



PROGRAMME FOR PATIENTS

THURSDAY, 25 SEPTEMBER 2025

ROOM CARLO 1

08.00-18.00	Secretariat Opening Hours and Registrations
08.30-08.45	Amyloidosis Alliance Introduction and Actions Giovanni D'Alessio (Italy)
08.45-10.00	SESSION 1 DAILY LIFE WITH TRANSTHYRETIN AMYLOIDOSIS <i>Chairs:</i> Rosaline Callaghan (Ireland), Juan Gonzales Moreno (Spain)
08.45-09.00	A Toolkit for patients living with TTR Amyloidosis CM David Gregory (UK)
09.00-09.15	Physical activities in ATTR-CM: what can I do? What should I avoid? Stefano Perlini (Italy)
09.15-09.30	Physical activities in ATTR-PN: what can I do? What should I avoid? Amanda Peltier (USA)
09.30-09.45	Digestive disorders and nutrition for ATTR Amyloidosis patients Maria Cappello (Italy)
09.45-10.00	Discussion
10.00-10.30	COFFEE BREAK
10.30-11.30	SESSION 2 DAILY LIFE WITH TRANSTHYRETIN AMYLOIDOSIS <i>Chairs:</i> Jean-Christophe Fidalgo (France), Roberta Mussinelli (Italy)
10.30-10.45	Emerging strategies to improve fatigue and pain management Violaine Plante-Bordeneuve (France)
10.45-11.00	Connecting the dots: the disease's psychological impact on patient's quality of life Martina Smorti (Italy)
11.00-11.15	How to manage multidisciplinary appointments? Steven Maupou (France)
11.15-11.30	Discussion



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11.30-12.45	SESSION 3 BENEFITS OF PHYSICAL ACTIVITIES <i>Chairs: Catilena Bibiloni (Spain), Pietro Guaraldi (Italy)</i>
11.30-11.45	Physiotherapy: when to start, which benefits and for whom? Alan Levi (UK)
11.45-12.30	Benefits of yoga: a practical session Inés Limón (Spain)
12.30-12.45	Discussion
12.45-14.15	LUNCH
14.15-14.30	Occupational therapy in ATTR amyloidosis: A cornerstone of holistic care <i>This symposium is sponsored by BAYER</i>
14.30-16.00	SESSION 4 THE CAREGIVERS DIMENSION <i>Chairs: Jaime Christmas (New Zealand), Lucia Galan (Spain)</i>
14.30-15.00	Two personal experiences Gabriella Gervasi (Italy), Susan Gregory (UK)
15.00-15.15	The role of caregivers and their relationship with doctors Celine Labeyrie (France)
15.15-15.30	Disability is a family matter Nicoletta Balbo (Italy)
15.30-15.45	The disease's psychological impact on caregivers Giulia Sandoli (Italy)
15.45-16.00	Discussion
16.00-16.30	COFFEE BREAK



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16.30-17.45	SESSION 5 IMPACT OF ATTR AMYLOIDOSIS ON FAMILY AND PERSONAL DIMENSION <i>Chairs:</i> Laura Obici (Italy), Vince Nicholas (UK)
16.30-16.45	The patient voice: how to explain the disease to my family? A personal experience Lionel Martinez (France)
16.45-17.00	Connecting the dots: genetic counselling when and how? Milena Paneque (Portugal)
17.00-17.15	Controversies and debates: pro and cons of early genetic test Emily Dixon (UK)
17.15-17.30	Financial and professional impact: how to deal with it? Dominique Thirry (France)
17.30-17.45	Discussion



JOINT PROGRAMME for DOCTORS and PATIENTS

THURSDAY, 25 SEPTEMBER 2025 ROOM CARLO 1

09.30-10.30 **ROUND TABLE: BASIC AND CLINICAL RESEARCH IN AMYLOID DISEASES: WHERE ARE WE GOING?**
This session is supported by BridgeBio
Vittorio Bellotti (Italy), Giovanni D'Alessio (Italy), Julian Gillmore (UK)

10.30-10.45 **Holistic Management of ATTR: Addressing unmet needs**
This symposium is sponsored by ALNYLAM

10.45-11.15 **COFFEE BREAK**

11.15-12.15 **SESSION 1
CONTROVERSIES AND DEBATES: HOW WE MONITOR DISEASE PROGRESSION?**
Chairs: David Gregory (UK), Violaine Plante-Bordneuve (France)

11.15-11.35 **Use of guidelines: pros and cons**
Marianna Fontana (UK), Pablo Garcia-Pavia (Spain)

11.35-11.55 **Patient reported outcome measures**
Hans Nienhuis (The Netherlands)

11.55-12.10 **Discussion**

12.10-12.30 **The psychological burden of ATTR-CM: Challenges and coping strategies**
This symposium is sponsored by BAYER

12.30-13.30 **SESSION 2
SYMPTOMATIC MANAGEMENT OF ATTR AMYLOIDOSIS**
Chairs: Agnès Farrugia (France), Simone Longhi (Italy)

12.30-12.45 **Urologic aspects**
Ricardo Pereira E Silva (Portugal)

12.45-13.00 **Gastrointestinal aspects**
Jonas Wixner (Sweden)

13.00-13.15 **Cardiac aspects**
Diana Bonderman (Austria)

13.15-13.30 **Discussion**

13.30-14.30 **LUNCH**



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FRIDAY, 26 SEPTEMBER 2025

ROOM CARLO 1

14.30-14.50	COLLABORATE Initiative (Empowering patients to address unmet needs of Adult-Onset Rare Disease through Shared Decision Making) <i>This symposium is sponsored by PFIZER</i>
14.50-15.10	Presentation of Amylife Survey <i>Chair:</i> Giovanni Palladini (Italy) Thibaud Damy (France)
15.10-16.40	ROUND TABLE HOLISTIC APPROACH TO ATTR AMYLOIDOSIS: WHERE ARE WE GOING? <i>Chairs:</i> Keith Dares (Canada), Andoni Echaniz-Laguna (France), Scott D. Solomon (USA)
15.10-15.25	Central nervous system manifestations Luisa Sousa (Portugal)
15.25-15.40	Eye involvement Angelo Minnella (Italy)
15.40-15.55	Targeted approaches: present and future Francesco Cappelli (Italy)
15.55-16.10	The role of geriatricians Manuel Sanchez (France)
16.10-16.25	Discussion
16.25-16.40	Conclusions Laura Obici (Italy), Giovanni D'Alessio (Italy)