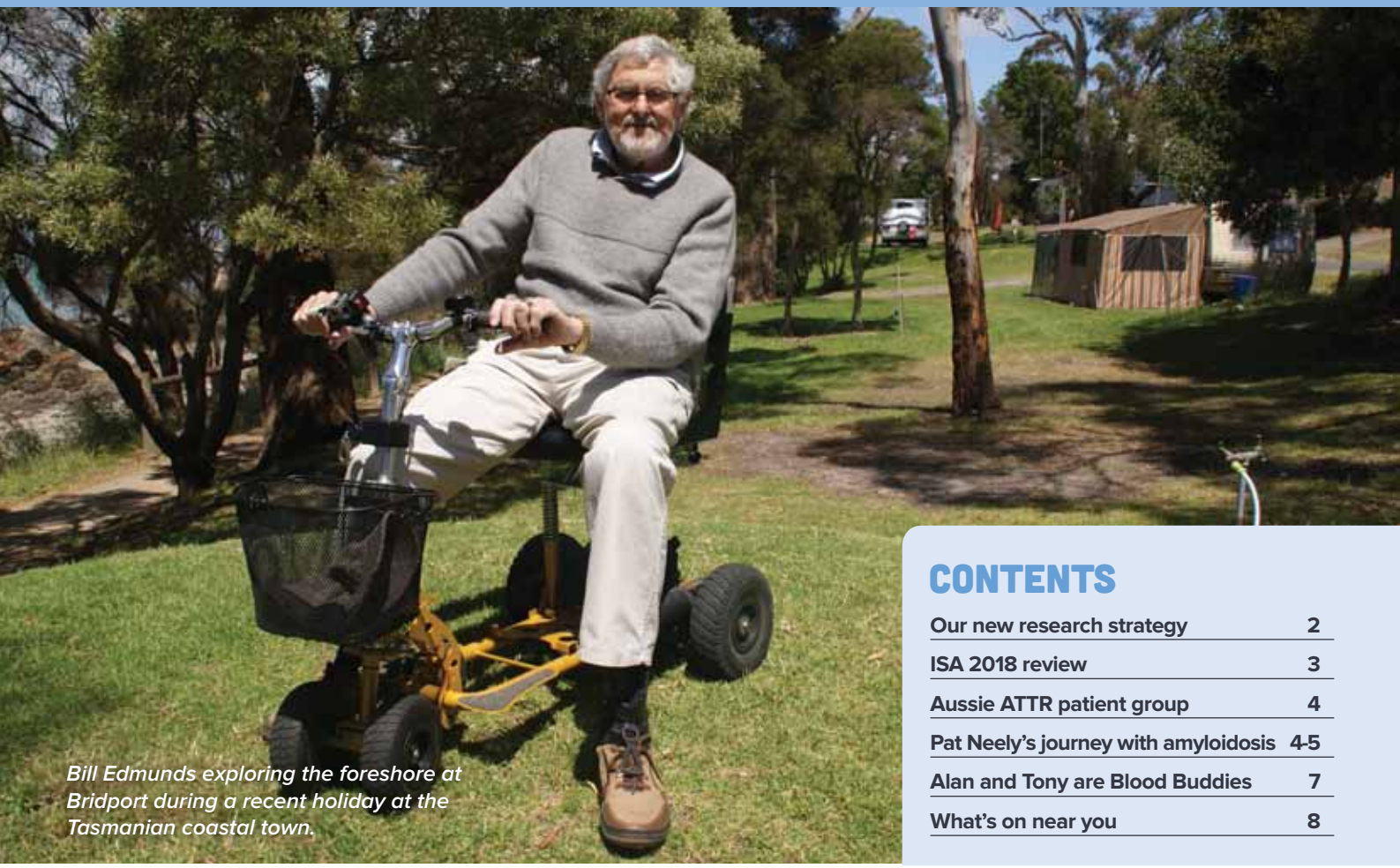
# AMYLOIDOSIS NEWS

For people with amyloidosis & their families

Leukaemia Foundation
VISION TO CURE
MISSION TO CARE

ISSN 2208-2069

JANUARY 2019 | leukaemia.org.au | 1800 620 420

*Bill Edmunds exploring the foreshore at Bridport during a recent holiday at the Tasmanian coastal town.*

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# BILL TELLS HIS STORY OF HAVING AMYLOIDOSIS IN VERSE

**For two years before discovering he had AL amyloidosis in August 2011, Bill Edmunds was "really unwell" and struggled to get through a full day at his part-time university job.**

"I'd have a short snooze on the desk," said Bill, 75, of Hobart.

*I was increasingly aware that something wasn't right, Often very tired, couldn't understand my plight. (2009)*

It was only in retrospect that Bill realised his journey with amyloidosis began when he had a lot of trouble with atrial fibrillation.

*Treatment for atrial fibrillation (AF) was followed for the year. Extreme tiredness continued unabated, the why just wasn't clear. (2010)*

When his heart disease medication made no difference to his AF, Bill's physician looked into it further, came up with Waldenström's macroglobulinaemia – a form of lymphoma – and referred Bill to an oncologist.

"He said 'you'll probably die of something else. We won't worry too much about it', because it was slow moving," said Bill.

*Cardiologist, physician, oncologist and of course G.P. Haematologist, urologist, neurologist were some I had to see.*

When Bill asked his specialist about a host of other symptoms – fatigue, loss of balance and aching in his lower legs – more tests revealed his light chain readings were very high.

"I was told 'you've got amyloidosis and you're pretty ill, we'll start chemo on Monday'. That was on the Friday night and at that stage I was in hospital," said Bill.

*I'd contracted two diseases, both considered rare, One I thought was fair enough, but two just wasn't fair! (2011)*

Bill Edmunds began writing poetry at high school and during his 34 years as a school principal verse was his way of telling humourous stories about his staff. For the last eight years, Bill has used bush poetry to capture developments on his journey with amyloidosis, stanzas of which are featured throughout this story.

***I wonder what would have been, had years behind been changed,***
***Had my health been robust, and my days not rearranged.***

*Continued on page 6.*

# OUR NEW RESEARCH STRATEGY INVESTS IN INNOVATION

**The Leukaemia Foundation's new research strategy supports medical research that drives rapid advancements in treatments, encourages the careers of promising scientists and discovers new diagnostics and novel therapies. Giving Australians access to global clinical trials is another key aim.**

CEO, Bill Petch said this new research framework came from consulting with the Leukaemia Foundation's stakeholders over the last two years.

"We have turned our attention to investment in innovation – in diagnosis, treatments and improving quality of life across the blood cancer spectrum," said Bill.

"And by forging new, strong research partnerships with leading research agencies, including HSANZ, Cancer Australia, the Centre for Blood Transplant and Cell Therapy's Centre of Research Excellence, our new research program is powered for maximum impact.

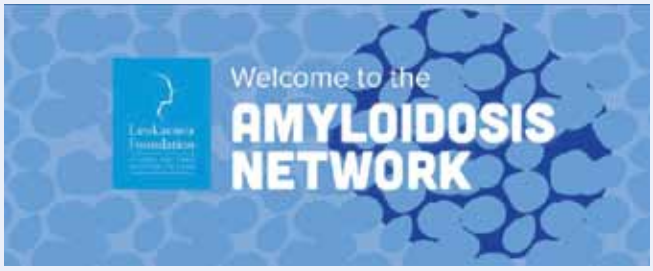
"Our research priorities are understanding the biology of blood cancers, tailor-made therapies to treat each patient's cancer and the psychosocial aspects of blood cancer.

"Other key areas will include innovative clinical trials, new therapies and prevention research which includes investigating risk factors and possible causes of blood cancers."

*Bill Petch, Leukaemia Foundation CEO.*

Our current (2017-2019) multi-million dollar funding commitment to research will grow over coming years in line with generous support from the community.

**To find out more about our new research program visit: leukaemia.org.au/research**




# A PLACE TO CONNECT, ASK QUESTIONS & SHARE EXPERIENCES

**More than 200 people have joined the Amyloidosis Network group on Facebook since its launch by the Leukaemia Foundation in mid-2016.**

Having access to a closed 'members only' network means you don't have to face the challenges of an amyloidosis diagnosis on your own.

General Manager, People Living With Blood Cancer, Emma Craig, said the empathy and support members provide to each other through this forum has exceeded expectations for the group.

Here is a selection of comments from the group's discussion:

*"I still marvel at how the internet can bring people together."*

*"The group is a great sounding board."*

*"It is so good to read all the different stories."*

Members joining the group often introduce themselves by summarising their diagnosis and treatment experiences:

*"I was diagnosed with AL amyloid in 2011, it was detected in my liver & spread to my heart. I had CTD chemo (26/12/2011 - 26/03/2012), then a course of VD chemo (07/05/2012 - 24/06/2013). Have had my stem cells harvested ready for transplant when required. I suffered complete heart block in May 2016 & had a Pacemaker fitted in June 2016... I started on the NEOD trial in March... "*

This safe and private online space enables members to share their personal experiences with these rare diseases, at any time:

*"I have NHL and AL amyloidosis and find this group a great source of reassurance when you need it. Somebody will always be able to assist or point you in the right direction if needed."*

*"I was blessed to receive my new heart January 2016. I then was required to have a stem cell transplant July 2016, which had put my amyloidosis in remission. It's been a tough journey but I am now back at work four days a week and doing well."*

The network is a great place to visit for up-to-date on information about further Leukaemia Foundation support you can access, such as our telephone forums and new education materials:

*"Many doctors don't know that much about it. Leukaemia Foundation puts out a little booklet which I found very useful - simple and easy to understand... "*

In this friendly, supportive environment, people are open to sharing their feelings. It's an ideal forum to express concerns, ask questions, and offer tips and feedback on many aspects of one common theme – living with these complex diseases:

*"Just wondering if anyone had any hints for dealing with insomnia?"*

*"No sorry I am the opposite, I suffer from fatigue. I quite often have little sleeps in the day, then sleep a solid 10 hours, no dreaming just a deep sleep but still wake up tired in the morning. This disease does not seem to have many guidelines."*

Some members have partners, parents, children, or significant others with an amyloidosis diagnosis. This forum provides a way for them to connect with others in similar situations, to hear their stories and share their hope.

*"My Dad has recently been diagnosed with multiple myeloma and cardiac amyloidosis. It's been a rough year... I thought connecting with some support groups might be helpful... Looking forward to being part of the discussions."*

*"It's a tough battle, even for the carers. Amy is a very challenging extra player in our lives. This group means that you don't have to do it alone!"*

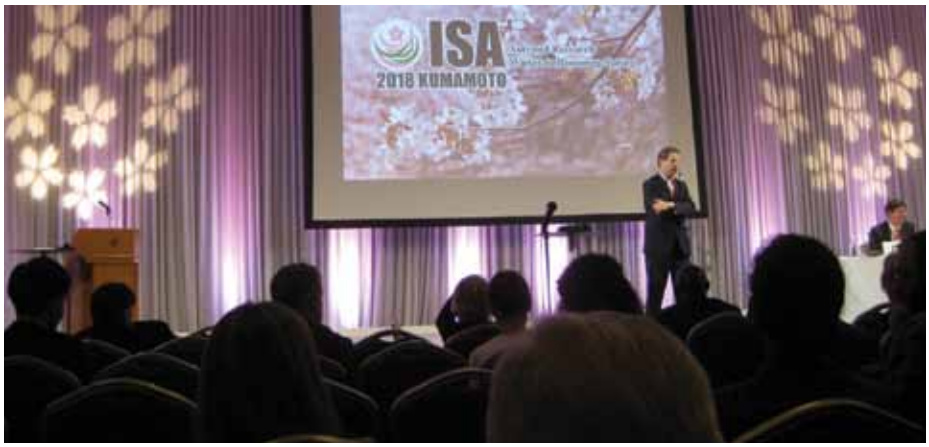
And finally:

*"Thanks everyone for your kind words and information."*

**To join the Amyloidosis Network on Facebook visit: facebook.com/groups/AMYLFA/**

# ISA 2018 REVIEW – RESEARCH LEADS TO BETTER UNDERSTANDING AND MORE EFFECTIVE TREATMENTS

Pat Neely, who was among the six Australians* and 760 delegates from 39 countries who attended the XVI International Amyloidosis Symposium in Japan, gives a brief overview.




**Early diagnosis is vital for best outcomes in all types of amyloidosis and this was emphasised by keynote speakers at the International Society of Amyloidosis' biannual research meeting, Amyloid Research - Winter to Blooming Spring, in March 2018.**

An online survey by the American Amyloid Research Consortium of patients (diagnosed with all types of cardiac amyloidosis) and carers, from the U.S., UK, Netherlands, Spain and France, showed 37% of patients were diagnosed more than a year after the onset of initial symptoms, with on average, three physician visits before a diagnosis was established.

### Understanding amyloidosis

Much progress has been made in understanding the multifaceted molecular mechanisms of the biochemically different systemic amyloidoses. But there is great variability, which is not understood, said Professor Per Westermark (Uppsala University, Sweden).

Advances in immunohistochemistry, immunoelectron microscopy, proteomics and genotyping have made the process of correctly diagnosing and typing easier. And diverse clinical serology and radiological tests have greatly improved staging and predicting prognosis.

Professor Christoph Rocken (Pathology Department, University of Kiel, Germany) commented that appropriate diagnosis and classification of amyloid can't rely on a single "one-fits-all assay" but rather on a step-wise diagnostic procedure, including appropriate histological assessment and consideration of clinical information and expertise.

Several papers and posters discussed new ways of providing prognostic information in AL amyloidosis through consideration of the depth of haematological and organ response.

### Advances in AL amyloidosis treatment

One of the keynote speakers, Professor Angela Dispenzieri (Mayo Clinic, U.S.), reminded the audience that prior to 1972 the outlook for AL patients was dire. Hopes were lifted with the introduction of melphalan and prednisolone but prognosis remained poor.

Stem cell transplants (SCT) were introduced in the U.S. in 1996. A Mayo Clinic report concluded that through experience, better assessment and selection of patients, new technology and improved drugs, mortality rates had declined substantially over the years, making SCT an effective therapy for highly selected patients, usually without cardiac involvement.

Melphalan and dexamethazone continue to be used but other treatments have come online, expanding choices and improving outcomes. These include the proteasome inhibitors (bortezomib, ixazomib, carfilzomib) and immunomodulatory drugs (thalidomide, lenalidomide, pomalidomide).

Treatment options remain limited, patients can now be offered different treatments at different times, as needed.

Novel drugs targeting the amyloid deposits in the body, now being developed to complement current cytotoxic anti-amyloid treatment, may hopefully revolutionise treatment.

### Novel therapies under investigation

Doxcycycline, an antibody, has been shown to disrupt amyloid fibrils. Adding doxycycline to chemotherapy is showing positive results in cardiac AL.

Daratumumab, an anti-plasma cell antibody, is showing promise in suppressing amyloidgenic light chains.

11-1F4, an amyloid fibril-reactive monoclonal antibody, is designed to target amyloid deposits by directly binding to a conformational epitope present on human light-chain amyloid fibrils.

Anti-Sap research, pairing the small molecule agent (miridesap) with the experimental anti-SAP monoclonal antibody (dezamizumab) to reduce or clear amyloid deposits from the body, has been put on hold.

Professor Giampaolo Merlini (University of Pavia, Italy) raised the fact that AL amyloidosis patients are fragile and highly sensitive to treatment and require a risk-adapted approach for the selection of the most effective and best tolerated anti-clone drugs and regimens. Early cardiac death remains a major unsolved problem.

### New drug trials for the ATTR diseases

Most significant advances since ISA 2016 were in the ATTR field, with a greater understanding of the pathogenesis of these diseases leading to new treatments.

Chemotherapy is not an option, and few treatments are available for Australians with ATTR with the exception of liver transplantation in hATTR.

Diflunisal, a nonsteroidal anti-inflammatory drug available in Australia, is shown to reduce progression in neurological impairment and improve quality of life in hATTR, and appears to slow or halt disease progression in hereditary and wild-type ATTR-CA.

Australian delegates met with the drug companies developing and trialling the new drugs, inotersen, partisiran and tafamidis, to discuss access for Australian patients.

With new treatments on the horizon, a need was expressed for the development of biomarkers to help determine patients' responses to therapy and learn more about the mechanism of these diseases.

** Professor Peter Mollee, Mrs Pat Neely (Brisbane), Professor Graeme Stewart, Dr Fiona Kwok (Sydney), Dr Simon Gibbs (Melbourne), Dr Noemi Howarth (Adelaide).*

# PAT'S JOURNEY WITH AMYLOIDOSIS

**Pat Neely has dedicated the best part of 20 years to amyloidosis, a disease she first encountered with her husband's diagnosis and subsequent death.**

Despite working as a medical social worker in many medical teams in Australia and the UK, Pat had never heard of amyloidosis, and her husband, Mervyn, a respected Brisbane surgeon didn't know much about amyloidosis either.

"So his diagnosis in 1998 was a steep learning curve for us both and our family," said Pat.

She and Mervyn had been preparing to travel to Canada, to attend a medical conference and going on to the UK to catch up with relatives, when his ankles began to swell. That symptom, and a troublesome dry cough, prompted him to consult a colleague.

No real health concerns were found after having many tests except slight left ventricular failure and he was encouraged to consult a cardiologist on his return to Australia, which he did.

A diagnosis of AL amyloidosis was quickly made following a heart biopsy and chemotherapy was started immediately. After one round, it was decided to proceed to stem cell collection and stem cell transplant. Sadly, following the stem cell collection, Mervyn suddenly died.

"My family and I were in complete shock as anyone is when a loved one suddenly dies," said Pat.

Although she returned to work – "what else could I do?"– Pat was troubled by many unanswered questions about her husband's treatment and the part she had played in his care.

"I will always be so grateful to Mervyn's cardiologist for giving my family and me the time to discuss these worrying questions."

"It was obvious when Mervyn died that many of his medical colleagues knew little about amyloidosis which was often misdiagnosed at that time," she said.

There were few treatments available and no Australian amyloidosis support services. Over the next few months Pat was encouraged by many of these doctors to consider using her medical social work skills to find ways to build amyloidosis patient support and education services and raise awareness across Australia.

"I realised I could not do this without understanding a little more about amyloidosis," said Pat, who then embarked on contacting the medical directors of the amyloidosis centres in America, and she travelled to the newly opened National Amyloidosis Centre in London.

"I was so grateful for the support and encouragement I received, and many of these doctors remain friends to this day."

At that time an American patient started an online 'list serve' service.

"I joined and learnt so much from the patients posting and gradually felt more confident in supporting and educating the Australian patients who were by then being referred to me."

During this time, Mervyn's cardiologist, Dr Liz Donnelly, Pat, and St Andrew's Hospital (Brisbane) designed a simple online teaching video. It was directed at cardiologists, with the message: 'if you see patients with the following symptoms, do you think of amyloidosis?'.

In 2002, the Leukaemia Foundation in Queensland had begun to offer accommodation to AL amyloidosis patients undergoing treatment. Pat was invited to present her ideas at a meeting with the Queensland CEO, the Director of Support Services and Professor Doug Joshua, Director of the Institute of Haematology, Royal Prince Alfred Hospital (Sydney).

This led to a further meeting between three Brisbane haematologists, a renal physician and cardiologist, the Leukaemia Foundation's national CEO and Pat to discuss how to progress amyloidosis services across Australia.

"Several goals were suggested that evening which over time have slowly been reached," said Pat.

These were:

- to form a collaborative group amongst medical professionals treating all types of amyloidosis in Australia,
- to invite an eminent overseas amyloidosis specialist to conduct workshops around Australia,
- to find a research project that would raise awareness about amyloidosis diagnosis and treatment across Australia, and
- to find ways to build support and education services across Australia.

Pat became the Leukaemia Foundation's volunteer amyloidosis support consultant in 2003, working across Australia with staff, patients and



# AUSSIES INVITED TO JOIN ATTR PATIENT GROUP

**Vince O'Donnell is reaching out to Australian patients living with hereditary ATTR amyloidosis (hATTR) or wild type ATTR (ATTRwt).**

This follows his attendance at a meeting of the newly formed international patient and family group, the Amyloidosis Alliance (AA), in Paris, last September.

The AA was formed at the 1st European ATTR meeting for doctors and patients in Paris in 2017 and is an initiative of patient groups in the Netherlands, France and Italy.

The aim of the AA is to become a global group representing amyloidosis patients and families, and Vince was selected to represent Australian patients at this year's meeting.

"I am extremely grateful to have been given the opportunity to attend this meeting," said Vince, who was nominated by Ellen Reid, the founder of Amyloidosis Australia (**amyloidosis.com.au**) and sponsored to attend the meeting by Pfizer.

Vince was among representatives from amyloidosis patient groups from 20 countries (Argentina, Brazil, Bulgaria, Cyprus, France, Germany, Israel, Italy, Japan, Mexico, Netherlands, Poland, Portugal, Russia, Spain, Sweden, UK, U.S. and Venezuela).

"It was a very full one-day conference," said Vince.

"The final pledge was that the AA focus on awareness/diagnosis, treatment, research, communication and advocacy, and that initial efforts be concentrated on Amyloid Transthyretin (ATTR) which includes the hereditary and wild types.

At the Paris meeting, Vince networked with participants to develop links and relationships and now he's working on strengthening and developing opportunities for Australians living with ATTR and their carers.

"I am keen to start a conversation with Australian patients about how we proceed from here," said Vince.

**To get involved, contact Vince by email: vnt1955@icloud.com**

Read Vince's experience with amyloidosis on page 8.

doctors to build the greatly needed services.

"Although amyloidosis is not related to leukaemia, I was grateful to the Foundation for recognising the needs of patients and families, supporting me and giving me office space and a phone," said Pat.

Haematologist, Dr Peter Mollee, who is now Director of the Princess Alexandra Hospital (PAH) Amyloidosis Centre, had returned from Canada in 2003 and expressed his interest in amyloidosis.

He set up the PAH Amyloidosis Clinic, now a busy amyloidosis centre, and in 2008, was chief investigator of the first treatment trial for AL amyloidosis patients in Australia. The MM8 trial was run through the Australasian Leukaemia & Lymphoma Group and the Leukaemia Foundation provided funding.

"This trial certainly helped to raise awareness," said Pat, who conducted the psychosocial arm of this trial.

She interviewed patients and their partners at diagnosis and six months later, to learn how they had gained information about their disease, what information they would like to have received, and whether a better understanding of their disease had helped with their overall emotional state.

Pat has presented her research findings at international amyloidosis meetings and much of this information was used when Pat researched and compiled, with the help of doctors and patients, the content for the Leukaemia Foundation booklet, *Understanding Amyloidosis*. First published in 2010, it has been reviewed and updated twice, and is still widely used around Australia.

In 2005, the Leukaemia Foundation offered to partly fund a visit by the Medical Director of London's National Amyloidosis Centre, Professor Philip Hawkins, and Pat undertook to raise $10,000 towards Professor Hawkins' fares. Professor Hawkins and Pat spoke at workshops for doctors and patients in Brisbane, Sydney, Melbourne and Adelaide.

"His visit certainly put amyloidosis on the Australian medical map," said Pat.

At that time patient support services were starting up in America, and the Reid family launched the website, Amyloidosis Australia, which has helped many patients.

"We all knew each other and shared ideas," said Pat, whose consultancy role within the Leukaemia Foundation slowly developed across Australia.

She worked directly with patients, often by phone, and educated staff about amyloidosis. Support and education meetings for patients were started in several capital cities and Pat travelled at her own expense to speak at these, and to meet patients.

Pat started this publication, *Amyloidosis News*, in 2007. She worked closely with Leukaemia Foundation staff and an advisory group of patients, finding and reviewing useful articles and patient stories.

After the Leukaemia Foundation appointed a paid amyloidosis coordinator, in 2012, Pat was invited by Dr Peter Mollee to join his amyloidosis team at the PAH as honorary amyloidosis support and education officer.

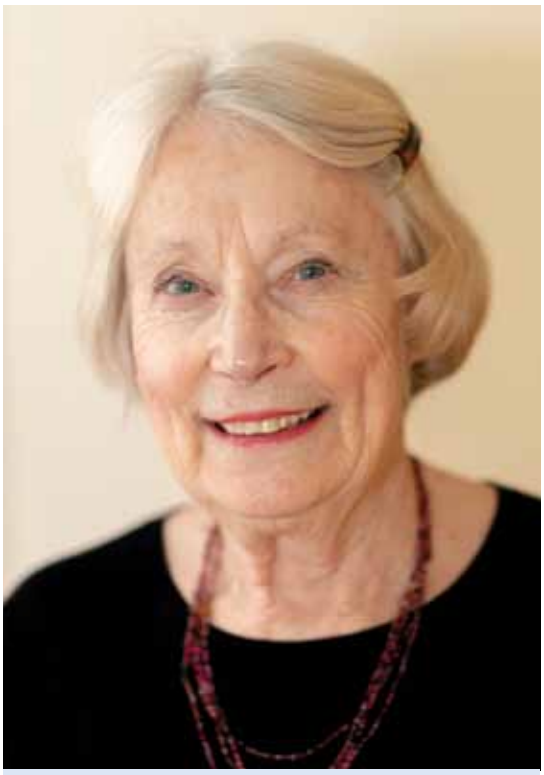
During her five years in this role, Pat saw all new patients and offered ongoing support and education as needed. She also worked closely with the PAH Research Foundation, amyloidosis patients and families, arranging education and awareness events and raising money for amyloidosis research.

"As part of the PAH team, I learnt so much more about the treatment of this devastating group of diseases," said Pat.

And by listening to patient's stories, she learnt how important good supportive care is for quality of life, as they live with the overwhelming symptoms caused by the deposition of the amyloid protein in the organs.

Pat is an inaugural member of the Australian Amyloidosis Network (AAN) – a group of doctors and health professionals from the Australian Amyloidosis Centres in Brisbane, Sydney, Melbourne and Perth, and other amyloidosis specialists, dedicated to improving diagnosis, treatment, support and education for patients with all types of amyloidosis. Pat proudly represents and advocates for patients on this body. She passionately believes in patient participation in treatment decisions.

Pat was on the AAN organising committee and presented at the 2017 series of workshops for doctors, patients and families in Sydney, Melbourne and Brisbane. And she is on the organising committee for the 2019 workshops, to be held in five capital cities in May. *(See page 8.)*



*Pat Neely has volunteered 20 years of service to amyloidosis awareness, patient support and education.*

Pat is also working with haematologist, Dr Fiona Kwok, from the Westmead Amyloidosis Centre, compiling content for the AAN website, due to go live early this year.

A member of the International Society of Amyloidosis, Pat has attended all the international symposia on amyloidosis since 2004 and has been consulted about building support services in Europe and America.

Pat is blessed with boundless energy and is curious by nature. During her long professional career, she has served on numerous medical committees and boards while working full-time, much of this as director of a busy social work department.

She has many interests including music and ballet, has many friends, cares for a large garden, and enjoys a very close relationship with her three children, their partners and her six grandchildren.

**The Leukaemia Foundation acknowledges and thanks Pat for her efforts and personal contribution in raising awareness of amyloidosis in Australia, support for those living with amyloidosis and ensuring best outcomes for those yet to be diagnosed.**

# CONTINUED: BILL TELLS HIS STORY OF HAVING AMYLOIDOSIS IN VERSE

"I had amyloidosis pretty badly by the time I was diagnosed," said Bill, and his initial reaction was "let's get on with it", and Joy, his wife of 52 years, felt the same way.

"What can we do but make the most of it and the beauty is... the sun still comes up."

Chemotherapy reduced Bill's light chains from 2500+ to 400, and his stem cells were collected and stored in early-2012.

Then he had further cycles of more intense chemo, but to little effect. Bill's light chains started rising again and when they reached 800 he was told he had 18 months to live unless he had a stem cell transplant.

*I was absolutely devastated when this news was told! What was there left to do? What would the future hold? (2012)*

"Age wasn't a concern... I'd looked after myself pretty well and hadn't smoked, but the haematologist was worried I wouldn't get through it," he said.

"She decided to go ahead and give the transplant a go. I didn't get the full amount of chemo because they didn't think I could stand it."

*I gathered my resources to improve my quest to live, I knew a positive approach would be imperative! (2012)*

Bill was 69 when he had the transplant in Hobart in September 2012.

"It's been good, it stabilised everything, but since then, little things keep falling apart. You're not out of the woods, but you survive.

*Issues continue to raise their head, Wherever the Amyloid path has lead. (2016)*

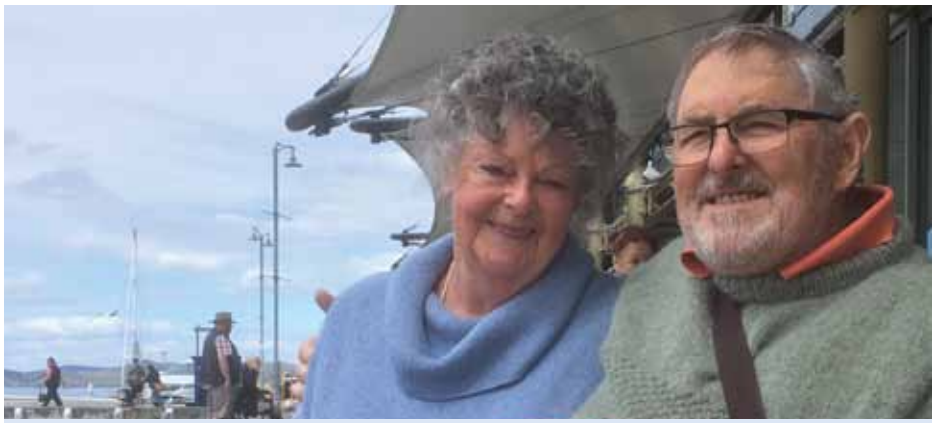
"The chemo destroyed my teeth, so I've had to have dentures in the last two years.

"The amyloid lodged in my bladder, so I have a suprapubic catheter because my bladder isn't flexible anymore.

"The muscles and nerves in my lower legs are not good, so I use forearm crutches for balance.

"And my left knee had disintegrated and I've just had that replaced," he explained.

"My immune system has been impaired, so every month I have immunoglobulins, which is the only major treatment I have now."



*Joy and Bill Edmunds on the docks in Hobart last November after his recovery from knee replacement surgery.*

*Joy was always there for me each minute of each day, Her support was never ending in so many varied ways. (2012)*

Bill's light chains are in the normal range (fluctuating from the mid-20s to 32) and he is monitored with a blood test every three months "in case the Waldenström's rears its head or the amyloidosis takes hold again".

"The Waldenström's is still there but I'm not treated for that," he said.

"The transplant stablised the amyloidosis but they won't say I'm in remission. It could come back at any time, so I make the most of each day.

"It does impact on my life and Joy's," said Bill.

"She's basically given up her life and interests for the last nearly 10 years that I have been on this journey."

*The effect on Joy was rather tough, her life on hold for me, As chauffeur, carer and a wife, Joy would share my destiny. (2011)*

A couple of years after getting amyloidosis, Bill and Joy went to the Leukaemia Foundation's general support group meetings in Hobart.

"Just listening to the experience of others, specialists giving advice, and information about various things like diet, diagnosis and difficulties associated with chemotherapy was fantastic," said Bill.

*The Leukaemia Foundation through its meetings of support, Helped us know and understand, the info that we sought. (2014)*

This year Bill has spent nearly two months in hospital.

He had a chest infection in April-May "that was pretty bad for nearly a fortnight". Having a hernia repaired "took an extra couple of days because I'm slow in healing", and he was in hospital for a month for knee replacement surgery and rehabilitation in October.

Fatigue and peripheral neuropathy are ongoing symptoms that Bill deals with on a daily basis.

*Three years since the transplant, gave extended time, The effects of the amyloid, continued their climb. (2015)*

Bill continues to diarise the ups and downs of his ongoing experience with amyloidosis in what he describes as "doggerel verse".

"It doesn't fit the rhymes and metres of traditional poetry very well but it tells a good story," he said.

"With the amyloidosis, I get very fatigued, so I don't write as often as I would like. It's my goal to write more but I don't seem to be able to get in that free and easy mood. I just feel tired a lot."

When *Amyloidosis News* spoke to Bill, he and Joy were heading off in their caravan to spend a couple of weeks at "a beautiful little seaside town" in north-east Tasmania.

"Some of our friends are joining us as well and that is a bonus.

"The plan is to give Joy a change of scene because she has been running around after me for the last six weeks".

*By changing to an auto, driving became a breeze, I could still tow the caravan, accomplished with ease. (2013)*

**Bill's reflections about his life's experiences on amyloidosis and much more can be read on his website: billedmunds.com**

# BLOOD BUDDIES ENJOY THE CHANCE TO SHARE EXPERIENCES

**Blood Buddies Alan Friedman and Tony Collins have had vastly different amyloidosis journeys but they value each other's perspective on their difficult diagnosis and treatment experiences.**

Alan, from Perth, and Tony, from Adelaide, both 60, have been Blood Buddies since mid-2018.

"Alan is actually my second buddy," said Tony.

"I really enjoy the program and want to give others going through the disease a sense of hope, which I think is often absent when receiving an amyloidosis diagnosis."

Tony was diagnosed in 2010 with AL amyloidosis, which mainly affected his heart and lungs. He's now eight years down the track and his disease has stabilised, with very few side-effects.

"I remember how difficult those early days were. You're often given the worst case scenario and the rarity of the disease means there's not a huge deal of information available," said Tony.

"I wanted to know everything about amyloidosis so I went to all the Leukaemia Foundation education seminars and read *Amyloidosis News* which is where I found out about Blood Buddies."

The phone-based peer support program matches and connects those diagnosed with a particular blood cancer with a trained volunteer who has the same diagnosis. The aim is to offer reassurance, support, encouragement and hope.

"At the beginning, the conversation centres a lot on the disease; how you were diagnosed and the treatment path you go on. Eventually you start speaking about life in general and how you manage everyday things," said Tony.

Alan received a double whammy diagnosis of myeloma and AL amyloidosis affecting his kidneys in November 2014.

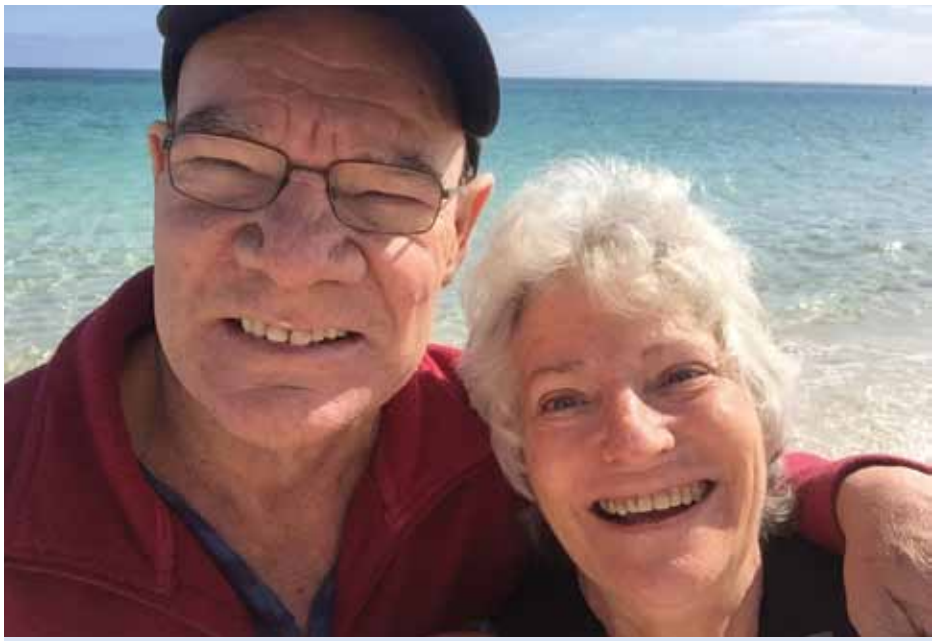
"I was visiting my daughter in Tasmania and felt unwell the whole trip. I had some blood tests when I got back to Perth and within a couple days was told I had three months to live," said Alan.

"I started treatment immediately and 12 months in I was put on dialysis to manage my kidney failure. I've been on dialysis for three years now, which has kept me going."

Alan joined the Blood Buddies program after he and his wife, Maxine attended a Leukaemia Foundation Cooking for Chemo event.

"The Leukaemia Foundation support coordinator encouraged me to sign up for the program after we got chatting at the event," said Alan.

"Blood Buddies was perfect for me because the Perth support group often meets on a day I'm getting dialysis, so I can't make it.



*Alan Friedman and his wife, Maxine, on holiday at Busselton last November.*

*Blood Buddy, Tony Collins.*

"I would never have been able to connect with another amyloidosis patient if it wasn't for the program.

"Tony and I have had completely different journeys, he is quite well and has been able to get back into work. That won't be possible for me with my kidneys basically gone.

"It's quite interesting to see how the same disease can have such a different impact for each of us.

"I've also enjoyed the social aspect of our chats as we're the same age and getting to know someone from a different state is always nice.

"I'd recommend this program to anyone who can't easily access the amyloidosis community – it makes you feel like you're not going it alone," said Alan.



### WE'RE LOOKING FOR AMYLOIDOSIS BLOOD BUDDIES

If you're interested in using your personal amyloidosis experience to help others through their journey, please consider signing up as one of our volunteer Buddies. Volunteers can be a patient or anyone who has cared for a person with amyloidosis.

Would you make a good Buddy?

- You have a balanced and positive (yet realistic) attitude towards treatment and outcomes.
- You have a non-judgemental and respectful attitude to people's differing values and cultures.
- You have excellent communication and listening skills.
- You display warmth, sensitivity and flexibility.

Blood Buddy volunteers adhere to all Leukaemia Foundation policies and procedures including of the Blood Buddies program guidelines.

**For more information about the Blood Buddies peer support program and to register your interest in becoming a Buddy or being matched with a Buddy, email: bloodbuddies@leukaemia.org.au or call 1800 007 343.**

# WHAT'S ON NEAR YOU

| NEW SOUTH WALES | | |
|---|---|---|
| **Sydney Metro** | | |
| 8 May | | Australian Amyloidosis Network biennial touring workshop for health professionals and patients |
| **QUEENSLAND** | | |
| **Brisbane Metro** | | |
| 20 Feb | 11.30am-2pm | Amyloidosis luncheon, ESA Village |
| 11 May | | Australian Amyloidosis Network biennial touring workshop for health professionals and patients |
| **Regional Queensland** | | |
| 5 Feb | 10am-12pm | Coffee, Cake & Chat, Mackay |
| **SOUTH AUSTRALIA** | | |
| **Adelaide Metro** | | |
| 14 Feb | 10am-12pm | Amyloidosis/MPN/MDS Support Group (also 11 Apr, 13 Jun, 8 Aug, 10 Oct) |
| 20 Feb | 10am-12pm | Northern Adelaide Support Group (also 17 Apr, 19 Jun, 21 Aug, 16 Oct) |
| 5 May | | Australian Amyloidosis Network biennial touring workshop for health professionals and patients |

| SOUTH AUSTRALIA *(continued)* | | |
|---|---|---|
| **Regional South Australia** | | |
| 13 Feb | 10am-12pm | Port Lincoln Support Group |
| **VICTORIA** | | |
| **Melbourne Metro** | | |
| 4 May | | Australian Amyloidosis Network biennial touring workshop for health professionals and patients |
| **WESTERN AUSTRALIA** | | |
| **Perth Metro** | | |
| 14 May | | Australian Amyloidosis Network biennial touring workshop for health professionals and patients |
| **Bunbury** | | |
| 7 Feb | 10.30am-12pm | Bunbury Blood Cancer Support Group (also 4 Apr, 6 Jun) |
| **Peel** | | |
| 21 Feb | 10.30am-12pm | Peel Blood Cancer Support Group (also Mar 21) |

**The 2019 Education and Support Program Event Calendar (including Australian Capital Territory, Northern Territory, Tasmania and myeloma events) will be available soon on our website: leukaemia.org.au**

| AUSTRALIAN AMYLOIDOSIS NETWORK |
|---|
| **Victorian and Tasmanian Amyloidosis Service, Melbourne** |
| Weekly Monday morning clinic at Box Hill Hospital<br>Fortnightly multi-disciplinary team meeting with cardiologists, neurologists, nephrologists, radiologists, histopathologists, haematologists and gastroenterologists |
| Contact/referrals: simon.gibbs@monash.edu Masa.Lasica@monash.edu 1300 342 255 |
| **Westmead Amyloidosis Clinic, Sydney** |
| Monthly Friday morning clinic at Westmead Hospital<br>Clinic attended by haematologists, immunologists and neurologists, with support from cardiologists, rheumatologists and nephrologists. Provides genetic testing for hereditary amyloidosis |
| Contact/referrals: elizabeth.galea@health.nsw.gov.au 02 9845 8738 |
| **Princess Alexandra Hospital Amyloidosis Centre, Brisbane** |
| Fortnightly Friday afternoon clinic at Princess Alexandra Hospital<br>Clinic staffed by a team of health professionals including cardiologists, haematologists, neurologists, renal physicians, pathologists, specialised nurses and social workers |
| Contact/referrals: Amyloidosis@health.qld.gov.au 07 3176 5772 |

# EARLY DIAGNOSIS KEY FOR VINCE

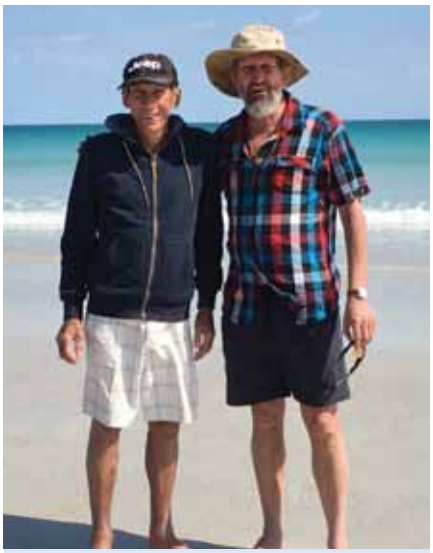
**One week before his brother's formal diagnosis with amyloidosis in 2014, Vince O'Donnell discovered he carried genes that predisposed him to familial amyloid polyneuropathy (FAP) and familial amyloid cardiomyopathy (FAC).**

Both conditions were in the report Vince received from a genetic company he sent saliva samples to, to find out about his health and heritage.

"Looking back, hindsight tells us our dad and grandmother had the amyloidosis gene," said Vince, 63, of Queensland.

Within weeks of each other, Vince and his brother Laurie* were both formally diagnosed with FAP and FAC, but Vince's diagnosis was early.

Given his prognosis was seven years and he was 59, Vince "had some harsh decisions to make".



*Laurie and Vince O'Donnell at Broome in mid-2016.*

So, he and his wife, Terri retired, sold their Brisbane home, bought a caravan, and have since travelled extensively.

"I know it [amyloidosis] is affecting me but I know I have a fair way to go yet," said Vince, who sees his amyloidosis haematologist twice a year, his heart specialist on an annual basis, and is treated with diflusinal.

"A combination of things has helped me get to where I am now. Retirement is one. Not going to work every day means less stress. Also, early medication, good family support and a good diet," he said.

** Laurie O'Donnell died in November 2017, three years after his diagnosis. Vince and Laurie's other sibling, Steve, does not carry the genes for FAP and FAC (County Donegal strain).*



**Join the Amyloidosis Network closed group on Facebook: facebook.com/groups/AMYLFA/**
**Visit leukaemia.org.au for our latest Education and Support Program Event Calendar.**
**To register for an education or support event, freecall 1800 620 420 or email info@leukaemia.org.au**

Leukaemia Foundation
VISION TO CURE
MISSION TO CARE

## CONTACT US

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