

**A brief overview of AMAA**

Our organisation was initiated by a collective of like-minded patients, carers and friends who recognised a severe lack of support and information services for people affected by asbestos in the Gold Coast, Tweed and Northern Rivers Region.  The Asbestosis and Mesothelioma Support Group (AMSG) was established to fill this void and since this time it has grown in strength and number, resulting in a name change in 2014 to the Asbestosis and Mesothelioma Association of Australia (AMAA). Initially established for the local Tweed and Gold Coast Region, AMAA now provides support to patients from across Australia and indeed has assisted patients diagnosed overseas. AMAA is proud of our ability to offer patient focussed services and programs, while also disseminating information and guidance to people affected and/or concerned about asbestos in the broader community.  We seek to improve health and support services for people with asbestos related diseases, their families and the community. Our goals are that sufferers of asbestos related diseases will be offered a better quality of life and have access to greater treatment options and care, and awareness of asbestos identification, management and safe handling is improved to ultimately lead Australia to be asbestos free.

**The importance of the role of ASEA**

Over the past thirteen years AMAA has participated in and supported various national initiatives and programs designed to address the legacy of asbestos in Australia and improve patient outcomes.  We have travelled to conferences, participated in round table discussions, offered independent feedback from the patient perspective and lobbied various levels of government.  This tireless work is carried out by unpaid volunteers and patients who are keen to see change, yet the progress has often been slow, non-existent or frustrating as the issues were hand-balled between various arms and/or levels of government.  Since the establishment of the ASEA, this frustration has been replaced by enthusiasm, optimism and hope as there has been real and substantial change in the engagement with stakeholders and the recognition of the patient voice in asbestos related issues.

The Asbestos Safety and Eradication Agency has played a pivotal role in bringing together all relevant stakeholders, both nationally and internationally, including but not limited to industry representatives, government agencies and bodies, union delegates, asbestos patient organisations, medical professionals and researchers.   AMAA recognises the important role that the ASEA plays in streamlining the efforts of all stakeholders to bring about actual and real change - we have made significant strides in addressing asbestos issues through the leadership and guidance offered by the ASEA.  This progress would never have been possible without the drive, direction and determination of the ASEA.  The ASEA acts as an independent body to assist in bringing together the disparate stakeholders and since its establishment, has worked to offer clarity of vision and scope, as well as the coordination of the activities relating to the administration, management and resolution of issues.

**Challenges to the ASEA's roles and functions**

The efforts of ASEA are to be applauded and acknowledged as forging a fundamental shift in the management of asbestos related issues in Australia and abroad.  The ASEA is heralded domestically as a beacon of hope and a symbol of our national commitment to addressing the legacy of asbestos, while also being feted internationally as world's best practice and a role model for other governments to follow.

Yet AMAA is concerned that the capacity of ASEA to carry out its fundamental role and functions has been hamstrung over the years by significant underfunding.  This has been a source of great angst, frustration and concern for our organisation, as the issue of asbestos in Australia needs to be dealt with as a matter of national priority.

The ASEA needs to be provided stable, consistent and substantial funding without interference or uncertainty.  The work undertaken by the ASEA has real impact and many outside stakeholders, including AMAA, rely on the guidance, support and leadership of ASEA in our everyday operations.

We have been directly impacted in recent years by the alarming trend of funding being withheld or reduced to the ASEA and these actions have caused significant distress to our members and supporters who look to the ASEA as the government representative on these issues.  I

f the ASEA is not taken seriously or funded appropriately then it is a very strong signal to our members, and those of our counterpart organisations, that our concerns are not taken seriously and the safety and welfare of the broader community is being put at risk due to financial uncertainty.  In our opinion, such ad hoc funding is a severe disadvantage to the ASEA realising its full potential and the long term impact of their work will be undermined without confirmed sustained and substantial funding.

In 2015, AMAA was the proud recipient of a grant from the ASEA to assist us in establishing our Asbestos Community Outreach Centre.  These funds provided the foundation for our organisation to offer a broad range of patient focussed programs and services, while also improving our engagement with the broader community about asbestos safety, identification and management.  The ongoing cost of operating the Centre has been borne by our members and supporters through fundraising, donations and bequests.  We rely entirely on the efforts of volunteers to help us keep our costs down, despite the demand on our service increasing and the scope of our awareness programs growing.  We are proud of our activities and the outcomes of our efforts achieved through the Centre, however, it is a tireless effort for our community to continue to financially support the program.  We are aware that we cannot seek further supplementary funding from the ASEA when they themselves are not adequately funded to pay for their own operations and/or programs/services.  This is a huge disappointment as we know the ASEA is being hindered in its ability to reach its potential and also support organisations, such as ours, in delivering real outcomes in the community.

We were also alarmed that the ASEA Council did not include a formal representative of the asbestos support group organisations.  It is our experience that the voice of the patient community provides invaluable insight and perspective that balances the opinions of other stakeholders.  By not having a formal position to recognise the patient community on the Council, the ASEA is restricting its scope and diminishing the level of respect given to victims of asbestos disease.  Accordingly, AMAA strongly favours the inclusion of a provision guaranteeing a place on the Council for a representative of patient support groups.

**Recommendations for the ASEA Review**

We strongly recommend that the review of the Asbestos Safety and Eradication Agency currently being undertaken give consideration to the:

* Continued independence of the ASEA in its role and functions both nationally and internationally.
* Increased funding levels for ASEA to have stable, consistent operations and scope to undertake its vital leadership role and functions.
* Additional funding to establish a grants program for the ASEA to support the work of stakeholders in working with sufferers of asbestos related diseases and/or eradication and awareness programs.
* Guarantee of a patient representative on the ASEA Council.

AMAA has also had the opportunity to review and consider the submission to the ASEA Review put forward by the ACTU.  We strongly support their submission and recommendations.