure 8. Total Health Spending per Capita, 2014**

![Chart showing health spending per capita](image2)

Adapted from Modernising the Serbian health system. The need for a reliable decision-making compass. The Economist Intelligence Unit. 2016. US = United States
The Approach

LIPA, along with the three other patient organisations, started advocating for systemic changes that would improve the availability of innovative drugs. As Serbia does not have a health technology assessment process, they hired an expert on pharmacoeconomics who helped create a Pragmatic Value Assessment (PVA) System that would be used to assess all relevant aspects of the reimbursement decision-making process such as:

- Cost effectiveness;
- Clinical benefit;
- Social issues;
- Ethical aspects.

The PVA concept and how it could be integrated into the existing health system was presented to the Minister of Health. However, the proposal was denied as elections were about to take place and the Minister was uncertain if he would be re-elected.

Undaunted, the group turned to the media where real-life stories about patients with lymphoma and other types of cancer who were waiting for life-saving treatments were profiled on television during prime time and published in newspapers.

A media and social media campaign were also developed entitled: “How close are we to having up-to-date healthcare in Serbia?” The campaign comprised a panel discussion which discussed how to implement the PVA into the existing system. All stakeholders (HCPs, patients, ambassadors, European Union delegates, etc.) were invited to participate. The stakeholders gave speeches on how they envisioned healthcare being improved in Serbia. The speakers were:

- Martin Koehring, Managing Editor and Global Healthcare Lead, The Economist Intelligence Unit;
- John McDonoug, Professor, Harvard TH Chan School of Public Health, Boston, and Director, of the school’s Center for Executive and Continuing Professional Education;
- A patient representative;
- A government representative.

Results

Following the campaign:

- A case study on Serbia’s healthcare system was published in The Economist;
- Information from The Economist’s case study was sent to all stakeholders;
- The Ministry of Health, the Health Insurance Fund and the Serbian government were heavily criticised, resulting in the Minister of Health agreeing to list another 23 medications on the reimbursement list;
- Patient representatives are now included in decision-making bodies at the Ministry of Health and the Health Insurance Fund;
- The four patient groups who originally joined forces have now expanded to 12 patient groups.

Key Learnings/Take Home Messages

- Develop solutions to problems that are actionable.
- Never give up.
- Change is possible.
Moving Forward

The 2017 Report Card on Lymphomas clearly demonstrates the need for patient centricity. Until patients are invited into the discussion on their care, many will continue to struggle with their patient experience. Patient organisations are a great resource for day-to-day understanding of the patient experience. LC strongly urges HCPs to involve the patient as an active participant in their journey.

Additionally, we suggest that patients and patient organisations are invited to be a part of the research process early on to ensure feasibility of the treatment protocol and drug information. This will help immensely in educating patients on the protocol and side effects, as well as ensure the therapy meets patient requirements.

As LC uncovers how long patients are dealing with side effects from their lymphoma experience, it is no longer acceptable for patients to go without proper subtype information and supportive care. Patient organisations and other support services can play a key role in this, especially if the HCPs and the healthcare system do not have time or the resources.

The continued lack of clinical trials in some countries is disheartening. LC calls on the research community to find ways of involving all countries in clinical trials especially in light of the challenges with clinical trial enrolment. Greater efforts are also needed to guarantee that clinical trials look at both the short-term and long-term outcomes to ensure that patients can achieve an enduring remission as well as optimal quality of life.

While LC recognises the need to approve therapies faster so patients benefit sooner, LC is concerned about the growing trend of approving therapies based on less stringent evidence. LC is investigating this further and will provide members with its perspective in the coming months.

The failure to fund or reimburse therapies, including novel ones, to keep pace with regulatory approval is unacceptable. Insurance companies and funding/reimbursement bodies need to make greater efforts to help patients get the treatment they need without adding to patients’ anxiety during what is already a stressful time.

Many patients and their caregivers are not receiving the supportive care they need. Patients need more than an effective treatment: they and their caregivers need to know where they can get reliable help for all issues they face from the time of diagnosis until they are not dealing with any issues relating to their cancer.

LC commends those members (OHLB Kraujas, Lithuania and LIPA, Serbia) for undertaking initiatives to remove impediments to care.

Each step any member takes – whether big or small – makes a difference as it will result in patients receiving better care.
As a Coalition we call for:

- Patients to be listened to and heard in a way that respects their input, dignity, intelligence and capacity for making informed decisions about their care and impact on their life.

- HCPs to refer patients and their caregivers to patient organisations so they have support from the time of diagnosis to when they are no longer dealing with issues relating to their cancer;

- Improvement in access to all needed therapies.

To ensure that all LC members have timely access to good quality information to share with their patients so they start from a level playing field, LC will continue to:

- Monitor and report on the funding/reimbursement and regulatory policy changes as they occur around the world;

- Report global data in a usable format that is in sync with health technology assessment requirements;

- Maintain the global resource on lymphoma facts and statistics on the LC website including updating information on therapies as they receive both regulatory and funding/reimbursement approval;

- Continue to ensure that clinical trial information is readily available to the patient community. This will be accomplished by regularly updating the global database and ongoing reporting through the member newsletter.

All information will be available in LC’s Global Database.
Sources


8. Personal communication with Dr. L. Sehn, July 26, 2017.


11. Modernising the Serbian health system. The need for a reliable decision-making compass. The Economist Intelligence Unit. 2016.

Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>FDA</td>
<td>Food and Drug Administration</td>
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<tr>
<td>GPS</td>
<td>Global Patient Survey</td>
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<tr>
<td>HCPs</td>
<td>healthcare professionals/providers</td>
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<td>LC</td>
<td>Lymphoma Coalition</td>
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<tr>
<td>LIPA</td>
<td>Udruženje Obolelih od Limfoma</td>
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<tr>
<td>OHLB</td>
<td>Oncohaematological Patients’ Association of Blood</td>
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<td>USA</td>
<td>United States of America</td>
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“Until patients are invited into the discussion on their care, many will continue to struggle with their patient experience.”
To transform the lymphoma landscape ensuring patient centricity is defined by people affected by lymphoma in order to improve patient outcomes across all health system decisions.

This report is a valued product of the Lymphoma eInformation Project (LeIP)

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

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WORLD LYMPHOMA AWARENESS DAY – 15 SEPTEMBER.