

Dear LC Members:

We are very pleased to announce that Pru Etcheverry has accepted the position of Regional Director for the newly formed Lymphoma Coalition Asia Pacific region (LCAP), effective 23 April 2018.



Pru recently spent more than 15 years successfully leading Leukaemia & Blood Cancer New Zealand (LBCNZ). During her tenure as CEO, LBCNZ developed from a small organisation with a team of just two part-time people to one of New Zealand's most prominent Not for Profit Organisations. She was honoured as an Officer of the New Zealand Order of Merit (ONZM) this past year, in recognition of her work.



As many of you already know, Pru is particularly passionate about advocating on behalf of patients and ensuring they have access to the best treatments and care. Under her leadership, several new drugs were funded in New Zealand and a national patient support service was established. To support this, Pru was also able to successfully establish significant income streams which continue to achieve year-on-year growth.

Pru has shared her talents with LC through her dedication to its growth since 2005 where she served on the steering committee and then voted by the Board as Chair in 2013, where she profoundly impacted the growth and development of the organisation.

As a new region developed for LC, there will be much work over the coming months to determine the requirements of the LCAP member organisations and the key areas where action is needed. Pru is the ideal person to take on this role of development and growth. She will continue to be based in New Zealand.

We are thrilled that Pru is staying in our field as her commitment and dedication will take the LCAP region to great heights.

Warm regards,

Karen

STANDARDS OF EXCELLENCE PROGRAM



Congratulations to Lymphoma Canada and Campaigning for Cancer who have the first Standards of Excellence (SOE) badges!

[Lymphoma Canada](#) was the first organisation to submit and can now proudly display all 4 badges on their website, as their support documents meet the criteria established for all components of the SOE program.

[Campaigning for Cancer](#) (South Africa) has successfully completed the work for the *Governance* and *Organisational Process & Continuity Planning* categories and applied for these two badges.

Please remember the next review date for the SOE program is 31 May 2018 and all work must be completed and submitted by this date. More information is available [HERE](#) (member log in required).

RESEARCH

- Cancer Survivors Need More Focus on Non-Medical Needs and Policies. These problems were highlighted in a special issue of the Journal of Cancer Policy, which explored the needs for more long-term research, better cross-analyses of different cancer types, and improved support for cancer survivors. [READ MORE](#)
- Phase II results for the use of rituximab and chemotherapy combo for primary central nervous system lymphoma (PCNSL). [READ MORE](#)
- Emerging treatment strategies in mantle cell lymphoma (MCL). [READ MORE](#)

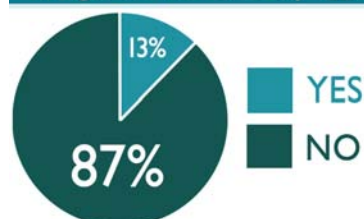
WEIGH-IN WEDNESDAY

Lymphoma Coalition is excited to announce the launch of Weigh-In Wednesday (WIW)!

WIW is a quick poll that goes live each week on Tuesday evening EST and closes Thursday evening EST on the [LC website home page](#), [Facebook page](#) and [Twitter account](#). The poll asks a simple question that can be answered by choosing one of two provided responses. It is easy and fast for participants. The results are announced on Friday.

As an example, a recent WIW asked if participants had participated in a clinical trial. 13% indicated yes; 87% said no.

Weigh-In Wednesday



The goal is to encourage conversation on hot topics, keep current on patient feedback and add information to our databank of patient information. Please repost the WIW polls or link to the website to encourage participation. If you have questions you would like asked, they can be submitted to for consideration [HERE](#).

RESOURCE LIBRARY

The [Resource Library](#) has moved to the public side of the Lymphoma Coalition website, from its previous location in the members section. You can now access the library from a button on the right-hand side of the home page. This valuable resource contains over 2,000 pieces of information on lymphoma diagnosis, treatment, research, support and lifestyle, taken from credible sources. Content is updated on a bi-weekly basis to ensure the information stays current.

WHATS APP



LC is forming member WhatsApp groups to diversify ways we can communicate with each other. If you would like to be part of these groups, please share the name, what area they may be responsible for (such as communication) and phone number of the people within your organisation who should be included. Email the information [HERE](#).

LCE NEWS



I'm delighted to have joined the Lymphoma Coalition Europe (LCE) as the new Regional Director. I'm grateful for the warmth of the reception I've received from everyone. The year ahead will be an exciting one, and I'm particularly looking forward to the global summit in Prague in July, when we will all be together. Natacha and I are in the process of planning the LCE break-out sessions and already have the makings of an interesting and engaging programme – but if anyone has any ideas or suggestions for what we should cover, then it's not too late, and we would like to hear from you jonathan@lymphomacoalition.org.

Natacha has done an amazing job over the past few months, working tirelessly for the LCE to ensure it continues to support the membership and stay involved in key European initiatives.

I plan to continue, support and build on achievements to date, putting into action the current LCE plan, strengthening the existing collaboration, support and sharing between membership organisations, raising the profile of lymphoma and the LCE across Europe, and developing other collaborations and partnerships that will benefit us all. I'm keen to ensure that the LCE's work is driven by the needs of the membership and reflects what would help each organisation in its crucially important work of supporting people affected by lymphoma and advocating for their needs.

I have some ideas for the information, resources and tools that would support that work and believe there are some key cross-European projects that we could develop in the fields of clinical trials, patient experience and outcomes data, and involvement in health technology processes. Such projects could benefit the Coalition and all its members in our mission to improve the lives of people dealing with a lymphoma diagnosis.

Feel free to contact me or Natacha about any aspect of the LCE's work.

Jonathan

LCE is Proud of its Members



As part of its mission to support patients, APCL has been increasingly aware of the need to support families who face financial hardship when they must temporarily move to receive a bone marrow transplant (or accompany a relative in such circumstances). In Portugal there are few Bone Marrow Transplant Units: two in Lisbon, two in Porto, and one in Coimbra. Thus, APCL is planning the first Casa de Acolhimento in Lisbon, for haematological oncology patients and their families to stay while the patient undergoes a transplant and during their recovery, ensuring the patient has the emotional, face-to-face support from their family through the entire treatment. [READ MORE](#)



The Norwegian Directorate of Health recently invited patient associations to provide input into the new cancer strategy for 2018 to 2022. The blood cancer association was represented at the meeting by Tone Hansen. Hansen is one of two representatives from the Cancer Society Partnerships. They have reviewed the various target areas and progress to date. "It is important that psycho-socialism has increased focus. This is gratifying because it's very much in-line with what the Blood Cancer Society has been working towards for many years. Cancer rehabilitation, co-operation, follow-up of late effects and centralization of the work of rare cancer diagnoses are other things we have pointed out," says Hansen. [READ MORE](#)

Photo: Hansen discusses the new cancer strategy with the leader of Partnership Against Cancer, Kjell Magne Tvedt.





Stowarzyszenie Wspierające
Chorych na Chłoniaki
„Sowie Oczy”

At the end of 2017 a group of sixteen patient organizations, including Polish Lymphoma Association "Sowie Oczy", appealed to the ministers of health and finance to amend the financial plan for the National Health Fund for 2018 so it includes the establishment of a principle of allocating 17% of the Fund's budget to expenditure reimbursement. Seeing a lot of positive reimbursement decisions made in the past several months, patients are concerned that without additional funds the continuation of this practice will not be possible. This would mean the needs of thousands of oncology patients would not be met. Because of this advocacy action, the Ministry of Health is working now on an amendment to the Reimbursement Act, which would allow for an increase in the reimbursement budget. Additionally, patient representatives sent a petition to the associations of enterprises from the pharmaceutical industry, which pointed out that the increase in public spending on medicines would only translate to improved patient outcomes if the price of products was in-line with the Polish level of development. Patient organizations promise to watch closely the pace of work, because the total budget for reimbursement for 2018 has minimal growth compared to the entire NFZ budget. This results in delays accessing therapies for many months.

NEWS FROM EUROPE

LCE at the EBMT 2018



The 44th Annual Meeting of the European Society for Blood and Marrow Transplantation (EBMT), Lisbon, 18

Mar to 21 Mar 2018, included the 12th EBMT Patient, Family and Donor Day, dedicated to people who have had/are going to have a bone marrow or stem cell transplant, anyone affected by blood cancer or a blood disorder, their relatives, caregivers and donors. The program allowed those involved to exchange experiences, learn from each other and learn more about the latest research from a panel of specialists. LCE took part in this unique and memorable experience and had an exhibition booth for the scientific meeting. Thank you, Anita and Guy, for spending time and promoting the good work of the members. The EBMT's focus is: Stem Cells, Cell Therapy, Regenerative Medicine, Autoimmune Diseases, Blood Disorders, Gene Therapy, Immune Therapies and Marrow.



Philips' Jan Kimpen elected COCIR president

The European Coordination Committee of the Radiological, Electromedical and Healthcare IT Industry (COCIR) elected the chief medical officer of Philips, Jan Kimpen, as its new president on March 14th. His direct, hands on experience with patients in a high-profile clinical environment adds an important new dimension to COCIR's expertise. Kimpen joined the University Medical Center Utrecht, one of the largest healthcare organizations in the Netherlands, in 1997 as professor and chairman of Pediatrics, and became President of the Board in 2009. At UMC Utrecht, he strengthened ties with the world-renowned Netherlands Cancer Institute at the Antoni van Leeuwenhoek Hospital (NKI-AVL) and the Netherlands Pediatric Oncology Center. Jan is interested in how to coordinate care across the health continuum, focusing on value-based care solutions that deliver better patient outcomes at lower costs.



eunetha HTA at the European level: Working together on HTA will elevate standards

After almost a decade of gradually escalating cooperation, HTA at the European level faces a crucial decision. If EU countries don't find a way to move forward with the Commission's January proposal for mandatory use of clinical assessments, there's no clear successor to EUnetHTA 3, the current collaborative effort, whose objective is trying to save duplication of efforts on assessments. Most countries have yet to voice their decision. Former EUnetHTA officials say concerns about lowered standards are unfounded. "Everybody is digging in the same mine of evidence, the same type of studies, and when it comes to how that evidence is used, there's a sufficient degree of overlap between [member countries'] own clinical assessments and the joint clinical assessments performed by EUnetHTA to justify combining forces." The report for the Commission showed 48 HTA bodies surveyed in the EU and Norway look at the same four core aspects of clinical assessment: health problems and current use of technology; description and technical characteristics; safety; and clinical effectiveness. Working together on HTA will elevate standards, increasing transparency through standardisation, and accountability. National HTA bodies will be able to reallocate their resources on economic, political and moral factors.