



AMAA QUARTERLY NEWS

ASEA INTERNATIONAL ASBESTOS CONFERENCE

AMAA representatives report back on the success of the 2nd Annual Asbestos Safety and Eradication Agency Conference held in November 2015.

Page 5



AMAA Officially Opens Asbestos Community Outreach Centre

The official opening of the AMAA Asbestos Community Outreach Centre was held on Wednesday 25 November 2015 as part of Asbestos Awareness Week 2015. The Centre will act as a hub for the Gold Coast, Tweed and Northern Rivers regions offering information, support and assistance to sufferers of asbestos related diseases and their family and friends.

AMAA Ambassador, Mr Bob Hendricks, proudly officiated the proceedings including the ribbon cutting by guests of honour, Mr Peter Tighe, CEO of the Asbestos Agency, and Professor Nico van Zandwijk, the CEO of the Asbestos Diseases Research Institute (ADRI) who each gave presentations on the role of asbestos awareness and the advances in the treatment of asbestos related diseases.

Continued on Page 4

In this Edition

- Page 2 Life Memberships; AMAA Meeting Details; Member Profile.
- Page 3 Call to Action – Keytruda treatment
- Page 4 AMAA Asbestos Community Outreach Centre Opening
- Page 5 ASEA Conference; AMAA Year in Review.
- Page 6 Christmas Fun 2016; AMAA Raffle Results
- Page 7 Support for Members; AMAA Contact Details

"AMAA offers a network of friendship, support and hope to patients with asbestos related disease, their families and friends"

AMAA Life Memberships

For the first time in our ten-year history, AMAA has awarded lifetime memberships as a way of commemorating the tireless dedication and support of key AMAA members – Nic and Jenny Bos and long serving AMAA Patron Professor Nico van Zandwijk.

Mr Peter Tighe, ASEA CEO, presented plaques honouring these special members at the official opening of the AMAA Asbestos Community Outreach Centre.

The members resolved that the work of these three members was noteworthy. Prof Nico’s work has been fundamental in enhancing the medical understanding of asbestos diseases. Nic and Jenny Bos have tirelessly given to AMAA since forming the group nearly a decade ago and they have helped educate the broader Australian community of the dangers of asbestos.

Congratulations Professor Nico, Nick and Jenny! The AMAA members salute your efforts!



GROUP MEETING DATES

AMAA Members and friends meet on the **FIRST WEDNESDAY** of each month at Seagulls Club. Come join us!

10.30 am (NSW Time)

Gather at Mangrove Restaurant for coffee or tea.

11.00 am

Meeting - Pelican Room.

3 February

2 March

6 April

3 May

1 June

6 July

4 August

7 September

5 October

2 November

7 December (Christmas Lunch)



AMAA Member Profile: The Noordman Family

We are proud to share with you a photo of our members from the Netherlands, Maarten and Jikkemien Noordman.

Jikkemien was diagnosed with Mesothelioma and has been treated with Keytruda. Jikkemien lived

HOPE FOR ASBESTOS CANCER: KEYTRUDA

A new immunotherapy drug called Keytruda (scientifically known as Pembrolizumab or MK-3475) is demonstrating positive outcomes for asbestos cancer (mesothelioma) patients.

Keytruda is not listed on the Pharmaceutical Benefits Scheme (PBS) for mesothelioma in Australia so asbestos cancer patients must pay for this potentially life saving drug themselves.

Every year in Australia, **200 people die from asbestos cancer** (mesothelioma) and another 600 people are diagnosed each year with the deadly disease. For the average Australian battling asbestos cancer the average survival is **only 9-12 months (less than 10% chance of surviving more than 5 years after diagnosis)**.

Currently, publically funded treatments for mesothelioma include surgery, radiotherapy and chemotherapy. But, there are now scientific and medical treatment advances that greatly improve patient quality of life and survival.

This cost is crippling families and many patients don't have the money to pursue this potentially life saving option. Many patients simply cannot work due to their condition and to face astounding medical bills and treatment costs is too much for bear. Asbestos cancer patients need access now or will continue to die waiting for fair access to life saving treatment!

UNTIL KEYTRUDA IS PBS LISTED, ASBESTOS CANCER PATIENTS WILL PAY THOUSANDS OF DOLLARS FOR THE



“There is hope for asbestos cancer”

HOW CAN YOU HELP?

- **BECOME A MEMBER** of Asbestos and Mesothelioma Association of Australia (AMAA) today so we can continue to lobby for asbestos cancer patients.
- **COMPLETE THE AMAA PETITION** with your family, friends and colleagues.
- **MEET WITH YOUR LOCAL FEDERAL MEMBER** and demand change!
- **WRITE TO FEDERAL HEALTH MINISTER HON. SUSSAN LEY** to share your story and ask what she is doing to make positive change for Australian families dealing with asbestos cancer.

Continued from page 1

Mr Stuart Burrows, General Manager of Seagulls, formerly welcomed AMAA to the Seagulls complex and highlighted the Club's commitment to ensuring the ongoing success of the relationship between AMAA and the Seagulls team. He noted that it was important to Seagulls that they continue to engage their members with community initiatives and the services and facilities offered by AMAA were to be of great benefit to their 15,000+ membership. AMAA are equally proud to be joining the Seagulls community and take this opportunity to again thank the management, staff and members for the welcome we have received.

The climax of the proceedings was the handing over of a \$12,500.00 cheque to Prof. van Zandwijk for mesothelioma research. With the help of some very generous members and supporters AMAA has donated almost \$14,000.00 to ADRI this year alone.

AMAA was proud to have not only our members and special guests in attendance at this momentous occasion, but also representatives from unions, industry and community representatives. There were in excess of 75 people present on the day and those who sent their apologies due to ill health were honoured with a Minute Silence as a way of extending support and friendship.

The ceremony is the most significant development since AMAA (formerly AMSG) was first established in 2006 almost ten years ago. Formerly known as the Asbestosis and Mesothelioma Support Group (AMSG), AMAA has grown in size and scope to validate the need for this important service.



Left: Peter Tighe, CEO ASEA, praises the role of AMAA.

Above: Prof. van Zandwijk accepts research funds from Nick Bos.

The Centre is located in the Seagulls Club Complex, Gollan Drive, Tweed Heads West, New South Wales. There is ample free parking onsite and the office is wheelchair accessible. The office will be staffed entirely by unpaid AMAA volunteers.

Asbestos Safety and Eradication Agency

International Conference on Asbestos

Awareness & Management 2015

Asbestos advocates, patients, researchers, physicians, union and industry representatives from around the world, converged in Brisbane for two days in November at the 2nd Annual International Asbestos Conference hosted by ASEA.

Keynote speakers gave presentations on asbestos awareness, management and best practice in dealing with asbestos. There were moving patient stories shared highlighting the devastating impact of asbestos related diseases on everyday Australians. There were wonderful insights into medical research being undertaken to treat asbestos cancer and ADFA Advocate Lou Williams shared her experience receiving Keytruda.

AMAA volunteers, Nick and Jenny Bos, Michaela Carr and Kimberley Crawford and Tilly Ryan represented AMAA at the event. Our stall was well attended and we were able to distribute AMAA resources to the 360 delegates. The Gala Dinner was also a conference highlight with lots of fun and networking.

The members of AMAA extend gratitude to ASEA for their support of AMAA's attendance and participation at this important annual event.

For more information about the conference, including guest speaker notes, please visit the ASEA website:

www.asbestossafety.gov.au

Or contact ASEA on their NEW telephone number 1300 326 148. The latest ASEA newsletter, *Asbestos Matters*, is also available online.

AMAA Highlights - 2015

The past 12 months have been productive for AMAA as we have grown and evolved in size and scope. We came together as a community to host memorable events and participate in asbestos initiatives including:

Fadden Seniors & Carers Expo

Parliament House Luncheon, Canberra

Patient Roundtable – Access to Medicines, Sydney

AMAA Memorial Service, Kirra

ADFA Race Day 2015

RCA Gala Dinner, Melbourne

The membership of AMAA grew greatly in 2015 and we were delighted to celebrate achieving over 100 active members.

Our continued success would not be possible without the support of our members, volunteers, generous donors and sponsors.

We thank you all for your ongoing kindness.



DID YOU KNOW?

ASEA was established in July 2013 to provide a national focus to issues relating to asbestos including asbestos management, awareness and safety initiatives. ASEA is internationally recognized as the leading agency in driving change in asbestos

It's the most wonderful time of the year!
AMAA Members Celebrate Christmas 2015

The highlight of the 2015 AMAA events calendar this year was without doubt our highly enjoyable annual Christmas celebration. This year over 40 members and guests came together to enjoy lunch and frivolity at the Currumbin RSL. The location was idyllic and set the scene for a wonderful afternoon of fun!

Members were asked to dress in their Christmas best and a lot of crazy wigs appeared throughout the afternoon. Awards recognizing the best dressed were given – it was a very hard decision for the impartial judge!

Mother Christmas (Joy Pomfrett) gave out secret Santa gifts and some of our members were awarded with certificates of appreciation for their services to AMAA in 2015. The AMAA Raffle Prizes were drawn – another successful fundraiser for ADRI research into asbestos diseases.



Congratulations to the four lucky raffle prize winners drawn at the Christmas function:

1st Prize: Kevin Bell (Ticket 0730)
 2nd Prize: Kath Thorburn (Ticket 1304)
 3rd Prize: Beryl Hughes (Ticket 0436)
 4th Prize: Mary Flessler (Ticket 0310)

AMAA member Judy Garretty won the \$50.00 Cheese Cake Shop voucher for selling the most

AMAA Members Celebrate (clockwise from top):
 Robyn Schatz;
 Joy & Wade Pomfret;
 and, Michaela Carr.

AMAA Support Service: a free program for you

AMAA is pleased to be able to offer members and friends access to support from our Member Support Officer, Joy Maguire.

Joy is a qualified Social Worker with extensive experience in offering support and assistance to people dealing with significant life change. She personally understands the challenges of asbestos related diseases, particularly mesothelioma, and is available to speak to you and/or your family/friends if you require.

Initially, Joy will be available to speak with you over the phone or meet with you in our office by appointment. At this stage, she will be available one day per week so make sure you book your time ASAP.

To organize an appointment with Joy please contact our office on 1800 017 758.



"Never feel you are alone.

AMAA offers you and your family a hand of hope."



Postal: PO Box 1178 Tweed Heads NSW 2485

Telephone: 1800 017 758

After Hours: 0417 705 534

Email: info@asbestosassociation.com.au

The Asbestosis and Mesothelioma Association of Australia is a registered charity and donations of \$2.00 or more are tax deductible.

Please consider supporting us in our efforts to offer support to asbestos patients and advocate for justice and better care.

ACN: 602 979 000

www.asbestosassociation.com.au

AMAA ASBESTOS COMMUNITY OUTREACH CENTRE

Open Monday to Friday (excl. Public Holidays)

10.00am to 2.00pm (NSW time)

Seagulls Club, Gollan Drive, Tweed Heads West, New South Wales 2485

Proudly supported by Seagulls Club and funded with the support of ASEA.

Offering free information, support, and friendship. It's your place!