Submission
No 31

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

Organisation:	Muscular Dystrophy Association NSW
Name:	Mr David Jack
Position:	Chief Executive Officer
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Submission to the PADP Inquiry by the Muscular Dystrophy Association NSW

Name: David Jack

Designation: Chief Executive Officer

Authority to lodge submission: Board of Muscular Dystrophy Association NSW

Submission

Muscular Dystrophy Association NSW (MDANSW) welcomes the PADP inquiry and wishes to make a submission to the inquiry. This submission is informed by over 50 years of service delivery to our client group and discussion by our Board and the Equipment Committee of the MDANSW Board which has the following charter:

1. To be an authoritative source of advice for members on equipment and its provision
2. To advocate on behalf of its members
3. To provide emergency support to members.
4. To be a final avenue for financial support to members.

MDANSW represents the interests of persons with muscular dystrophy and their families and carers. Our clients access equipment through the PADP scheme and have had varied experiences with the PADP program.

Our clients cover a broad range of ages and severity of disability but share the same goal and that is to be treated in a dignified, supportive and compassionate way.

As an example of the challenges faced by our client group, a person with duchenne muscular dystrophy will live a shortened life usually surviving to their early twenties. They will require the following pieces of equipment to have any quality of life.

1. powered hoist and sling for transferring from bed to chair etc, cost approximately $2,500
2. shower/commode chair, cost approximately $1,200
3. powered wheelchair, costing between $10,000 to $15,000
4. air or gel seating for wheelchair, costing between $600 to over $4,000
5. high low electric powered bed, cost approximately $5,000
6. pressure relief overlay mattress and pump, cost approximately $500
7. VPAP or BiPAP breathing support machine, costing between $4,500 to $8,000

A total cost between $24,300 to about $36,200. During their life some of these pieces of equipment will need to be replaced as the person grows and/or their condition deteriorates.

People that have other types of muscular dystrophy and allied neuromuscular disorders require some or all of the above equipment but over a significantly longer time frame and may need to replace items three or four times. Therefore it may cost upwards of $100,000 over their life time.

This puts an intolerable burden on the family and the Government has taken this responsibility on when they instituted the PADP scheme in the1980's.

Our clients have had significant difficulties in accessing equipment through PADP, often being told they are eligible but have been placed on a waiting list that usually extends to two years. For some that is 10% of their entire life!

Our Association has for the last fifteen years diverted much needed research funding to cover the gap that exists between our client members and the PADP scheme because the lives of our members are precious.

We believe that the quality of life of our client members is being jeopardised by the inadequate funding and the inordinate length of time it takes to supply this essential and life enhancing equipment.

I would like the opportunity to personally inform the inquiry on behalf of our members and supporters and I will be available to address the inquiry if invited.

With kind regards

David Jack
Chief Executive Officer
Muscular Dystrophy Association NSW