



Matthew Hayden  
Patron

# Parent Project Australia Inc.

Embracing the Duchenne muscular dystrophy community



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The Secretary  
House Standing Committee on Family, Community, Housing and Youth  
[fchy.reps@aph.gov.au](mailto:fchy.reps@aph.gov.au)

Re: Inquiry into Better Support for Carers

PPA is a national non-profit education and research network formed 5 years ago to support Australian scientists and families affected by the most common and severe disease under the broad umbrella of disorders known as muscular dystrophy. Duchenne and Becker muscular dystrophy are known as the dystrophinopathies and differ only in severity as both are caused by mutations to the biggest and first-identified gene in the mid 1980's. One in 3,000 males is born with Duchenne, and one in 18,000 males is born with the less severe form, Becker.

Midway through the affected youth's second decade, Duchenne presents as similar to quadriplegia or "Locked in" syndrome. Our sons and very rarely daughters, lose all mobility and use of their upper body. They cannot raise a cup to their own mouths or hug someone. Manual wheelchairs are never an option and electric chairs, hoists and beds are gradually joined by bi-pap machines and cough assist machines. Anywhere between mid-teens and mid-twenties, our valiant boys succumb.

Our families, particularly parents and more particularly mothers, often bear the greatest burden of care for boys and youths with Duchenne. For a typical example of our common story, please visit our RSS feed site and view "A Mother's Tears" by Mrs Pam Bianchi, our current secretary.

<http://www.pageflakes.com/debrobins> For more information about Duchenne and Parent Project Australia, visit our homepage and scan our activities to date. [www.parentproject.org.au](http://www.parentproject.org.au)

Last Sunday, we made the terms of reference for this inquiry the topic of our fortnightly live chat session. As a result of these discussions and others we have had whilst networking for a combination of 30 years as carers of males with Duchenne, and with the blessing of our management committee, Pam and I have listed the following facts about our lives with DMD, in order for our leaders to grasp the nature of care for our parents, siblings and wider family. A lack of consideration for our children features strongly and causes us greater anxiety because they are our world:

1. Some years ago a study showed that the cost (both personal and social) of rearing a child with DMD to age 20 in Australia was around 3 Million, yet we have not invested significantly in the laboratory and clinical research which would expedite treatments, not only for Duchenne but for all types of muscle injury: workplace, sporting and cardiac disease.
2. In April 10, Child Neurology, Kenneson, et.al., <http://tinyurl.com/4szm4x> suggested that individuals with MD, have expenditures 10 to 20 times greater, relative to others without MD; and from 15-19 yrs have the highest number of hospital visits. Yet respiratory equipment like cough assists, which would reduce hospitalizations are not available on government medical aides subsidy schemes.
3. Experienced physiotherapists are critically short in our centres of excellence. This professional is the most important person in a boy's life. An experienced physiotherapist can add up to a decade of quality life by preventative care, saving society the need for many invasive orthopaedic and respiratory interventions, not to mention corrective equipment and hospitalizations. Everyone is being disadvantaged by the shortage with some families no longer receiving any service at all in some areas.

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Our therapy services cannot compete with the wages offered in the public health system for instance. Immediate recruitment, domestically and overseas, is required, wage rises and incentives to acknowledge the importance of this holistic and practical profession for Duchenne and no doubt other disabilities.

4. The prognosis of our disorder is very predictable in terms of universal milestones yet the services granted across states and within states are not comparable. i.e. respite, re-current funding packages, wheelchair repairs, educational/vocational assistance, recreation, equipment subsidies, transport costs etc. There are huge disparities based on age, geographical location and city Vs country, advocacy ability etc. We request national benefits and sales tax/subsidy considerations for equip, transport, electricity for life-support etc.
5. As we save our government for providing care to severely disabled dependants, carers sacrificing their careers and employment should receive greater support and acknowledgement via information, services and financial assistance.
6. Qld Government re-current funding packages or Family/Adult packages are like winning the lottery – a handful are given out whilst hundreds apply.
7. Benefits based on age of the disabled person throughout Australia are discriminatory as are other causes for a high level of unmet need.
8. There is a great disparity between service providers with some doing a very good job and others very nonchalant in their attitude to supply and provision of our support needs.
9. As a group of overburdened carers, we are often too tired to advocate for our children. Our carers need an advocate/case manager who is disability specific and who has access to a comprehensive database of benefits to assist all equally.
10. Our children require independent living/palliative care centres so that they can experience adulthood and so that carers can experience a period of retirement from 24hr work.
11. Our children and carers require adequate respite services and national support for their vocational and educational pursuits.
12. As members of an international association, we are aware that overseas models exist from which we can learn a great deal. Rather than reinvent the wheel, why not draw from some of these successful models?

Thank you for this opportunity to share some facets of our members' lives as carers.

Yours very truly



Deborah Robins  
President  
Parent Project Australia Inc



Pam Bianchi  
Secretary  
Parent Project Australia Inc

The opinions expressed do not necessarily represent those of Parent Project.