

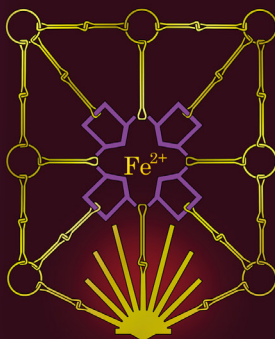
INTERNATIONAL CONGRESS OF PORPHYRINS AND PORPHYRIAS

September 21–25, 2024

Pamplona (Spain)

PRELIMINARY PROGRAM

ICPP 2024

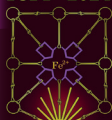


ipnet
INTERNATIONAL PORPHYRIA NETWORK

With the participation of:

ciber | **EHD**

CENTRO DE INVESTIGACIÓN BIOMÉDICA EN RED
Enfermedades Hepáticas y Digestivas



Dear Colleagues, dear friends,

We are extremely honored to welcome you to The International Congress of Porphyrins and Porphyrias (ICPP 2024) which will take place on September 21-25, 2024 in Pamplona, Spain, bringing together clinicians, researchers, scholars, caregivers, patients and their families for three days networking and learning about the latest research in the porphyria field.

We are preparing an exciting program to learn about and discuss the latest advances in our understanding of the natural history, management and treatment of hepatic and erythropoietic porphyrias.

And, "by the way", once in Pamplona don't miss the opportunity to start walking the Way of Saint James, "El Camino"!

See you all in Pamplona!

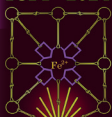
Best regards from,



Sverre Sandberg
Ipnet President



Antonio Fontanellas
President of ICPP 2024



SCIENTIFIC COMMITTEE FOR ICPP 2024

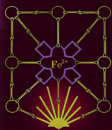
Dr. Antonio Fontanellas	CIMA - Navarra University, Spain.
Dr. Bruce Wang	University of California San Francisco, United States
Dr. Jasmin Barman	Triemli City Hospital, Switzerland
Dr. Aasne A. Aarsand	Haukeland University Hospital, Norway
Dr. Makiko Yasuda	Icahn School of Medicine at Mount Sinai, United States
Dr. Laurent Gouya	Hôpital Louis Mourier, France
Dr. Janneke G. Langendonk	Erasmus University Medical Center, Netherlands

LOCAL ORGANIZING COMMITTEE FOR ICPP 2024

Dr. Matias A. Ávila	CIMA-Navarra University, Pamplona, Spain
Dr. Antonio Pineda	CIMA-Navarra University, Pamplona, Spain
Dr. Jordi To-Figueras	University of Barcelona, Barcelona, Spain
Dr. Oscar Millet	CIC bioGUNE, Derio, Spain
Dr. Delia D´Ávola	Navarra University Clinic, Madrid, Spain
Dr. Isabel Solares	Navarra University Clinic, Madrid, Spain
Ms. Fidela Mirón	Spanish Federation of Rare Diseases (FEDER)
Dr. Rafael Enríquez de Salamanca	University Hospital 12 de Octubre, Madrid, Spain
Dra. Paula Aguilera	Hospital Clinic, University of Barcelona ,Barcelona, Spain

September
21-25, 2024

ICPP 2024

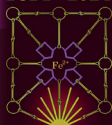


INTERNATIONAL
CONGRESS OF
PORPHYRINS AND
PORPHYRIAS



FACULTY

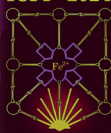
Dr. Aasne Aarsand	Haukeland University Hospital, Norway
Dr. Karl Anderson	University of Texas Medical Branch, Galveston, TX, US
Dr. Matías A. Ávila	CIMA-Navarra University, Pamplona, Spain
Dr. Michael Badminton	University Hospital of Wales Cardiff, UK
Dr. Manisha Balwani	Icahn School of Medicine, Mount Sinai, New York, US
Dr. Jasmin Barman	Triemli City Hospital, Switzerland
Ms. Nicole Castellano	American Porphyria Foundation (APF)
Dr. Delia D´Avola	Navarra University Clinic, Madrid, Spain
Dr. Robert Desnick	Icahn School of Medicine, Mount Sinai, New York, US
Dr. Jean Charles Deybach	Hôpital Louis Mourier, Paris, France
Dr. Yonatan Edel	Ben-Gurion University in the Negev, Beer Sheva, Israel.
Dr. Antonio Fontanellas	CIMA-Navarra University, Pamplona, Spain
Ms. Liz Gill	IPNET Patient Representative
Dr. Laurent Gouya	Hôpital Louis Mourier, France
Dr. Iqbal Hamza	University of Maryland, Baltimore, US
Dr. Aneta Ivanova	St. Ivan Rilski University Hospital, Sofia, Bulgaria
Dr. Louisa Kluijver	Erasmus Medical Center, Rotterdam
Dr. Eric Lai	Sloan-Kettering Institute, New York, US
Dr. Janneke Langendonk	Erasmus University Medical Center, Netherlands
Dr. Mattias Lissing	Karolinska University Hospital, Stockholm, Sweden
Dr. Amy Medlock	University of Georgia, Athens, GA US
Dr. Peter Meissner	University of Cape Town, Cape Town, South Africa
Dr. Oscar Millet	CIC bioGUNE, Derio, Spain



Dr. Anna E. Minder	Zürich City Hospital, Zürich, Switzerland
Ms. Fide Mirón	Spanish porphyria assoc. (AEP) & rare diseases (FEDER)
Dr. Reem Mustafa	McMaster University, Hamilton, Canada
Dr. Bindu D. Paul	Johns Hopkins University, Baltimore, MD, US
Dr. Petro Petrides	Ludwig Maximilians University, Munich, Germany
Dr. John Phillips	University of Utah, Salt Lake City, Utah, US
Dr. Patricia Renard	University of Namur, Namur, Belgium
Dr. Antonella Roetto	University of Turin, Turin, Italy
Dr. Eliane Sardh	Karolinska University Hospital, Stockholm, Sweden
Dr. Penelope E. Stein	King's College Hospital, London, UK
Dr. Miguel P. Soares	Instituto Gulbenkian de Ciência, Oeiras, Portugal
Dr. Isabel Solares	Navarra University Clinic, Madrid, Spain
Dr. Mark Sonderup	University of Cape Town, Observatory, South Africa.
Dr. Ulrich Stölzel	Klinikum Chemnitz, Chemnitz, Germany
Dr. Sverre Sandberg	Haukeland University Hospital, Bergen Norway
Dr. Jordi To-Figueras	University of Barcelona, Barcelona, Spain
Dr. Emanuela Tolosano	University of Torino, Torino, Italia
Dr. Iñaki F. Troconiz	Navarra University, Pamplona, Spain
Dr. Paolo Ventura	University of Modena and Reggio Emilia, Modena, Italy
Dr. Staffan Wahlin	Karolinska University Hospital, Stockholm, Sweden
Dr. Bruce Wang	University of California San Francisco, US
Dr. Makiko Yasuda	Icahn School of Medicine, Mount Sinai, New York, US
Dr. Jessica Zucman-Rossi	INSERM, University of Paris, France

September
22-25, 2024

ICPP 2024



INTERNATIONAL
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PATIENT'S DAY

CIMA
(Centro de Investigación
Médica Aplicada)

Av. de Pío XII, 55
31008 Pamplona, Navarra

[ASSEMBLY ROOM CIMA BUILDING]



SATURDAY

September 21st, 2024

15.00 - 18.30

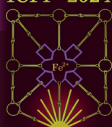
PATIENT'S DAY IN SPANISH

Disease education for patients in Spanish: interactive workshops for patients with porphyria and as well as other rare diseases (mitochondrial diseases) workshops on topics such as the importance of genetic tests, diagnosis capabilities, available and innovative therapies, patient-centered care, the use of complementary medicines for healthy diets, and mental health and art workshop.

17.00 - 17.20

Coffee Break

Art exhibit with pieces provided by attendees as a creative way to raise awareness about the rare disease and the impact it has on patients and their families.



SUNDAY

September 22nd, 2024

09.30 - 13.00

PORPHYRIA PATIENT´S DAY

09.30 - 13.00

Welcome

Diagnosis capabilities and available therapies,

Recent advances

Regional and global porphyria patient associations

Global Patient advocacy update

Real patient and caregiver stories

Role reversal-ask the patient experts!

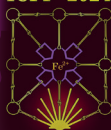
NOTE;

Coffee break (10:30-11:00)

& Lunch break (13:00-15:00)

SUNDAY
September 22nd, 2024

ICPP 2024



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PORPHYRIAS

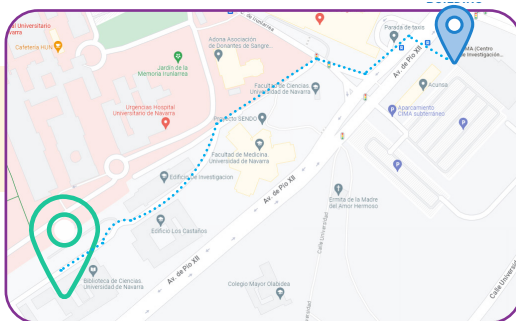


ICPP 2024 CONGRESS

FACULTY OF SCIENCE
(Universidad de Navarra)

C. de Irunlarrea, 1, 31008
Pamplona, Navarra

**[ASSEMBLY ROOM OF
THE SCIENCE LIBRARY BUILDING]**



13.30 *OPENING SECRETARIAT & DELIVERY DOCUMENTATION AND POSTER HANGING*

15.00 - 15:15 **Welcome ceremony and opening remarks ICPP**

15.15 - 17.15

SESSION 1 **GUIDELINES FOR TREATMENT AND PATIENTS' FOLLOW-UP**

15.15 - 15.55 Development of evidence-based guidelines for acute porphyrias

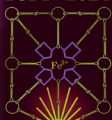
15.55 - 16.15 Basic needs in countries where there is a lack of specialist services

16.15 - 16.35 Long-term complications in AHP

16.35 - 17.15 Selected abstracts presentation

17.15 Welcome reception

19.00 *Meet&Greet for young clinicians/scientists*



08.30 - 10.30

SESSION 2 GENETIC AND MOLECULAR MECHANISMS OF HEME SYNTHESIS AND REGULATION

08.30 - 09.15 Heme synthesis and succinate in the regulation of pluripotent states transitions

09.15 - 09.35 Computational approaches for mapping heme biology

09.35 - 09.55 Heme: the missing link in the pathogenesis of severe malaria

09.55 - 10.30 Selected abstracts presentation

10.30 - 11.00 *Coffee break and poster visit*

11.00 - 13.00

SESSION 3 HEME METABOLISM AND CELLULAR ENERGY: INTER-ORGAN HEME SIGNALING AND IMPORT/EXPORT SYSTEMS

11.00 - 11.45 Inter-organ heme signaling

11.45 - 12.05 The inhibition of heme synthesis/export systems in specific liver cells

12.05 - 12.25 ALAS1 knockdown increases microRNA biogenesis in mammalian cells

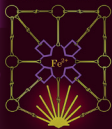
12.25 - 13.00 Selected abstracts presentation

13.00 - 14.30 *Lunch and poster visit*

14.30 - 15.00 **Industry Symposium**

MONDAY
September 23th, 2024

ICPP 2024



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15.00 - 17.00

SESSION 4 HEME IN PATHOPHYSIOLOGY

15.00 - 15.45 Molecular mechanisms in hepatocarcinogenesis

15.45 - 16.05 Inhibiting heme synthesis to modulate cell metabolism and counteract tumor initiation and progression

16.05 - 16.25 Role of the bilirubin/biliverdin reductase axis in neuroprotection

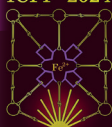
16.25 - 17.00 Selected abstracts presentation

17.00 - 17.30 *Coffee break and poster visit*

17.30 - 19.30

SESSION 5

17.30 - 19.30 IPNET GENERAL ASSEMBLY



08.30 - 11.00

SESSION 6 **CURRENT THERAPIES FOR ACUTE HEPATIC PORPHYRIAS (AHP)**

08.30 - 09.15 Use of Givosiran in acute hepatic porphyrias: World experience

09.15 - 09.35 Natural history of AHP in US patients

09.35 - 09.55 A new model of AIP in NHPs

09.55 - 10.30 Selected abstracts presentation

10.30 - 11.00 *Coffee break and poster visit*

11.00 - 11.30 **Industry Symposium**

11.30 - 13.00

SESSION 7 **NEW INSIGHTS AND POTENTIAL TREATMENT APPROACHES IN ERYTHROPOIETIC PORPHYRIAS**

11.30 - 11.50 Iron metabolism in EPP

11.50 - 12.10 Phlebotomy in EPP

12.10 - 12.30 Predicting and Improving Osteoporosis in EPP

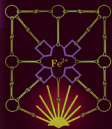
12.30 - 12.50 Innovative therapies in congenital erythropoietic porphyria (CEP)

12.50 - 13.00 Selected abstracts presentation

13.00 - 15.00 *Lunch and poster visit*

TUESDAY
September 24th, 2024

ICPP 2024



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15.00 - 18.00

SESSION 8 EMERGING THERAPIES FOR ERYTHROPOIETIC PORPHYRIAS

15.00 - 15.30 Industry Symposium

15.30 - 16.00 Industry Symposium

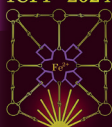
16.00 - 16.30 Industry Symposium

16.30 - 17.00 ***Coffee break***

17.00 - 17.30 Industry Symposium

17.30 - 18.00 Industry Symposium

20.00 FAREWELL DINNER



08.30 - 10.30

SESSION 9 RATIONAL APPROACH(ES) TO DIAGNOSIS
AND CARE IN AHPS

08.30 - 08.50 Laboratory diagnosis of porphyrias - challenges and potential solutions

08.50 - 09.10 Classification of acute hepatic porphyria gene variants - the Ipnets
variant database

09.10 - 09.30 Drug safety

09.30 - 10.30 Selected abstracts presentation

10.30 - 11.00 *Coffee break and poster visit*

11.00 - 13.00

SESSION 10 RATIONAL APPROACH(ES) TO DIAGNOSIS AND CARE
IN CUTANEOUS PORPHYRIAS

11.00 - 11.30 Industry Symposium

11.30 - 11.50 Reversible attransferrinemia in a patient with chronic enteropathy

11.50 - 12.10 Selected abstract presentation

12:10 - 13.00 Expert panel: Diagnostic and Clinical conundrums. Critical issues to
resolve and future directions

13:00 - 13.30 Posters awards and Congress Closing ceremony



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EVENTS & TRAVEL SOLUTIONS

TECHNICAL SECRETARY:

Oasis Events & Travel Solutions

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