



International PNH  
Interest Group

# **2<sup>nd</sup> IPIG CONFERENCE**

May 15-16, 2025, Paris, France





# MESSAGE from the Conference Chairs

Dear Friends and Colleagues,

It is a great honor to welcome you to the 2nd International PNH Conference in Paris.

The mission of the International PNH Interest Group (IPIG) is to advance the optimal treatment and care of individuals living with paroxysmal nocturnal hemoglobinuria (PNH) and related conditions. We are committed to providing education, information, and training to healthcare providers while also supporting research into innovative and effective therapies and improving patient access to approved treatments worldwide.

Over the next two days, we look forward to engaging in stimulating discussions and thought-provoking debates, featuring scientific presentations, abstracts and posters, novel agents, and roundtable discussions on pressing topics in PNH. This conference also offers valuable opportunities to network with leading scientists and experts who are shaping the future of PNH research and treatment.

I would like to extend my sincere gratitude to our esteemed faculty for their invaluable contributions, our corporate partners for their generous support, and the dedicated organizing committee whose tireless efforts have made this conference possible. A special thank you to Europa, our local organizer, whose hard work and dedication have been instrumental in bringing this event to life.

On behalf of the IPIG Board, I wish you a productive and inspiring conference, as well as a memorable and enjoyable stay in Paris.



**Antonio M. Risitano, MD, PhD**  
President and Chair  
of the IPIG Board



**Régis Peffault de Latour, MD, PhD**  
Treasurer of IPIG Board and Local Organizer  
Head of the French Reference Center  
for Aplastic Anemia and PNH

# GENERAL INFORMATION



## CONFERENCE VENUE

Novotel Paris Centre Eiffel Tower  
61 quai de Grenelle  
75015 Paris



## WELCOME DESK – OPENING HOURS

15 May 2025 from 7:30 am to 7 pm  
16 May 2025 from 8 am to 1 pm



## BADGE

Badges are nominative and non transferable. Wearing your badge is mandatory at all times during the conference.



## FOOD & BEVERAGE

Coffee breaks and lunches will be served in the exhibition area.



## PREVIEW ROOM

The preview room will be open during the opening hours of the conference. It is located in the Louvre room (next to the exhibition area).



## CLOAKROOM

A cloakroom is available next to the welcome desk. Participants are requested not to leave any personal belongings after closing time.



## WIFI

A free Wifi is available throughout the conference areas.  
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## EBAC®

This programme is accredited by the European Board for Accreditation of Continuing Education for Health Professionals (EBAC®) for 12 hours of external CE credits. Each participant should claim only those hours of credit that have actually been spent in the educational activity.

# PROGRAMME

## Thursday May 15th

**07:30** Arrival: Coffee & Pastries

**08:10-08:25** Welcome by Antonio Risitano, President and Chair of the IPIG board

**08:25-08:30** Welcome by Régis Peffault de Latour  
Treasurer of IPIG Board and Local Organizer

**08:30-09:15** **SESSION I: IPIG Award for Lifetime Achievement in PNH**  
Amphitheater AB  
Moderators: Petra MUUS, Leeds, UNITED KINGDOM,  
Antonio RISITANO, Naples, ITALY

08:30 PNH: from an anecdotic disease to a medical success  
Gérard SOCIÉ, Paris

**09:15-10:15** **SESSION II: Biomarkers in the Era of Proximal Inhibition**  
Amphitheater AB  
Moderators: Morag GRIFFIN, Leeds, UNITED KINGDOM,  
Jun-Ichi NISHIMURA, Suita, JAPAN

09:15 The complementologist opinion  
Véronique FREMEAUX-BACCHI, Paris

09:30 The clinical opinion  
Austin KULASEKARARAJ, Londres, UNITED KINGDOM

09:45 Discussion

**10:15-10:45** Coffee break

**10:45-11:15** **SESSION III: Oral Presentation**  
Amphitheater AB  
Moderators: Edouard FORCADE, Pessac,  
Britta HÖCHSMANN, Ulm, GERMANY

10:45 **O-1** - High Proportion of PNH Type II Neutrophils, i.e Relative Percentage? 3%, Is Associated With Thrombosis in Patients Displaying a PNH Clone >1%: Evidence From Analysis of The 5-Year French Observatory  
Orianne WAGNER-BALLON, Créteil

11:00 **O-2** - Maternal and fetal pharmacokinetics of pegcetacoplan in paroxysmal nocturnal hemoglobinuria: A case report of use in pregnancy  
Benjamin CHIN-YEE, London, CANADA

# PROGRAMME

## Thursday May 15th

### **11:15-12:45 SESSION IV: Challenging Situations in 2025**

Amphitheater AB

**Moderators:** Bruno FATTIZZO, Milan, ITALY,  
Flore SICRE DE FONTBRUNE, Paris

- 11:15 Anticoagulation and complement inhibition: can we stop?  
Richard KELLY, Leeds, UNITED KINGDOM
- 11:25 Discussion
- 11:45 Switch from anti-C5 to proximal inhibition  
Jens PANSE, Aix-la-Chapelle, GERMANY
- 11:55 Discussion
- 12:15 Complement inhibition in pediatric patients  
Russell WARE, Cincinnati, UNITED STATES
- 12:25 Discussion

### **12:45-14:00 Lunch**

### **14:00-15:00 SESSION V: Complement Inhibition: State of Art**

Amphitheater AB

**Moderators:** Saskia LANGEMEIJER, Nijmegen, NETHERLANDS,  
Christopher PATRIQUIN, Toronto, CANADA

- 14:00 Where we are?  
Camilla FRIERI, Avellino, ITALY
- 14:20 For PNH patients, where is best to inhibit complément?  
Lucio LUZZATTO, Florence, ITALY
- 14:40 Discussion

### **15:00-15:30 SESSION VI: Oral Presentation**

Amphitheater AB

**Moderators:** Pedro DE LIMA PRATA, Limoges,  
Orianne WAGNER-BALLON, Créteil

- 15:00 **O-3** - PNH in Brazil: multicenter perspectives on clinical outcomes and anti-complement therapy in a resource-limited setting  
Caio JUSTINO, Sao Paulo, BRAZIL
- 15:15 **O-4** - 24-week analysis of a phase 2 study of HSK39297 monotherapy for paroxysmal nocturnal hemoglobinuria  
Gong YUEMIN, Nanjing, CHINA

### **15:30-16:00 Coffee break**

# PROGRAMME

## Thursday May 15th

### **16:00-16:30 SESSION VII: Nurse Practitioner in PNH**

Amphitheater AB

Moderators: Louise ARNOLD, Leeds, UNITED KINGDOM,  
Kohei HOSOKAWA, Kanazawa, JAPAN

16:00 PNH Nursing Experience 'From Little Things Big Things Grow'  
Michael BROWN, Melbourne, AUSTRALIA

### **16:30-17:30 SESSION VIII: Patients Global Alliance**

Amphitheater AB

Moderator: Pascale BURMESTER, Cologne, GERMANY,  
Béatrice DREXLER, Bâle, SWITZERLAND

16:30 Patient wish

17:00 Patient wish

### **17:30-19:00 SESSION IX: Poster Session**

Amphitheater C

Poster Walk Facilitators: Carlo DUFOUR, Gênes, ITALY,  
Hubert SCHREZENMEIER, Ulm, GERMANY

The detailed list of posters can be consulted p.12 to p.17



# PROGRAMME

## Friday May 16th

**08:00** Arrival: Coffee & Pastries

**08:30-09:00** **SESSION X: Oral Presentation**

Amphitheater AB

Moderators: Magali LE GARFF TAVERNIER, Paris,  
Charles PARKER, Salt Lake City, UNITED STATES

08:30 **O-5** - ARV1 is a component of the first step enzyme complex of  
GPI biosynthesis  
Yoshiko MURAKAMI, Osaka, JAPAN

08:45 **O-6** - The natural history of congenital genetic CD59 deficiency  
Dror MEVORACH, Jerusalem, ISRAEL

**09:00-10:30** **SESSION XI: Clonal Hematopoiesis**

Amphitheater AB

Moderators: David ARATEN, New York City, UNITED STATES,  
Simona PAGLIUCA, Nancy

09:00 PNH  
Jaroslaw MACIEJEWSKI, Cleveland, UNITED STATES

10:00 Discussion

**10:30-11:00** Coffee break

**11:00-13:00** **SESSION XII: Complement Inhibition Around the Globe**

Amphitheater AB

Moderators: Yosr HICHERI, Marseille,  
Phillip SCHEINBERG, Sao Paulo, BRAZIL

11:00 IPIG Registry  
Jeff SZER, Melbourne, AUSTRALIA

11:15 IPIG Guidelines  
Rodrigo CALADO, Ribeirao Preto, BRAZIL

11:30 PNH in China  
Bing HAN, Beijing, CHINA

11:45 PNH in Asia  
Lily Lee WONG, Kota Kinabalu, MALAYSIA

# PROGRAMME

## Friday May 16th

- 12:00 PNH in India  
Amit KHURANA, Surat, INDIA
- 12:15 PNH in Eastern Europe  
Jaroslav CERMAK, Prague, CZECH REPUBLIC
- 12:30 Max Foundation  
Pat GARCIA-GONZALEZ, Seattle, UNITED STATES

**12:45-13:00** Conclusion by Régis Peffault de Latour, Paris

**13:00-14:00** Lunch & departure

# POSTERS

- P-01** Pregnancy with Paroxysmal Nocturnal Hemoglobinuria: A Case Series with Review of the Literature  
Yara ALDOSARI, Riyadh, SAUDI ARABIA
- P-02** The global paroxysmal nocturnal hemoglobinuria (PNH) patient registry: highlights of the data from the first three years  
David ARATEN, New York, UNITED STATES
- P-03** Accurate quantification of paroxysmal nocturnal hemoglobinuria clone in neutrophils: added value of anti-CD16 antibody in eliminating eosinophil contamination.  
Bouchra BADAOU, Créteil,
- P-04** Paroxysmal Nocturnal Hemoglobinuria with active thrombosis Improved by Pegcetacoplan: A Case Report  
Yazeed Salem BAJUAIFER, Riyadh, SAUDI ARABIA
- P-05** Clinical profile of patients with paroxysmal nocturnal hemoglobinuria (PNH) receiving complement protein 5 inhibitors: results from a real-world study  
Maria-Magdalena BALP, Basel, SWITZERLAND
- P-07** Subanalysis of patients included in Spain in Commodore II and Commodore I trials  
Silvia DE LA IGLESIA, Bilbao, SPAIN
- P-08** The effect of pregnancy on the pharmacokinetics and pharmacodynamics of eculizumab  
Mendy BOERSMA-TER AVEST, Nijmegen, NETHERLANDS
- P-09** Onset of Neutropenia and decrease in the neutrophil paroxysmal nocturnal hemoglobinuria (PNH) clone size despite a persistently high monocyte PNH clone. What does it happen with the PNH neutropoiesis?  
Andres BRODSKY, Buenos Aires, ARGENTINA
- P-10** Treatment of PNH with complement inhibitors - a single center experience  
Jaroslav CERMAK, Prague, CZECH REPUBLIC
- P-11** Patient satisfaction with use of complement inhibitor injector in paroxysmal nocturnal hemoglobinuria in the United States  
Dharmik DESAI, Waltham, UNITED STATES
- P-12** Phase III COMMODORE 2 and 1 trials: characterization of breakthrough hemolysis events in patients with paroxysmal nocturnal hemoglobinuria (PNH) treated with crovalimab or eculizumab  
Catherine FLYNN, Dublin, IRELAND
- P-13** Danicopan as add-on therapy to ravulizumab or eculizumab in patients with paroxysmal nocturnal hemoglobinuria: Long-term patient-reported outcomes from the phase 3 ALPHA trial  
Flore Sicre De FONTBRUNE, Paris,

- P-14** Aplastic anemia successfully treated with eltrombopag during pregnancy: A case report  
Sandra FREY, Essen, GERMANY
- P-15** Paroxysmal nocturnal hemoglobinuria (PNH) associated neutropenia resolution in patients (pts) treated with proximal complement inhibitors (CIs)  
Sarvarinder GILL, Hackensack, UNITED STATES
- P-16** PNH Treatment: Options, Clinical and Laboratory Monitoring, and Response Assessment  
Sihem KEBAILI, Constantine, ALGERIA
- P-18** Oral iptacopan monotherapy leads to long-term improvements in patient-reported HRQoL and investigator-assessed signs and symptoms of PNH: 48-week results from phase III APPLY- and APPOINT-PNH trials  
Bing HAN, Beijing, CHINA
- P-19** Thrombosis and encapsulated bacterial infection rates in patients with paroxysmal nocturnal hemoglobinuria who received pegcetacoplan: Nearly 3 years of post-marketing experience  
Peter HILLMEN, Waltham, UNITED STATES
- P-20** Reduced iron overload with pegcetacoplan treatment in eculizumab-experienced patients with paroxysmal nocturnal hemoglobinuria  
Peter HILLMEN, Waltham, UNITED STATES
- P-21** Benefit of pegcetacoplan in patients with paroxysmal nocturnal hemoglobinuria irrespective of baseline transfusion status  
Britta HÖCHSMANN, Ulm, GERMANY
- P-22** New treatment dynamics in PNH - a chart review of 211 US PNH patients and how physicians are adapting to new treatment options  
Tucker HURTADO, Exton, UNITED STATES
- P-23** Diagnosis and management of PNH Experience of the Hematology Department Constantine- Algeria  
Sihem KEBAILI, Constantine, ALGERIA
- P-24** Phase III randomized COMMODORE 2 trial: 2-year efficacy and safety of crovalimab in patients with paroxysmal nocturnal hemoglobinuria (PNH) naive to complement inhibition  
Richard KELLY, Leeds, UNITED KINGDOM
- P-25** The effect of oral iptacopan monotherapy on hematological parameters in patients with PNH is consistent regardless of the prior anti-C5 treatment received: A post hoc analysis of the APPLY-PNH trial  
Austin KULASEKARARAJ, London, UNITED KINGDOM

- P-26** Early response in complement inhibitor naïve patients with paroxysmal nocturnal hemoglobinuria treated with pegcetacoplan in the Phase 3 PRINCE trial  
Austin KULASEKARARAJ, London, UNITED KINGDOM
- P-27** Role of rescue doses for the management of breakthrough hemolysis events occurring during crovalimab treatment for patients with paroxysmal nocturnal hemoglobinuria (PNH)  
Austin KULASEKARARAJ, London, UNITED KINGDOM
- P-28** A case of clonal hemopoiesis in PNH patient (trisomy 8, DNMT3A mutation) who was previously diagnosed with Castleman disease and treated for melanoma of the skin in the past  
Olena KYSELOVA, Kyiv, UKRAINE
- P-29** Both rare PNH cells and minor PNH clones should be considered as genuine PNH clones: insights from analysis of the 5-year French nation-wide multicenter observational study  
Magali LE GARFF-TAVERNIER, Paris,
- P-30** Real-world drug adherence, persistence, and healthcare resource utilization in patients with paroxysmal nocturnal hemoglobinuria in the USA: The ADVANTAGE study  
Andrew MESSALI, Boston, UNITED STATES
- P-31** Real-world adherence with pegcetacoplan in paroxysmal nocturnal hemoglobinuria compared with previously reported oral medication adherence rates  
Jinny MIN, Waltham, UNITED STATES
- P-32** A Single Institution Experience of Iptacopan in Paroxysmal Nocturnal Hemoglobinuria  
Mark ORLAND, Cleveland, UNITED STATES
- P-33** Long-term outcomes of pegcetacoplan treatment in patients with paroxysmal nocturnal hemoglobinuria and baseline hemoglobin levels greater than 10 grams per deciliter  
Jens PANSE, Aachen, GERMANY
- P-34** Relationship between hemoglobin, fatigue, and health-related quality of life in patients with paroxysmal nocturnal hemoglobinuria (PNH): results from a real world study  
Jens PANSE, Aachen, GERMANY
- P-35** Efficacy and safety of pozelimab plus cemdisiran versus ravulizumab in patients with paroxysmal nocturnal haemoglobinuria who are naïve to complement inhibition  
Christopher PATRIQUIN, Toronto, CANADA

- P-36** Characterization of clinically significant breakthrough hemolysis in patients with paroxysmal nocturnal hemoglobinuria treated with pegcetacoplan  
Régis PEFFAULT DE LATOUR, Paris,
- P-37** A first report from the COMPLETE study on the real-world effectiveness of pegcetacoplan in patients with paroxysmal nocturnal hemoglobinuria (PNH)  
Régis PEFFAULT DE LATOUR, Paris,
- P-38** Guidelines for the Diagnosis and Management of Paroxysmal Nocturnal Hemoglobinuria (PNH) at Hospital Universitário Walter Cantídio.  
Rafaela PITOMBEIRA, Fortaleza, BRAZIL
- P-39** Disappearing PNH-clone during effective complement inhibition  
Eira POIKONEN, Helsinki, FINLAND
- P-40** Methodical determination of a phase 3 dose of zaltenibart, an investigational monoclonal antibody, for treatment of paroxysmal nocturnal hemoglobinuria (PNH)  
J. Steve WHITAKER, Seattle, UNITED STATES
- P-41** Zaltenibart (OMS906), an alternative pathway MASP-3 inhibitor for paroxysmal nocturnal hemoglobinuria (PNH): phase 3 trial designs  
Lemuel RIVERA FUENTES, Seattle, UNITED STATES
- P-42** Real-world cohort with paroxysmal nocturnal hemoglobinuria treated iptacopan shows improved clinical parameters: Evidence from a Managed Access Program  
Silvia SANZ, Barcelona, SPAIN
- P-43** Phase III COMMODORE 1 trial: 2-year efficacy and safety of crovalimab in patients with paroxysmal nocturnal hemoglobinuria (PNH) who switched from ravulizumab  
Jörg SCHUBERT, Riesa, GERMANY
- P-44** Treatment burden in patients with PNH treated with intravenous C5 inhibitors: an in-depth interview survey study  
Yasutaka UEDA, Osaka, JAPAN
- P-46** Phase III randomized COMMODORE 1 trial: 2-year safety and efficacy of crovalimab in patients with paroxysmal nocturnal hemoglobinuria (PNH) who switched from eculizumab  
Mustafa YENEREL, Istanbul, TURKEY

# SPONSORS

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## Media coverage of the Conference



IPIG 2025 is compliant with CVS Ethical Medtech

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The background of the entire page is a photograph of the Pont-Neuf bridge in Paris, France, taken during the "blue hour" or sunset. The bridge's ornate stone balustrade and numerous glowing street lamps are visible. In the distance, the city skyline and the dome of St. Sulpice church are silhouetted against the warm, orange and purple sky. The bridge's reflection is visible in the water below.

[www.ipig2025.com](http://www.ipig2025.com)