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Interest Group

Paroxysmal Nocturnal Hemoglobinuria: What we have learned from the introduction of new therapies

67th ASH Meeting and Exposition
Friday Satellyte Symposia
December 5th
7:00 a.m. - 10:00 a.m. Eastern time
OCCC - Tangerine Ballroom F1

This program is supported by independent educational grants from AstraZeneca, Novartis, Roche, Sobi and Apellis

Independent Medical Education Grant Support

- Alexion
- Apellis
- Novartis
- Roche
- Sobi

Thank you to our Annual Supporters!

- Alexion
- Amgen
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- Omeros
- Regeneron
- Roche
- Samsung
- Sobi

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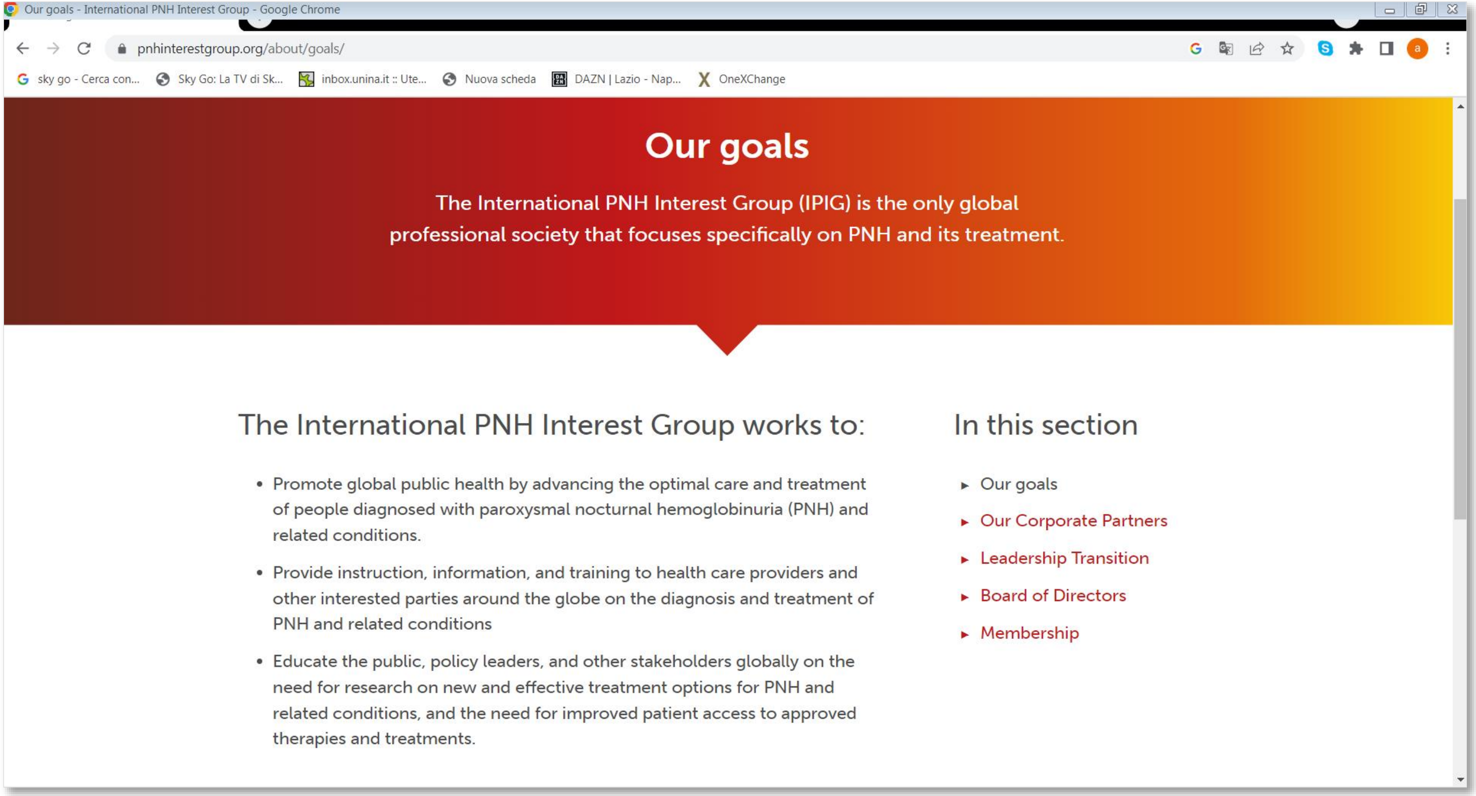
Who are we?

Information courtesy of Professor Antonio M. Risitano.



Our goals

The International PNH Interest Group (IPIG) is the only global professional society that focuses specifically on PNH and its treatment.

The International PNH Interest Group works to:

- Promote global public health by advancing the optimal care and treatment of people diagnosed with paroxysmal nocturnal hemoglobinuria (PNH) and related conditions.
- Provide instruction, information, and training to health care providers and other interested parties around the globe on the diagnosis and treatment of PNH and related conditions
- Educate the public, policy leaders, and other stakeholders globally on the need for research on new and effective treatment options for PNH and related conditions, and the need for improved patient access to approved therapies and treatments.

In this section

- Our goals
- Our Corporate Partners
- Leadership Transition
- Board of Directors
- Membership

Information courtesy of Professor Antonio M. Risitano.

Membership Reach

More than 800 members
in 73 countries

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Our mission:

The mission of the International PNH Interest Group is to advance optimal treatment and care of people living with paroxysmal nocturnal hemoglobinuria (PNH) and related conditions; to provide instruction, information, and training to health care providers; and to help further research on new and effective treatment options and improved patient access to approved therapies and treatments.

Information courtesy of Professor Antonio M. Risitano.

IPIG missions

Patients

Worldwide

Education

Science

Registry

Research

Patient advocacy

Collaboration

Pharmaceutical companies

Friendship

Information courtesy of Professor Antonio M. Risitano.

Board of Directors

- Antonio Risitano, MD, PhD – President & Chair of the Board
- Charles Parker, MD – Chair Emeritus
- Régis Peffault de Latour, MD, PhD – Treasurer
- Jeffrey Szer, BMedSc, MB, BS – Secretary
- Louise Arnold, ACP, MSc
- Rodrigo T. Calado, MD, PhD
- Bing Han, MD, PhD
- Kohei Hosokawa, MD, PhD
- Richard Kelly, MBChB, PhD
- Petra Muus, MD, PhD
- Jun-ichi Nishimura, MD, PhD
- Russell E. Ware, MD, PhD
- Neal S. Young, MD

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Patients and Patients’ Advocacy

Information courtesy of Professor Antonio M. Risitano.

Treatment accessibility: The 2024 challenge

Information courtesy of Professor Antonio M. Risitano.

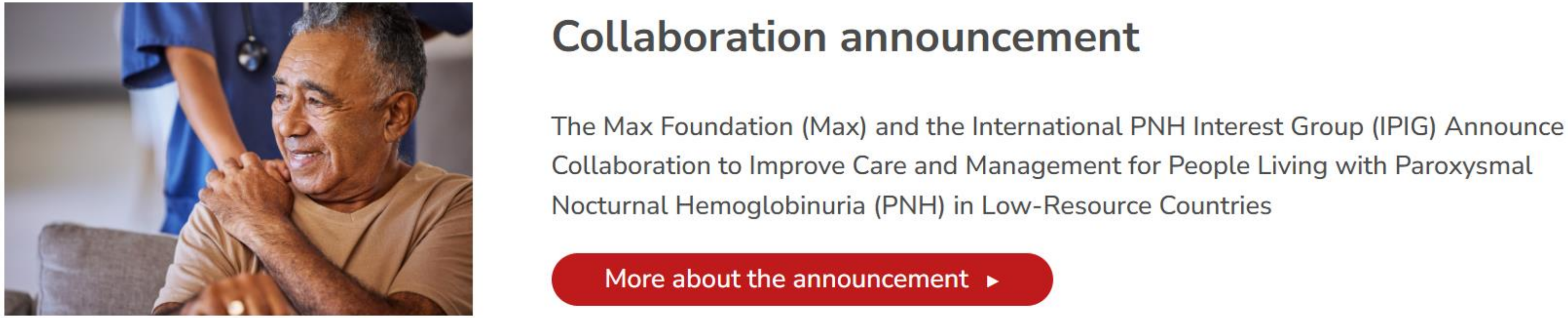
Our partnership with the MAX Foundation

Accelerating health equity, one patient at a time

Learn more at: https://themaxfoundation.org/news/the-max-foundation-expands-collaboration-with-novartis/

Information courtesy of Professor Antonio M. Risitano.

Our partnership with the MAX Foundation



Collaboration announcement

The Max Foundation (Max) and the International PNH Interest Group (IPIG) Announce Collaboration to Improve Care and Management for People Living with Paroxysmal Nocturnal Hemoglobinuria (PNH) in Low-Resource Countries

NEWS PROVIDED BY

The Max Foundation →

Dec 18, 2024, 09:00 ET

- IPIG joins Max's Humanitarian Partnership for Access to Critical Treatments (Humanitarian PACT) and will provide medical education and training on PNH care and management
- Max will provide access to innovative treatment as part of the multi-stakeholder collaboration focused on eradicating survival disparities in 53 low-resource countries
- People living with this rare blood disease require frequent blood transfusions, experience debilitating symptoms of fatigue, and without treatment, have a high risk of thrombosis and a shortened lifespan

Learn more at: https://themaxfoundation.org/news/the-max-foundation-expands-collaboration-with-novartis/

Information courtesy of Professor Antonio M. Risitano.

Our partnership with the MAX Foundation

December 2024

Role of IPIG & Expert Consultants

- **The Max Foundation:**
  - Operationalize the medication delivery for PNH patients in select LMICs, as per Max Access Solutions guidelines
  - Provide accompaniment services to patients to ensure quality of care for these patients
  - Coordinate activities of various partners in the Humanitarian PACT

- **IPIG and expert consultants**:
  - Support education and training for Max team and partner health care professionals, patients, and patient support groups in eligible countries
  - Support identification of potential collaborators for PNH in LMICs
  - Facilitate conversations and partnership engagement with the goal of expanding access to treatment and diagnostics

Learn more at: https://themaxfoundation.org/news/the-max-foundation-expands-collaboration-with-novartis/

Information courtesy of MAX Foundation

Our partnership with the MAX Foundation

Program implementation update: 37 patients identified

- ☐ **Bhutan**
5 patients

- ☐ **Cambodia**
5 patients

- ☐ **Jamaica**
12 patients

- ☐ **Kenya**
3 patients

- ☐ **Nepal**
12 patients

- Meningitis B vaccine not registered or available in countries continues to be a barrier
- Jamaica is expected be first country to enroll patients following disruptions caused by hurricane Melissa. Drug is already at the hospital
- Experts from IPIG have trained physicians in Jamaica, Nepal and Ethiopia; and scheduled training for others

Information courtesy of MAX Foundation

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Science

Information courtesy of Professor Antonio M. Risitano.

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Global PNH Registry Update

IPIG PNH Registry Overview

IPIG PNH Registry
International PNH Interest Group

- A single registry for all patients with PNH, regardless of their treatment status or type of therapy they are receiving
- It will collect information about the course of PNH in patients (natural history), the management of patients and information about the safety of PNH treatments and how well they work
- All PNH patients are eligible to join the registry, providing they give informed consent
- Information collected by clinicians when a patient joins the registry and every 6 months afterwards
- Patients will be asked to complete health assessment questionnaires at the same time points

IPIG PNH Registry Management

- The registry owned and managed by IPIG - a not-for-profit professional society, comprising PNH experts, patient advocates and those involved in PNH research
- IPIG aims to improve the care and treatment of patients with PNH by providing guidance, information and education to healthcare providers
- IPIG is the sponsor of the registry and will oversee the operation and maintenance of the registry through the IPIG Registry Committee
- Multiple pharmaceutical partners (currently 5) are collaborating to support the registry
- A clinical research organisation (CRO), ICON is responsible for registry operations for IPIG

Current Recruitment Status
(28 November 2025)

IPIG PNH Registry
International PNH Interest Group

31 sites open:

- Germany
- Spain
- UK
- USA
- France
- Switzerland
- Netherlands

741 patients recruited

First patient consented:

- 10th May, 2024

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IPIG PNH GUIDELINES

Progress

Hemoglobinuria

- PICO questions set
- Questions on GradePRO and Rayyan
- GRADE result discussion
- Delphi question poll

Chronic hemolytic anemia with perpetual hemosiderinuria (**Marsala-like urine**)

- Final panel meeting in scheduled in Marsala (February 2026)

*: Marchiafava, 1928

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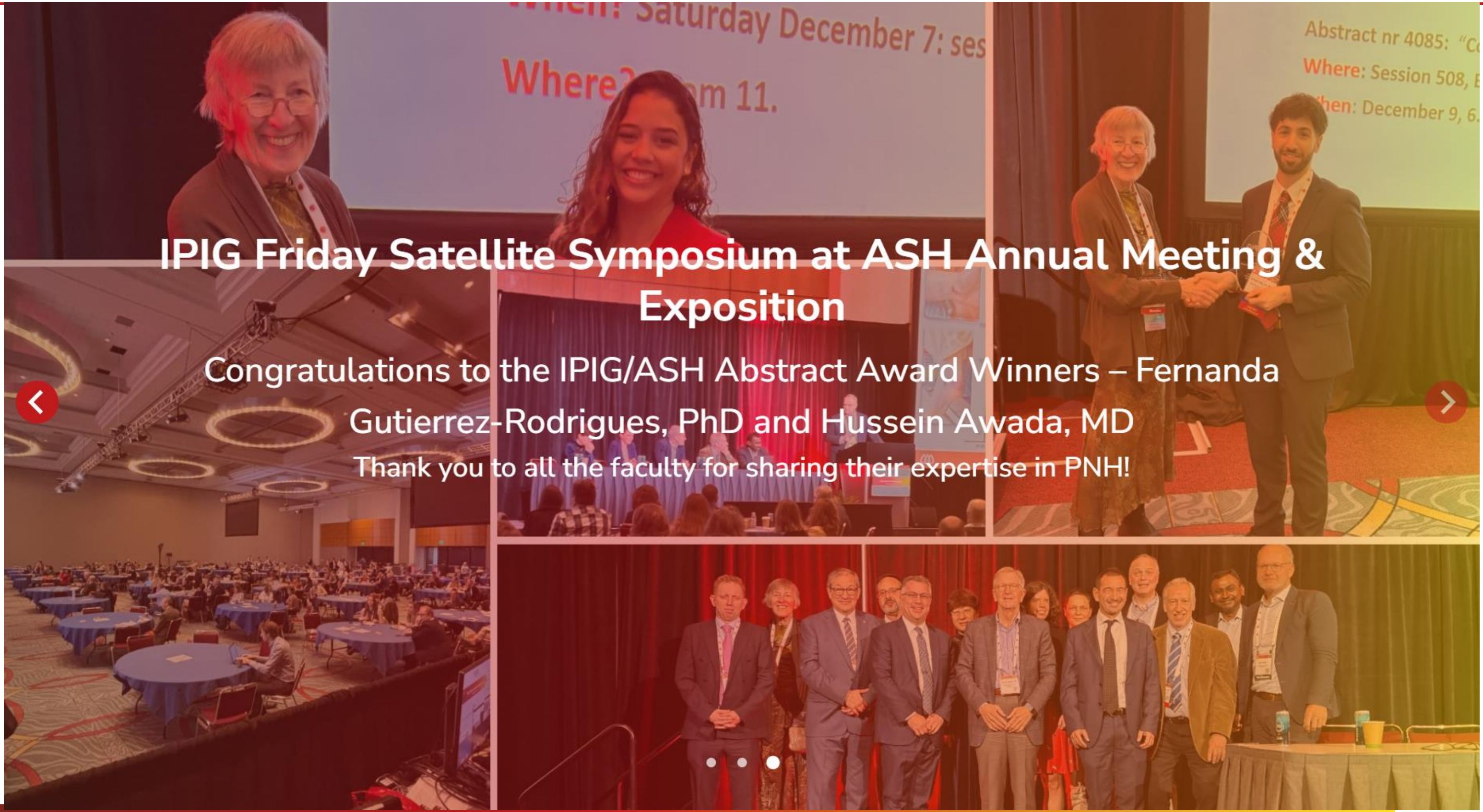
Education

Information courtesy of Professor Antonio M. Risitano.

IPIG at ASH: our Friday Satellite Symposium



IPIG Friday Satellite Symposium at ASH Annual Meeting & Exposition

Congratulations to the IPIG/ASH Abstract Award Winners – Fernanda Gutierrez-Rodrigues, PhD and Hussein Awada, MD

Thank you to all the faculty for sharing their expertise in PNH!

Information courtesy of Professor Antonio M. Risitano.

IPIG endorses high-level PNH meetings

ESH-EBMT-EHA-IPIG 4th Translational Research Conference

Bone Marrow Failure and

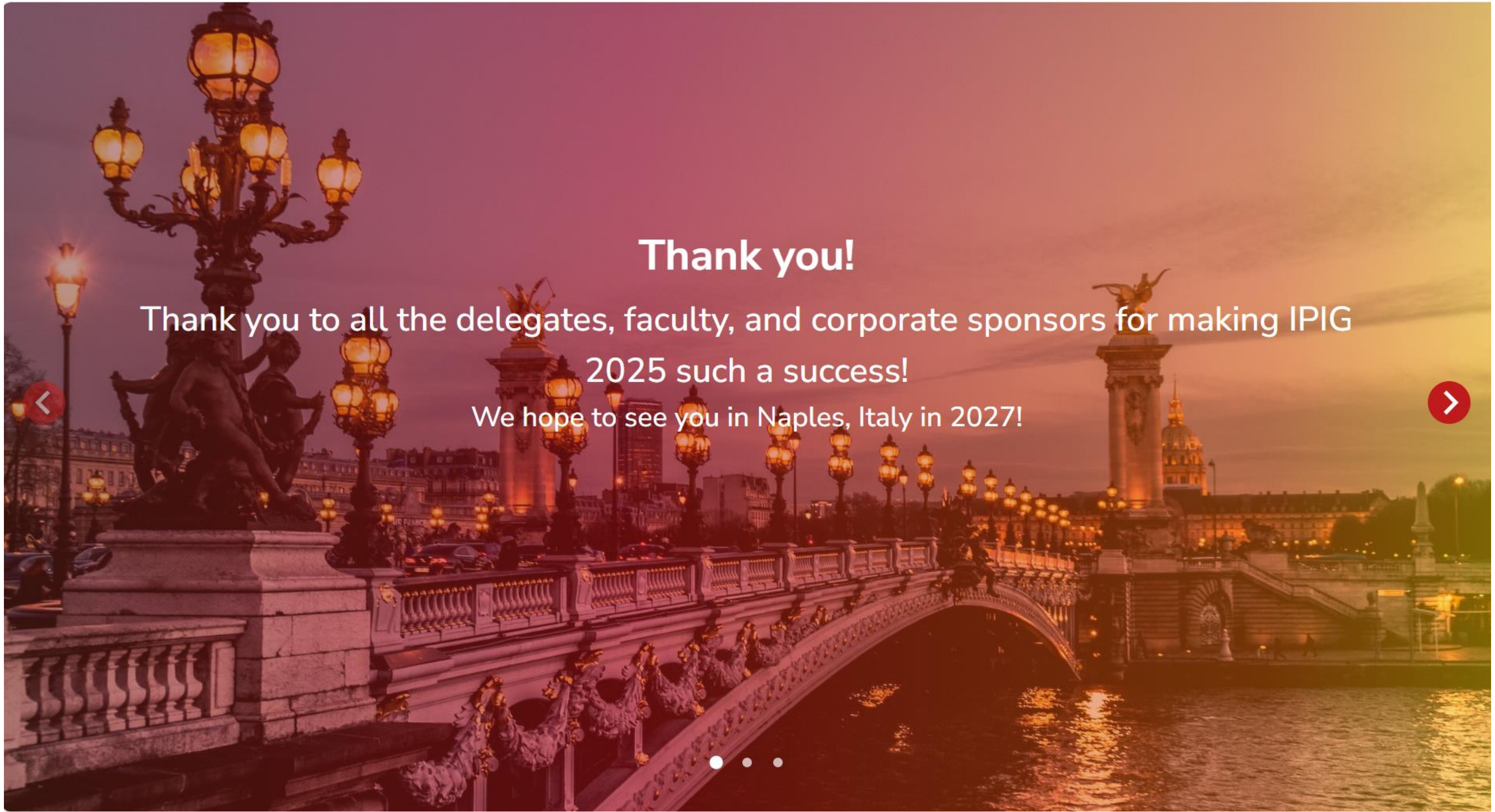
Leukaemia Predisposition Syndromes

SAVE THE DATE
November 6-8, 2026
Vienna, Austria

#ESHBMFS2026

Information courtesy of Professor Antonio M. Risitano.

2nd IPIG Conference



Thank you!

Thank you to all the delegates, faculty, and corporate sponsors for making IPIG 2025 such a success!

We hope to see you in Naples, Italy in 2027!

Information courtesy of Professor Antonio M. Risitano.

3rd IPIG Conference

- Abstracts: oral, flash oral and e-posters
- Travel grants for young investigators and low-income geographic areas
- Info about registration, abstract submission and travel grants available soon
- **Looking for corporate partnerships**

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SAVE THE DATE

3rd IPIG CONFERENCE

MAY 19-21, 2027, NAPLES, ITALY

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Grants and Fellowships

Information courtesy of Professor Antonio M. Risitano.

Travel grant awards

ESH-EBMT-EHA-IPIG 3rd Translational Research Conference: Bone Marrow Failure and Leukemia Predisposition Syndromes

IPIG Travel Grant Award Winners

Camilla Freiri & Anjali Shah

Information courtesy of Professor Antonio M. Risitano.

Travel grant awards

ASH-IPIG Abstract Achievement Awards in PNH

The ASH-IPIG Abstract Achievement Awards in PNH program is a partnership between the International PNH Interest Group (IPIG) and the American Society of Hematology (ASH) to recognize meritorious PNH research.

The ASH-IPIG Abstract Achievement Awards in PNH are intended to help defray the costs of attending the IPIG and ASH Annual Meetings, held consecutively in December. Through this program, IPIG awards up to two $2,000 grants annually to trainees (undergraduate student, medical student, graduate student, resident physician, or post-doctoral MD or PhD fellow) who are the first or senior author and presenter of the most meritorious PNH-focused abstracts submitted to ASH in the fields of red cells and erythropoiesis or bone marrow failure.

In this section

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- Conferences
- About us

Information courtesy of Professor Antonio M. Risitano.

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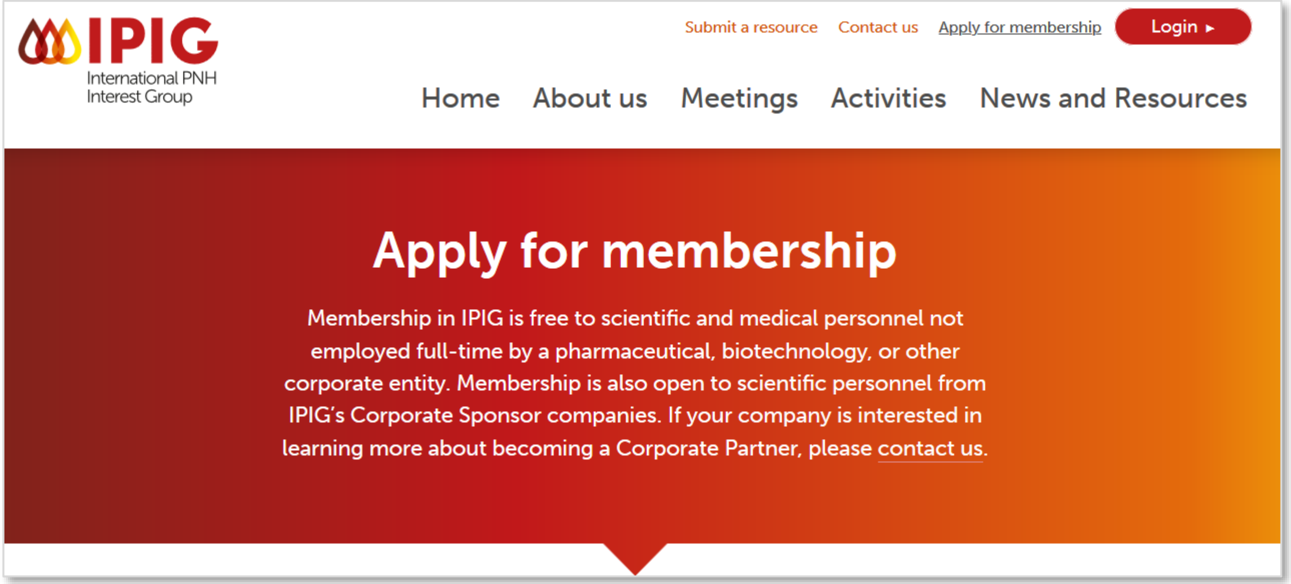
We are listening to you!!!

Please help with suggestions and ideas

Information courtesy of Professor Antonio M. Risitano.

Please register your membership on our website

Your registration on our website ensures that your information and our member database are current



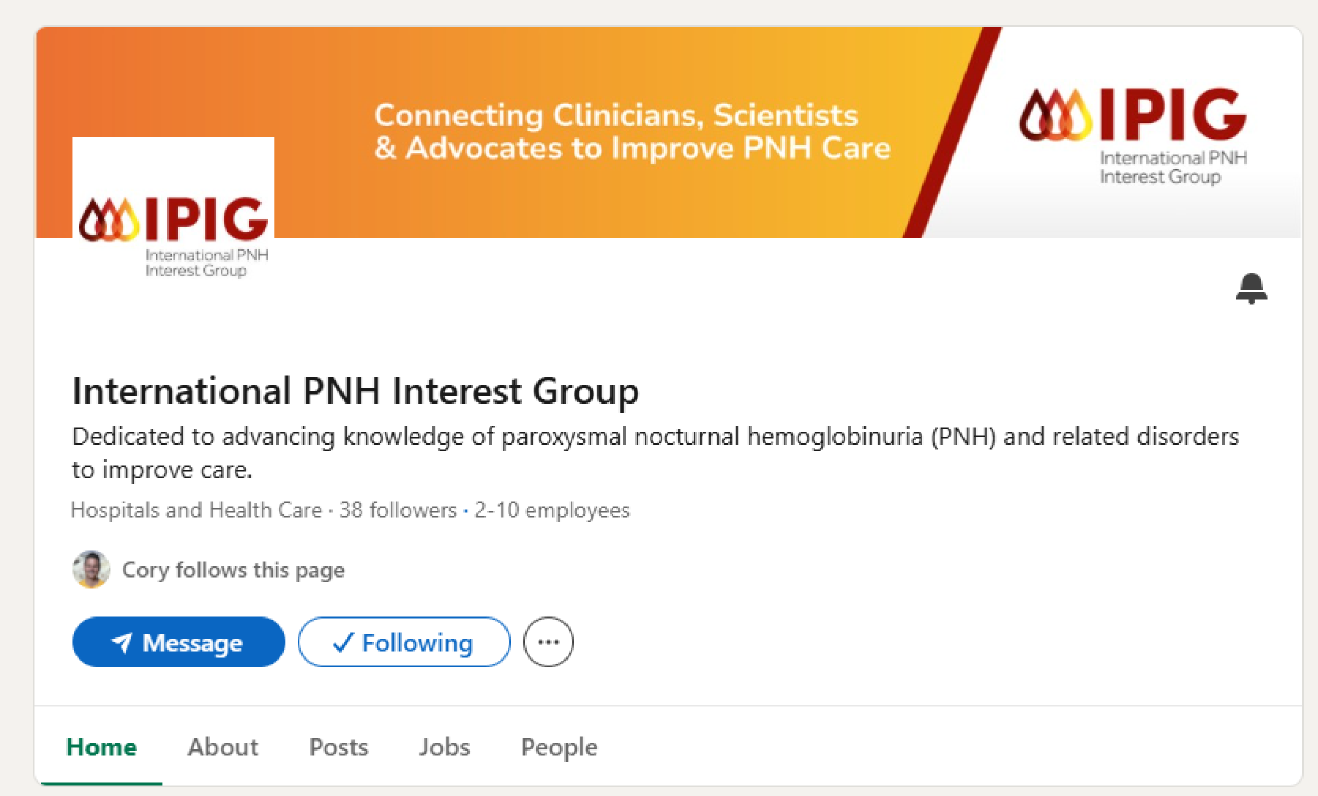
Apply for membership

Membership in IPIG is free to scientific and medical personnel not employed full-time by a pharmaceutical, biotechnology, or other corporate entity. Membership is also open to scientific personnel from IPIG's Corporate Sponsor companies. If your company is interested in learning more about becoming a Corporate Partner, please contact us.

https://www.pnhinterestgroup.org

Information courtesy of Professor Antonio M. Risitano.

Please follow us on LinkedIn!



International PNH Interest Group

Dedicated to advancing knowledge of paroxysmal nocturnal hemoglobinuria (PNH) and related disorders to improve care.

Hospitals and Health Care · 38 followers · 2-10 employees

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ASH-IPIG Abstract Award 2025

Information courtesy of Professor Antonio M. Risitano.

Matthew Holt, MBChB
University of Leeds and Leeds Teaching Hospitals NHS Trust

Information courtesy of Professor Antonio M. Risitano.

Caitlin Roger, BSc (Hons)
University of Edinburgh

Information courtesy of Professor Antonio M. Risitano.