

15 June 2018



OVER 35 YEARS OF CARE AND SERVICE TO THE COMMUNITY

Dear Members and Friends

Greeting to you all and I hope you will weather successfully this Winter Season. Also, it gives me great pleasure to announce in brief the forthcoming events for this calendar year 2018 (more information in the Spring Newsletter).

Asbestos Awareness Week 19 November to 23 November 2018 As always, the purpose of the Asbestos Awareness Week is to provide to the community at large information on risks associated with asbestos which is still in situ in many homes and industrial utilities. In addition, there will be more information available on the current medical research associated with available treatments for malignant mesothelioma. More detailed information of our activities will be available in our Spring Newsletter.

Ecumenical Memorial Service 2018 for those who have died from asbestos caused diseases will be held on Friday 23rd November 2018 at the Redemptorist Monastery on Vincent Street, North Perth, at 9:30am. The **Memorial Photograph Presentation** of our passed members will be available again, so anyone wishing to include a photo, please send by email to reception@asbestosdiseases.org.au or call 1800 646 690 for other options.

ADSA Christmas Picnic 2018 Sunday 2nd December 2018 Please save the date for Sunday 2nd of December to attend the ADSA Christmas Picnic at Whiteman Park. As in previous years, the roast lunch will be provided by our gourmet chef Randall and entertainment by Rhythm n Groove band, Father Christmas and Kids in Sport for the junior brigade.

1. **ASBESTOS COMPENSATION BILL 2013 Provisional Damages & Benefits to Disabled Relatives**

As previously mentioned in numerous newsletters since 2013, this particular Legislation seems to be heading nowhere. The Hon. John Quigley, Attorney General, visited our office as a part of the Community Cabinet Program on Monday 28th May this year. To our understanding, the 2013 Bill was sent to the Insurance Commission of Western Australia (ICWA) for assessment of the likely liability to ICWA which may directly affect the State of Western Australia. The former liberal government Attorney General the Hon. Michael Mischin used clever tactics to frustrate the 2013 Bill and some 18 months ago he told me that the Bill was sent to ICWA for assessment of liability to Government. Our organisation has over the years experienced appalling disregard by ICWA and in particular offensive innuendos about asbestos diseases victims and their families. ICWA has written many letters over the years to State Governments about how our organisation is continuing to financially damage ICWA through ADSA members receiving compensation for "non-existing" asbestos conditions. One of the letters in our possession states that some of the 500 workers who allegedly were seeking damages for asbestos conditions which many simply did not have. Amongst other things they have recommended to Governments that the Workers Compensation Act should be amended as follows: (1) That the determination of the Pneumoconiosis Medical Panel within the Worker's Compensation Act no longer be binding upon the parties; (2) all existing determinations of the Pneumoconiosis Medical Panel can be reassessed and compensation adjusted accordingly; (3) any disputes should be decided by the Worker's Compensation Board. The Amendments should be initiated urgently and before any of the actions currently before the Courts are decided so that they are not seen as a response to any particular decision. ICWA also have impugned by inference the Medical Panel of wrongdoing and amongst other things recommended consideration to provide specific legislative protection to the Medical Panel Members against negligence actions (Surely our West Australian doctors are beyond reproach and inference of wrongdoing of the Medical Panel should have brought charges against misguided officers of ICWA). Therefore, our organisation has no confidence that ICWA will provide information at arm's length review of the actual liability to the State of Western Australia. I also had the opportunity to mention to Hon. John Quigley, Attorney General, during our visit, that the likely liability to the State will be in the vicinity of around 5% or less should the current compensation bill be legislated. Also I mentioned that the majority of the compensation claims will be with James Hardie (some 75%), and the other 20% to various entities other than ICWA.

ADSA members would be most grateful to Hon. John Quigley Attorney General for his consideration to allow the Executive Officer and President of the ADSA to peruse the report from ICWA on a very confidential basis.



2. THE RISKS ASSOCIATED WITH ASBESTOS

Asbestos cement products were widely used within the Australian community as building materials. Technically speaking, asbestos cements products are fibre bound materials of asbestos and cement with excellent mechanical and construction properties. Those asbestos products were useful as flat or corrugated plates (asbestos sheets) with or without another layer for cladding of facades and roofs with asbestos component of some 15-20%. Also cement pipes with asbestos components usually contain 20-30% crocidolite and amosite (blue and grey asbestos) fibres. Biological impact of asbestos dust seems to be well spread over the years throughout the Australian community. The reason being the process of weathering and erosion of asbestos products takes place with the passage of time (usually asbestos products subject to commencement of weathering to release asbestos fibres after 17 years of use as fencing, roofing and other uses). Therefore one has to consider how much asbestos we still have in the community around Australia which is polluting our homes and environment. Conservatively speaking there are at present some two million Australians who had sufficient exposure to be at risk to develop asbestos diseases such as Mesothelioma, Lung Cancer and other non-malignant diseases. Over the last several years there has been an enormous phenomena to renovate old asbestos houses or to remove asbestos fences and some outbuildings such as sheds or cubby-houses. It would appear that some of the do-it-yourself and registered builders are failing to embrace safety precautionary measures to prevent the release of asbestos fibres into the environment. It would appear such investigations are not a priority of local Government Authorities. **Since it is virtually impossible to remove all carcinogenic asbestos fibres which are now contaminating our environment on a daily basis. For this reason the intervention of our Federal Government is most urgently needed to substantially fund lifesaving mesothelioma research. Regrettably, Federal Governments thus far have totally ignored the plight of asbestos victims which are dying in large numbers annually.** Western Australia in particular is the Capital of mesothelioma patients, per capita of population. Notwithstanding the scourge of asbestos diseases, Western Australia is particularly well placed to provide remedies to the victims of asbestos diseases through research which is recognized throughout the medical community worldwide. It would be greatly appreciated that our members and friends reading this newsletter also read Professor Anna Nowak's update on mesothelioma research.

3. PROFESSOR ANNA NOWAK - LATEST UPDATE ON MESOTHELIOMA RESEARCH

It has been a very busy few weeks for the National Centre for Asbestos Related Diseases (NCARD) team and for me in particular, as I have attended two international cancer conferences and presented the first results of the DREAM clinical trial at both. In early May I attended the International Mesothelioma Interest Group (iMig) meeting in Ottawa, Canada. I was privileged to be asked to give a talk on "Immuno-oncology – beyond PD-1". This cryptic title refers to the increasing interest around use of a group of treatments which release the brakes on the immune system, called 'PD-1 blockade' or 'checkpoint blockade' treatments. Treatments such as pembrolizumab (Keytruda) and durvalumab (tested in the DREAM study) belong to this family. However, although these medications can be effective in some people, they still have a long way to go. Unanswered questions include – how can we predict who these drugs work best in? How can we combine these drugs with other new treatments to help them work better? How can we combine these drugs with standard treatments? These were some of the topics I covered in my talk. At the iMig meeting, other presentations which members may be interested in included:

A small study combined two immunotherapies, nivolumab and ipilimumab, and found that they could be given together in people with mesothelioma, although there were more side effects than giving one immunotherapy alone (INITIATE trial). There was promising activity against the tumour, although it certainly wasn't effective in everyone. These results are being confirmed in a larger study (versus chemotherapy) which some patients at Sir Charles Gairdner Hospital have taken part in (BMS-743 trial). Final results are not expected for another year or so, and until then, this combination remains very costly and not readily available.

About 1 in 5 people with mesothelioma have 'PD-L1' on their tumour. These may be the group of people who benefit the most from immunotherapies. However, having this marker doesn't guarantee benefit, and not having it doesn't mean that no benefit is possible – in other words, it provides a bit of guidance but is not a very good test at the moment. Because of the uncertainties around this test, it is not widely used or available in clinical practice yet.

Long carbon nanotubules can cause mesothelioma in mice and may represent a future risk for people developing mesothelioma, even when there is less exposure to asbestos in our environment. It is not yet proven to cause mesothelioma in people, however this is very worrying indeed!

Involving a specialist palliative care team in the care of people with mesothelioma from immediately after diagnosis does not improve people's quality of life or symptom control more than involving palliative care when needed (results from the RESPECT study). This study was presented by A/Prof Fraser Brims from Perth. There are three main take-home messages from this: i. not everyone has symptoms that need palliative care involvement when mesothelioma is first diagnosed; ii. oncologists, respiratory physicians and specialist nurses caring for people with mesothelioma can also manage good symptom control and supportive care along the way; iii. doctors and specialist nurses can recognise when people need help from a specialist palliative care team and do make the referrals at this time. These results were reassuring, but they also tell us that if your specialist suggests a referral to a palliative care/symptom control team, it's probably a good idea to take that advice. Remember that you or your family can also ask for a referral if it hasn't been raised, and you think it would be helpful.

Under some circumstances, use of radiotherapy to areas of mesothelioma which are causing symptoms can be highly effective in reducing symptoms such as pain. Although this has been thought likely for a long time, this was the first real 'proof' through a clinical trial that this was actually so. We continue to use radiotherapy in this way at Sir Charles Gairdner Hospital.

As I write this, I'm just on my way back from the annual American Society of Clinical Oncology (ASCO) meeting in Chicago. There I presented more detail on the DREAM study – an Australia-wide clinical trial which combined a new immunotherapy (durvalumab) with standard chemotherapy (cisplatin and pemetrexed) for people who had never had previous treatment for mesothelioma. More than 20 of 54 people on the DREAM study were treated by my team, and our sincere thanks go to those people who took a leap into the unknown for a new treatment. Although this was a relatively small study, it demonstrated that this combination could be given without any unexpected side effects. The side effects of chemotherapy were present, as were the side effects of the immunotherapy, however they are quite different and are also experienced at different times. The two could be combined safely. The results in the first 31 people showed that for every two people 'expected' to get a major tumour shrinkage on chemotherapy alone, adding immunotherapy gave one more tumour shrinkage. ie. it added 50% benefit again in terms of tumour shrinkage. It also seemed to delay the time until the tumour started growing again. Overall, the results were exciting enough to encourage us to try to move forward to a 'randomised controlled trial'. This is the next important step in developing promising treatments, and is the only way it can be properly proven that a new treatment is better than an existing standard. We will need about 300 patients on that trial, and it is likely to take up to three years to complete. It is not yet guaranteed that we will have the funding to be able to do this trial, but I sincerely hope that we will be in a position to see this through. It would be wonderful if this work, which had its birthplace at NCARD in WA and for which preliminary work was in part supported by ADSA donations, were able to truly improve length and quality of life for people with mesothelioma.

4. ADSA WALK FOR RESEARCH AND AWARENESS 2018

The ADSA Walk 2018 is our biggest yet! We start from the iconic West Australian landmark Wave Rock near Hyden. For the full details see the back page of the Newsletter.

We are also launching a new website for the ADSA Walk, adsawalk.org.au, you can view the website on your computer, tablet, and mobile phone, by typing adsawalk.org.au in the address bar of your internet browser or search engine.

Read about previous ADSA Walks and follow the new posts as the clock ticks down to the ADSA Walk 2018!

ADSA WALK AROUND TOWN 2018 - HARVEY WEDNESDAY 12TH SEPTEMBER 2018

As part of the ADSA Walk we have a day for the ADSA Walk Around Town and in 2018 we will be in the unique South West town of Harvey on Wednesday 12th September 2018 from 11am to 2pm. The Harvey Walk Around Town is a 1km loop that features many of the historic buildings in Harvey. There are prizes for the most laps between 11am and 2pm and for teams the most feet on the ground. Please encourage family, friends, and work mates to complete a Registration Form for the Harvey ADSA Walk Around Town and join us for a fun day! Call 1800 646 690 or email simone@asbestosdiseases.org.au for more information and a Registration Form.

The ADSA Walk is of vital importance so that we can support our world-renowned researchers to continue with their noble work to treat patients and find a cure for mesothelioma. All donations to the ADSA Walk 2018 go to the continued funding of the ADSA PhD Scholarship in Mesothelioma and are tax deductible.

5. FUNDRAISING GOLF TOURNAMENT Sunday February 17th 2019 Meadow Springs Golf Club

Our Vice President Dave Hall has received a magnificent caravan donated from Rockingham RV as the Hole-in-One Prize. In addition there will be other valuable prizes and upon conclusion of the tournament lunch at the club room followed by a presentation of trophies and a fundraising auction for Mesothelioma research. To register your team please call our office on toll free number 1800 646 690.

6. PERIODIC EXAMINATIONS OF PERSONS EXPOSED TO ASBESTOS

Dr Deleuil is available at our Osborne Park office for medical check-ups and referrals on every Tuesday and Thursday from 10:00am. To make an appointment to consult Dr Deleuil, please call our office number on 9344 4077 or country members and friends can call our toll free number 1800 646 690.

7. FUNDRAISING RAFFLE

The ADSA current Winter fundraising raffle tickets are now available and we would greatly appreciate assistance from members and friends with at least one book of ten tickets amongst their friends and acquaintances.

For now, my very best wishes and kindest regards,



Robert Vojakovic AM JP
PRESIDENT

Walk for Research and Awareness 2018



Wave Rock, Hyden to Perth - 9 September 2018 to 14 September 2018



ADSA Walk Team 2017 Mawson Road, Beverley



ADSA Walk Team 2017 with family friends and supporters walking up to Parliament House

The ADSA Walk 2018 is taking us to mysterious places starting at the iconic Wave Rock in Hyden. From there the ADSA Walk Team walk through the centre of the Wheatbelt stopping in Kondinin, Kulin, Wickepin, Narrogin, Williams, Quindanning, Harvey, Yarloop, Waroona, Pinjarra, and Serpentine.

The Asbestos Diseases Society of Australia Walk for Research and Awareness is an annual event to raise lifesaving funds for medical research into a cure for asbestos caused cancers and to raise awareness of the risks of asbestos exposure. To sponsor an ADSA Walk participant or to make a donation please call 1800 646 690 or go to the ADSA webpage www.asbestosdiseases.org.au

Dates & Locations of the ADSA Walk 2018

Sunday	9 Sep	We leave Perth
Monday	10 Sep	Wave Rock, Hyden to Kulin
Tuesday	11 Sep	Kulin to Quindanning
Wednesday	12 Sep	Harvey ADSA Walk Around Town
Thursday	13 Sep	Harvey to Serpentine via Yarloop
Friday	14 Sep	Wellington Street Train Station to Parliament House

Harvey ADSA Walk Around Town 2018

Wednesday 12th September 2018 - 11am to 2pm

The ADSA Walk Around Town 2018 is in Harvey on 12th September 2018 from 11am to 2pm. Please encourage family, friends, and work mates to complete a Registration Form for the Harvey ADSA Walk Around Town and join us for a fun day!!



Mysterious Wave Rock



"Surfs Up" at Wave Rock

Stay in touch via

ASBESTOS DISEASES SOCIETY OF AUSTRALIA INC

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