

Report from the Chair

A/Prof Peter Mollee

- Milestones
- Company limited by guarantee
 - Dec 2021
- Charitable status
 - May 2022
- Board members



Associate Professor
Peter Mollee

Chairman
Founding member of the AAN

Medical Director Queensland
Amyloidosis Service



Associate Professor
Hasib Siddiqi

Treasurer
Founding Member of the AAN

Medical Director Fiona Stanley
Hospital Amyloidosis Service, Perth



Dr
Olga Motorna

Alternate Director for
Dr Simon Gibbs

Victorian and Tasmanian
Amyloidosis Service (VTAS) Acting



Dr
Fiona Kwok

Founding member of the AAN

Medical Director Westmead
Amyloidosis Services, Sydney



Ms
Cathy Davies

Joined the Board in Sep 2024

ICU Clinical nurse specialist and educator



Ms
Merran Brookman

Joined the Board in June 2022

CPA, Financial and Accounting
services



Mr
Peter Bridgman

Joined the Board in July 2022

Barrister specialising in public policy
and corporate governance

Our team – non-Board positions



Dr
Dariusz Korczyk
Company Secretary

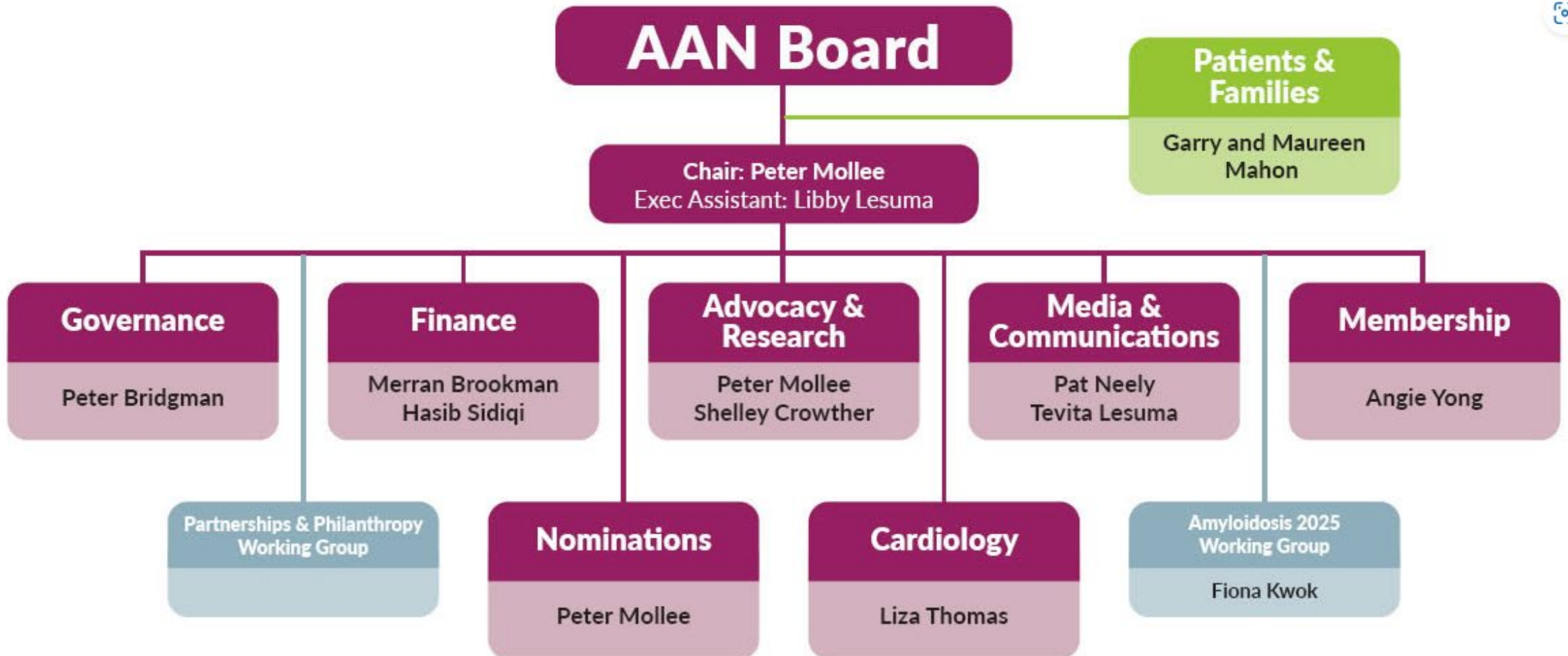


Mrs
Pat Neely AM
Company Secretary



Mrs
Libby Lesuma
Executive Assistant

AAN subcommittees



Membership

Now over 350 members!

- 70 specialists
- 45 trainees/nurses
- 250 patients and families

Newsletters

- Patients and Families
- Health care professionals



AAN PATIENT AND FAMILY ADVISORY COMMITTEE – MAY 2024 NEWSLETTER

Greetings: As we move into the colder months of the year it is tempting to drift into a winter “funk.” However, there are always unexpected events that raise our spirits and remind us that life can be beautiful and inspiring at any time of the year. The brilliant display of the southern lights (aurora australis) on the nights of 11 and 12 May seen from the southern half of Australia counts as one of the beautiful. The story of David Fajgenbaum (link below), although not related directly to amyloidosis, falls into the inspiring.



Education - Australian National Amyloidosis Day

May 8, 2024

Patients and Families Program

| | |
|--|---------------------|
| AAN Chairman's report | Dr Mollee, Brisbane |
| AAN Patient and Family Advisory Committee report | Mrs and Mr Mahon |
| Immunoglobulin Light Chain Amyloidosis Update | Dr Lan, Perth |
| Cardiac Amyloidosis Update | Dr Braumwol, Perth |
| Amyloidosis Neuropathy | Dr Sheikh, Brisbane |

- *Organised by Dr Hasib Siddiqi*

Education – World Amyloidosis Day 26 Oct 2024

Patients and Families Program

| | |
|--|----------------------|
| Management of ATTR cardiac amyloidosis | Dr Peck, Box Hill |
| Symptom management in multi-organ amyloidosis | Dr Paxton, Box Hill |
| ATTR and AL amyloidosis clinical trials in Australia | Dr Motorna, Box Hill |

Healthcare Professionals Program

| | |
|--|---------------------------------|
| Amyloid neuropathies: an approach to diagnosis and treatment | Dr Carroll, St Vincent's Sydney |
| AL amyloidosis update: response assessment and emerging therapies | Dr Wisniewski, Box Hill |
| Advances in the diagnosis and treatment of ATTR cardiac amyloidosis: A clinician's perspective | A/Prof Hare, The Alfred |

- *Organised by Dr Olga Motorna*

Education – Optimal Care pathway for AL amyloidosis

88 page document!

AAN contributors

- Carole Bartlett
- Antonia Carroll
- Simon Gibbs
- James Guntun
- Fiona Kwok (co-chair)
- Darren Lee
- Peter Mollee (co-chair)
- Pat Neely
- Gay Kun Yap
- Angie Yong

AL Amyloidosis

Your guide to best cancer care

About this guide
Being told you have or could have AL amyloidosis can be overwhelming. A lot can happen quickly, and you might have many questions. This resource can help to guide you, your family, and friends through this experience.

Is AL amyloidosis a blood cancer?
Amyloidosis is the name given to a group of rare disorders in which abnormal proteins misfold forming amyloid fibrils. The body cannot break down amyloid proteins easily and they clump together and can deposit and/or accumulate in any tissue and organ of the body. As these deposits progressively build up, they interfere with the working of the body's organs. Without treatment, this will eventually lead to

Optimal care pathway for people with AL Amyloidosis

Quick reference guide

The optimal care pathways describe the standard of care that should be available to all cancer patients treated in Australia. The pathways support patients and carers, health systems, health professionals and services, and encourage consistent optimal treatment and supportive care at each stage of a patient's journey. Seven key principles underpin the guidance provided in the pathways: patient-centred care; safe and quality care; multidisciplinary care; supportive care; care coordination; communication; and research and clinical trials. This quick reference guide provides a summary for clinicians of the *Optimal care pathway for people with AL Amyloidosis*.

Please note that not all patients will follow every step of the pathway.

Step 1: Prevention and early detection

| | | |
|--|--|--|
| Prevention The cause of AL amyloidosis is unknown, and there are currently no effective prevention strategies. | Of those with a monoclonal gammopathy, structural changes to immunoglobulin light chains make them more likely to misfold and form amyloid fibrils. | General health checklist <input type="checkbox"/> Recent weight changes discussed and the patient's weight recorded <input type="checkbox"/> Alcohol intake and smoking status discussed and support offered if appropriate <input type="checkbox"/> Physical activity recorded <input type="checkbox"/> Referral to a dietitian considered |
| Risk factors <ul style="list-style-type: none">• age (occurs mainly in people aged over 40)• gender (slightly more common in males)• a pre-existing monoclonal gammopathy (small proportion go on to develop AL amyloidosis). | Early detection Routine screening for AL amyloidosis is not currently recommended in the general population. For patients with a known diagnosis of a monoclonal gammopathy (MGUS, smouldering myeloma, multiple myeloma) a high index of clinical suspicion and careful assessment can facilitate early diagnosis of AL amyloidosis. | |

Optimal care pathway for people with AL amyloidosis

FIRST EDITION

Endorsed by:
ALLG <www.allg.org.au> ANZTCT <www.anztct.org.au> Cancer Council <www.cancer.org.au>
HSANZ <www.hsanz.org.au> Leukaemia Foundation <www.leukaemia.org.au>
Australian Amyloidosis Network <www.aan.org.au> Myeloma Australia <www.myeloma.org.au>

Education

- Targeting GPs
 - Dr Yap (GP AAN) member
 - “Amyloidosis” article for AusDoc newsletter
- Professional Medical Society meetings
 - ISA 2024 (Faculty representation and speakers)
 - Clinical Proteomics Symposium 2023
 - Blood Scientific Meeting
 - Cardiology Scientific Meeting
- Pharma seminars
 - Cardiac amyloidosis seminar, run by United Clinical, 1100 registrants
 - Pfizer’s cardiac amyloidosis meeting
 - Tafamidis launch
 - Janssen’s H3 meeting

Media and Communications www.aan.org.au

The screenshot shows the homepage of the Australian Amyloidosis Network (AAN). At the top, there are navigation buttons for 'DONATE TO THE AAN', 'JOIN THE AAN', and 'MEMBER LOGIN'. Below this is the AAN logo and a navigation menu with links for Home, Patients and Carers, Health Professionals, Clinical Trials, AAN Resources, Events, and Contact Us. The main content area is divided into several sections:

- Hello and welcome:** A purple banner with text explaining amyloidosis and the AAN's role. It includes a link to 'find out more about us >'.
- World Amyloidosis Day:** A green banner announcing virtual education programs for Patients and Families (Saturday October 26) and Doctors and Health Professionals (Thursday October 31). Registrations open on October 14.
- Here to help:** A section with two buttons: 'Patients & Carers' and 'Health Professionals', with a link to tailored portals.
- Footer:** A dark green bar with news items: 'patients with neuropathy', 'Tafamidis for ATTR CA listed on the PBS from May 1', and 'PBAC recommends patisiran for'.
- Bottom Section:** Three columns: 'Patient Experiences' with a photo of a group of people, 'News' with a headline 'PBAC Submissions on ATTR' and a photo of a person, and 'Upcoming Events' with two event cards: 'NOV 7 6:00 pm - 7:00 pm AAN 2024 AGM' and 'MAY 3 May 3, 2025 - May 13, 2025 Amyloidosis 2025 Workshops and Meetings'.

Practical resource for Australian doctors, patients and carers

- Information about amyloidosis
- Details of AAN services:
 - Where we are
 - Who we are
 - How to refer
- Section on **Clinical Trials**
 - Regularly updated
- Upcoming Educational events
- Videos of past Workshops and Seminars
- Patient Stories
- Donations page

**Currently undergoing a REVAMP
watch this space!**

Media and Communications

- AAN Brand Review and Style Guide
- Communications policy
- Updated medical information for website
- Updated patient and family information for website



**Australian
Amyloidosis
Network**
Working together
Seeking a cure

Patients and Families Advisory Committee

- Monthly meetings, chaired by Garry and Maureen Mahon
- Activities
 - review of the AAN web site
 - the preparation of a quarterly newsletter for patients
 - planning for the nation-wide 2025 May education workshops and meetings
 - review of best models for AAN to provide patient support
 - AAN Strategic Plan development
 - presence at Amyloidosis Alliance AL amyloidosis meeting in Belgium
 - advocating with PBAC for new therapies e.g. vutrisiran

Patient support

- Virtual (telephone) support service
 - Psychoemotional support
 - Health navigation
 - Basic information on amyloidosis and access to therapy
 - Links to educational resources eg websites, online booklets, endorsed you tube videos etc
 - Providing patients with the right questions to ask
- Build up web site support programs
- Web site page spelling out what support is available and where
- On-line chat support/education sessions
- Face to face support meeting partnering with the state amyloidosis centres

Cardiology

Publications

- CSANZ AAN Consensus paper on cardiac amyloidosis
- ATTR snapshot paper

Education

- Cardiology amyloidosis interest group every 3 months
- CSANZ annual scientific meeting in Perth (August 2024)
 - Breakfast sessions (sponsored by Pfizer): Hasib Sidiqi and Jay Baumwol
 - Expert consensus document presentation: Liza Thomas
 - Diagnosing AL amyloid: Hasib Sidiqi
- Website updates

ATTR registry

- Fund raising to support creation and maintenance of the registry for 2 years

2024 Australia–New Zealand Expert Consensus Statement on Cardiac Amyloidosis



Nicole K. Bart, MBBS, DPhil^a, Diane Fatkin, BSc(Med), FRACP, FSCANZ^a, James Gunton, MBBS, PhD^b, James L. Hare, PhD, FRACP^c, Dariusz Korczyk, FRACP, FCSANZ, DDU^d, Fiona Kwok, PhD, FRACP^e, Kaitlyn Lam, MBBS, PhD^f, David Russell, BMedSci, FRACP, FCSANZ^g, Hasib Sidiqi, MBBS, PhD^h, Tim Sutton, FRACP, FCSANZⁱ, Simon D.J. Gibbs, FRACP, FRCPA^j, Peter Mollee, MMedSc, FRACP, FRCPA^k, Liza Thomas, MBBS, PhD^{l,*}

Advocacy

New PBS listings

- Tafamidis for ATTR cardiomyopathy
- Patisiran for ATTRv with neuropathy

Under consideration

- Vutrisiran for ATTRv with cardiomyopathy

New MBS listing

- NT-ProBNP or BNP (single test) for non-hospital request



Trials

AL amyloidosis

Newly diagnosed

- CAEL101 program
- Affirm-AL

Relapsed (BCL2 inhibitors)

- Viber-M
- ZN-d5

Relapsed (T cell engagers)

- APG-2575
- M24-209
- Teclistamab for Previously Treated AL Amyloidosis (in collaboration with EMN)
- SAR445514

Relapsed (CD38 monoclonal antibody)

- ALLG M24 (in collaboration with French investigators)

Other

- Cardiac transplantation followed by ASCT in patients with AL amyloidosis



ATTR amyloidosis

Anti-amyloid fibril antibodies

- AT-02 (pan-amyloid depleter)
- ALXN2220 (ATTR depleter)

CRISPR TTR knockdown

- Magnitude (NTLA-2001 CRISPR)


Other

- Sydney ATTR study
- PAH carpal tunnel screening study
- Screening for cardiac amyloidosis in patients with newly identified conduction disease

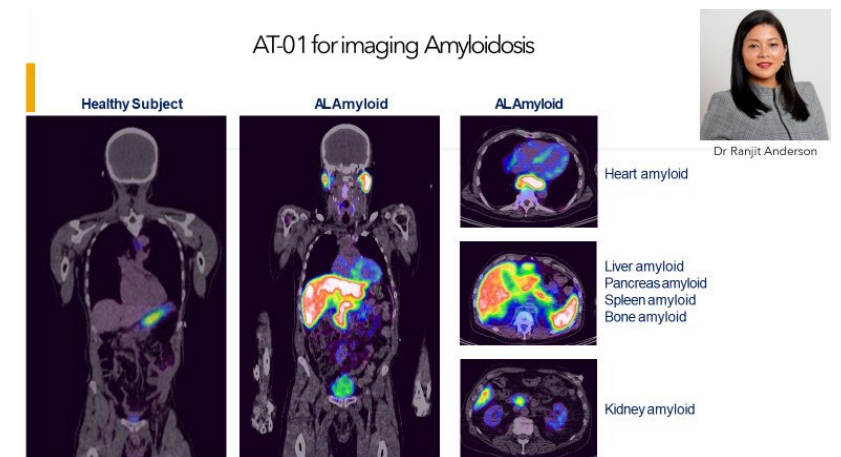

Research

- ISA meeting
 - 3 travel scholarships
 - > 10 accepted abstracts
- Snowdome grant
 - Dr Sabdia, PhD student
 - Personalized mRNA vaccines for AL amyloidosis
- AT-01 amyloidosis imaging study
 - Dr Ranjit Anderson, MPhil student
 - Novel pan-amyloidosis scan



 Snowdome Foundation

2024 Gunn Family Haematology Fellowship Awardee



AAN Strategic Plan

- To provide training and education of medical professionals, patients and their carers
- To undertake and promote research
- To advocate, in partnership with patients with amyloidosis and medical professionals, to ensure equitable access to the best possible treatments
- To enhance awareness and to promote the multi-disciplinary management of amyloidosis patients
- To enhance the quality of life of patients of amyloidosis

• To improve diagnosis, treatment, and quality of life for people with amyloidosis.

• To provide information and support for health professionals and people affected by amyloidosis.

• To undertake amyloidosis research and advocacy.

AAN Values



Respect

We honour the dignity and individuality of each person affected by amyloidosis. We are committed to valuing diverse experiences and perspectives, and we foster an environment of mutual respect among patients, families, medical professionals, and all stakeholders.



Compassion

We approach every aspect of our work with deep empathy and understanding. We are dedicated to supporting patients, families, and caregivers through their journeys with amyloidosis, offering comfort and care at every step.



Integrity

We uphold the highest standards of honesty and transparency in our interactions and operations. Our commitment to ethical practices ensures that our patients, families, and partners can trust us to act in their best interests and with unwavering dedication.



Innovation

We are innovative and proactive in finding solutions to the challenges associated with amyloidosis. By effectively utilising available resources and seeking new opportunities, we aim to enhance patient care, support research, and drive progress in the fight against this disease.



Collaboration

We believe in the power of teamwork and partnership. By working closely with medical professionals, researchers, patients, families, and other stakeholders, we harness collective expertise and resources to advance care, support, and research for amyloidosis.

AAN Strategic Pillars



Improving Patient Outcomes

Working in partnership with others to improve the lives of patients with Amyloidosis.

Strategic Goal

Establish an accessible patient support program by 2025

Campaign for early diagnosis and coordinated multidisciplinary care by 2026

Ensure patient voice heard at AAN Committee and Board Level

Develop education services for patients and families

Advocate for improved access to new treatments and technologies

Work with international and local organisations to improve patient support and education



Building Knowledge

Promoting research and sharing reputable information about Amyloidosis across the related stakeholders.

Strategic Goal

Establish multiple research related initiatives by 2025

Create accessible ways for health professionals and patients to share information about Amyloidosis by 2024

Establish amyloidosis teaching programs for medical students, registrars, general practitioners, specialists, nurses and other health professionals by 2026



Financial Sustainability

Creating a financially viable organisation to provide support to the AAN Community for long-term success.

Strategic Goal

Raise \$3m over 5 years

Establish sustainable funding for the AAN for the next 5 years



Organisational Excellence

Maintaining best operational and governance practices for managing a patient focussed not-for-profit organisation.

Strategic Goal

Ensure key AAN decision makers meet the business needs of the organisation by 2025 and on-going

Operate the AAN at best practice as a registered Australian charity
Maintain clear internal communications to ensure AAN Strategic directions are met
Establish the most practical and efficient AAN Committee structure and compositions within 2 years

Thank you