Activity Report 2023
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 2023 to December 2023.

The **CML Horizons 2023 conference** was a highly anticipated and successful event that brought together a total of **131 registrants.** Among the attendees, there were **19 newcomers**, adding fresh perspectives to the CML community. Additionally, the conference **attracted 93 virtual attendees**, further expanding the reach and accessibility of the event.
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 2023 Hybrid Conference - CML Advocates Network

CML Advocates Network has now grown to over 130 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 130 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 2023

For World CML Day 2023, 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.

We prepared campaign materials for social media in 12 different languages: English, French, Arabic, German, Hebrew, Russian, Ukrainian, Macedonian, Italian, Serbian, Spanish and Polish.

Throughout the #WCMLD23 campaign we hosted themed photos and patient's CML stories of what Putting a spotlight on CML means to our community.
Over the course of a month, we gathered 68 photos and 28 stories.

See more here: World CML Day 2023 - CML Advocates Network

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**

CMLAN Academy – Online Learning Platform

Turn the theory into practice! Improve your CML patient advocacy skills!

CML AN has been working hard to establish and expand a long-term program, an international-wide Online Academy, to support CML patient advocates in their efforts in improving the lives of people living with CML across the world, aiming at delivering comprehensive courses on a wide range of relevant topics – striving to enable the network to acquire new knowledge and expand current, learn and build their skills up to a level which will bring a better recognition, increase the advocacy impact in every single corner of the world and help them sustain their organisation.

To bring this learning closer to a broader network of its patient advocates is only achievable by enabling learning no matter which country of the globe they live in through delivering a tool in a format of **Online Blended Learning**!

Acute Leukemia Global Summit 2023

The Global Summit is dedicated to the development of ALAN members as patient advocates (established organisations and individual advocates) and deals with important topics for acute leukemia patients and carers, with a mix of medical and advocacy sessions.
The conference offers the opportunity to support and facilitate the quality of education and also provides opportunities to be able to exchange ideas, interact and share best practice. It also provides a platform to start networking across borders and build alliances.
Deliverables

ALAN Global Summit took place from5th to 7th May 2023, in Frankfurt (Germany). More than 40 participants from more than 35 countries attended the event in person.

https://acuteleuk.org/2023-alan-global-summit/

#BeLeukemiaAware Awareness Campaign

- https://acuteleuk.org/project/awareness-campaign/?53
- https://acuteleuk.org/3-months-to-wld23/
- https://www.youtube.com/channel/UCtP_XXDLbTA2Sr_37Qr2ajw

Objective

- The campaign continues to address the previous years' campaign topics, sharing knowledge about signs, symptoms and early detection, and underlining the importance of visiting the doctor when experiencing symptoms.
- It also includes contents dedicated to patients, carers, general public and to GPs.
- We also create tailored activity around existing external awareness days (focusing on the relevance to acute leukemia), where we will be supportive of wider campaigns.

Deliverables

Social media campaign: #BeLeukemiaAware #WLD23 #WorldLeukemiaDay #Leukemia #PatientAdvocacy #BloodCancerAwarenessMonth Tool kit and social media calendar shared 3 months in advance

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ALAN 2023 Webinars

- Latest advances in treatment of AML and what it means for patients
- Latest advances in treatment of ALL and what it means for patients
- How is the risk classification in AML driving treatment intensity? (Speaker: Prof. Lars Bullinger)
- The importance of MRD in acute leukemia (Speaker: Prof Michael Heuser)
- Preparing for EHA
- Reading scientific posters and articles
- Peer-to-peer support in leukemia patient advocacy: Staying in touch with patients and carers (in collaboration with ABRALE)
- Insights into caregiving: physical, social and emotional challenges for caregivers (in collaboration with LLS)

MPN Horizons 2023 Conference: Understanding the New Complexity of MPNs

13 – 15 October 2023, Zagreb, Croatia

MPN Advocates Network (MPN AN) held its **8th MPN Horizons Conference** from **13th to 15th October 2023 in Zagreb, Croatia.** The conference brought together **around 60 representatives of patient advocacy groups** from around **30 countries** over the course of **3 days** to **Learn, Share and Grow.**

During the conference, attendees gained medicinal understanding and advocacy training. They were able to continue sharing ideas, exchange information on what patient organisations are doing to overcome challenges, and how they can work together to strengthen their organisations.

The daily feedback we were receiving from our members showed that the event was a huge success. Everyone felt the uniqueness of the MPN Community that MPN Advocates Network created, from all corners of the globe.

See more information here: https://www.mpn-advocates.net/mpn-horizons-2023-conference/

MPN Advocates Network Global Survey

The MPN Advocates Network **Global Survey** is being conducted by the MPN AN. It is done **by patients for patients**. The research will be conducted to determine **all unmet needs**, **problems**, or **issues** that patients with MPN are facing. The **goal** is to **provide**

patients and **advocates** the resources and knowledge to assist them at local support organisations.

The basic objective of the survey is to document and quantify the differences in the MPN patient experience around the world. The survey consists of about 50 questions covering the whole patient experience, from drug availability to financial impact. It is run electronically and analyzed by professionals.

The eventual aim is to publish the survey's findings in a peer-reviewed journal. It is also hoped that the resulting dataset will become a reusable resource for research and advocacy. It will be published.

Phase 1 was completed in 2019, providing over 1700 responses globally, 80% from the USA, UK, the Netherlands and Canada. Phase 2 is ongoing, with translations into Spanish, Hindi, Italian, Arabic, Korean and Japanese.

World CLL Day 2023

- On 1 September 2023, for the third time the global CLL community joined forces to raise awareness of chronic lymphocytic leukemia (CLL) and give a voice to those affected by this diagnosis.
- World CLL Day was initiated by the global CLL community in 2021. The awareness raising campaign is since launched every 1 September.
- The World CLL Day 2023 campaign mainly focused on understanding the vulnerabilities and challenges faced by CLL patients, particularly their mental health.
- Using the hashtags **#WCLLD23**, **#WithTeamCLL**and **#MentalHealth**, the campaign highlighted the real mental health issues stemming from the uncertainty and chronic nature of CLL, with a special emphasis on the challenges during Active Monitoring ("Watch & Wait").
- The campaign aimed to ensure that patients do not face mental health issues alone, emphasizing the importance of support, information, and connection.

CLL Clinical Trials Hub

- Signposting and information service tool on CLL clinical trials.
- For hosting on CLLAN website.
- Desktop research and analysis to bring together existing global, regional and local clinical trial directories hosting CLL clinical trials (often very complex and too difficult to use and understand).
- Include support with educational information and guidance on use.

CLL Advocacy Toolkit

- Toolkit to support local development (new starts, early development) by providing education / capacity building and supportive materials
- Topics: "Starting a new group", "Communication", "NGO Management & Sustainability", "Engaging with Stakeholders" and others.
- Includes identification of HCP/advocate-champions, closing gaps in CLL support provision outside the clinic (iwCLL/CLLAN collaboration).
- Project team: Focus Group: 18 advocates from 15 countries (all regions), Core Working Group: 8 advocates from 8 countries

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IMI2 "HARMONY Alliance" on big data for better health Outcomes: CML Advocates Network is coordinating patient community input

The Innovative Medicines Initiative (IMI) has approved HARMONY, a 5-year project that aims to foster better access and care for patients with various hematologic malignancies (HM) with the use of big data. The project is made up of 51 partners from 11 European countries, including 7 pharmaceutical companies. Patient input from the hematology patient community is coordinated by Jan Geissler, and the CLL Advocates Network, the Acute Leukemia Advocates Network and the MPN Advocates Network, all hosted by the Leukemia Patient Advocates Foundation, are involved.
See https://www.harmony-alliance.eu/

This is just a selection of the main projects coordinated within the Leukemia Patient Advocates Foundation, run mostly on a volunteer basis by CML patients and carers.

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 2024