NEWSLETTER SUMMARY – Amyloidosis Alliance Conference 2025, Baveno, Italy

Prepared for the Australian Amyloidosis Network (AAN)
Wednesday 24 September 2025

Introduction

I had the honour and privilege of attending the 2025 Amyloidosis Alliance Conference in Baveno, Italy, as a representative of the Australian Amyloidosis Network. This international gathering brings together patient organisations, clinicians, researchers, and advocacy leaders from around the world to work collaboratively toward better outcomes for people living with ATTR Amyloidosis.

What the Amyloidosis Alliance Does — and Why It Matters

The Amyloidosis Alliance is a global network of national patient organisations united by the mission to:

- Raise worldwide awareness of amyloidosis
- Promote early and accurate diagnosis
- Advocate for equitable access to the highest standards of care
- Reduce the social and health burden of the disease
- Support the development of new national patient organisations

Why This Matters for Australia

For Australia, being part of this network is essential. Participation ensures that:

- We stay informed about global developments, new treatments, and clinical trials
- The specific needs and experiences of Australian patients are represented on the world stage
- We build strong international partnerships that strengthen advocacy efforts at home
- Australia contributes to — and benefits from — global research, education, and policy initiatives

Amyloidosis Alliance Conference – Day One Summary

Baveno, Italy | Wednesday 24 September 2025

The first day of the Amyloidosis Alliance Conference was dedicated to delegates from national amyloidosis organisations. Discussions centred on strengthening global collaboration, sharing knowledge, and empowering patient organisations to advocate effectively in their countries. The day highlighted both the accomplishments of the Alliance over the past year and the initiatives planned for the future.

Session One – Strengthening the Alliance

The opening session focused on the role and achievements of the Amyloidosis Alliance. Delegates emphasised the importance of a united international network to reduce the social and health burden of amyloidosis worldwide.

Key highlights over the past 12 months:

- Promoting World Amyloidosis Day through posters, publications, and awareness campaigns
- Implementing and publishing the AMYLIFE study, advancing research and understanding
- Supporting initiatives that improve diagnosis and standards of care in regions with limited access, including Latin America

A central theme was the power of unity: by joining forces, national organisations create a strong, collective voice that can influence governments, health authorities, and pharmaceutical companies.

Alliance Objectives:

1. Raise global awareness of amyloidosis
2. Promote early diagnosis and advocate for the highest standard of care
3. Highlight the health and social burden to policymakers and pharmaceutical companies to improve patient access to therapies

Why Australian Participation Matters:

- Staying informed about advances in diagnosis, treatment, and clinical trials
- Representing the needs of Australians with amyloidosis
- Building strong international connections to improve care globally

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Session Two – AMYLIFE Survey Update

This session focused on the ongoing AMYLIFE Survey, which aims to support earlier diagnosis and ensure access to high-quality, multidisciplinary care.

Survey Goals:

- Development of an interactive platform to present global results
- Creation of an international report summarising trends and patient experiences
- Exploration of a business model for pharmaceutical companies to purchase country-specific data
- Enabling national organisations to use their data in negotiations with local companies

Data Snapshot:

- **300 patients and 650 carers** participated, including **188 Australians**
- Key findings:
    - Significant delays in diagnosis and treatment
    - Need for better education for patients, carers, and healthcare professionals
    - Importance of holistic, multidisciplinary care (cardiology, haematology, neurology, allied health, mental health)

Future Plans:

The survey will be published in multiple scientific journals and formally presented at the 2026 ISA Conference. Patient-focused resources, including animated videos, will support widespread dissemination.

Session Three – Supporting the Creation of New National Alliances

Delegates explored strategies to help establish amyloidosis organisations in countries where they do not yet exist.

Key Initiatives:

- Welcome packs outlining the Alliance mission and benefits
- Encouraging new organisations to join the Alliance
- A dedicated committee to support the creation of national groups
- Mentorship programs pairing emerging alliances with experienced organisations

These initiatives aim to increase global representation and strengthen advocacy worldwide.

Session Four – Supporting Latin American Countries

This session highlighted strategies for building awareness and advocacy networks in Latin America.

Discussions included:

- Identifying key stakeholders (clinicians, patient leaders, policymakers)
- Promoting awareness and education
- Supporting the establishment of national patient organisations

The importance of tailored approaches for low-awareness regions was emphasised.

About the Amyloidosis Alliance Conference

The Amyloidosis Alliance Conference is an international forum bringing together patient organisations, clinicians, researchers, and advocates.

The conference aims to:

- Share global knowledge and best practices
- Strengthen international collaboration
- Amplify patient and caregiver voices
- Promote awareness of the health and social burden of amyloidosis
- Support the development of new national alliances

By uniting delegates worldwide, the Alliance builds a powerful platform for advocacy, policy influence, and improved patient outcomes.

Amyloidosis Alliance Conference – Key Highlights (Baveno, Italy)

Patient & Carer Sessions

1. Holistic Approach to ATTR Patients

Strong focus on treating patients as whole individuals — addressing physical, emotional, psychological, and social needs.

Unmet needs include:

- Delayed diagnosis
- Limited mental health support
- Fragmented or poorly coordinated care

2. Proposed Improvements in Patient Care

- Expanded genetic counselling services
- Increased use of telehealth and clinical trial participation
- Nurse-led multidisciplinary models to strengthen continuity of care

3. Role of Nurses

Nurses were recognised as central to:

- Patient education
- Advocacy
- Emotional support
- Guiding patients through complex care pathways

4. Need for a Patient-Centric Approach

Requires:

- Adequate funding
- Strong collaboration among clinicians, researchers, and patient groups

5. Addressing Genetic Stigma

Need to:

- Investigate stigma associated with hereditary ATTR
- Develop national stigma-reduction strategies
- Educate health professionals

6. Expansion of Genetic Counselling

Counselling must balance scientific accuracy with compassion and emotional safety.

7. Nurse-Led Clinics for ATTR-CM

Proposal to assess nurse-led clinics to improve continuity, monitoring, patient education, and early detection of complications.

8. Improving Public Awareness

Encouraging:

- National awareness campaigns
- Clear, accessible patient resources

- Community outreach efforts

9. Collaboration With Rare Disease Organisations

Rare Disease Day identified as a key opportunity for widespread awareness.

10. Principles for Predictive Genetic Testing

Predictive testing must balance:

- Precision
- Compassion
- Psychosocial support

11. Foundations of Good Genetic Counselling

Genetic counselling should remain:

- Empathetic
- A safe space for autonomous decision-making
- Supported through national strategies and patient associations

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Clinical Sessions

12. Cardiology – Measuring Cardiovascular Fitness

- Six-Minute Walk Test highlighted as a simple, effective tool
- Patients encouraged to remain active within safe limits
- Monitoring includes biomarkers, patient feedback, walking distance, and arrhythmia detection
- Beta-blockers and diuretics should be used cautiously

13–14. Neurology & Functional Impairment

Amyloidosis can affect sensory, motor, and autonomic nerves, leading to:

- Weakness
- Balance issues
- Orthostatic symptoms

Exercise recommendations differ by disease stage.

Safety priorities:

- Avoid over-exertion
- Avoid extreme heat

- Maintain hydration
- Use mobility aids when necessary

15. Gastroenterology

Common issues include diarrhoea, constipation, and weight loss. Misdiagnosis remains common due to vague symptoms.

16. Multidisciplinary Care Is Essential

Clear message across sessions:

- Amyloidosis requires coordinated, multidisciplinary care
- Strong communication between patients and all specialists is vital for safety and quality of life

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17. Dedicated Carer Session – Recognising the Burden and Supporting Wellbeing

Carers: The Hidden Backbone of Amyloidosis Care

A full afternoon session was devoted to the experiences of carers — whose contributions are essential yet often invisible.

Key Challenges Identified:

Carers often experience:

- Depression and mental health strain
- Invisible fatigue from constant vigilance
- Emotional strain and emotional ambivalence (love, duty, frustration, exhaustion)
- Loneliness and social isolation
- Professional and financial hardship

What Carers Need:

- More psychological and emotional support
- Access to professionals who listen without judgement
- Practical coping strategies (stress management, boundary setting, communication tools)
- Recognition as part of the extended care team

Delegates agreed that supporting carers is essential for ensuring patient wellbeing and maintaining family stability.

Closing Note

Australia’s participation in the Amyloidosis Alliance Conference ensures that the voices of Australian patients, families, and carers contribute to global progress. By working collaboratively with international partners, we strengthen advocacy, share knowledge, and help secure better outcomes for all people affected by amyloidosis.