



# ALAN

Acute Leukaemia Advocates Network

The Acute Leukemia Advocates Network (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 to deliver tailored services to acute leukemia patients and carers on the national level and join forces between organisations across countries – e.g., on the policy and research level.

All ALAN activities are

- Patient-led
- Collaborative
- Evidence based

In 2021, ALAN worked on number of projects, for which details are provided below.

- Projects ongoing from 2020
  - o [Global Quality of Life Survey](#)
  - o [Capacity Building / Advocates Development Programme](#)
- New projects
  - o [Expand network, grow ALAN presence](#)
  - o [Grow engagement with existing ALAN members](#)
  - o [Online continuous education](#)
    - a. Webinars
    - b. Seminars
    - c. Global summit
  - o [Patient experience survey](#)
  - o [Patient preference study](#)
  - o [Acute Leukemia Awareness Campaign](#)

In addition, ALAN

- Has been involved in multiple external projects, such as HARMONY, WECAN, MRD Testing Collaborative group, European Cancer Organisation, T2 Evolve, IMI-SISAQOL, Meet-AML, etc.  
Details of projects: <https://acuteleuk.org/projects/>
- Attended major congresses (EMBT, EHA, ESMO, ASH)
- Have been advocating for patient advocates to be recognized at the American Society of Hematology and be able to attend the annual congress.  
Details: <https://acuteleuk.org/calling-on-ash-to-include-patient-advocates/>
- Have had various speaking opportunities.
- Has signed a collaboration agreement with SES  
Details: <https://acuteleuk.org/alan-and-scientific-education-support-announce-new-strategic-collaboration-in-acute-leukemia/>

For more information, please visit [www.acuteleuk.org](http://www.acuteleuk.org)



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## Global Quality of Life Survey

<https://acuteleuk.org/project/global-quality-of-life-survey/?53>

<https://acuteleuk.org/publications/>

### Objective

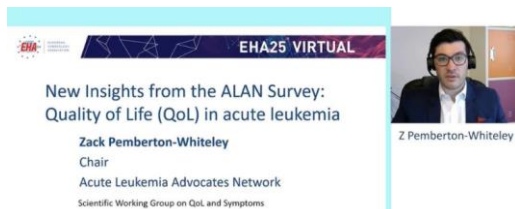
Multi-country survey to generate data, understand issues and gather information on the current and emerging treatment landscape, experiences and quality of life of patients.

- Help create evidence about quality of life at different points in the acute leukemia patient journey
- Aid patient advocates and advocacy groups to inform and influence stakeholder communities, industry 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).

### Deliverables

#### EHA 2020

- Presentation “New insight from ALAN survey” in the EHA SWG QoL and Symptoms session on “Advances in the use of PRO in hematology”



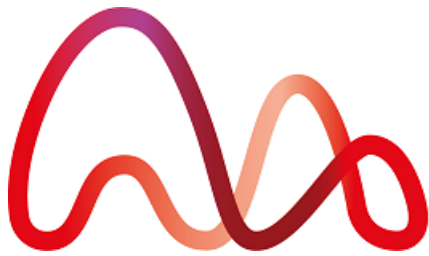
- Poster presented: <https://acuteleuk.org/wp-content/uploads/2020/06/ALAN-EHA-Poster-Identifying-factors-associated-with-variations-in-QoL-for-Patients-with-Different-AL-Types-final-draft.pdf>

### Status

Completed ☒

Note: We are currently finalizing a publication which has been submitted but came back with comments to be implemented.

Our initial plan was also to create some educational materials dedicated to HCPs and to patients and caregivers. We have decided to wait for results of the global patient experience survey and address needs from both surveys.



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## Advocates Development Programme

<https://acuteleuk.org/project/project-3/?53>

<https://acuteleuk.org/alan-advocate-development-program-adp-is-kicking-off-on-10th-december-2020/>

### Objective

A skilled and well-prepared member organisation can advocate more effectively and efficiently at a national level, to overcome barriers and challenges. Also, the development of individual advocates at European and national level will help in achieving the desired impact in representing the acute leukemia community.

### Deliverables

Develop a programme that combines disease specific topics (knowing the disease, existing treatment, guidelines, R&D roadmap, regulatory roadmap etc.) with cross-disease areas (clinical research process, patient reported outcomes, trial protocols, basics of statistics, regulatory processes, and evidence-based advocacy).

The course aims to develop capacity to become an even more effective and empowered patient advocate that serves acute leukaemia patients and carers by understanding clinical research and development, mechanisms of accessing diagnostics and drugs, interaction with stakeholders like clinicians and industry, and the basics of evidence-based advocacy.



8 patient advocates selected by ALAN. Advocate Development Programme is by application / invite only, as trainees should be most likely to apply knowledge, not only do this out of personal interest.

Webinar 1	10 Dec 20	Kick-off: overview on the ADP, and why are we advocates. General discussion and homework related to ASH.
Webinar 2	14 Jan 21	How clinical development works, the drug development process, and why patient involvement matters.
Webinar 3	18 Feb 21	Key elements of clinical trials protocols and study endpoints Reading scientific papers and posters
Webinar 4	11 Mar 21	Statistics and why they matter to advocacy.



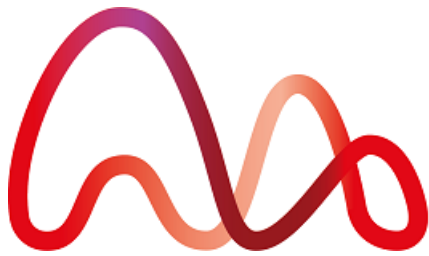
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Webinar 5	15 Apr 21	Acute leukemia big picture (biology and clinical mechanisms of the disease), current treatment landscape, clinical challenges, current guidelines.
Webinar 6	20 May 21	Preparation for EHA: What's in store?
Webinar 7	23 Jun 21	Levels of evidence, and evidence-based patient advocacy.
Virtual Congress meeting training	22 Jul 21	Highlights from EHA.
Virtual Congress meeting training	16 Sep 21	Examples for patients advocates in action
Webinar 8	14 Oct 21	The importance of Patient Reported Outcomes (PRO) and Quality of Life, and PRO instruments used in AML/ALL.
Webinar 9	25 Nov 21	Working with industry & Community Advisory Boards (CABs)
Virtual Congress meeting training	16 Dec 21	Close-out and summary. Recap on ASH. New acute leukemia cancer data at ASH, plus virtual poster and session walk. Your future as patient advocates.

## Status

Completed



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## Expand network, grow ALAN presence

### Objective

- Increase ALAN awareness and visibility: build audience, grow presence, and create engagement
- Grow membership – focusing on existing organisations and countries where there are gaps
- Focus on boosting engagement and retention
- Drive traffic to ALAN website
- Website up to date and used as a reference for acute leukemia community

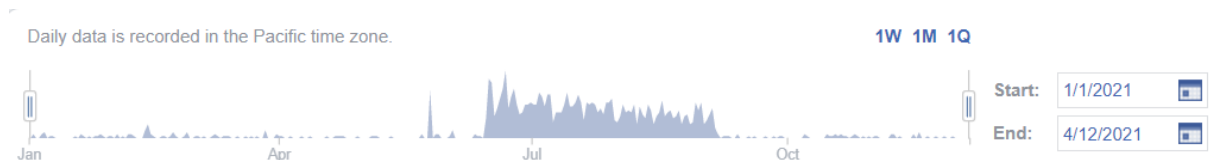
### Deliverables

Membership: <https://acuteleuk.org/membership/members/>

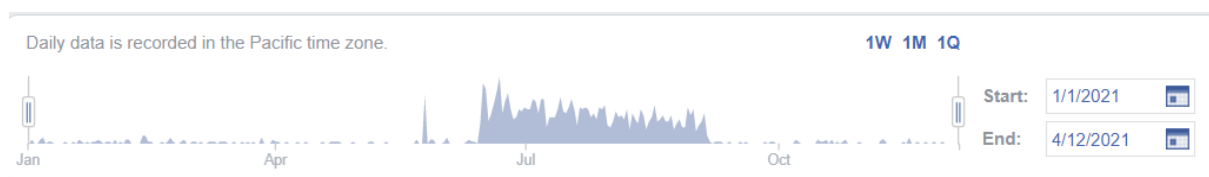
- 46 members
- From 39 countries

Social media – presence is increasing

- Facebook
  - Number of followers – Total number of followers 1850



- Page like – Total page likes 1764

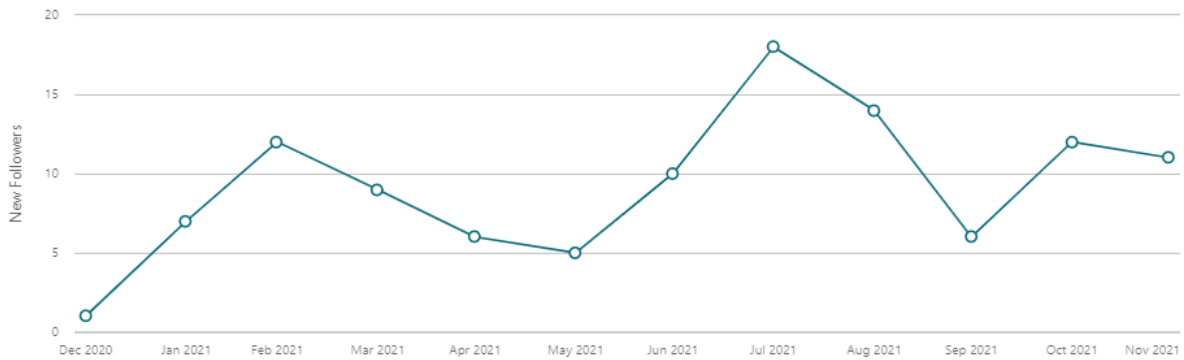


- Twitter
  - Average number of new followers / months: 25
  - Profile visits > 2000k / month since June
- LinkedIn
  - Number of followers



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- Instagram account
  - o Created 07 June 2021
  - o Accounts reached Q4 2021:337k
  - o Accounts engaged Q4 2021: 7424
  - o 137 followers

Website – up to date and used as a reference website

Status

Completed



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## Grow engagement with existing ALAN members

### Objective

While we have been developing the ALAN network, it is important that we grow the engagement with the existing members, who are the voice of the acute leukemia patients and their families on national level.

### Deliverables

- Individual meetings held with 10 member organizations.
  - o Actions which came out from the meetings were all followed up.
    - E.g., Creation of COVID-19 guidance
    - E.g., Sharing of ALAN documents
    - E.g., Support individual organization where needed
- Regional meetings organized prior to the virtual Global Summit.

### Status

Completed ☑

## Online continuous education

### Objective

- Continuous Education / Training on medical and advocacy topics relevant to acute leukemia community.
- And outreach to advocates (e.g., those that cannot attend conferences, multiple people from each PAG, individual patients with an interest in acute leukemia, etc.)

### Deliverables

- 5 webinars
- 6 seminars post EHA
- 1 online summit
- 3 new educational videos on AML, ALL, APL

- Webinars

<https://acuteleuk.org/project/webinars-and-seminars/?53>

- o **Drug Development**
  - Speaker: Samantha Nier
  - <https://acuteleuk.org/webinar-drug-development/>
- o **COVID-19 vaccination and immune challenges for leukemia**
  - Hosts: ALAN and CLL AN
  - <https://acuteleuk.org/joint-webinar-cll-an-alan-on-covid-19-vaccination-and-immune-challenges-for-leukemia-11th-february-4pm-cet/>
- o **Patient involvement in clinical development**



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- Speaker: Jan Geissler
- <https://acuteleuk.org/webinar-patient-involvement-in-clinical-development/>
- **The clinical trials we want!**
  - Speaker: Bettina Ryll
  - <https://acuteleuk.org/join-our-webinar-on-24th-march-2021-1pm-cet-the-clinical-trials-we-want/>

- Seminars

<https://acuteleuk.org/project/webinars-and-seminars/?53>  
<https://acuteleuk.org/upcoming-seminars/>

	Day 1 29 June 2021	Day 2 06 July 2021	Day 3 13 July 2021
17.00 - 17.30	Highlights from EHA: ALL	Highlights from EHA: AML	Deep dive and highlights from EHA: APL
17.30 - 18.00			
18.00 - 18.30			
18.30 - 19.00	Break	Break	Break
19.00 - 19.30	Pediatric leukemias	Secondary AML MDS	CAR-T MRD
19.30 - 20.00			
20.00 - 20.30			

- Global summit

<https://acuteleuk.org/project/project-4/?53>  
<https://acuteleuk.org/second-acute-leukemia-global-summit/>

- Regional sessions reporting

Before the global summit, we met with groups from LATAM, from Middle East Africa and from Eastern and Western Europe to discuss projects, challenged faced, needs and all that is relevant to the region. These discussions were reported by our great speakers:

- LATAM: Fernando Piotrowski, Executive Director ALMA (Argentina)
- Middle East Africa: Bahija Gouimi, President and founder of AMAL Association (Morocco)
- Eastern Europe: Mirjana Babamova, HEMA – Association for support of patients and caregivers of Hematology diseases (Macedonia)
- Western Europe: Anne-Pierre Pickaert, Care4Access, representing Association Laurette Fugain (France)

- Using evidence for advocacy impact

We then had a session on evidence-based advocacy with a training given by Zack Pemberton-Whiteley followed by concrete examples presented by various organizations and a panel discussion.





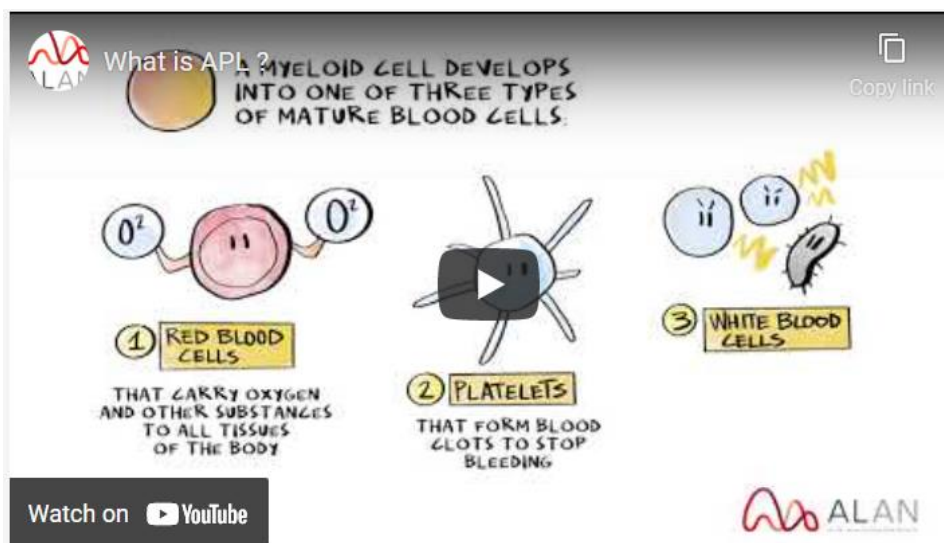
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- Zack Pemberton-Whiteley, Chair of ALAN and CEO of Leukaemia Care (UK)
- Jana Pelouchova, Chair of Diagnoza Leukemie (Czech Republic), founder CML Advocates Network
- Lauren Pretorius, CEO Campaigning for Cancer (South Africa)
- Tracey Iraca, Executive Director MDS Alliance (USA)

- 3 new educational videos on AML, ALL, APL

<https://acuteleuk.org/educational-video-about-what-aml-all-and-apl-are-and-their-signs-and-symptoms-now-available/>



Status

Completed

Patient experience survey

<https://acuteleuk.org/project/patient-experience-survey/?53>

Objective

Multi-country survey to generate data, understand issues and gather information on the current and emerging treatment landscape, experiences and quality of life of patients.

- To identify priority topics, assess areas of change (since the ALAN 2019 survey) including (but not limited to) COVID.
- Create further evidence about patient experience and quality of life at different points in the acute leukemia patient journey.
- Aid patient advocates and advocacy groups to inform and influence stakeholder communities, industry, and policy makers – enabling evidence-based advocacy.
- Help to identify and communicate the varying levels of information, care and support available for patients and caregivers.



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## Deliverables

- Survey opened on 1<sup>st</sup> September and is opened until end of December 2021
- Translated in English, Brazilian Portuguese, French, German, Hebrew, Italian, Korean, Simplified Chinese, Spanish and Russian



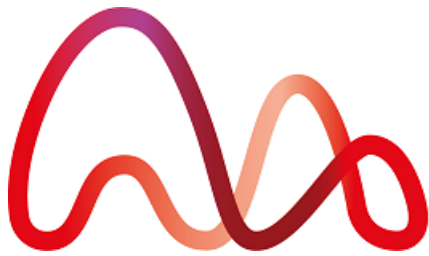
- Respondents (numbers as of 07<sup>th</sup> January 2022)

- Type of leukemia

Acute lymphoblastic leukaemia (ALL)	104
Acute myeloid leukaemia (AML)	311
Chronic lymphocytic leukaemia (CLL)	1194
Chronic myeloid leukaemia (CML)	889
Other leukaemia (Please specify)	131
(blank)	
<b>Grand Total</b>	<b>2629</b>

- Country

Afghanistan	1
Argentina	33
Australia	64
Austria	4
Bangladesh	1
Belgium	7
Bolivia	20
Brazil	12
Bulgaria	1
Cambodia	1
Canada	110
Chile	11
Colombia	18
Costa Rica	10
Croatia	10
Czech Republic	1
Denmark	42
Dominican Republic	3
Ecuador	11
Estonia	4



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Finland	7
France	57
Georgia	2
Germany	50
Ghana	8
Greece	9
Guatemala	20
Honduras	7
Hungary	1
India	9
Indonesia	13
Ireland	26
Israel	70
Italy	1
Kazakhstan	14
Kenya	15
Kyrgyzstan	3
Lebanon	1
Libya	1
Macedonia (FYROM)	1
Malaysia	13
Mauritius	1
Mexico	7
Morocco	5
N / A	10
Namibia	1
Nepal	13
Netherlands	18
New Zealand	46
Nigeria	31
Norway	1
Palestine	1
Panama	4
Paraguay	1
Peru	1
Philippines	30
Poland	4
Portugal	2
Romania	1
Russia	13
Senegal	1
Slovenia	3
South Africa	4



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South Korea	48
Spain	14
Switzerland	4
Tanzania	1
Thailand	6
Tunisia	1
Turkey	1
Ukraine	59
United Arab Emirates (UAE)	1
United Kingdom (UK)	1309
United States of America (USA)	147
Uruguay	1
Venezuela	5
Vietnam	1
(blank)	141
<b>Grand Total</b>	<b>2629</b>

## Status

Completed

## Note:

What still needs to be done in 2022

- We will run an independent carer survey at the beginning of 2022.
- Analysis and management report
- Presentation of findings at major congresses (EHA 2022, ASH 2022)
- Based on both surveys, creation of educational materials

## Budget

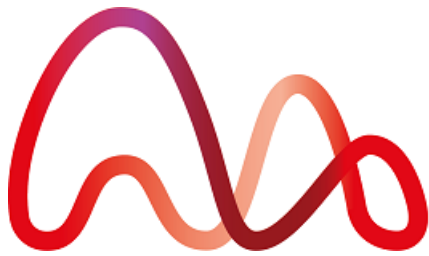
## Patient preferences for acute leukemia treatment outcomes

### Objective

- Better understand the outcomes of importance to patients and to illustrate their relative importance
- Better understand and characterise the heterogeneity in patients' preferences
- Support future technology appraisals and promote access to future treatment options

### Deliverables

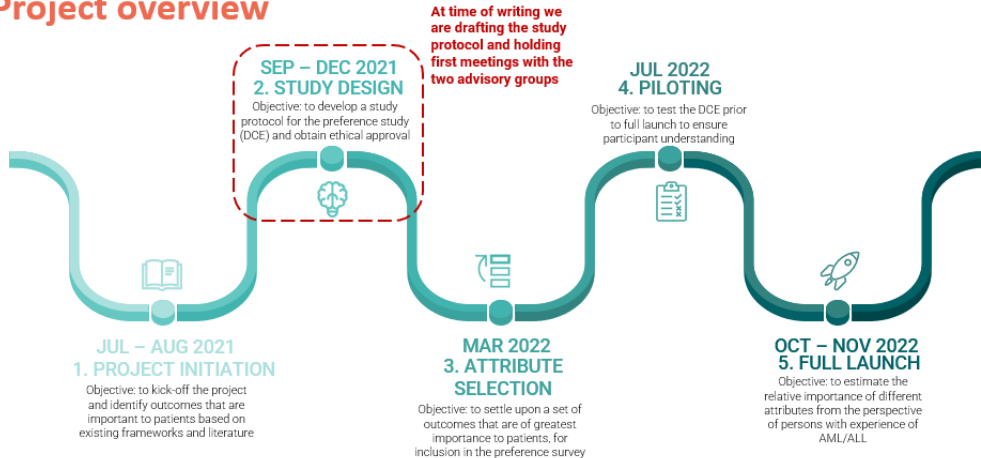
- Project Overview



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## Project overview



## What did we learn during the first phases of the project?

- From literature review
  - There are a **wide range of treatment outcomes** that have been raised as important
  - **Remission status** may be a factor that affects the preferences of people with acute leukemia
  - Many of the treatment outcomes would be relevant for a **range of acute leukemia patients** –and can be grouped together into a smaller set of broader outcomes
  - Quantitative patient preference studies are feasible, and the results suggest that:
    - Survival and remission related attributes are **typically the most important**
    - This is often **closely followed** by side effects and time spent in hospital / mode of administration
    - The quantitative preference study results **align reasonably well** with the findings from the other types of research study explored in the review
    - But, notably, the **industry-sponsored studies were more focused on a specific context** and less likely to contain the wider range of outcomes that matter to patients
- From stakeholders' interviews
  - In practice, first-line treatment decisions may often be overwhelming for patients – examining patients' preferences for first-line treatments specifically may be challenging/biased
  - The life philosophy of people with acute leukemia may, in part, explain their preferences for different treatment options – it may be worth trying to examine this
  - We need to keep in mind the post-Covid world when designing our study (such as the current implication of long hospital stays)
  - Broad studies may be applicable in a wide range of decision-making contexts – but not all!



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- We should aim to maximize the study sample size and try to recruit patients with various (sub)types of acute leukemia, to maximize the relevance of the study results
- Clear language and thoughtful visual presentation of the tasks are appreciated by patients and can help to minimize drop-out
- From ALAN workshop and from workshop with sponsors
  - We will proceed to design a discrete choice experiment (DCE) that will be broad and therefore relevant across the acute leukemia patient population
  - Questions were raised about which attributes to include (e.g., side effects and the possibility of grouping them) – this will be carefully considered in the next phase and informed by patients
  - Carers will be recruited and asked to respond as proxies (answering on behalf of patients)
  - Selection bias needs to be considered in relation to sample representativeness and remission status (both of which relate to the recruitment approach)
  - There is an interest in expanding the study to other countries, which will be explored using the current UK study as a template
  - Heterogeneity across disease types will be explored (and by country if applicable) – but the extent to which this is possible will depend on the sample size

Status

Completed

Note:

What still needs to be done in 2022

- Submission study to EC
- Attribute selection
- Piloting
- Study Launch
- Analysis and report

Acute Leukemia Awareness Campaign

<https://acuteleuk.org/project/awareness-campaign/?53>

<https://acuteleuk.org/4th-of-september-is-world-leukemia-day/>

<https://acuteleuk.org/1-month-to-world-leukemia-day/>

<https://acuteleuk.org/2-months-to-world-leukemia-day/>

<https://acuteleuk.org/3-months-to-world-leukemia-day/>



# ALAN

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## Objective

- Continue raising awareness about (acute) leukemia and symptom 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 (#WLD #WorldLeukemiaDay).
- We will 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

September 4th became World Leukemia Day, an awareness day that has been designed by Acute Leukemia Advocates Network (ALAN), CLL Advocates Network, CML Advocates Network and Leukaemia Care to raise awareness of leukemia and the signs and symptoms.



- New and previous materials can be used at any time:
  - <https://www.worldleukemiaday.org/>
  - <https://drive.google.com/drive/folders/1QJDpvkyqKVHTG-7HFLE3Ycc2nK6rlcZw>
- Social media toolkit produced and shared 3 months prior to WLD.
- Materials created include
  - #WLDTalks
  - <https://youtube.com/playlist?list=PLGULQKZixIfSE3cyeFb9PqiWHpflsSHq0>
  - Spot <https://youtu.be/x7JAqDfGNw4> (viewed 137k times)
  - Infographics on symptoms (+ Translations) <https://acuteleuk.org/acute-leukemia-info/>
  - Printables
- Social media insights shared on 13th September.

## Status

Completed



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Report writing  
Samantha Nier  
ALAN Network Manager

Report review and approval  
Zack Pemberton-Whiteley  
ALAN Chair