

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

#ATTRAmyloidosis2023



PROGRAMME

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)

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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)



PROGRAMME



PATIENTS ASSOCIATION CHANNEL

Thursday November 2nd

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: Agnès Farrugia and Jean-Christophe Fidalgo

Physical training for Amyloidosis Patients

Agnès 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 communicate 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 2nd

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

Rocio Eiros

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

21:00 pm

DINNER

DOCTORS CHANNEL

Thursday November 2nd

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** (IntelliAtx)

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 Bellotti

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: Mazen Hanna 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
- 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
- EPLONTERSEN IMPROVES AUTONOMIC NEUROPATHY SYMPTOMS IN HEREDITARY ATTR: AN ANALYSIS FROM NEURO-TTRANSFORM

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. Mazen Hanna

Nerve imaging.



DOCTORS CHANNEL

Thursday November 2nd

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

21:00 pm

DINNER



DOCTORS AND PATIENTS
CHANNEL

Friday November 3rd

08:10 - 09:00 am

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

Chairs: Agnès 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 Lucia 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 3rd

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
Speakers and chairs

04:15 - 04:30 pm

Conclusion



GENERAL INFORMATION

VENUE



ILUSTRE COLEGIO OFICIAL DE MÉDICOS DE MADRID

Santa Isabel, 51.28012 Madrid

Phone: +34 915 385 100

DATES

November 2-3, 2023

LANGUAGE

English: English-Spanish translation available

REGISTRATION

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

Registration fee includes: attendance, certificate, coffee breaks (Thursday and Friday), Lunch (Thursday and Friday) and dinner (except Patients**) VAT Included

* To get this fee It is compulsory to send the secretariat a certificate acreditating that the attendee is fellow or nurse.

Technical Secretariat can receive **new registrations until 27th October 2023**. After this date registrations should be manage at the venue, once the congress had started.

Cancellation policy

Until 30/09/2023	100% refund
From 01/10/2023	No refund

For more information:
www.attramyloidosis2023.com

ACCOMMODATION

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

Accommodation fee includes breakfast. VAT Included.

Cancellation policy

Until 20/09/2023	80% refund
Until 30/09/2023	50% refund
From 01/10/2023	No refund



Hotel NH Nacional

Paseo del Prado, 48
28014 Madrid
Tel. 914 29 66 29

For more information:

www.attramyloidosis2023.com

DINNER

RESTAURANTE NUBEL. MUSEO REINA SOFÍA

Address: Argumosa 43. 28012, Madrid

CERTIFICATES

Certificates will be emailed 7 days after the meeting

REGISTRATION AND INFORMATION

www.attramyloidosis2023.com

TECHNICAL SECRETARIAT



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