



MEMBERSHIP

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

contact@pnhga.org







PNH
GLOBAL
ALLIANCE

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Contact us!



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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:

- Another Life (Russia)
- Aplastische Anämie & PNH e.V. (Germany)
- Asociación de Hemoglobinuria Paroxística Nocturna (Spain)
- 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)
- PNH Nordic (Scandinavia)
- PNH Support Association of NZ (New Zealand)
- Associação dos Familiares, Amigos e Pessoas com Doenças Graves, Raras e Deficiências (AFAG, Brazil)
- PNH Patient Support India (India)
- PNH Srbija (Serbia)
- PNH Support Association Australia Inc (Australia)

WHAT WE DO

Our Vision

All PNH patients globally have access to optimal care and treatment.

Our Mission

We collectively advocate on behalf of all PNH patients.

Our Objectives

Access:

Maximising access to medicines for all patients

Research & Development:

Supporting Research & Development (R&D) to understand, test, treat and cure PNH including by advocating for PNH patients to be actively involved in R&D from start to finish

Advocacy:

Representing patients, advocating and raising awareness with stakeholders relevant to the PNH community

Education:

Sharing relevant information and educating ourselves

DONATIONS

The Alliance members are charitable organisations or initiatives 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.

The PNH Global Alliance is a non-profit organisation. All positions are held on a voluntary basis. If you wish to support the the organisation please contact us or use our bank account:

IBAN: NL77ABNA0877597847

BIC: ABNANL2A

Dutch Chamber of Commerce number 75270854. Info available at www.kvk.nl

