



ALAN

Acute Leukemia Advocates Network

# ALAN GLOBAL SUMMIT

#ALANsummit

[www.acuteleuk.org](http://www.acuteleuk.org)

# #ALANSUMMIT

# INTRODUCTIONS

# About ALAN



- History – Founded in July 2017
- ALAN is hosted under the umbrella of the Leukemia Patient Advocates Foundation (LePAF), a patient-led, charitable, non-profit foundation based in Switzerland.
  - Its mission is to improve the lives and survival of patients affected by leukemia and other hematological malignancies.
  - In order to improve the life and survival rates of leukemia patients worldwide and in order to support their relatives, the foundation offers an international platform for the education of and the exchange between patients advocates as well as their organizations.
  - The foundation cooperates with the most influential players that deal with the research and therapy of hematological cancers as well as healthcare policy and patient advocacy.
  - The foundation acts as a legal entity for four self-sustained patient advocacy networks
    - CML Advocates Network (CMLAN)
    - MPN Advocates Network (MPNAN)
    - CLL Advocates Network (CLLAN)
    - Acute Leukemia Advocates Network (ALAN)

# About ALAN

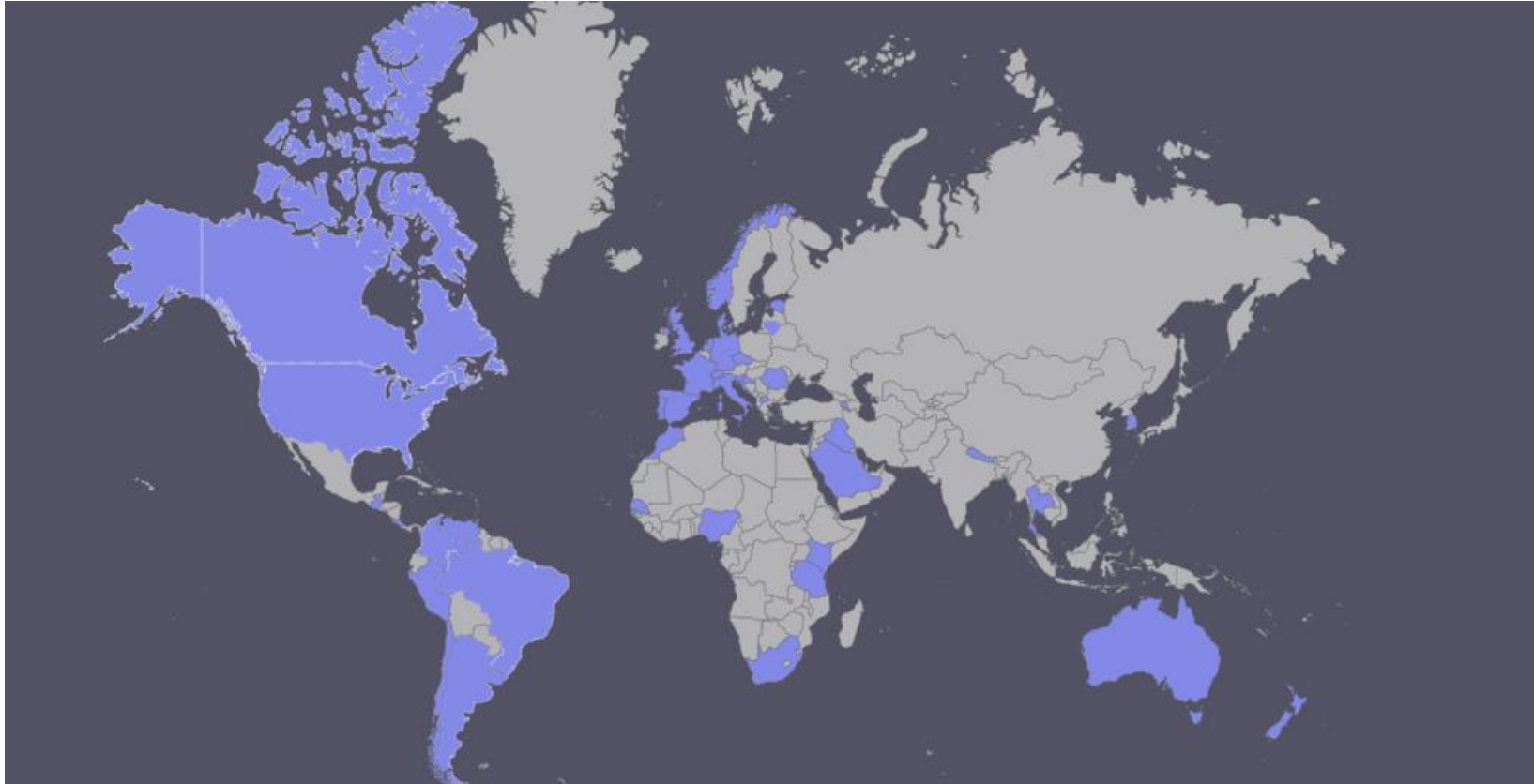


- ALAN is:
  - an independent global network of patient organisations
  - dedicated to changing outcomes of patients with acute leukemia
  - by strengthening patient advocacy
- It aims to:
  - build capacity in the members of the network - deliver tailored services to acute leukemia patients and carers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

# About ALAN



- Members of ALAN



- Welcome to our 4 new members: Sawera (Switzerland), Estonian Leukaemia and Lymphoma Patients' Society (Estonia), MPN Patient Advocacy Group Thailand (Thailand), AGIL (Senegal), Blood Cancer Foundation Tanzania (Tanzania)

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# About ALAN



- Current Steering Committee



**Zack Pemberton-Whiteley**

Chair & Steering Committee member  
Email: [zack@acuteleuk.org](mailto:zack@acuteleuk.org)



**Jan Geissler**

Steering Committee member /  
LePaf representative  
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**Sophie Wintrich**

Steering Committee member  
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**Anne-Pierre Pickaert**

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**Cheryl Petruk**

Steering Committee member  
Email: [cheryl.petruk@cmpnrf.ca](mailto:cheryl.petruk@cmpnrf.ca)

- Are you interested in joining the Steering Committee? Let us know !



# About ALAN



- Network Management



**Samantha Nier**

Network Director

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**Christine Leiser**



**Alastair Gray**



# About ALAN



- As a growing network, ALAN has to ensure that relevant documentation is in place to ensure business continuity and sustainability of the organization
  - Create / Formalize and implement:
    - Governance
    - Operating Rules
    - Code of conduct and Ethical Framework
    - Procedures and policies
    - Business continuity plan
  - Ensure GDPR compliance.
  - Submission of the EMA application when ALAN meets the criteria to do so.
  - Strengthen collaboration with other networks on European and international levels.



ALAN's activities are:

- Patient-led
- Collaborative
- Evidence-based