



## MEMBERSHIP

If you are part of, or know a PNH patient organisation who may wish to join our Alliance, please contact us here:

[pnhglobalalliance@gmail.com](mailto:pnhglobalalliance@gmail.com)



**PNH**  
GLOBAL  
ALLIANCE

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*Contact us!*



**PNH**  
**GLOBAL**  
**ALLIANCE**

The PNH Global Alliance is a non-profit organisation, comprising PNH patient organisations from all over the world



## WHO WE ARE

The Alliance was formed in December 2018 to share information and expertise, collaborate on common challenges, join forces on issues important to our community and leverage our combined voice for the benefit of the PNH patient community. Our members are set out below:

- AAMAC (Canada)
- AAMDSIF (USA)
- Another Life (Russia)
- Aplastische Anämie & PNH e.V. (Germany)
- Asociación de Hemoglobinuria Paroxística Nocturna (Spain)
- Canadian Association of PNH Patients (Canada)
- Jedni na Milion - Stowarzyszenie Pacjentów z PNH (One in a Million - Poland)
- PNH Support (England, Wales and Northern Ireland)
- PNH Ukraine
- Stichting AA & PNH Contactgroep (the Netherlands)
- Stiftung Lichterzellen (Germany)

## WHAT WE DO

The overall aim of the Alliance is to collaborate in order to advocate in the best interests of PNH patients worldwide.

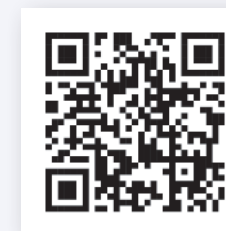
Examples of specific objectives of the Alliance:

- maximising access and availability of medicines for all PNH patients
- promoting research and development for medicines and procedures to treat and cure PNH
- advocating for PNH patients' active involvement in the research and development process of medicines from as early as possible
- representing the PNH patient community in meetings and events relevant to us
- raising awareness among healthcare professionals of the symptoms of PNH in order to promote timely diagnosis and appropriate treatment
- collecting and spreading best practice of care, treatment and cure for PNH
- being involved in regulatory processes which license and approve medicines
- educating ourselves on the latest developments in research for dissemination to the patient community

## DONATIONS

The Alliance members are predominantly volunteer organisations with very limited financial resources, if any. The work of the Alliance is primarily undertaken by patients, who volunteer alongside their paid jobs. Donations will enable us to undertake our aims and objectives for the benefit of the global PNH patient community. A tax receipt can be provided on request.

**Bank NL77ABNA0877597847**  
<https://pnhglobalalliance.org/donate/>



**Dutch Chamber of Commerce number 75270854. Info available at [www.kvk.nl](http://www.kvk.nl)**

