



**get in touch**

for more information on RAIN and how to become a member!

## Our story so far...

Our story began at ASH 2019, when a group of healthcare professionals and patient advocacy group representatives came together to identify and better understand unmet needs faced by the rare anaemias community.

The outcome of this meeting was the agreement that there was a need to form a global alliance of physicians, patient advocacy groups, and industry—all with expertise in rare anaemias—to help address at least some of the unmet needs.



### Mission

Improve the health and quality of life of people with rare anaemias.



### Vision

Empower and strengthen patient advocacy groups supporting rare anaemias by establishing a global network!

With your help, we aim to:

Implement and/or establish national policies specific to rare anaemias

Ensure equal access to diagnosis and treatment

Initiate and support research by bringing the patient perspective to the drug development process

Render novel therapies accessible to patients

RAIN recently hosted our first meeting with a selection of organisations from the community to gain further insight to support the launch of the network. Here are the outcomes:

How can we differentiate RAIN from existing initiatives?

- By bringing global initiatives together
- By improving access to treatments
- By creating global consensus statements
- By building a network of global experts to support local physicians treating rare anaemias
- By becoming a large global organisation that focuses on rare and ultra-rare anaemias
- By being a platform—uniting the rare anaemias community so we can collaborate and learn from one another

How can we meet the unmet educational needs in rare anaemias?

- By educating physicians to better identify symptoms and correctly diagnose patients
- By educating lab technicians on how to handle blood correctly
- By providing education on how to deal with opioid- or drug-seeking patients
- By eradicating the stigma around rare anaemias
- By raising awareness of global guidelines within the healthcare community

What do we want to achieve in the next 3 years?

- Expansion of the network
- A focus on advocating awareness of rare and ultra-rare anaemias
- Better care for adults living with rare anaemias, on a global scale
- Global access to safe blood
- Preparation of a range of translated materials, to support patients globally

To achieve our mission, we need your help!

**email us** for more information and to get involved.

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