

# 4TH INTERNATIONAL ATTR Amyloidosis meeting for patients and doctors



November, 2-3 2023

Venue:

**ILUSTRE COLEGIO OFICIAL  
DE MÉDICOS DE MADRID**

Santa Isabel, 51. 28012 Madrid

*ciber* | cv



**PROGRAMME**

[attramyloidosis2023.com](http://attramyloidosis2023.com)

**MADRID**

**ORGANIZED BY:**



Hospital Universitario  
**Puerta de Hierro**  
**Majadahonda**



European  
Reference  
Network

for rare or low prevalence  
complex diseases

Network  
Heart Diseases  
(ERN GUARD-HEART)

*ciber* | **CV**



## ORGANIZING COMMITTEE

**Prof. Pablo Garcia-Pavia**

University Hospital Puerta de Hierro Majadahonda, Madrid

**Dr. Esther Gonzalez-Lopez**

University Hospital Puerta de Hierro Majadahonda, Madrid

**Prof. Julian Gillmore**

National Amyloidosis Centre, University College London, London, UK

**Prof. David Adams**

Centre de référence des Neuropathies amyloïdes familiales  
et autres neuropathies rares France

**Prof. Thibaud Damy**

Centre de référence des Amyloses Cardiaques France

**Dr. Laura Obici**

Amyloidosis Research and Treatment Centre,  
IRCCS Fondazione Policlinico San Matteo, Pavia, Italy

**Jean-Christophe Fidalgo**

President of the Amyloidosis Alliance

**Catelina Bibiloni**

ABEA Asociación

**Agnès Farrugia.**

Director of the Amyloidosis Alliance

**David Gregory**

Patients organization (Ukatpa)



## VENUE



**ILUSTRE COLEGIO OFICIAL DE MÉDICOS DE MADRID**  
Santa Isabel, 51. 28012 Madrid  
Phone: +34 915 385 100



**PATIENTS ASSOCIATION CHANNEL**

**Thursday November 2<sup>nd</sup>**

08:30 - 09:00 am

**Introduction by a spanish representant  
of the Health ministry**

09:00 - 09:45 am

**Amyloidosis Alliance Introduction and Actions**

09:45 - 10:45 am

**DAILY LIFE WITH AMYLOIDOSIS**

Chairs: Agnes Farrugia and Jean-Christophe Fidalgo

**Physical training for Amyloidosis Patients**

Agnes Morier

**Occupational Therapy and hATTR Amyloidosis**

Aina Gayà

**Complementary treatments. The French experience**

Julie Pompougnac

**Dietary issues: nutrition**

Jonas Wixner

10:45 - 11:30 am

COFFEE BREAK

11:30 - 01:00 pm

**HOW TO BECOME AN INVOLVED PATIENT?**

**How to comunicate with Doctors?**

David Gregory

**Educational program to learn more about your disease?**

**Understanding your medical tests**

Christine Chiti

**Role of the patients Organisations to support patients**

01:00 - 02:30 pm

LUNCH TIME



**PATIENTS ASSOCIATION CHANNEL**

**Thursday November 2<sup>nd</sup>**

02:30 - 3:30 pm

**A vision toward a more holistic approach to care in hereditary ATTR amyloidosis (Alnylam)**

Catilena Bibiloni

**Older adults with rare diseases – barriers and solutions for equitable access to care (Pfizer)**

3:30 - 5:00 pm

**CAREGIVERS SUPPORT NETWORK<?**

Chair: Laura Obici

**Importance of self-care (physical, mental & emotional wellbeing)**

Jaime Christmas

**When to seek help as a caregiver and where to find help**

Melvin Carr

**How to be empowered in the role of caregiving**

**Being resilient no matter the outcome**

Lucinda Nicholas

5:00 - 5:30 pm

COFFEE BREAK

5:30 - 6:30 pm

**DARE TO SPEAK ABOUT**

Chair: Thibaud Damy

**Palliative care, what it means and what it does not mean, the myth and the truth**

Kenneth Lång

**Genetic testing for family members genetic counseling**

**Discussion about sex and the impact of Amyloidosis**

Ferrán Martínez



DOCTORS CHANNEL

Thursday November 2<sup>nd</sup>

08:30 - 09:00 am

**Introduction by a spanish representant  
of the Health ministry**

09:00 - 09:45 am

**Precision Therapeutics With CRISPR-Based Technology:  
Preparing for a New Era of Medicine (Intelliactx)**

**Welcome and Introduction**

Pablo García-Pavia

**The Road to Precision Medicine**

Pablo García-Pavia

**Advances in Gene Editing: From a Nobel Prize–Winning  
Publication to Applications in Clinical Practice**

Rodolphe Barrangou

**Preparing for the Future: How Clinicians Can Include  
Precision Medicine in the Management of ATTR  
Amyloidosis**

Marianna Fontana

**Q&A**

09:45 - 10:45 am

**LATEST ADVANCES IN PATHOPHYSIOLOGY**

Chairs: Laura Obici and Julian Gillmore

**How do fibrils start?** Vittorio Belloti

**How do fibrils grow?** Lorena Saleices

**How do fibrils dissapear?** Philip Hawkins

10:45 - 11:30 am

COFFEE BREAK



11:30 - 01:00 pm

**LATEST DATA FOR PATIENTS DIAGNOSIS IN  
A CHANGING WORLD**

Chairs: Hanna Mazen and Isabel Conceicao

**State of the art.** Julian Gillmore

**Abstract session**

- [99mTc] TC-HYDROXYDIPHOSPHONATE UPTAKE IN SOFT TISSUE REFLECTS AMYLOID LOAD IN SUBCUTANEOUS ABDOMINAL FAT TISSUE AND HARBORS PROGNOSTIC VALUE IN WILD-TYPE TRANSTHYRETIN AMYLOIDOSIS PATIENTS
- ENABLING THE DEVELOPMENT OF SERUM TTR AS A BIOMARKER FOR TREATMENT OF ATTR AMYLOIDOSIS
- FIFTY YEARS OF EXPERIENCE WITH HEREDITARY TRANSTHYRETIN AMYLOIDOSIS FIRST REPORT FROM SVEATTR
- LONGITUDINAL ANALYSIS OF SERUM NEUROFILAMENT LIGHT CHAIN LEVELS AS MARKER FOR NEURONAL DAMAGE IN HEREDITARY TRANSTHYRETIN-RELATED AMYLOIDOSIS
- RESULTS OF A POPULATION-BASED GENETIC SCREENING PROGRAM FOR HEREDITARY TRANSTHYRETIN AMYLOIDOSIS.
- SKIN BIOPSY AS A DIAGNOSTIC TOOL FOR ATTRV NEUROPATHY IN THE UK

01:00 - 02:30 pm

LUNCH TIME

02:30 - 03:30 pm

**Symposium Alnylam**





03:30 - 5:00 pm

**LATEST DATA ABOUT PATIENTS' TREATMENT IN A CHANGING WORLD**

Chairs: Esther González López and Thibaud Damy

**State of the art.** Andoni Echaniz Laguna

**Abstract session**

- ANTI-PEG ANTIBODIES REDUCE THE THERAPEUTIC EFFECT OF PATISIRAN IN PATIENTS WITH HEREDITARY TRANSTHYRETIN AMYLOIDOSIS
- CARDIAC AND NEUROLOGICAL STABILITY IN ATTRV PATIENTS ON GENE SILENCING THERAPY
- CLINICAL CONSEQUENCES OF BETA-BLOCKER WITHDRAWAL IN TRANSTHYRETIN AMYLOID CARDIOMYOPATHY
- EPLONTERSEN IMPROVES AUTONOMIC NEUROPATHY SYMPTOMS IN HEREDITARY ATTR: AN ANALYSIS FROM NEURO-TTRANSFORM
- PHASE 3 NEURO-TTRANSFORM STUDY: EFFICACY AND SAFETY OF EPLONTERSEN AT WEEK 85
- TRANSITIONING FROM INOTERSEN TO EPLONTERSEN IN PATIENTS WITH HEREDITARY TRANSTHYRETIN AMYLOIDOSIS POLYNEUROPATHY

05:00 - 05:30 pm

COFFEE BREAK

05:30 - 06:30 pm

**LATEST TOOLS IN THE FIELD**

Chairs: Marianna Fontana and Christoph Rocken

**Neurofilaments.** Mary Reilly

**PET tracers.** Hanna Mazen

**Nerve imaging**



06:30 - 07:15 pm

**Improving outcomes in ATTR amyloidosis: clinical and real-world perspectives** (Pfizer)

**Stabilizing the tetramer: an established strategy**

Laura Obici

**Optimizing outcomes in ATTR-CM with early diagnosis and management**

**ATTR-CM in clinical practice: suspicion, management, and beyond**

Esther González-López

**Panel discussion and Q&A**



DOCTORS AND PATIENTS  
CHANNEL

Friday November 3<sup>rd</sup>

08:10 - 09:00 am

**TRIBUTE TO PR RAPEZZI. ELENA BIAGINI, GIOVANNI D'ALESSIO, MATHEW S. MAURER**

Chairs: Agnes Farrugia and Pablo Garcia Pavia

09:00 - 09:45 am

**Symposium AstraZeneca**

09:45 - 10:45 am

**HOW TO MANAGE SYMPTOMS FOR?**

Chairs: Marianna Fontana and Lucía Galán

**Dyspnea / heart failure.** Esther González López

**Arrhythmia.** Peter Van der Meer

**GI manifestations.** Jonas Wixner

10:45 - 11:30 am

COFFEE BREAK

11:30 - 01:45 pm

**HOW TO MANAGE SYMPTOMS FOR?**

Chairs: Andoni Echaniz-Laguna and Mary Reilly

**Peripheral neuropathic manifestations**

Marcia Waddington Cruz

**Central neurological manifestations and pain**

Isabel Conceição

**Synovial manifestations**

Oscar Westin

**Ocular complications**

01:00 - 02:00 pm

LUNCH TIME



**DOCTORS AND PATIENTS  
CHANNEL**

**Friday November 3<sup>rd</sup>**

02:00 - 02:45 pm

**ATTRibute-CM and acoramidis: A panel discussion examining a prospective investigational treatment for ATTR-CM.** (Bridge Bio)

**ATTRibute-CM: acoramidis (AG10) in patients with ATTR-CM**

Julian Gillmore

**Panel discussion and Q&A**

Julian Gillmore, Mark McGovern and Pedro Pina

02:45 - 04:15 pm

**ATTR TREATMENTS IN 2023 AND BEYOND**

Chairs: Pablo Garcia-Pavia and Julian Gillmore

**Current treatments available for H-ATTR. Latest info**  
Thibaud Damy

**Current treatments available for WT-ATTR. Latest info**

**Ongoing Clinical Trials**

Francesco Cappelli

**Combined specific therapies. Current and future role**  
Mathew S. Maurer

**From innovation to patient, how to ensure that patients benefit from treatments**

04:15 - 04:30 pm

**Conclusion**



## REGISTRATION

	Before 30/09/2023	From 30/09/2023
General registration	350 €	400 €
Fellow / Nursery*	150 €	200 €
Streaming	125 €	175 €
Patients	30 €	30 €
Patients with dinner	60 €	60 €
Patients (online only)	Free	Free
Industry	400 €	450 €

## ACCOMMODATION

	Double (single use)	Double
Hotel NH Nacional	200 €	230 €

