



## CLLAN Advocates Network (CLLAN)

### Network activities & priorities 2020/2021 and outlook 2022 onwards

## CLLAN activities & priorities 2020/2021

The CLLAN Steering committee has agreed on projects and activities in the following four areas:

1. Communication, outreach and visibility
2. Education / capacity building
3. Analysis and advisory activities
4. Network Management

Specifically, these are:

### 1) Communication, outreach and visibility

- **Community Forum:** Launching of a new Community Forum for members and participants of CLL Horizons conferences for exchange and good practice sharing during the COVID-19 pandemic and beyond. Official forum launch end of April 2020.
- **COVID-19 & CLL Resources:** The CLL Advocates Network is closely monitoring the strategies being implemented in various countries to manage the COVID-19 virus. Much of the information about COVID-19 does not address the concerns of people with chronic lymphocytic leukaemia (CLL). We have therefore developed a COVID-19 and CLL patients Statement to fill this gap and provide extra advice for CLL patients. The statement is updated on a continuous basis and available in 14 languages by now. Besides the statement, on our website we are
  - a) informing about upcoming COVID-19 online events
  - b) publishing a compilation of useful online events (webinars, recordings, video streams, video interviews, and other digital resources on COVID-19 and CLL)
  - c) sharing COVID-19 related CLL advocacy activities
  - d) publishing CLL-specific scientific studies related to COVID-19
  - e) supporting initiation and propagation of a platform to collect evidence-based, patient-lead COVID-19-related studies considered of special interest to CLL patients

- **COVID-19 & CLL evidence generation and publication:** A CLLAN project to actively encourage patient advocacy groups to do their own surveys on “How the COVID-19 pandemic has affected CLL patients and patient advocacy groups”. CLLAN will then pull existing and new survey data from all groups together to carry out a meta-analysis towards writing of a paper for consideration to upcoming scientific and medical conferences (e.g. ASCO, ASH, and others). This initiative will be led by our Steering Committee member Deborah Baker who is taking the specialist education programme on “Evidence-Based Advocacy: Evidence generation and publication” run by WECAN (the Workgroup of European Cancer Patient Advocacy Networks).
- **New Website:** On going - development and spring launch of new CLLAN website platform in set up that offers patient organisations and patient advocates the opportunity to network and share best practice outside of national meetings, patient communities and congress. Official forum launch end of June 2020.
- **Communications channels & operational resources:** Implementation of a social media & coms plan with coordinated content population and updates to include member activities. Expand email support & workshare platforms, admin tool kit etc.
- **Participations:** Since April 2020, the CLL Advocates Network is a member of WECAN, the Workgroup of European Cancer Patient Advocacy Networks. Furthermore, there are continuous discussions with iwCLL organisers to develop working relationship with iwCLL (explore inclusion of patient experience plenary session at iwCLL2021, posters, abstracts, document patient journey, and advocacy track sessions). Besides the above, the CLL Advocates Network is participating & collaborating in key multi-country projects that will lead to improved care and support of CLL patients, including, but not limited to, working with the HARMONY project, Euro Blood Net, Lymphoma Coalition.
- **CLL Advocates Network & EHA:** Enable representatives of CLLAN to attend and participate in EHA activities and potentially other meetings and conferences to increase visibility and networking.

## **2) Education / capacity building**

- **CLL Horizons September 2021 Krakow:** CLL Horizons 2019 feedback reports have been forwarded. CLLAN will continue to build on the successful collaborations between the CLL clinical community during iwCLL19 and CLL Horizons 2019 in Edinburgh. The next in person CLL Horizons is in planning and set up for Krakow in September 2021 to coincide and collaborate with the next iwCLL international conference. Hosting Horizons 2021 alongside iwCLL21 again will aid delivery of the CLLAN objective of inclusion of patient sessions in the main plenary agenda of iwCLL. Hosting CLL Horizons alongside iwCLL also

offers efficiency savings and availability of speakers and latest science. **Important note:** given the current situation, it is difficult (if not impossible) to predict if a regular in-person conference will be possible for all interested participants in 2021. We might have to consider a combination of both digital and in person, i.e. split between in person and digital attendance to make the conference more widely available for immune compromised participants (which would result in reduced budget due to reduced travel and accommodation needs). Since there will not be an in person CLL Horizons Conference in 2020, we plan to carry on digital workshops that follow up from CLL Horizons 2019 sessions and digital capacity building webinars in place of CLL HZ20 (see next bullet “Digital Workshops capacity building 2020”).

- **Digital workshops capacity building 2020:** R&D, health policy and the imminent needs of cancer patients do not stop with the pandemic. Powerful patient advocacy, patient engagement and patient input is more important than ever. CLLAN plans to implement series of digital workgroups to help our members find new ways to virtually train and inform patients (e.g. in meetings with clinicians while physical patient days cannot take place) and to explore changing clinical practice and issues arising from COVID-19 pandemic key challenges and changing advocacy practices and solutions. The first workshop will be on *“The importance of the relationship between patient advocacy and clinical groups and how to develop these partnerships”*. Further digital workshops will come as a continuation of CLL Horizons 2019 workshop sessions also. Details will be announced as they become available. Digital workshops and working group initiatives will also function as a digital alternative/accompaniment to the traditional CLL Horizons in person capacity building model, providing topical CLL sessions as webinars rather than in an in person CLL Horizons 2020.

### **3) Analysis and advisory activities**

- **CLL Needs Analysis Survey (ATLAS):** The CLL advocates Network is in the process of developing an Atlas of CLL patient resources across the world, to be hosted on the new CLLAN website. The continued outreach survey of organisations and groups supporting CLL patients will inform the development of this resource. This survey aims to identify the unmet needs of the community as well as adding access possibilities and to develop sound membership statistics. By doing this, we aim at creating a solid first step to strategic advocacy in order to remove barriers.

### **4) Network Management**

- **Monthly Teleconferences/Web Meetings:** Regular oversight of key projects by steering committee, reviewing progress of working groups on meeting 2020 goals, scan of CLL environment to see where CLLAN can play a role. Explore with members and the CLL community.
- **2-Day Steering Committee CLLAN Strategy planning Meeting:** This two-day meeting brought together the CLLAN Steering Committee members together to allow for strategic planning for 2020, alignment on 2020 priority projects, review & analysis of 2019 activities and preparation of 2020 projects. The meeting was held in Barcelona on 15-16 February 2020. The meeting was facilitated by an external moderator. Next SC meeting planned for 2021 (if COVID-19 allows).
- **Staff:** Recruitment of Nicole Schroeter as temporary Project Manager from March to Sept 2020 to support the day-to-day management of the network. Nicole works as freelance Project Manager specialized on pharmaceutical companies and patient advocacy organisations. Recent projects in the area of patient advocacy include work for Patvocates, CML Advocates Network & CML-CAB, LeukaNET, Myeloma Patients Europe, Patient Power, MDS Alliance, Hematology ePAG Project Management Office and the Hematology Community Advisory Board (Hem-CAB), and the European Patients' Academy (EUPATI). In her role as Project Manager of the CLL Advocates Network she is coordinating, managing and streamlining the Board's operations, managing the communication among board members and with existing and potential members, tracking and following-up on action items, scheduling and managing calls, meeting and events, managing project in alignment with the objectives of the network, fostering partnerships with other networks. From October 2020, the CLL Advocates Networks plans to recruit a permanent staff member.
- **Governance:** Elaboration of the governance manual / rulebook that shall regulate basic rules, operating procedures, reporting procedures, responsibilities, accountability & commitments, election of new SC members, engaging with volunteers.

## **Outlook: Projects & activities from 2022 onwards**

### **In the area of education / capacity building**

- **Advocate Development Program (ADP):** We plan to explore the feasibility of carrying out a 12 months in-depth training programme on patient advocacy, customized for a small group of leading patient advocates of our community with the support of an experienced service provider. ADP usually combine disease specific topics with cross-disease areas such as clinical research process, patient reported outcomes, trial protocols, basics of statistics, regulatory processes, evidence-based advocacy, etc.). ADPs are delivered through blended learning methodology: e-Learning sessions delivered by experts through webinars and Face2Face sessions.

### **In the area of analysis and advisory activities**

- **CLL Community Advisory Board:** in close collaboration with the Lymphoma Coalition, the CLL Advocates Network plans to collaborate with a CLL Community Advisory Board (CLL-CAB) and take on part of the CAB activities and contents. The CAB will be hosted by the Lymphoma Coalition based on the proven ECAB model implemented by the HIV patient community and EATG and followed by the CML community. CABs are community-run advisory boards where the patient community decides on the topics of highest relevance and impact for the patient community. CABs have the objective of providing researchers, academics, government, policy makers, authorities and the pharmaceutical industry with advice and input on different issues that impact on patients' lives. They aim to promote best-in-class CLL research as well as the harmonisation of good clinical practice, standard of care and access to best available CLL therapies and diagnostic tools. CABs operate under confidentiality, which is of paramount importance for the smooth and efficient functioning. Details on topics and stakeholders are being discussed.