

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

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#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

08:00 - 08:30 am

REGISTRATION

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 (Marseille, France)
and Jean-Christophe Fidalgo (Gemenos, France)

Physical training for Amyloidosis Patients

Agnes Morier (Paris, France)

Occupational Therapy and hATTR Amyloidosis

Aina Gayà (Palma de Mallorca, Spain)

Complementary treatments. The French experience

Julie Pompougnac (Paris, France)

Dietary issues: nutrition

Jonas Wixner (Umeå, Sweden)

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 (Kansas, US)

Educational program to learn more about your disease?

Cecile Cauquil (Paris, France)

Understanding your medical tests

Christine Chiti (London, UK)

Role of the patients Organisations to support patients

Catelina Bibiloni (Palma de Mallorca, Spain)

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 (Pavia, Italy)

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

Jaime Christmas (New York, US)

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

Melvin Carr (Oklahoma, United States)

How to be empowered in the role of caregiving

Rocio Eiros (Salamanca, Spain)

Being resilient no matter the outcome

Lucinda Nicholas (London, UK)

5:00 - 5:30 pm

COFFEE BREAK

5:30 - 6:30 pm

DARE TO SPEAK ABOUT

Chair: Thibaud Damy (Paris, France)

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

Kenneth Lång (Piteå, Sweden)

Genetic testing for family members genetic counseling

Inés Losada (Palma de Mallorca, Spain)

Discussion about sex and the impact of Amyloidosis

Ferrán Martínez (Madrid, Spain)

21:00 pm

DINNER



DOCTORS CHANNEL

Thursday November 2nd

08:00 - 08:30 am

REGISTRATION

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-Pavía (Madrid, Spain)

The Road to Precision Medicine

Pablo García-Pavía (Madrid, Spain)

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

Rodolphe Barrangou (North Carolina, USA)

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

Marianna Fontana (London, UK)

Q&A

09:45 - 10:45 am

LATEST ADVANCES IN PATHOPHYSIOLOGY

Chairs: Laura Obici (Pavia, Italy) and Julian Gillmore (Barnet, UK)

How do fibrils start? Vittorio Bellotti (Pavia, Italy)

How do fibrils grow? Lorena Saleices (Dallas, US)

How do fibrils dissappear? Philip Hawkins (London, UK)

10:45 - 11:30 am

COFFEE BREAK



DOCTORS CHANNEL

Thursday November 2nd

11:30 - 01:00 pm

LATEST DATA FOR PATIENTS DIAGNOSIS IN A CHANGING WORLD

Chairs: Mazen Hanna (Ohio, UK) and Isabel Conceicao (Lisboa, Portugal)

State of the art. Julian Gillmore (Barnet, UK)

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

Stemming the multisystemic progression of hATTR amyloidosis – how do we turn the tide? (Alnylam)

Welcome and introductions

Julian Gillmore (London, UK)

Turning the tide: Evolution of the patient care pathway

Mazen Hanna (Ohio, UK)

Turning the tide: Therapeutic innovation in hATTR amyloidosis

Isabel Conceição (Lisboa, Portugal)

Ask the experts

All speakers

Summary and close

Julian Gillmore (London, UK)

This is an Alnylam-sponsored promotional symposium; organised and funded by Alnylam Pharmaceuticals. It may contain information on Alnylam medicinal products; for healthcare professionals only.

03:30 - 5:00 pm

LATEST DATA ABOUT PATIENTS' TREATMENT IN A CHANGING WORLD

Chairs: Esther González (Madrid, Spain) López and Thibaud Damy (Paris, France)

State of the art. Andoni Echaniz-Laguna (Paris, France)

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

DOCTORS CHANNEL

Thursday November 2nd

05:00 - 05:30 pm

COFFEE BREAK

05:30 - 06:30 pm

LATEST TOOLS IN THE FIELD

Chairs: Marianna Fontana (London, UK) and Christoph Rocken (Magdeburg, Germany)

Neurofilaments. Mary Reilly (London, UK)

PET tracers. Mazen Hanna (Ohio, UK)

Nerve imaging. Chiara Briani (Padova, Italy)

06:30 - 07:15 pm

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

Stabilizing the tetramer: an established strategy

Laura Obici (Pavia, Italy)

Optimizing outcomes in ATTR-CM with early diagnosis and management

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

Esther González-López (Madrid, Spain)

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

Chairs: Agnès Farrugia (Marseille, France)
and Pablo García Pavia (Madrid, Spain)

Elena Biagini (Bologna, Italy)

Giovanni D'Alessio (Italian patient)

Mathew S. Maurer (New York, US)

**Taking Action to Improve the Patient Journey With ATTR:
Shared Perspectives From Patients and Providers**

(PeerVoice - supported by an educational grant from
AstraZeneca)

Welcome and introduction

Laura Obici (Pavia, Italy)

**Panel discussion: Seeing ATTR Through One Another's
Eyes: Opportunities to Optimise the Patient-Physician
Partnership**

09:00 - 09:45 am

Laura Obici (Pavia, Italy), Lucía Galán (Madrid, Spain) and
David Gregory (Shrewsbury, United Kingdom)

**Panel discussion: Taking the Next Step Together:
Action Items in ATTR for Providers and Patients**

Laura Obici (Pavia, Italy), Lucía Galán (Madrid, Spain) and
David Gregory (Shrewsbury, United Kingdom)

**Audience Questions, Faculty Discussion, Final
Remarks, and Conclusion**

No treatments will be discussed at the symposium

09:45 - 10:45 am

HOW TO MANAGE SYMPTOMS FOR?

Chairs: Marianna Fontana (London, UK) and Lucía Galán (Madrid,
Spain)

Dyspnea/heart failure. Esther González López (Madrid, Spain)

Arrhythmia. Peter Van der Meer (Utrecht, Netherlands)

GI manifestations. Jonas Wixner (Umeå, Sweden)

DOCTORS AND PATIENTS
CHANNEL

Friday November 3rd

10:45 - 11:30 am

COFFEE BREAK

11:30 - 01:45 pm

HOW TO MANAGE SYMPTOMS FOR?

Chairs: Andoni Echaniz-Laguna (Paris, France) and Mary Reilly (London, UK)

Peripheral neuropathic manifestations

Marcia Waddington Cruz (Rio de Janeiro, Brasil)

Central neurological manifestations and pain

Isabel Conceição (Lisboa, Portugal)

Synovial manifestations

Oscar Westin (Copenhagen, Denmark)

Ocular complications

01:00 - 02:00 pm

LUNCH TIME

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 (London, UK)

Panel discussion and Q&A

Julian Gillmore, Mark McGovern and Pedro Pina



DOCTORS AND PATIENTS
CHANNEL

Friday November 3rd

02:45 - 04:15 pm

ATTR TREATMENTS IN 2023 AND BEYOND

Chairs: Pablo Garcia-Pavia (Madrid, Spain) and Julian Gillmore (Barnet, UK)

Current treatments available for H-ATTR. Latest info

Thibaud Damy (Paris, France)

Current treatments available for WT-ATTR. Latest info

Jose Nativi-Nicollau (Jacksonville, Florida)

Ongoing Clinical Trials

Francesco Cappelli (Florence, Italy)

Combined specific therapies. Current and future role

Mathew S. Maurer (New York, US)

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

Speakers and chairs

04:15 - 04:30 pm

Conclusion



GENERAL INFORMATION



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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