

28 July 2017

Dear Members and Friends



OVER 35 YEARS OF CARE AND SERVICE TO THE COMMUNITY

It gives me great pleasure to announce that the **Asbestos Disease Compensation Bill 2013** which was introduced into WA Parliament by the Hon Kate Doust in 2013 will be reintroduced into WA Parliament most likely this year. It is regrettable that the former WA Government failed to support such an important legislation which would have ensured a better outcome for our disabled members and their families and would bring the Western Australian compensation Laws on a par with the rest of Australia.

1. WALK FOR MESOTHELIOMA RESEARCH AND ASBESTOS RISK AWARENESS

This year the Asbestos Diseases Society Walk for Research and Awareness will commence on 10 September and conclude on 15 September at Solidarity Park near the rear of Parliament House. Simone from our office has worked with enormous dedication to make this Walk successful. We are walking from Merredin to Perth with the focus this year on the ADSA Walk Around Town in Northam with the hope that as many members and friends can join in this rewarding and important fundraising event. 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.

Please refer to the back page of this newsletter for more comprehensive information about the 2017 ADSA Walk.

The ADSA Walk 2016 raised \$120,000 which is the initial funding for an ongoing PhD mesothelioma research scholarship to attract the best clinicians/scientists researching and working with mesothelioma patients. The scholarship will commence this year and will be supervised by Professor Anna Nowak and the NCARD team at the University of Western Australia.

All funds raised by the ADSA Walk 2017 will go to the continued funding of this unique PhD program. It would be greatly appreciated if members and friends support this year's Walk to provide much needed funds so that our researchers can continue their great work to provide treatments and discover a cure for mesothelioma.

Robert and Rose Marie would greatly appreciate as many as possible members and friends to join them in Northam for the ADSA Walk Around Town on Thursday 14 September 2017 to meet the ADSA Walk Team and walk with them around Northam. Please see the details on the back page of the Newsletter.

2. ECUMENICAL MEMORIAL SERVICE 2017

The Ecumenical Memorial Service in remembrance of those who have died from asbestos-related diseases will be held on Friday 24 November 2017 at the Redemptorist Monastery, Vincent Street, North Perth commencing at 9:30am. This year will mark the twenty-second year that we have held the Ecumenical Memorial Service to continue the remembrance, to honour, celebrate and mourn our passed members and friends. Anyone wishing to provide a photograph of their loved one to be included in the **Memorial Photograph Presentation** during the service please contact the office. All photographs received by our office will be copied for the presentation and the original will be returned if so requested.

3. PERIODIC EXAMINATIONS OF PERSONS EXPOSED TO ASBESTOS

The most important part of the periodical examinations is to detect early onset of malignant asbestos diseases, lung cancer and malignant mesothelioma. Early detection of lung cancer can lead to successful outcomes and remission. Malignant mesothelioma still remains a lethal disease, which however when detected at an early stage, can be treated with a multidisciplinary approach leading to a reasonable longevity of survival. **Regrettably, a large number of our members and friends who had previous occupational or domestic exposure to asbestos appear to be complacent** and are not taking advantage of the opportunity of periodical examinations made available by our organisation. 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.



4. FUNDRAISING RAFFLE

The Winter fundraising raffle will be drawn on Wednesday 6th September 2017. Raffle tickets are still available and it would be greatly appreciated that members and friends consider disseminating at least a book of ten tickets amongst their friends and acquaintances. As always the funds raised are used exclusively for the benefit of the ADSA members, their families and for the advancement of asbestos-diseases medical research.

5. NEW ASSOCIATIONS INCORPORATION ACT 2015 (WA)

The Associations Incorporation Act 2015 (WA) (Act) repeals and replaces the Associations Incorporation Act 1987 (WA). All incorporated associations in Western Australia will need to develop an understanding of the requirements under the new Act, and ensure that their rules, internal governance, and record keeping practices comply with the new requirements. The new Act came into operation on 1 July 2016. A transition period of three years will allow associations to update their constitution rules in accordance with the proposed rules. The Committee of our organisation (ADSA) canvassed the issues at the last two meetings to consider minor necessary amendments of our constitution to introduce the proposed model changes. The amendments will be nominal as constitution already contains a number of the proposed model changes. The required changes must be included in the Constitution by 30 June 2019. The Committee have already canvassed the changes and indeed accepted the model changes as required by the Act. They will be more or less placed into our Constitution by next year. More details of the model changes will be included in the Spring newsletter this year.

6. ADSA CHRISTMAS PICNIC SUNDAY 3 DECEMBER 2017

Please reserve Sunday 3 December this year for the ADSA Christmas picnic at Whiteman Park commencing at the usual time from 10:30am. More details will be provided in the next newsletter.

7. THE LATEST UPDATE ON CLINICAL TRIALS OF MALIGNANT MESOTHELIOMA AT SIR CHARLES GAIRDNER HOSPITAL, PERTH

Since our last update in February, an earlier clinical trial from SCGH has been presented at the American Society of Clinical Oncology annual meeting, some other clinical trials have come to an end, and others have started.

The Nintedanib trial: Professor Anna Nowak was privileged to present the results of the first nintedanib trial at the American Society of Clinical Oncology conference in Chicago in June. In the results she presented, from 87 people who were treated with either standard chemotherapy or standard chemotherapy PLUS nintedanib (a tablet anti blood-vessel drug), people with epithelioid type mesothelioma who had chemotherapy plus nintedanib gained an average extra 4 months before the tumour grew, and an average extra 5 months life expectancy. While these results are very exciting, it's important to remember that they are preliminary. The clinical trial to confirm these results is ongoing. 450 people worldwide are now being recruited to this **ongoing nintedanib trial** which is also open currently at SCGH. The ongoing trial is for people who have never had previous chemotherapy for mesothelioma and have an epithelioid type disease. In this study, everyone is treated with standard chemotherapy, and in addition, everyone takes a tablet twice daily. This tablet is either nintedanib, or a placebo (inactive tablet). Once chemotherapy has finished, after a maximum of 6 treatments, the nintedanib or placebo tablets continue for as long as the cancer is controlled. People on this study won't know if they are on nintedanib or placebo, but both groups will be closely monitored for side effects and benefits, and everyone will get standard chemotherapy. This study is likely to continue for a number of months.

The DREAM trial this trial will almost certainly be completed by the time this newsletter is published. With just 5 spots left around Australia, **DREAM trial** will shortly have recruited 54 people having their first treatment for mesothelioma. An incredible 23 people on this study are being treated at Sir Charles Gairdner Hospital, which will have taken just 8 months from first to last patient starting (Australia wide). This trial combines standard chemotherapy with an immunotherapy (durvalumab) to understand if adding immunotherapy to chemotherapy makes chemotherapy work more effectively. This trial was a direct development from our laboratory research program. We are so grateful for the support from patients in participating in this study and look forward to getting an answer quickly to understand the value of this approach for people with mesothelioma.

The FRAME trial opened in April 2016 and has nearly completed enrolling the full number of participants. Just one more participant is needed before we will close the trial and analyse the results. This study is for people who have previously had one or two types of chemotherapy for mesothelioma. 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. In the **FRAME trial**, participants take an anti-FGFR tablet twice a day. We use regular CT screening and monitoring of side effects to understand if the anti-FGFR tablet is a helpful technique for treatment of mesothelioma. As with DREAM, we hope to be able to report these results in the next year.

The CA209-743 trial name is a bit of a mouthful, and also a complex trial to describe. People with newly diagnosed mesothelioma who have never been treated with chemotherapy will be treated with **either standard chemotherapy, or a combination immunotherapy (ipilimumab plus nivolumab)**. As this is a 'randomised' clinical trial, neither the participant nor the doctor get to choose which treatment is received, but that treatment is taken for as long as it

is working (immunotherapy), or to a maximum of 6 treatments for chemotherapy. We expect that with the DREAM trial closing, more people will choose to participate in this trial, which will remain open for a number of months.

The Anetumab trial has now closed to new patients, however some people are continuing to receive treatment. As this is a large international trial which SCGH participated in, it may be some time before we know whether anetumab is more effective than a second type of chemotherapy for people who have had one previous type of chemotherapy for mesothelioma. Watch this space.

The RESPECT trial the results of this international study will be presented by Associate Professor Fraser Brims at the World Lung Cancer Conference in Hyogo, Japan, later this year. **RESPECT trial** randomly assigned 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 were referred to a palliative care doctor when their oncologist or respiratory physician thought they needed it - for example if their usual doctors needed additional help controlling symptoms like pain and breathlessness. **SCGH included more people on this study than any other hospital worldwide**, however sadly highlighting how many people are diagnosed with mesothelioma in Western Australia. Hopefully we will be in a position to update members and friends reading our newsletter on the results of this trial study later in our Christmas Newsletter.

In the last newsletter update on clinical trials, we discussed when and why a trial closes. So what happens when the analysis has been completed? Whether the results are positive or negative, the results from a clinical trial are usually presented in a talk at an international conference. A brief synopsis of the results are submitted, and hopefully it is chosen for a presentation. This would usually be the World Lung Cancer Conference, the International Mesothelioma Interest Group Meeting, or the American Society of Clinical Oncology meeting. This allows the positive or negative results to be quickly communicated to other doctors and scientists working in the field, and to bring anything new back to their patients. After that, the results are written up as a journal article for publication in the scientific literature. This is a detailed description of the treatment, the effects on tumour growth and how long people lived for, and the side effects. Journal articles are then 'peer reviewed' by three or four experts in the field, who can ask for further detail on the findings or interpretation. Sometimes the first journal (or even the second...or third...) will reject the article, which then needs to be submitted to another. This is more common if the results are negative! Full and transparent publication of the results should be the final outcome of any properly conducted clinical trial, and it is considered unethical to 'hide' results if something didn't work. It's equally important to let people know what didn't work as what did work, so we don't make the same mistake twice.

If any members of our Society are interested in participating in any of these above mentioned trials, the first step (if you do not attend Sir Charles Gairdner Hospital) is to ask your oncologist to contact Professor Anna Nowak or her research fellow Dr Wei-Sen Lam for more information about whether the trial might be suitable for you.

8. FUNDRAISING GOLF TOURNAMENT

The 4 Ball Ambrose Fundraising Golf Day to raise funds for mesothelioma medical research will be held at Meadow Springs Golf Club in Mandurah on 18th February 2018. As in previous years, the Ambrose 4 rules will apply, that means we need teams of 4 players and the closest ball of the team to the hole will be considered. Our Vice President Dave Hall is working hard to acquire as many sponsors as possible so that asbestos diseases medical research can be enhanced. One of the sponsors, Mr Ryan Baran from Hitech Marine Centre situated in 12 Uppill Place, Wangara, is generously providing as a **HOLE-IN-ONE PRIZE** a brand-new Reflex 485 Chianti powered by a new Mercury 75HP EFI 4-stroke, on a single axel braked trailer, licensed with an inshore safety kit to the value of **\$39,990.00**. There will be additional prizes for the tournament which will be provided in more details in next newsletter. However, since we are limited to 25 teams of 4, please call our office to acquire registration at your earliest as we do not want anyone to be disappointed. Please observe the picture of the boat hereunder.

For now, my very best wishes and kindest regards,



Robert Vojakovic AM JP
PRESIDENT



Walk for Research and Awareness 2017



Merredin to Perth - 10 September 2017 to 15 September 2017

1 Merredin • 2 Bruce Rock • 3 Yoting • 4 Quairading • 5 Beverley • 6 York • 7 Northam • 8 Perth



Welcome to the ADSA Walk 2017! 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 mesothelioma and to raise awareness of the risks of asbestos exposure. The ADSA Walk 2017 is from Merredin to Perth via Bruce Rock, Quairading, Beverley, York, and Northam. 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 and Locations of the ADSA Walk 2017

Sun	10 September	We leave Perth and drive to Merredin
Mon	11 September	Merredin to Yoting via Bruce Rock
Tue	12 September	Yoting to Beverley via Quairading
Wed	13 September	Beverley to Northam via York
Thu	14 September	ADSA Walk Around Town Northam
Fri	15 September	Perth Train Station - Parliament House

ADSA Northam Walk Around Town

The ADSA Walk Around Town 2017 is in Northam on Thursday 14 Sept from 10am to 2pm. This is a 2km loop starting at the Village Green (Fitzgerald St) that takes in the Avon River and the Northam Large Suspension Bridge. Fun prizes for the most laps and most feet on the ground for teams. Please encourage family, friends and work mates to complete a Registration Form for the Northam ADSA Walk Around Town and join us for a fun day! Looking for a Registration Form? Please call 1800 646 690 or you can email simone@asbestosdiseases.org.au

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