



9 March 2016



OVER 35 YEARS OF CARE AND SERVICE TO THE COMMUNITY

Dear Members and Friends

Our organisation the Asbestos Diseases Society of Australia Incorporated (ADSA) will hold its Annual General Meeting (AGM) on **Sunday 3rd April 2016 at 2pm** at the usual place, 11 Royal Street, Osborne Park - City of Stirling Library - Osborne Park Community Centre. The Centre is located almost diagonally from our office in a north-east direction, behind the BP service station situated on the corner of Main and Royal Street - opposite the Osborne Park Hotel car park. Limited parking is available under the Osborne Park Library building off Royal Street. However, abundant parking can be accessed in the car park of the Osborne Park Hotel and the Osborne Park Supermarket adjacent to the Osborne Park Hotel, almost directly opposite the ADSA Office.

All members and friends are cordially invited to attend the 2016 AGM. Afternoon tea and light refreshments will be served upon conclusion of the meeting. There will also be an opportunity to meet and have an informal chat with guest speakers and with other members and friends, including those with similar medical conditions to exchange their information and experience. **To assist with catering arrangements, please call our office on 9344 4077 to confirm the number of persons attending AGM.**

The formal part of the AGM Agenda will include receiving reports from the office bearers of the Society's activities in connection with the preceding calendar year and the election of Office Bearers and ordinary Committee Members of the Asbestos Diseases Society of Australia Incorporated for the Calendar Year 2016. The current members of the Management and ordinary Committee of the Asbestos Diseases Society of Australia Inc. have accepted nomination for the 2016 Calendar Year. However, additional nominations will be considered provided they are in writing, co-signed by two financial members of the ADSA, accompanied by the written acceptance of the nominee who is a financial member of the ADSA. The nominations should be addressed to the Electoral Officer of the ADSA PO BOX 1394, Osborne Park 6916 and received by the closure of the office on 5pm, Thursday 31st of March 2016.

Upon conclusion of the formal part of the Agenda several eminent speakers have graciously accepted our invitation to attend the AGM (and to present the latest medical research investigations and treatments of asbestos malignant diseases such as Lung Cancer/Mesothelioma). Dr Helen Clayson, specialising in the care of mesothelioma patients in the United Kingdom for 30 years. Professor Anna Nowak latest mesothelioma research. Tim Hammond, Snr Barrister, will provide information on the illegal imports of asbestos products into Australia. Simon Millman, legal practitioner with Slater and Gordon, will summarise the progress of our joint ADSA/Slater & Gordon submission to the Law Reform Commission of Western Australia regarding the Legislative Amendments to include Provisional Damages and Damages for Gratuitous Services for the benefit of asbestos diseases victims and their families. Dr Greg Deleuil on the Eric Saint Memorial Award.

1. 2015 CALENDAR YEAR

Preceding Calendar Year as in previous years showed increased numbers of asbestos caused diseases and in particular malignant mesotheliomas and lung carcinomas. Sadly, more than 300 of our members and friends have succumbed to asbestos caused diseases during the 2015 Calendar Year.

Medical Research and Awareness Fundraising Walk 2015 – Albany to Perth Walk was greatly received by country folks as we walked through Gnowangerup, Broomehill, Katanning, Woodanilling, Wagin, Highbury, Narrogin, Cuballing, Pingelly, Brookton and Armadale to Perth. Our thanks and gratitude to the many sponsors of the Walk and the magnificent group of walkers for their dedication to make a difference. All the funds raised were presented for the benefit of mesothelioma and lung cancer patients.

The fundraising Golf tournament transferred from 2015 to St. Valentines' Day this year and it was a fabulous day at the Meadow Springs Golf Course. All funds raised will be presented again for the benefit of mesothelioma and lung cancer patients. Congratulations to our Vice President Dave Hall, his wife Elaine and their family, and including the many wonderful volunteers, generous sponsors Slater and Gordon, Scott Proctor General Manager of the Meadow Springs Golf Club and many others.



asbestos diseases society of australia inc.



As a part of **Asbestos Awareness Week 2015** our organisation again in conjunction with Royal Perth Hospital Nursing Staff provided asbestos information to raise awareness in the main Walkway of the Hospital. A meeting with the nursing staff of major Hospitals at the Asbestos Diseases Society office.

We attended conference with the Department of Health and the Cancer Council in connection with guidelines on asbestos cement fences. We also attended a Bunnings Balcatta Tradies Breakfast providing asbestos information to the tradies and answering questions about consequences of asbestos exposure and medical treatments.

Ecumenical Memorial Service 27th November 2015 was greatly received by our members and friends. The Church was filled to capacity for our inaugural Memorial Photo Presentation. We have received enquiries from members wishing to provide photographs of their departed loved ones to be shown during our Ecumenical Memorial Service 2016 which will be held on Friday 25th November. Anyone wishing to send a photograph to be included in this year service please contact our office.

2. LAUNCH OF THE MESOTHELIOMA HANDBOOK BY AUTHOR DR HELEN CLAYSON

With gracious consent of Dr Helen Clayson has given our organisation (ADSA) exclusive licence to publish her Mesothelioma Handbook in Western Australia for the benefit of our mesothelioma members and indeed all Australian mesothelioma patients. The handbook is a United Kingdom publication and will be tailored to meet the Australian criteria. The handbook provides a detailed insight into the disease, its treatment and support services so that sufferers can gain a deeper understanding and be able to better manage malignant mesothelioma. We hope this handbook will be of great benefit to our members diagnosed with mesothelioma and will be provided to all patients on request and will be free of charge. Senior Barrister Tim Hammond with a vast experience of asbestos litigation will launch the Mesothelioma Handbook at our AGM and to my understanding he is looking forward to speaking with our members after the AGM.

3. MALIGNANT MESOTHELIOMA

According to the Medical Journal of Australia, the overall rates of Malignant Mesothelioma in Australia have levelled off to around 50 mesotheliomas per million people per annum (equaling to 1,000 – 1,200 including ten-fold less in women). Further, the article mentions that the pattern of asbestos exposure patients with malignant mesothelioma is changing and the article describes three waves of the diseases. Although we agree with the article to some extent, but to our understanding we are now in the grip of the 4th wave of asbestos diseases and the 5th wave is not far off. Western Australian researchers into treatment of malignant mesothelioma are accredited to be one of the best and the only barrier to advance the life-saving research further is a lack of funds which ought to be provided by both the State and Federal Governments including the asbestos industrial wrong doers, CSR and James Hardie.

4. THE LATEST UPDATE ON CLINICAL TRIALS OF MALIGNANT MESOTHELIOMA AT SIR CHARLES GAIRDNER HOSPITAL

Mesothelioma clinical trials are the most important way of understanding whether a new treatment, or a new way of using an existing treatment, is actually an improvement over usual care. There are two important aspects to going onto a clinical trial – Firstly, the person who is asked to participate needs to fit the criteria for the clinical trial. Every trial has restrictions on the eligibility of participation. For example, it may be about who is able to participate and it may be also about the treatment they have (or have not) already received or how health-wise they are and the normality of their blood tests, including other health history. Secondly, the persons who are eligible and asked to participate need to receive detailed information to understand what they are being asked to do, and then to voluntarily agree to take part. This is generally called ‘informed consent’ of patient participation.

The four trials mentioned hereunder are a snapshot of new and upcoming clinical trials, are in addition to other trials also available at Sir Charles Gairdner Hospital over the next few months.

1. The AMPLE2 trial. Some mesothelioma or other cancer patients who experience a build-up of fluid in the lung will likely need an ‘indwelling pleural catheter’, which is a tube placed into the space between the lung and the chest wall. Fluid can be taken out at hospital or at home – with suitable training. Doctors don’t know whether it is better to take fluid out every day, or to take it out only when the person becomes breathless. In the **AMPLE2 trial**, people with an indwelling pleural catheter are randomly assigned to take fluid out every day (at home), or to only have fluid drained when they feel more breathless. We want to understand whether draining the fluid out daily improves patient’s quality of life and breathlessness or when draining it intermittently. However we also want to know if taking fluid out every day leads to more infection risk and inconvenience. We also know that taking fluid out daily is more costly to the health system. This trial will help decide whether more or less frequent drainage is a better outcome for patients.

2. The RESPECT trial. A clinical trial in America showed that getting a specialist palliative care doctor involved in the care of patients with incurable lung cancer from the time of diagnosis was better than

involving them only at the end stage of cancer. Not only did the people with 'early palliative care' feel better, they actually are living longer. The American and Australian/UK health systems and use of palliative care are, however, very different. The **RESPECT trial** is randomly assigning people with a new diagnosis of mesothelioma to receive either immediate regular consultations with a specialist palliative care doctor, or to have 'usual care'. In usual care, people will be referred to a palliative care doctor when their oncologist or respiratory physician thinks they need it - for example if their usual doctors would like additional help controlling symptoms like pain and breathlessness. This trial will help decide whether the findings in US lung cancer patients are also true for people with mesothelioma who are living in Australia and the UK.

3. The FRAME trial. This trial will be open in April or May 2016. There is no standard treatment for people with mesothelioma who have already had chemotherapy, without preventing the continuous growth of the disease. Findings from the University of Western Australia laboratory teams working on mesothelioma research have found that blocking a molecule called 'FGFR' can slow growth of mesothelioma. Tablet treatment to block FGFR is under study in humans in a number of different cancers and we already know the tolerance and side effects of this treatment. In the **FRAME trial**, people with mesothelioma who have previously had chemotherapy will take the anti-FGFR tablet twice a day. We will use regular CT screening and monitoring of side effects to understand if the anti-FGFR tablet is a helpful technique for treatment of mesothelioma.

4. The DREAM trial. This trial will be open in the second half of 2016. Immunotherapy is currently an exciting frontier in cancer treatments. The **DREAM trial** will be available to people with mesothelioma who have never had chemotherapy. This trial combines standard chemotherapy with an immunotherapy, and continues with immunotherapy after six chemotherapy treatments have been completed. Professor Nowak's research team will use regular CT scans to monitor any side effects to understand, if adding immunotherapy to chemotherapy makes chemotherapy work more effectively.

From our experience, not everyone will be willing to participate in a clinical trial, and unfortunately some people who do want to participate may not be suitable patients for the trial. However, we are always working to have as many options available as possible and if you are a mesothelioma patient, you may consider speaking to your GP, Dr Deleuil at our office, or respiratory specialist preferably at Sir Charles Gardiner Hospital or other teaching hospitals whether a clinical trial is a beneficial option for you.

5. WITTENOOM

In December this year, it will be 50 years since closure of the blue asbestos mining and milling at Wittenoom, and regrettably more than 4,500 people who worked or lived at Wittenoom during its mining operation and those who lived and visited Wittenoom post-mining cessation will die from asbestos caused diseases.

Historically speaking, there has been no greater mining disaster in the world and Wittenoom is very likely on a par with other industrial disasters i.e. Minamata, Japan, 1932-1968; Seveso, Italy, July 10th 1976; December 3rd 1984 Bhopal, India; and Chernobyl, Ukraine, April 26th 1986. Regrettably the Western Australian and Commonwealth Government did very little to prevent the Wittenoom tragedy. Members and friends are advised to check our website as we will be posting historical stories about Wittenoom. Since this is the 50th year since Wittenoom closure, there are still a number of Wittenoom miners and their families living in Western Australia or other states, and we would indeed appreciate to connect with all of them if possible. We would like to provide them with information that may assist them in connection with medico legal issues or just merely assisting with getting in touch with former Wittenoom friends or acquaintances.

6. PROVISIONAL DAMAGES AND DAMAGES FOR GRATUITOUS SERVICES

On the 13th of February this year, we have sent the final Submission to the Law Reform Commission of WA Project 106, Discussion Paper Provisional Damages and Damages for Gratuitous Services. We have expressed our hope that the honourable members of the Commission will sincerely consider the implication of the current Legislation which was denying asbestos diseases victims the same fair and just outcome which is available in other States of the Commonwealth of Australia. It would appear from a past experience in connection with the Law Reform Commission investigating the rights of the beneficial Legislation to assist victims of asbestos diseases result in a negative outcome. Australia has the highest number of asbestos diseases in the world per capita of population and in contrast our laws seem to be out of touch in comparison to other countries in the world, and other states of Australia.

The Law Reform Commission will be reviewing the discussion paper Submissions and to our understanding their recommendation will be presented to the Government of Western Australia by June this year. I would like to express my gratitude and thanks to many wonderful people sending petitions in connection with the matter in question of gratuitous services and provisional damages. We are planning towards the end of May to send further petitions regarding the same issues but moreover directly appealing to the Western Australian Government to have some compassion and understanding for many grieving Western Australian families.

7. **ADSA 2016 FUNDRAISING WALK FOR MEDICAL RESEARCH AND AWARENESS**

This year our fundraising Walk will commence in September (exact date in next Newsletter) and will be 6 days from Geraldton to Perth. The Walk will take us to a number of beautiful mid-west towns, including Three Springs, Moora, Bindoon, Eneabba, New Norcia, etc. Exact details in the next newsletter.

So far we have in excess of more than 50 members and friends having expressed interest.

8. **THE ASBESTOS IN THE COMMUNITY**

We are receiving up to 50 calls per day on many issues associated with asbestos in the community, being asbestos fences, garages, eaves, roofing etc. The asbestos legislation is yet to be agreed upon to precisely deal with the issues of asbestos risks in the community. However, last year our organisation with other stakeholders participated in a discussion on asbestos guidance note on asbestos cement fencing. The Guidance Note provides advice on the identification and management of cement sheet fences made with asbestos-containing materials in residential settings. It is primarily for use by Local Government Environmental Health Officers as well as the public.

9. **PERIODIC EXAMINATIONS OF PERSONS EXPOSED TO ASBESTOS**

The most important part of the periodical examinations is to detect the early onset of malignant diseases, lung cancer or mesothelioma. One of the most experienced asbestos diseases GP in Australia, Dr Deleuil is available every Tuesday and Thursday from 9:30am to 12:30pm for consultation at our office in Osborne Park. Anyone wishing to make an appointment call our office on 1800 646 690.

10. **FUNDRAISING RAFFLE**

Autumn fundraising raffle tickets are now available and we would greatly appreciate assistance from members and friends to disseminate at least a book of ten tickets amongst their friends and acquaintances.

With best wishes and kindest regards,



Robert Vojakovic AM JP

PRESIDENT

*Very Best Wishes
to all members, friends and
their families
for a Pleasant and
Peaceful Easter

President,
Committee and Staff*



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