



**Australian Amyloidosis Network Ltd.**  
**Annual General Meeting Minutes 2022**

<b>Date:</b>	November 24, 2022
<b>Time:</b>	1900 AEDT
<b>Place:</b>	Virtual

<b>Attendees:</b>	<b>AAN Chair:</b> Simon Gibbs <b>AAN Company Secretary:</b> Pat Neely <b>AAN Directors:</b> Merran Brookman , Peter Mollee, Fiona Kwok, Hasib Sidiqi, Peter Bridgman <b>Other Attendees:</b> Joe Kochman, John Main, Alwyn Poole, Garry Mahon, Maureen Mahon, Ron, and Pam Edwards. Graeme Stewart, Nikki Bart, Angie Young, Mahima Kapoor, James Hare, James Nolan, Susan Both, Pat Clarke, Jay Baumwol, Emad Abro, Kay Peck, Harry van Kleef, Evan Bittner, Matthew BurrIDGE <b>Guest Speaker:</b> Prof Philip Hawkins
<b>Apologies:</b>	Jaime Christmas, Hugh Goodman, Julia Bradly, Julian Cooney, Chris Hayward, Dariusz Korczyk
<b>Proxies:</b>	NIL

## **The Chair's Report**

Pat Neely introduced the Chair of the AAN Board, Dr Simon Gibbs thanking him for his leadership and inviting him to give the Chair's report  
Questions were invited from the floor through the Chat line.  
The Chair's report was illustrated with slides.

Dr Gibbs welcomed everyone to the AAN AGM and acknowledged and expressed his delight that the AAN had become a Company with limited Guarantee in December 2021 and gained charitable status in May 2022.

Dr Gibbs thanked his fellow inaugural Board members, Dr Fiona Kwok, Associate Professor Peter Mollee, Associate Professor Hasib Sidiqi, and Mrs Pat Neely for all their hard work in bringing this about.

Dr Gibbs recognised and thanked the lawyer Annette Bradfield and facilitator, Tevita Lesuma for their assistance with:

- Constructing the AAN and writing the constitution
- Establishing the AAN as a Company
- Ensuring the AAN became a registered charity .

## **Expanding the AAN Board**

The inaugural Board has 5 members, comprised of the directors of the 4 Australian amyloidosis centres, as well as our patient advocate.

2 new board members have now been appointed through the Board appointment procedure.

Mr Peter Bridgman	Legal Director
Mrs Merran Brookman	Financial Director

## **AAN Subcommittees**

**Dr Gibbs outlined that sub-committees are responsible for much of the everyday running of the AAN. He summarised each of the subcommittees and their leadership.**

### **Governance**

Chaired by Peter Bridgman supported by Dr Peter Mollee and Pat Neely

### **Finance**

Merran Brookman, Finance Director and Associate Prof Hasib Sidiqi, Treasurer

### **Media and Communications**

Dr Fiona Kwok and Pat Neely

### **Membership Committee**

Chaired by Dr Simon Gibbs who indicated he would be stepping back to Deputy Chair.

Dr Gibbs has asked the Board to accept Dr Angie Yong, haematologist from SA, as the new chair of this committee.

### **Patient and Family Advisory Committee**

Chaired by Pat Neely. Comprising of 12 members, all amyloidosis patients or carers representing all states except Tasmania.

### **Cardiology**

Chaired by Professor Liza Thomas, Cardiologist at Westmead Hospital

### **Advisory, Research and Trials.**

Chaired Dr Peter Mollee and Mrs Shelly Crowther

Dr Gibbs outlined that Shelley Crowther has a lot of experience in Advocacy work for the Pharmacy Guild and APHRA. This committee has been formed but not yet met.

### **Nominations Committee**

Chaired by Dr Simon Gibbs

## **Achievements and Services Offered by the AAN**

Dr Gibbs informed the audience that the diagnosis of ATTR has increased, with referrals rising around Australia and the needs for these patients growing. Our achievements and services include:

### **1. Diagnosis and Management advice**

- includes histology reviews and MDMs in each state that has an amyloidosis service.

### **2. Access to novel drugs and drugs that may be difficult to obtain**

- Diflunisal for ATTR patients can be obtained under the Special Access Scheme.
- It was noted that ~ 150 patients around Australia are receiving diflunisal at this time.

### **3. Education and Support to patients, families, and health professionals.**

- this takes many forms, such as lectures (virtual and face to face), Grand rounds in hospitals, education and support surveys for patients looking at support and education needs. The AAN website remains a key service offering education and support
- Education Workshops for patients, families and health professionals are held every other year in most capital cities and include overseas guest speakers. The next meeting will be in 2023 with 3 overseas speakers.
- Monthly AAN grand rounds led by the medical director of the Westmead Centre, Dr Fiona Kwok, to discuss complex cases. Dr Gibbs thanked Dr Kwok for her leadership.
- The AAN web site has many sections for patients and families and health professionals:
  - Information on amyloidosis
  - Clinical trials
  - Upcoming events
  - AAN services
  - A new donation page with \$5000 already donated.
  - A very new membership portal opened at 10pm the previous evening.

Dr Gibbs thanked Dr Fiona Kwok , Pat Neely, and Don Francis the web site technical expert.

### **4. Genotyping to look for hereditary disease - Westmead Hospital**

### **5. Mass spectrometry service to assist subtyping.**

- Princess Alexandra Hospital is establishing such a service
- Dr Peter Mollee leads the research group for amyloid mass spectrometry, conducting a study to facilitate NATA accreditation

### **6. Facilitating cooperation and dialogue between those treating amyloidosis across Australia.**

- Consistent with the AAN motto "*Working Together, Seeking a Cure*", the AAN endeavours to assist amyloidosis services in Australia as much as possible to address unmet medical needs
- An example is as the growth of centres such as St Vincent's in Sydney and in Adelaide and the collaboration between the physicians in Tasmania and Canberra.

### **7. Lobbying for, establishing and recruiting to clinical trials**

- Actively recruiting or ongoing clinical follow up trials in the ATTR space
- In the AL space there are several trials currently open, including one in which the AAN through the Australian Leukaemia and Lymphoma Group, ALLG, is collaborating with the IFM in France. This is an AAN initiated study and is recruiting well.
- The AAN is moving into more early phase trials which is very exciting
- Dr Gibbs expressed his delight that all centres have tried to optimise clinical trial access for Australian patients

## 8. Advocacy

- Dr Gibbs noted that this is a major part of the AAN's work.
- This has involved zoom meetings with Pharma and other groups to negotiate greater access to novel treatments for patients
- All AAN delegates visiting the ISA meeting in Heidelberg were involved in meetings with Pharma making sure the AAN was not left off the table for drug access research opportunities and clinical trial access.
- One example of the pharma companies the AAN has really been engaged with is Pfizer, pushing for sensibly priced Tafamidis and compassionate access supply and assisting with PBAC submissions that will hopefully lead to PBS drug reimbursement. Unfortunately to date this has been a failure so far as it has been in NZ and the UK.
- Other examples include:
  - Intellia
    - Encouraging CRISPA studies in ATTR next year.
  - Bridgebio
    - There is AAN representation on steering committee for AG 10 trials.
  - Alnylam
    - The AAN continues to advocate to ensure patisiran becomes available in Australia soon. Dr Gibbs announced at the meeting that that patisiran for the treatment of ATTR hereditary neuropathy had been TGA licensed the previous day. Now working with Alnylum to obtain PBS listing.
  - Janseen
    - Lobbying for TITAL-1 study to come to Australia
    - Working with Janssen and supporting the PBS in the reimbursement of the first active treatment for amyloidosis, Daratumumab with bortezomib, cyclophosphamide and dexamethasone. The hope is that Daratumumab should be available by January 1, 2023. This will be a huge breakthrough after Australia was heavily involved in the Andromeda study that proved the efficacy of Daratumumab in the frontline treatment of AL amyloidosis

Dr Gibbs expressed his hope that there would be more government interaction next year.

## 9. International relationships

- The AAN has always worked well with the British and of course Professor Philip Hawkins, including potentially cooperating in a new bone scintigraphy stud
- Strengthening partnerships with the New Zealanders, through work with NZAPA, NZ Myeloma summit, Grand Rounds
- Working with the Americans, Canadians, Greeks, and British endeavouring to get the price of Tafamidis reduced.

## 10. Publications

- An AAN article has been accepted by the International Medical Journal. IMJ
- Dr Peter Mollee and Dr Simon Gibbs have been authors in the International Society of Amyloidosis, ISA, amyloidosis guidelines.
- Also involved in the Myeloma Society of Australia, MSAG, guidelines for the treatment of AL amyloidosis.
- AAN guidelines for the treatment of ATTR are being completed by Dr Nicky Bart, St Vincent's Sydney

## **11. Presenting Research**

- Abstracts presented at the ISA, CSANZ and BLOOD meetings.
- Dr Gibbs offered the AAN's congratulations to Dr Dariusz Korczyk for being recognised at the ISA meeting for excellence in research.

## **12. Registries**

- Through work over the preceding 12 to 18 months, AL amyloidosis has been added to the Monash University Myeloma and Related Diseases Registry (MRDR)
- Thanks was given to Associate Professor Peter Mollee and Dr. Masa Lasica.
- An ATTR amyloidosis registry being developed, and funding sorted out by Dr James Hare and Dr Simon Gibbs working with Pharma, Monash, and the Cardiology subcommittee.

## **Plan and Strategies for the next 12 months**

- Continue and possibly expand the AAN's services by potentially adding additional services and affiliates to the AAN, e.g. St Vincent's Hospital, Sydney
- To run workshops in 7 capital cities of Australia with 3 international speakers in May 2023
- Appoint a General Manager for administrative support, organising workshops, etc.
- Seek grant opportunities and build research collaboration.
- Conduct a concerted membership drive
- Create a fund-raising committee and start a fund-raising drive.

Dr Gibbs thanked his Board colleagues and asked them to join with him in encouraging other doctors, health professionals and patients and families to become members of the AAN.

Dr Gibbs handed over the platform to the AAN's Financial Director, Mrs Merran Brookman and the Treasurer, Associate Professor Hasib Sidiqi for the Financial Report.

## **Financial Report**

Associate Professor Sidiqi, AAN treasurer, introduced this section, stating that it had been a very busy 12 months since the AAN had become officially listed as a company and a charity, with the successful registering of accounts and setting up a bank account.

Associate Professor Sidiqi thanked the Princess Alexandra Research Foundation in Brisbane on behalf of the AAN for the help they have given over several years managing the AAN's funds pro bono and to Associate Professor Peter Mollee for negotiating this arrangement.

The AAN's funds have now been transferred from the PA Foundation into the AAN's own account.

Professor Sidiqi reminded the audience and the Board that the AAN web site now had a Donation page which could be accessed through the donate button on the home page.

Mrs Merran Brookman, AAN Financial Director, continued the discussion.

Mrs Brookman thanked them for attending and agreed with A/Prof Sidiqi that it had been a very busy year since the AAN became a Company and a Charity. She said the financial report was quite simple this year. The AAN had run a "tight ship" making the most from each dollar received.

There have been four main revenue streams:

- Grants from pharmaceutical companies
- Generous Donations.
- Membership fees for patients and families, health professionals, doctors, and other interested parties.
- Event registration fees for meetings.

Historically, the largest expense the AAN has is the bi-annual amyloidosis conference running over a week across all major capital cities. The next workshops are scheduled for May 2023. The anticipated major expenses associated with this event include catering, flights and accommodation for overseas speakers, and venue hire. The approximate cost for the May 2023 education meetings is expected to be in the vicinity of \$ 217,000.

The next largest AAN expense is the web site, which is hugely important in connecting the amyloidosis community with information for health professionals and the patients.

The Donation and Membership pages are now open and can be activated through buttons at the top of the home

Other details of note:

- Only AAN asset is cash in the bank
- We have no liabilities
- The AAN funds are safeguarded through a comprehensive financial policy with rigid internal control through segregation of duties and dual authority for payment.
- Present financial situation carried forward is \$85,000  
Much of this was from previous amyloidosis event in 2020 which was interrupted by COVID which stopped the face-to-face events. Therefore, inadvertently, saving costs on catering, event space, accommodation etc.
- Because the Company is carrying this \$85 000 into the next financial year, this puts the AAN in a secure position from a continuity perspective to be able to carry on the work this organisation is involved with.
- This financial year the AAN expects to cover all expenses from the income and carry forward a surplus.

Mrs Brookman concluded by asking the audience if they had any questions, there were none.

Dr Gibbs thanked Hasib and Merran and commented that the finances were in good hands.



## FINANCE OVERVIEW

### STATEMENT OF COMPREHENSIVE INCOME FOR THE YEAR ENDING 30 JUNE 2023

	YTD ACTUAL	FULL YEAR BUDGET
<b>Income</b>		
Grant Revenue	-	217,000
Event Registrations	-	500
Donation Revenue	5567	15,067
Membership Revenue	2401	8,651
<b>Total Income</b>	<b>8,968</b>	<b>241,218</b>
<b>Expenditure</b>		
Administration Expenses	194	1,795
Advertising and Marketing Expenses		16,500
Event Support Expenses	1,030	211,200
<b>Total Expenditure</b>	<b>1,194</b>	<b>241,285</b>
<b>Operating Surplus / (Deficit) for the year</b>	<b>7,774</b>	<b>51</b>

### STATEMENT OF CHANGES IN FUNDS FOR THE YEAR ENDING 30 JUNE 2023

Balance at 1 July 2022	85,801
YTD Operating Surplus	7,774
Balance at 24 November 2022	93,575
Remaining Year Budget Operating Deficit	- 7,773
<b>Forecast Balance at 30 June 2023</b>	<b>85,852</b>

\* These unaudited accounts are prepared as Special Purpose Financial Statements and on a cash basis of accounting

## Acceptance of the Chair's report and the Financial reports

A motion was called to move that the chairman's report be to be accepted. This was moved by Assoc, Prof Peter Mollee, and seconded by Evan Bittner

## Guest Speaker

Dr. Simon Gibbs introduced Professor Philip Hawkins giving the audience some insight into his working relationship with Philip who was his boss at the National Amyloidosis Centre in London. Dr Gibbs described this time as one of the best experiences of his life.

Dr Gibbs expressed what an honour it was to have worked with Prof Hawkins whom he described as having a very inquisitive scientific mind, a huge passion for research and amyloidosis and who always showed great respect and kindness for his patients. He thanked Philip for the generous time he had given over the years supporting the work of those caring for amyloidosis patients in Australia.

Dr Gibbs proposed that.

*"The award of emeritus membership of the Australian Amyloidosis Network should be given to Professor Philip Hawkins of London, in recognition of his outstanding contribution in the field of amyloidosis, including his 20 years of support and education of Australian amyloidosis patients, carers, physicians and health care workers and for excellence in research into the diagnosis and treatment of all types of amyloidosis and related disorders"*

The audience were invited to unmute and say YES or NO to the proposal. No No's were recorded.

Dr Gibbs congratulated Professor Hawkins on becoming the inaugural Emeritus Member of the Australian Amyloidosis Network and invited him to give a talk on his career and what he had learnt along the way.

Philip thanked the audience and the many people in Australia he said he regarded as friends and complimented the AAN on all they had achieved in patient care to date.

***N.B. This talk is available, but not recorded in the minutes.***

At the close of Professor Hawkins's talk, Dr Gibbs and other expressed their thanks for his address.

The meeting moved on with Dr Gibbs inviting Dr Fiona Kwok to launch the membership portal.

## **Membership Portal**

Dr Kwok, joint chairman of the Website committee and Deputy Chair of the AAN, acknowledged that it had taken a long time to get to the point of launching the AAN membership portal.

Dr Kwok noted:

- Membership is now open to patients, carers, family members and other interested community members, health professionals and doctors.
- Membership applications can be accessed through the membership button on the home page of the AAN website.
- These applications are submitted to the Membership committee for approval

Dr Kwok thanked all those who had joined originally through the e-mail and now through the portal.

## **Governance of the AAN**

Peter Bridgman, the Legal Director of the AAN, was invited by Dr Gibbs to speak on governance.

Mr Bridgman noted:

- The AAN is a now accompany limited by guarantee and a charity with deductible gift status which influences how it is governed and regulated.
- At the AGM, there is usually the appointment of auditors to keep company records, audit, or review. Currently Mrs Merran Brookman, the AAN's financial director is fulfilling this role.
- A formal motion may be considered to appoint an auditor in 2023
- The AAN must have 5 directors and no more than 9.
- Currently there are 7, three non-medical and 4 medical specialists.
- Nominations committee has not been formed to date but will need to be in the coming year.
- All full AAN members have privileges and obligations including the right to participate and vote in annual general meeting and to participate in the activities of the company noted by Dr Gibbs in his address .



## Concluding Business

Dr Gibbs thanked everyone who has attended the AGM and Pat Neely, the Company secretary, for her help in arranging it.

Dr Gibbs again expressed his thanks to the Guest speaker Professor Philip Hawkins and invited any further comments from the audience.

Assoc Prof Peter Mollee extended personal thanks to Professor Hawkins for assistance he has given to him personally and everyone else in Australia over the years. He agreed with Dr Gibbs that Professor Hawkins has the ability to think outside the box and is dedicated to what is important to patients. He expressed his happiness that Philip had accepted this inaugural membership award.

Evan Bittner gave his thanks to Pat Neely for her work and to Dr Simon Gibbs for keeping him alive and walking beside him through some difficult times. He expressed his thanks to all the doctors working to improve patient care and expressed his hope and excitement that now everyone would go out and ask for donations for the AAN.

Pat Clarke expressed her thanks for an amazing night. She said had learnt so much more about research and expressed how grateful she was to all the doctors for what they do.

Dr Gibbs thanked all those who had made comments and drew the audience attention to Evan Bittner's story available on the web site. He thanked the audience for dialling in and invited them to join the workshops in May 2023 and in the meantime donate to the AAN.

As no elections were held, the meeting concluded at 2100 EDT

**Minute taker:** Pat Neely

**Signed:**

A handwritten signature in blue ink, appearing to read 'Simon Gibbs', is written over a light blue horizontal line.

**Name:** Dr. Simon Gibbs, Chair of the AAN

**Date:** 26th October 2023