

**Submission
No 3**

FIRST REVIEW OF THE DUST DISEASES SCHEME

Organisation: Bernie Banton Foundation

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Asbestos disease... takes your breath away!®

21 April 2017

Sharon Ohnesorge

Director

Legislative Council Standing Committee on Law and Justice

Parliament of New South Wales

Parliament House

6 Macquarie Street

Sydney NSW 2000

By email: lawandjustice@parliament.nsw.gov.au

Dear Ms Ohnesorge

We are thankful for the opportunity to provide a submission to the Committee's First Review of the Dust Diseases Scheme.

Please do not hesitate to contact myself or the Bernie Banton Foundation's CEO and Founder, Karen Banton, if you feel we can assist the Committee with further input.

Sincerely,

Rod Smith

Awareness and Support Co-ordinator
Bernie Banton Foundation

ABOUT THE BERNIE BANTON FOUNDATION

The Bernie Banton Foundation is a New South Wales based and registered, mesothelioma and asbestos related support organisation.

We are an apolitical, faith-based (non-denominational), not for profit organisation with authority to operate in all Australian states and territories.

The Foundation's Mesothelioma and Asbestos Related Support (MARS) Network is physically active throughout NSW and the ACT offering peer-based support and information, and referral and advocating services to those who have been diagnosed with mesothelioma cancer or another asbestos related disease (ARD), and to their carers and immediate family members, as well as those bereaved. Our Freecall Support Helpline, available Australia-wide, is open 24 hours a day, 7 days a week offering peer-based support and information from people who have, importantly, lived the mesothelioma or other asbestos diseases journey. We are also active online via our comprehensive website, blog and social media platforms.

Currently the Foundation's Mars Network has over 240 sufferers, carers and family members on our NSW and Dust Diseases Care related support database, with the vast majority being directly, or indirectly connected with Dust Diseases Care.

First Review of the Dust Diseases Scheme – April 2017

In August 2015, the Bernie Banton Foundation issued a press release indicating it would support any changes to the Dust Diseases Board structure that would benefit sufferers of dust diseases by shortening application lead times and would maintain or improve existing benefits and services. After studying the proposed changes to the legislation, the Foundation recommended a number of amendments – all of which were encompassed in amendments put forth by Rev Fred Nile and adopted by both Houses of Parliament into the present day legislation.

Whilst at the time we did not believe the DDB was broken, we did find through our Mesothelioma and Asbestos Related Support Network that many improvements needed to, and could, be made. It is for this reason we backed the final changes to the legislation and the resultant restructuring.

Certainly since the formation of the DDA, the application process appears to have become far quicker, and service delivery decisions would appear to be able to be made in an extremely timely fashion.

From this point of view the Foundation can only speak favourably.

However, there are still problems within the system that we are confident are being dealt with.

DDA APPLICATION PROCESS and SERVICE PROVISION

The vast majority of enquiries from sufferers, their carers and loved ones who are experiencing problems, stem from lack of initial knowledge about the DDA and if registered, a lack of understanding of entitlements that can be accessed and the due processes needed to access them.

We believe most problems come about due to over complicated paperwork being issued in the initial application and/or registration pack. This includes an application form and process that more often than not overwhelms people who are invariably already stressed due to having been diagnosed – let alone being faced with a mountain of daunting paperwork.

It is not uncommon to be contacted by a diagnosed sufferer of a dust disease, or their loved ones, who has sat on the DDA folder for many months, even years, purely because they could not face filling out the application form. In other cases, where a sufferer is diagnosed at an extremely late stage, it may be too challenging for a sufferer and their loved ones to physically or mentally have the fortitude or concentration to fill out an application form that would tax the majority of elderly folk (indeed most people) in everyday normal circumstances, let alone when totally stressed out.

This can lead to a sufferer or their loved one missing out on services they would have been entitled to, and often loss of substantial compensation. In fact, if an application has not been lodged prior to a sufferer's death, all compensation associated with the sufferer may be lost.

Likewise, if a sufferer is already registered with the DDA, many have no idea of what services they are entitled to, or can access, particularly if they have a slowly progressing disease. This we feel comes about due to being unable to process and retain the information given at the time of being diagnosed.

Often we find problems arise due to a lack of identification of the most appropriate family member for the caseworker to deal with. In most cases this is due to inaccurate information given by the sufferer when filling out the application forms.

It is obvious to us a lack of communication between the DDC and those registered with the DDA (and vice versa) is the main reason for the vast majority of any problems that arise. When the Foundation is alerted to a problem, and advocates on behalf of those concerned to Dust Diseases Care, invariably the problem is dealt with expediently by the DDC – we couldn't be happier with reaction times and the attitude of DDC staff from the top down, when an issue becomes apparent.

Recommendations:

[1] The application forms and process be put in very plain language and streamlined, allowing for the stressful time the applicant and family will undoubtedly be experiencing, particularly if having only recently been diagnosed.

[2] Clear and concise guidelines be drawn up highlighting the initial necessary steps to be taken, and explanation sensitively given (both verbally and in written form) that significant compensation and services may be lost, if an application is not made in a timely fashion.

[3] Pro-active systems and processes be put in place to allow for pre-determined checks and balances and follow up to take place – from time of responding to a request for application forms, or first knowledge of a potential recipient of DDA compensation or DDC service delivery.

[4] Amend the legislation to permit an extension of the process timeline, so as to allow an application to be submitted after a sufferer's death, if necessary. This would enable payment of, or reimbursement of, compensable expenses such as medical, hospital, funeral, etc., to the bereaved spouse or estate.

DUST DISEASES AUTHORITY – DISEASE CATEGORIES

The Dust Diseases Authority covers a wide and varied list of dust diseases contracted after being exposed to dust whilst working as an employee in NSW. However the list of diseases covered, whilst tried and true, is ageing and no longer is necessarily reflective of modern day work places, situations, standards and workplace dust caused diseases.

Recommendation:

To allow all workers to benefit equally, after contracting a debilitating disease caused by exposure to dust whilst working in NSW, we would encourage the Committee to institute a review of the dust related diseases eligible to attract compensation, and to be funded for research by the Dust Diseases Scheme.

DUST DISEASES BOARD

The Dust Diseases Board was legislated to enable an independent process to award grants to further research into the DDA listed legislated dust diseases, and to aid stipulated dust disease support organisations to function and perform their vital support, awareness and patient related advocacy services. The process of restitution of the DDB into its' new role has been understandably, a frustratingly long one, however would now appear to be up and functioning as intended.

Whilst the Dust Diseases Board funding is enshrined in legislation to provide the means to fund applicable research organisations, and support organisations, what is not legislated, is regulation enabling the DDB to fund research institution infrastructure. In this day and age, where every public dollar has more and more demands placed on it, research and support organisations are finding it harder and harder to finance their everyday running and infrastructure costs.

This statement contained in the 2009 Asbestos Diseases Research Institute (ADRI) Annual Report is worth reading and considering:

'Like other medical research institutes the staff of the ADRI will be dependent on their success in the NHMRC research grants scheme for their salaries. For every grant dollar a further 70c will be needed for the day-to-day running of the labs and the Institute in general. There is a need for additional funding from State Government for medical research institutes such as the ADRI. The ADRF is relying on past funds and current donations to continue research into asbestos-related diseases.' - 2009 ADRI Annual Report [ADRF Chair Report – The Hon. Bob Carr]

With this in mind, the Bernie Banton Foundation recommends for your consideration:

That the relevant legislation be amended to allow the DDB to award infrastructure funding to the ADRI on the following basis:

[1] The DDA will compile an Infrastructure Funding Grant Strategy and Application Document specific for ADRI, for approval by the DDB.

[2] Infrastructure funding grants may be awarded to a maximum dollar value, matching on a dollar for dollar basis, any research grant awarded by the NHMRC Peer-reviewed Grant Scheme to ADRI, for laboratory based DDA/DDB (approved) applicable research conducted wholly by ADRI employed full time researchers, at the Bernie Banton Centre.

[3] Grant(s) are to be tied to, and subject to ADRI and their relevant researcher(s) adhering to all terms and conditions as per the said NHMRC grant and any additional conditions or terms of the DDA/DDB.