



ALAN

Acute Leukemia Advocates Network

WELCOME

ACUTE LEUKEMIA GLOBAL VIRTUAL SUMMIT



ALAN

Acute Leukemia Advocates Network

OVERVIEW OF ALAN AND FUTURE PLANS

www.acuteleuk.org

WHO IS ALAN

About ALAN



- History – Founded in July 2017
- ALAN is:
 - an independent global network of patient organisations
 - dedicated to changing outcomes of patients with acute leukemia
 - by strengthening patient advocacy
- It aims to:
 - build capacity in the members of the network - deliver tailored services to acute leukemia patients and carers on the national level
 - join forces between organisations across countries – e.g. on the policy and research level

ALAN 2020 ACTIVITIES – UPDATE

Initiatives of the Acute Leukemia Advocates Network



- ALAN's activities are
 - Patient-led
 - Collaborative
 - Evidence-based

2020 Plans



- Acute Leukemia Global Summit
- Expand network and grow presence
- Global Quality of Life Survey (#ALQOL)
- Webinars
- Capacity Building – ADP
- Acute Leukemia Awareness Campaign

2020 Plans



Beside running its own projects, we are also involved in initiatives such as:

- HARMONY
- WECAN
- MRD Testing Collaborative
- European Cancer Organisation
- Share4Rare

Acute Leukemia Global Summit



- Why an acute leukemia Global Summit ?
 - development of ALAN members as patient advocates – established organisations and individual advocates
 - provide education on deals with important medical and advocacy topics for acute leukemia
 - exchange ideas, interact and share best practice
 - platform to network across borders and build alliances – bring together members to engage with ALAN and each other

Expand network, grow ALAN presence



- Presence on social media is growing
- **Website** Up to date and used as a reference website
- **Growing network** 40 members from 35 countries and still growing (<https://acuteleuk.org/membership/members/>)

Global Quality of Life Survey (1/2)

<https://acuteleuk.org/project/global-quality-of-life-survey/>



- **Background**

- Multi-country survey to understand patients' experiences, key issues, and unmet needs throughout their journey with acute leukemia.
- Help create evidence about quality of life at different points in the acute leukemia patient journey
- Aid advocates to inform and influence stakeholder communities – e.g. industry, clinicians and policy makers
- Help to identify and communicate the varying levels of information, care and support available for patients and caregivers
- Support education and information tools and programmes for acute leukemia healthcare professionals (HCPs)

Global Quality of Life Survey (2/2)

<https://acuteleuk.org/project/global-quality-of-life-survey/>



- **Key milestones**

- **ASH 2019:**

- Poster “Identifying differences in the quality of life of patients with acute leukemia: a global survey”

- **EHA 2020:**

- Poster “Identifying Factors Associated With Variations in Quality of Life for Patients with Different Acute Leukemia Types: a global survey”
- Presentation “**New insight from ALAN survey**” in the EHA SWG QoL and Symptoms session on “Advances in the use of PRO in hematology”

- **ASH 2020:** Abstract submitted

- **Q4 2020:** Journal Article and promotion to patient and medical communities

Webinars



- **Background:**
 - provide continuous education and training
 - outreach to advocates (e.g. those that can't attend F2F meetings, multiple people from each PAG)
- **Planning:**
 - First webinar held on 20th April 2020: “How to advocate for Acute Leukemia”
 - Attendance: about 30 pax
 - Regions: Europe, LATAM, Asia
 - Patient organisations, individuals, industry
 - Joint webinar ALAN/Share4Rare on 2nd September : “Patient advocates conducting research in oncology”

Other webinars will take place in 2020, stay tuned !

Capacity Building – Advocacy Development Programme



- **Background**

- empower advocates to be more effective and efficient
- at a national level (to overcome barriers and challenges) and at a regional and global level – to represent the acute leukemia community

- **What is it ?**

- 1 year-programme of sessions (theory and practice) delivered by experts with the support of a company (already selected)
- build advocacy capacity – on topics such as understanding R&D, accessing diagnostics and drugs, interaction with stakeholders like clinicians and industry, evidence-based advocacy
- Participants: max. 8
- Format: Virtual

- **Timing:**

- **End of September 2020** : Application process starts
- **December 2020** : Kick-off ADP

Acute Leukemia Awareness Campaign



- **Background**
 - Raise awareness about (acute) leukemia and symptom awareness, with a focus on the importance of early diagnosis.
 - Patients and advocates to lead the narrative – highlight the issues that are important to leukemia patients
- **Timing:**
 - All September: Blood Cancer Awareness Month **#BeLeukemiaAware**
 - 4th September : **World Leukemia Day #WLD20**
 - After September **#BeLeukemiaAware**
- **Materials that can be used at any time:**
 - <https://www.worldleukemiaday.org/videos>
 - <https://acuteleuk.org/world-leukemia-day-is-approaching-wld20/>



World Leukemia Day #WLD20 #WorldLeukemiaDay



Did you know?

September is Blood Cancer Awareness Month and Friday (September 4) was World Leukemia Day - an awareness day designed by [Acute Leukemia Advocates Network](#), [CLL Advocates Network](#), [CML Advocates Network](#) and [Leukaemia Care](#) to raise awareness about Leukemia, and its signs and symptoms. [Learn more here >](#)



Many things happened on social media !

Twitter Sep.

The Numbers

10.151M Impressions

1,513 Tweets

909 Participants

63 Avg Tweets/Hour

2 Avg Tweets/Participant



Twitter data from the #WLD20 hashtag from Thu, September 3rd 2020, 10:35PM to Fri, September 4th 2020, 10:35PM (Europe/London) - Symplur.

#WLD20 Participants



Facebook: 14 new ALAN followers on 4th

Actions on Page

17 August - 13 September

1

Total actions on Page ▼ 50%



Page Views

17 August - 13 September

163

Total Page views ▲ 66%



Page previews

17 August - 13 September

4

Page previews ▲ 33%



Page Likes

17 August - 13 September

25

Page likes ▲ 178%



Post reach

17 August - 13 September

819

People reached ▼ 59%



Story reach

17 August - 13 September

Get story insights

See stats on how your Page's recent stories have performed.

[Learn More](#)

Recommendations

17 August - 13 September



We have insufficient data to show for the selected time period.

Post engagement

17 August - 13 September

180

Post engagement ▲ 13%



Videos

17 August - 13 September

123

3-second video views ▲ 4000%



Linkedin: 14 new ALAN followers on 4th Sep.

QUESTIONS?