WELCOME

ACUTE LEUKEMIA GLOBAL VIRTUAL SUMMIT
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://acuteteuk.org/membership/members/)
Global Quality of Life Survey (1/2)


• **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)


- **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 20\textsuperscript{th} 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 2\textsuperscript{nd} 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

Many things happened on social media!

Twitter
- Sep.
- 10.151M impressions
- 1,153 Tweets
- 909 Participants
- 63 Avg Tweets/Participant

Facebook: 14 new ALAN followers on 4\textsuperscript{th} Sep.

Linkedin: 14 new ALAN followers on 4\textsuperscript{th} Sep.
QUESTIONS?