

DAY 1 – Inspire, Connect, and Educate

13h30– 14 | Networking – Find your buddy.

14-14h30 | Opening & Inspirational Keynote

Learning Objectives:

- Understand the summit goals and key themes.
- Build group cohesion through shared introductions and expectations.

14h30-16h00 Medical Session –Medical Update on Acute Leukemia

- Speakers: P. Rousselot, G. Marconi + patient advocates

Main Session:

1. A clear updated picture of the ALL and AML treatment decision trees
2. Updates on standard of care, new drug approvals, promising clinical trials, biomarkers/diagnostics
3. GvHD
4. CAR-T – is it still a promising option?

Additional topics covered:

- Children (AML/ALL, treatments, survival rates)
- Rare leukemias
- Management of side effects (short and long term)
- Support measures to improve the quality of life for patients during treatment
- Survivorship
- How can personalized medicine play a role in treating acute leukemia?
- The impact of AI and data science in leukemia research - How we can use new technologies to improve early detection

Learning Objectives:

- Gain an updated overview of ALL/AML diagnostics, treatment pathways and decision trees.
- Recognize emerging therapies, clinical trials, and the impact of personalized medicine and technology.
- Understand challenges and care differences in developing countries, pediatrics, and rare leukemias.
- Appreciate patient perspectives and experiences.

16h00– 16h30 | Break

16h30– 17:30 | Transition Toward Advocacy – From Experience to Action

Testimonies

Learning Objectives:

- Learn from personal and organizational advocacy journeys
- Discover successful support programs and key transitions from experience to action.

17:30 – 18h: Yoga with chair

18h-19h: SC meeting (close meeting for ALAN SC members)

19:00 Dinner

End of Day 1

Day 2 - Moving into Action

08:30 – 10:00 | Breakout Workshops: Advocacy in the acute setting – what is our reality and what can we do?

Format: Small Group Sessions (choosing from 3 topics + group report-outs)

Learning Objectives:

- Identify and dissect organizational, communication, and technical challenges in AL patient advocacy.
- Explore digital and AI solutions to streamline efforts and increase impact.

10:00-10:30 – Active Break run by volunteers

10:30-11:00

- Intro: How can patient organisations collect data and generate evidence.
- Data from EBA work

11:00-12:30: Turning Insights into Action (EBA) – what ALAN and its members have done.

Format: Plenary with all moderators + then move to speed networking for discussion – 1 moderator per table. Groups go across all the tables

Tables (1 to 6):

1. Awareness – WLD
2. Provision of information
3. How can technology and digital platforms enhance patient education and patient support
4. How country specific data from a global survey were used in advocacy work –
5. Country example – report from Think Tank event–
6. Emotional support

Learning Objectives:

- Understand the value and techniques of data collection in advocacy.
- Learn from EBA work and global data—how evidence drives program and policy change.
- Explore practical ways to generate and use evidence for local advocacy.

12:30 – 13:30 | Lunch

13:30 – 14:30: From Data Collection to Advocacy - QoL and pt pref. in acute leukemia

Format: plenary

- How does that translate to advocacy?
- Use the data for practical recommendations
- How can national organisations make use of the data?
- Discussion on the best QoL tool for ALL and AML.

Learning Objectives:

- Analyze the relationship between quality-of-life data, patient preferences, and advocacy outcomes.
- Devise strategies to apply research and survey findings to advocacy efforts.

14:30 – 15:30 | Roundtable: Turning Insights into Action (EBA)

Now that we have the data - what do we advocate for ?

Format: Roundtable + Live Polling

Learning Objectives:

- Debate and identify priority advocacy targets using new data.
- Define what “access” and “quality of life” mean locally and globally.

15:30 – 16:00 | Break

16:00 – 17:30 | Collaborative Workshop: Barriers to access

Format: Regional/Language-Based Groups

- Not limited to access to a drug e.g. Access to treatments/clinical trials/diagnostics identify what are the barriers
- Addressing disparities in leukemia care across different regions
- Emerging LMIC

Learning Objectives:

- Identify access barriers specific to treatment, trials, and diagnostics in different regions.
- Collaboratively design at least one actionable solution per group.

17:30 – 18:00 – Yoga

19:00 Dinner

End of Day 2

Day 3 : Staying Engaged & Expanding Impact

08:30 – 09:30 | SESSION: Access – Global Realities and Solutions

Format: Short Presentations + Panel

Understanding the differences in policies and environments across countries and strategies to overcome them

Learning Objectives:

- Gain insight into policy differences and approaches to improving access across countries.
- Learn from successful advocacy and policy-shaping case studies.

09:30 – 10:30 Collaboration with pharmaceutical companies and academic institutions, funding for leukemia research and trials

Format: debate

- Collaboration with pharmaceutical industry: What works and what doesn't work
- Collaboration with researchers:
- Collaboration with medical society
- Case studies on
 - expanding access to medications in various countries (especially government coverage of high-cost drugs)
 - Compassionate use
 - Effective collaboration between patient organizations and healthcare professionals
 - Planning and implementation of multinational joint education programs (for patients and caregivers)

Learning Objectives:

- Explore models for effective collaboration with industry and researchers.
- Learn how partnerships can increase access and drive research/education.

10:30 – 11:00 | Break

11:00 – 12:00 | Strategy Workshop: What to Advocate for Locally?

Format: Country/Partner Teams or Pairs

Learning Objectives:

- Synthesize summit learnings into a draft local advocacy micro-strategy.
- Collaborate with peers and ALAN SC for practical planning research alliances.

12:00 – 12:30 | Closing Session: Staying Engaged & Expanding Impact

Format: Cross-testimonies + Group Engagement

Learning Objectives:

- Reflect on the summit's impact and personal/professional growth.
- Commit to ongoing involvement and share key takeaways.

12:30 – 13:30 | Lunch - + departures