Activity Report 2024
of the Leukemia Patient Advocates Foundation

The Leukemia Patient Advocates Foundation (Stiftung Leukämiepatientenvertreter) has been registered in October 2011 as a non-profit foundation in Switzerland.

About the Leukemia Patient Advocates Foundation

The "Leukemia Patient Advocates Foundation" is a patient-led non-profit foundation in Switzerland. Its mission is to improve the lives and survival of patients affected by leukemia as well as their relatives by supporting leaders in providing help and support. It is a platform for discussions and best practice sharing to leukemia patient groups worldwide. The foundation collaborates with all stakeholders involved in research, treatment and care of leukemia patients. It hosts the global "CML Advocates Network" connecting over 130 leukemia patient organizations in almost 100 countries, see http://www.cmladvocates.net/members), and hosts the "CML Horizons" conference as the annual global leadership meeting that welcomes patient leaders from all world regions (http://cmladvocates.net/cmlhorizons).

This report covers the Foundation's activities in the period of January 2024 to December 2024.

The CML Horizons 2024 Hybrid conference in Vilnius, Lithuania was a highly anticipated and successful event, drawing a diverse group of attendees. A total of **120 participants** attended in person from **57 different countries**. Additionally, about **40 virtual** attendees joined the conference, further expanding its reach and accessibility

This diverse gathering represented **75 organizations from 57 countries**, showcasing the global impact and reach of the CML community. Participants came together with a shared goal of advancing advocacy efforts and improving the lives of individuals affected by CML.

For more information see: CML Horizons 2024 Hybrid Conference - Vilnius, Lithuania - CML Advocates Network

CML Advocates Network has now grown to over 140 organisations in almost 100 countries

The CML Advocates Network (www.cmladvocates.net) is a vivid virtual network specifically for leaders of CML patient groups, connecting over 140 patient organisations in almost countries by the time of this report. The worldwide network is designed and run by CML patients and carers who are registered patient group advocates and organisers. Its website's aim is to facilitate and support best practice sharing among patient group organisers across the world. The CML Advocates Network was created and is run independently by CML patients.

Its website features a constantly updated address list of all CML patient support groups, as well as an increasing number of valuable resources for patients and patient advocates to understand CML and to do effective patient advocacy.

The idea of the CML Advocates Network came up in discussions at the 4th International "New Horizons in Treating CML and GIST" conference in Dublin in 2005. The CML Advocates Network was then set up in 2007 by four patient groups from Germany, UK, Czech Republic and Israel to keep the international networking going also after the community's annual meetings. Over the years it has grown to a well-organized, world-spanning network.

See: https://www.cmladvocates.net/members/

World CML Day 2024

Observed annually on September 22nd, World Chronic Myeloid Leukemia (CML) Day raises awareness about this rare form of cancer and supports patients around the world. This day is dedicated to celebrating the advancements in the treatment of this type of blood cancer, to acknowledging the challenges faced by those affected, and to renew efforts to find a cure.

For World CML Day 2024, patient groups from around 40 countries united to raise awareness of Chronic Myeloid Leukemia (CML). As a group, we celebrated our ability to work together towards our common goal – finding a cure for all people with CML, no matter where they live. What would a cure for CML mean to you? Members shared their thoughts and event details!

Know Your CML application - Do you really Know Your CML?

Symptoms, test results, or side effects – as a CML patient, it can be easy to lose track of one's disease. To equip CML patients with all the features they need to monitor their disease properly, the CML Advocates Network has developed a powerful and versatile tool: the Know Your CML app, available for iOs and Android.

The application allows patients in an easy and convenient way to:

- record their health data, e.g. on symptoms, quality of life or side effects
- share a comprehensive health report within seconds
- find peer support and a CML patient organisation near them
- learn more about their disease through an extensive knowledge database
- find peer support and a CML patient organisation near them
- track their health by pairing their their fitness device
- monitor their BCR-ABL1 count and their blood levels over any period of time

For more information: **Know Your CML - CML Advocates Network**

Blood Cancer Patient Advocates Academy

In 2022 CMLAN has brought an online e-learning tool for its members, patient advocates, to benefit from learning on various subjects representing the field of their interest. By recognizing the necessity to bring this specific tool to the wider community, dedicated to establish a long-term program, CMLAN has joint its efforts with CLLAN, ALAN and MPNAN, members of LePAF, to transform this Online Academy to support their members in their efforts to improve the lives of people living with blood cancer across the world. The Online Learning Platform aims at delivering comprehensive e-courses on a wide range of topics representing common ground either specific to all of the networks or for the specific type of blood cancer. The Online Academy has now grown and, in 2024, was transformed into the Blood Cancer Patient Advocates Academy.

The Online Academy strives to enable blood cancer patient advocates to acquire new knowledge and expand current, learn and build skills up to a level which will bring a better recognition, increase the advocacy impact in every single corner of the world and help sustain their organisations. To bring this e-learning closer to a broader network of its patient advocates enabling learning no matter which country of the globe they live in, CMLAN, CLLAN, ALAN and MPNAN have chosen to use Online Blended Learning format!

#BeLeukemiaAware Awareness Campaign

Since few years, ALAN together with CML Advocates Network, CLL Advocates Network and Leukaemia Care focus on continuing raising awareness about (acute) leukemia and symptoms awareness with a focus on the importance of early diagnosis.

We propose to continue the #BeLeukemiaAware campaign all year, but with a particular focus on Blood Cancer Awareness Month in September and World Leukemia Day on 4th September.

Objective

In addition to materials and activities created in previous years, we will continue creating tailored activity around existing external awareness days (focusing on the relevance to acute leukemia), where we will be supportive of wider campaigns.

Exploring the Difference that Patient Involvement in HTA Makes in Cancer
https://acuteleuk.org/wp-content/uploads/2024/11/Exploring-the-difference-that-patient-involvement-in-HTA-makes-in-cancer.pdf

- This research used data from IQVIA's Market Access Insights database to identify the number of cancer patient group submissions (n=871) made to HTA agencies in Canada, England, France, Germany and Scotland between January 2020 and March 2023. It also looked at the openness of HTA agencies to patient involvement, informed by previous ALAN-commissioned research and the HTA recommendations made with and without patient group submissions.
- The number of cancer patient group submissions has been increasing in Canada (from 26 in 2020 to 27 in 2021 and 37 in 2022), England (26, 35, 50), France (26, 35, 50) and Scotland (21, 24, 28) from 2020 to 2022. That means more work has been done by cancer patient groups and the HTA agencies. Cancer patient group submissions fell in Germany over the same period.
- There isn't a clear picture of whether the cancer patient group submissions made a difference to HTA recommendations, although the approach is descriptive and not able to explore causality.
- The most open HTA agencies – CDA-AMC (formerly CADTH) in Canada, NICE in England and SMC in Scotland –have seen the highest proportion of cancer HTAs receive a patient group submission. It may also be capacity constraints are playing a role in whether cancer patient groups can respond to all HTAs in their cancer area.

- More research is needed to quantify the cost of patient involvement, the drivers for patient group decision-making on whether to submit or not and what difference submissions make to HTA recommendations. Case study research could add valuable insights to help guide when patient groups are most likely to be successful in shaping HTA recommendations to help optimize their input.

Patient Involvement in Health Technology Assessment of Medicines for the Purpose of Reimbursement: An Exploratory Comparative Report
https://acuteleuk.org/wp-content/uploads/2023/02/HTA-report_final.pdf

ALAN members and other patient groups representing those with acute leukemia have contributed to over 90 Health Technology Assessments (HTAs) for treatments conducted by HTA agencies across Canada, England, France, Germany and Scotland from 2020 to early 2023. Despite this significant effort, there is little that places our collective efforts into the wider context of who, how, where, when and what difference our submissions make to the recommendations made by HTA agencies that shape patient access to new treatments for acute leukemia.

- This research describes the opportunities for patient involvement in HTA across six countries in Europe and Canada, comparing the approach each HTA agency takes to patient involvement. It is based upon HTA agencies websites, including their native language sources, as well as the wider literature published between January 2020 and April 2023.
- The report also provides a resource for patient groups – within and outside of acute leukemia – to help them to identity the opportunities for involvement in HTA. Approaches to patient involvement and HTA continue to evolve

ALAN Carer preference study

ALAN conducted semi-structured interviews with caregivers, 20 in each of the USA and UK and 5 each in France, Germany, Italy and Spain, 60 in total.

Analysis of interviews was conducted using a reflexive thematic approach to identify key themes and insights as outlined by Braun and Clarke (2006).

- This involved coding generating succinct labels (codes) that capture and evoke important features of the data that might be relevant to addressing the research question.
- Next, we conducted a process of generating and refining themes, where themes are defined as pattern of shared meaning underpinned by a central concept or idea.

Key takeaways:

- The impacts on individuals as a result of caring for a loved one through diagnosis and treatment of acute leukemia are considerable and broad-ranging.
- Becoming a carer can have a significant impact on quality of life; carers often feel as though they are balancing multiple roles.

    - Caregiver responsibilities are time-consuming and often include activities such as housework, emotional support, medical assistance, hygiene and accompanying physical activities.
    - Carers frequently mention adverse effects on their emotional well-being, mental and physical health. The experience of caregiving can take a toll on an individual's own quality of life.
- Impacts on quality of life vary based on personal circumstances and experiences but can be categorized into the following themes:
    - Emotional burden,
    - Mental burden,
    - Carer's own health,
    - Professional impact,
    - Financial impact,
    - Social impact
    - Time burden.
- Carer concerns about the future were mainly related to fears of relapse or death of the patient
- Carers often play a supportive role in treatment decision-making. In general, they prefer treatments with less burden on the patient and themselves but are willing to make sacrifices to ensure the patient's needs come first.

The **MPN Advocates Network** leads several key initiatives to support patients with myeloproliferative neoplasms (MPNs) and their advocates worldwide.

MPN Horizons Conference 2024

The MPN Horizons Conference is the cornerstone event of the MPN Advocates Network, held annually to unite patient advocates, healthcare professionals, and researchers from across the globe. This unique gathering provides a platform for sharing updates on MPN research, treatment strategies, and advocacy techniques. The conference strengthens the international MPN community, fosters collaboration, and empowers advocates to drive change and improve patient care in their own countries.

MPN Awareness Day 2024

Each September, we lead MPN Awareness Day to shine a spotlight on myeloproliferative neoplasms and the people living with them. The campaign raises public awareness through coordinated global activities, educational content, patient stories, and social media outreach. By engaging both the public and healthcare stakeholders, we aim to increase understanding of MPNs, reduce stigma, and advocate for earlier diagnosis, better treatments, and more comprehensive patient support.

Global Survey

The Global Survey of MPN Patients' Needs is an ambitious international initiative designed to gather insights directly from patients living with MPNs. Through this survey, we aim to understand their challenges, unmet needs, and priorities in areas such as

treatment, communication with healthcare providers, and quality of life. The data collected helps shape more patient-centered care, guides advocacy efforts, and informs healthcare providers and policymakers worldwide.

MPNAN Webinars

Our MPNAN Webinars are a dynamic educational resource, offering regular online sessions tailored to the needs of both patient advocates and those living with MPNs. These webinars cover a wide range of topics—from medical updates and clinical trials to advocacy strategies and mental health—featuring presentations by leading experts and patient leaders. They serve as a vital tool for keeping the MPN community informed, connected, and engaged throughout the year.

CLL Horizons 2024

CLL Horizons 2024 has concluded successfully in Barcelona! The CLL Advocates Network (CLLAN) Steering Committee successfully held the 5th International CLL Horizons Conference from September 27 to 29 in the vibrant city of Barcelona, Spain. This hybrid event attracted participants both in person – 85 delegates from 41 countries – and virtually, fostering a global dialogue on chronic lymphocytic leukemia (CLL).

The conference featured a variety of comprehensive workshops and sessions aimed at enhancing participants' skills and knowledge.

Expert-led medical discussions provided insights from leading hematologists and supportive care specialists. Participants explored crucial topics, including CLL diagnosis, active monitoring, personalised treatment approaches, and updates on the latest research studies. Panel discussions examined the current treatment landscape of CLL, focusing on first-line treatments, re-treatment options, and new frontiers in CLL research.

LINK: https://www.clladvocates.net/cll-horizons-2024/

CLL IC Taskforce

The CLL Immune Challenges Taskforce – CLL IC Taskforce – is a multidisciplinary group of CLL patient advocates, clinicians, researchers and industry partners from around the world aiming to raise awareness of the impact that CLL immune challenges can have for patients, their families and clinical care teams to drive meaningful change in policy and practice.

The CLL IC Taskforce aims to build upon the legacy of the 2023 white paper, "Compromised: Uncovering the Immune-Related Challenges Facing People with Chronic Lymphocytic Leukaemia", a collaboration between AstraZeneca and CLLAN. This foundational document has inspired and shaped the CLL IC Taskforce's at every step.

To shape and co-develop the CLL IC Taskforce with the CLL community, several steps were taken across 2024:

Step-1 Virtual workshops
In July 2024, CLLAN hosted two virtual workshops which gathered 32 experts from 19 countries across the globe, including leading voices from the clinical and patient advocacy communities. During the workshops, participants engaged in rich discussions about policy and advocacy priorities which could be taken forward by the CLL IC Taskforce.
The workshops were kindly supported by AstraZeneca and Takeda, setting the stage for a multi-funded approach moving forward.

Step-2 Consensus building
Workshop participants engaged in a prioritisation exercise in autumn 2024 and discussions within the clinical and advocacy communities in January and February 2025. These engagements aimed to allow the community to prioritise and refine the CLL IC Taskforce's activities and work plan for 2025-2026.

The CLL IC Taskforce is committed to driving meaningful change through collaborative projects and initiatives.

LINK: https://www.clladvocates.net/cll-ic-taskforce/

WORLD CLL DAY 2024

The 2024 theme was "Level Up" – our call to action to ensure that those with CLL received the same attention, care, and opportunities for treatment as individuals with other types of cancer. However, 'leveling up' meant different things to different people and organisations. Some were focused on addressing local inequities specific to their regions. Participants were able to choose from the provided assets to shape their own campaigns. Organisations across various countries identified diverse needs and approaches to 'leveling up.' We encouraged all stakeholders to get involved and focus on what mattered most to them.

Campaign materials were designed and created in different languages with a communication plan to help stakeholders, members and supporters to get involved and prepare their own communications in the run-up to World CLL Day and shape their own activities.

LINK: https://www.clladvocates.net/world-cll-day/

This is just a selection of the main projects coordinated within the Leukemia Patient Advocates Foundation. The Foundation is formally represented by the following trustees of the Foundation:

- Jana Pelouchová (President, Czech Republic),
- Jan Geißler (Vice President and Managing Director, Germany)
- Giora Sharf (Treasurer, Israel),
- Erik Aerts (Board Member, Switzerland)

June 2025