



## PROGRAMME FOR PATIENTS

**THURSDAY, 25 SEPTEMBER 2025**

**ROOM CARLO 1**

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



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



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



## JOINT PROGRAMME for DOCTORS and PATIENTS

**FRIDAY, 26 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-Bordeneuve (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 psychology of patients with ATTR-CM, hurdles in daily life, fear of disease tactics to overcome**  
*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	<b>COLLABORATE Initiative (Empowering patients to address unmet needs of Adult-Onset Rare Disease through Shared Decision Making)</b> <i>This symposium is sponsored by PFIZER</i>
14.50-15.10	<b>Presentation of Amylife Survey</b> <i>Chair:</i> Giovanni Palladini (Italy) Thibaud Damy (France)
15.10-16.40	<b>ROUND TABLE</b> <b>HOLISTIC APPROACH TO ATTR AMYLOIDOSIS: WHERE ARE WE GOING?</b> <i>Chairs:</i> Keith Dares (Canada), Andoni Echaniz-Laguna (France), Scott D. Solomon (USA)
15.10-15.25	<b>Central nervous system manifestations</b> Luisa Sousa (Portugal)
15.25-15.40	<b>Eye involvement</b> Angelo Minnella (Italy)
15.40-15.55	<b>Targeted approaches: present and future</b> Francesco Cappelli (Italy)
15.55-16.10	<b>The role of geriatricians</b> Manuel Sanchez (France)
16.10-16.25	<b>Discussion</b>
16.25-16.40	<b>Conclusions</b> Laura Obici (Italy), Giovanni D'Alessio (Italy)