23/07/10

SUBMISSION TO THE DISABILITY CARE & SUPPORT PRODUCTIVITY COMMISSION

To Whom it May Concern,

Whilst I am a voluntary director/advocate/webmaster for a national non-profit for Duchenne muscular dystrophy, Duchenne Foundation, I make the following submission based on my individual perceptions and do not speak for families affected by Duchenne, by consensus (which we have done in the past, staging online chats prior to summarizing a submission). However, I believe that much of my story is common to those with whom I network regularly online and in person, for much of the past 15 yrs.

Background

Many times my son and I have participated in wider disability forums, consultations and inquiries. Many times in the past 20 yrs I have attended these meetings and made written & verbal submissions on behalf of my family and our wider physical disorder. Each time, nothing, no action has been taken and the huge expense of the inquiries have simply identified need - which everyone knows too well by now - is unmet. The present system creates unmet need. In the present system in Queensland only a handful in hundreds wins the lottery of affording even part-time facilities and care for a handicapped person, who will as a result, never have the opportunity to give his care giver adequate respite, let alone live independently from his parents. These successful people are usually part of the welfare system to begin with or have multiple children with the disorder. My family has only received flexi-hours by service providers (though both parents have always worked which means we have even less time for a normal family life or recreational life) and as a non-ambulatory early teen these were as low as a couple hours a week (often none where no carer could be found for months/years and this is common outside the Brisbane metropolitan area where we have always lived). At present, as an almost helpless and severely disabled youth for the past 13 of his 22 years, my son has 11 hours a week. This has only been the case since last year – prior to that, his first three years of university were completed completely unaided. How did he cope? Our government let him sit for periods on a public path until a passer-by moved his arm back onto his joy stick for him; our government didn’t care about his personal hygiene because he sometimes lacked the strength to hold his own urinal securely when alone; our government watched him put a pencil in his mouth to press the buttons on the elevator or arrive late to lectures because nobody came by to open heavy doors. He struggled with assignments and exams and he should have had the physical help that youths in other states of Australia had to complete his tertiary studies – some who would not leave the house without an aide supplied by their post-school service provision. Where was the equity? Since we have less access to respite in regional Qld, perhaps this lack of regard & services has also been due to him studying at a rural university? I am proud of my son for such independent spirit in the face of adversity that it beyond the comprehension of most people, but his life could have been made easier if we had both had more support.

In addition to this, we have been kept busy with medical and genetic advocacy for our children, pre-occupied with hope for saving their lives and the lives of their unborn peers in the future. In trying to raise the profile of Duchenne so that we can advocate for medical care that exists in other industrialized societies, Duchenne Foundation has been the lead organization in the establishment of a national genetic registry which will give all greater access to innovative international clinical trials. We are at present a member of the NMAQ which seeks comparable interdisciplinary medical and clinical services for Queensland to other states of Australia. We have not begun to lobby for the much needed life-saving equipment our youths should have, but chose instead to supply our clinical partners around Australia with this equipment via grants (from such wonderful foundations as Shane

Warne Foundation & St George Foundation) and fundraising so that access can be shared and so that we are leading in implementing the gold standards so that the practices will spread. However, individuals should have the funding to be able to buy equipment that is needed for quality of life. So having to struggle with day to day care AND battle for better care is a huge additional hurdle and for some families a first priority, when our political charters about persons with disabilities and access legislations should make living conditions for the disabled, a given.

The govt already has these answers, knows the extent of the problem and yet is content to let every mother and perhaps less often, other relatives, carry the burden of care, or the burden of guilt because she/he must work and cannot provide adequate care for 24 hours a day. Who has given these mothers any respite from waking sometimes 3-6 times a night to adjust a virtually paralysed human being in his bed? No one & often these women must not only function as home makers and carers every day following the nights, but many must engage in earning a living and hold a job as well. There is no point in identifying more unmet need. Now is the time to say “sorry” for the neglect by rectifying past mistakes as soon as possible...before this generation of mothers and their issue vanishes and the next generation, not quite so worn out, are doomed to keep plodding along in their wake.

Scope of the review
The Productivity Commission is requested to undertake an inquiry into a National Disability Long-term Care and Support Scheme. The inquiry should assess the costs, cost effectiveness, benefits.

There are two questions here. Where is the money to come from to provide care, treatment and equipment for persons with a disability and what support can our carers and disabled access to contribute to society and feel valued in return? The money can only come from compulsory saving in the form of a contribution/tax. As a founder/director/webmaster of a non-profit for Duchenne since 2003 (Duchenne Foundation) I know there is no easy way to fundraise from random donations/goodwill – a mandatory response is required to meet so much need. Australia may have to test an amount and adjust it if necessary in order to estimate the costs accurately in the eventuality that a person becomes severely disabled. I am not just talking about accident victims – many disabled persons affected by a medical/genetic disorder are equally ‘accident victims’. All members of society are at risk of being affected by genetic disease. It is not associated with any particular class or racial group but in the case of Duchenne it is more often than not, caused by a spontaneous mutation to the biggest gene in the body - no doubt from environmental contamination. I rarely meet a new family nowadays who had a family history, so genetic counselling is not the answer, nor reproductive technology, because with these things in place, the incidence is not dropping. It can happen to anyone’s son, grandson, brother uncle, cousin, friend. It is the most common and severe muscle pathology of childhood. Only by contributing to this possibility of an accident before, during and after birth, can we all rectify the injustice of so much unmet need.

I am an individual with a specific knowledge of my own son’s disorder, but I know he requires more time in the company of other people, access to 1st world medical and assistive equipment and more respite than we currently receive. A monthly one-night a month “turning service” like the one operating in the capital would be such a treat – the chance to sleep through the night, one night a month! When clients were asked for suggestions from a local service provider a handful of years ago, I suggested this service and offered to do more research, but the thought of having 2 young men turn disabled boys at night instead of in the daytime, was anathema and for this single additional nocturnal shift, the response was that it would be a whole new direction and require a new desk jockey with a computer to coordinate it! This is ridiculous, by thinking outside the square, much of what we need and want, should not amount to the insurmountable hurdles that some would have us believe. What makes such an idea possible in a large city but not in a rural one?

My son has completed his tertiary studies (Arts degree) despite very great adversity and a good measure of community service himself. He was stymied from doing more study and so now he is waiting to die. I do not know where to go, to find a new goal for him now. I do not know what will be his contribution to society beyond the advocacy contribution he made as a member of the youth roundtable in school and as a member of the regional disability council after school. As for myself, I have so many skills and ideas but I am not able to begin to find work online so that I can physically be a support for my son. These jobs are almost never advertised but I suspect if they existed, many carers could make a good contribution to society and lower their level of guilt for neglecting their disabled adult, by working online from home. By creating an online employment agency for carers, and advocating for positions for them in their domains of expertise, we would be supporting them to use their skills and raise their levels of satisfaction with their role as well as helping the economy and needing less welfare support and fewer external in-home carers.

In undertaking the inquiry, the Commission is to:

1. ***Examine a range of options and approaches, including international examples, for the provision of long-term care and support for people with severe or profound disability.***

One example that has come to me recently from a leading respiratory expert and physiotherapist in Belgium is interesting to me, having heard a lot about the thorough provision of care, services and equipment in The Netherlands and Denmark, neither of which are means tested. This is what Michel Toussaint had to say in an email dated 6/7/10. :

<snip>

Deb, Marie told me that you worried about the future of Doug. The question was if some of our Belgian Duchenne guys are working. Well, there are not much. There are several explanations for that.
First, the Belgian social system is so extended that handicapped people >21yrs old receive a disability pension (± 1600/month Austr. Dollars) that may be enough to live with their parents without working. In addition they receive a budget to live assisted by carers at home (± 3000/month Austr. Dollars). With this money, they may hire carers 24h/24. They lose this budget when they work, naturally.
Second, when they work but lose their job, they must wait for 6 months before retrieving their disability pension and budget.
And third, the disability being still progressing, it makes it difficult to work on the long term without heavy, extended and expensive technical and human aids.
Another point is that there is often bad weather in Belgium, and this makes it hard to move without well-adapted cars, vans or others, with a driver, etc.

I know my answer is not very positive, but I won't lie on a so sensitive matter. Parents of older Duchenne boys all worry about the future of their sons. This is hard, I know that. We are following more than 100 Duchenne in my Centre. I face with this reality every day!

<end snip>

We hear stories about the good level of care for boys/youths with Duchenne right through their 20's, 30's and beyond and we ask, "Why?". How can human life be so much more valuable in these small, overpopulated European countries and throughout much of the USA? How can it take my organization 3 yrs of lobbying to convince the government that we needed a National Duchenne database so that our kids can participate in potential strengthening clinical trials? The Belgium example is one of a great many – obviously everyone in Belgium feels that they should contribute to the maintenance and sanity of all people afflicted with disabilities through no fault of their own. Early intervention is possible with Duchenne but often a child can reach 6 yrs of age and be undiagnosed. Newborn screening in future for a number of genetic diseases, may change that but the same principle applies. With early intervention, a family can preserve their strength and become more resilient and less likely to crack under the strain.

Another online support volunteer via Duchenne muscular dystrophy networks, with both German and USA citizenship, has shared the German model with me, <snipped below>

<snip>

I showed the video to A's first aide, G, with whom I'm still in contact. He's from Hobart originally, but lived in a number of different places in Australia after college. He was an elementary school teacher. Eventually, he left teaching to work with kids in other contexts outside school. He didn't like the typical school hierarchy. He ended up in Germany and started working with A when he was in 2nd grade. That was one of the best things I ever did. He really helped A on his way to developing independence. We needed to get someone else when A entered puberty, because G was specialized in working with children and had as much trouble with an adolescent as I did. He really worked hard to get us the best replacement I could imagine, a guy who is just as good with teenagers as G is with children. We've been very lucky with these two.

Anyway, G was stunned when he saw the video and the mad as hell website. Now he's mad as hell too, signed their petition, and will try to make his Australian friends aware of the situation. One reason he was so surprised is that things like accessibility and civil rights legislation are better in Australia than here in Germany. He just assumed everything was better in Australia. This is one of the reasons it's so important to have these international contacts at different levels. We can see what is available elsewhere and realize we need to fight for it where we are.

Anyway, G ended with the following statement: "Now I know why I don't know how to translate my job title into English. It isn't" And it really isn't. He's a specialized type of aide with pedagogical training whose job it is to help people with a disability to become more independent. This doesn't exist in the US either. Germany does this very well, is good with durable medical equipment and long-term care, but is terrible on accessibility, anti-discrimination legislation, and inclusion in schools or the workplace. So I have my worst fights in these areas. I dream of a day where the playing field is level all over.

I think you've laid a good basis with Doug's independence. The question is how do you keep going from here. A lot of kids with DMD are just smothered by anxious parents who keep them as children forever. There's a guy near us who is nearing 40. He doesn't even drive his power chair by himself anymore. The technology is there which would make it possible for him. He could get it. But his mom had a steering unit put in the back and she drives him. She's been a mother hen all his life. He's still a child. You've given Doug a situation in which he could grow into a man. Now what he really needs is the sort of independent managing of his own personal care attendants that JM used to write about. He needs a couple of people who work for him who he directs to do the things that he can't do, like get him dressed, help him with toileting, eating, and all that. It's just a crime that he can't simply apply for this and get it funded.

The following information might be interesting to have when you're lobbying, just to show that a disability insurance can work and what pitfalls their might be when designing it.

Germany has a compulsory long-term care insurance which is separate from but related to the compulsory health insurance. It works like this: When I am employed somewhere, the employer deducts a percentage of my pay from my pay check and sends it to the health insurance company of my choice. One sum is for health insurance and a much smaller sum for long-term care insurance, a separate insurance based with the same company. The employer is also required to pay a certain amount towards both insurances as well, how much is calculated based on what I earn. It's part of the cost of employing someone. There are similar systems for the self-employed. For the unemployed, their unemployment insurance makes the payments for them. Family members who don't work are insured free of charge with whichever family member has the highest income. Children can be insured for free with their parents up to I believe 27, unless they have a real job in which case they are insured on their own. If a person becomes disabled, the person is eligible for long-term care. How much exactly is determined by the degree of disability. The money can be used to compensate a friend or relative of choice, who then also gets payment toward their retirement pension. It can also be used to employ professionals.

This system alone unfortunately does not pay for all of the care that someone with a condition like DMD needs, who essentially needs someone around the clock. It was designed primarily with seniors in mind who need someone to come in a few times a day. In the case of people who need more care, there is a secondary funding system available which takes the person's income into account, also the parents' income in the case of a minor. As a university lecturer, I don't earn enough to have to pay anything towards A's care. If I were a wealthy attorney on the other hand, I would have to pay something. I don't know the formula, but you have to be well into the upper middle class to have to pay part of the care, the sort of person who then might have to sadly downgrade from a BMW or a Mercedes to a normal car like what the rest of us drive in order to pay for the care. The system isn't perfect. I had to fight to get the extra care beyond what the normal insurance pays, but I did get it.

Once a person needs a ventilator, the care is paid for by health insurance, as a person qualified to manage a vent is needed.

So for A’s, the setup looks like this: He has 17 hours per week of this special pedagogically skilled aide who is paid for by youth services. He has a right for up to 24 hours of assistance which is partially paid for by long-term care insurance and partially by this secondary system which steps in after you go beyond the maximum. Since he has the 17 hours of the pedagogical aide and is in school or at a youth rec centre most of the day, he typically 'only' has about 12 hours of the regular long-term care per day during the week and 22 hours on Saturday and Sunday. (I insist on two hours in the morning with nobody else in the house so I can get up and have a cup of tea, read the paper, eat breakfast and so on, while the kids are still sleeping and without anyone else around.) A first world country can finance this. Germany does. Holland has similar structures. I'm sure a bit of research would yield quite a few European countries with a system which is at least partially insurance based.

Now if Germany would only wake up and realize that their school system is in flagrant violation of the UN Convention for the Rights of Persons with Disabilities which they (finally) signed! Most kids with disabilities are still segregated in "special" schools. Getting A in a 'normal' school was something that I actually didn't have to fight for, but, we're in Berlin, not out in the countryside. For many here, that is a fight they can't win. The state of Hesse for example even argued that education is a state matter, and the state of Hesse didn't sign the treaty, only Germany did, so Hesse isn't bound by it. I could scream when I hear these things!
<end snip>

G refers to Duchenne Foundation’s recent fundraising and trial for non-invasive ventilation for our older youths who cannot leave their bedrooms and rely on night time ventilation only. See our respiratory page which outlines both this device including a wonderful feedback of the outcomes from one of the young men.

Indeed some states of Australia have respiratory services which supply diurnal ventilators and others do not, in Qld for instance only nocturnal ventilators are supplied, not daytime portable vents so that our boys can have some quality of life using NIV as opposed to invasive ventilation. G believes that these things are a “given” with their system of care and he expands on this system in a second post....

<snip>

Here are a few details about the German system that I forgot:

For the chronically unemployed who end up on welfare, their payments to long-term care insurance (and also for health insurance) are part of their welfare benefits. As a result, literally everyone is in the system in one way or another: as an employee or as a self-employed person, as an unemployed person, as a welfare recipient, or as a family member of someone who is insured in one of the previous ways.

The health insurance companies that also do the long-term care insurance are a special sort of non-profit company. I'm not really sure how to explain it in English. These are incorporated entities that are regulated by an area of law that also applies to the government. They are not for-profit companies. They have to be responsible and transparent in the same way that government entities need to be, but they aren't government entities. There is competition between them, but they all have a basic catalogue of services they are required by law to offer.

This catalogue is fairly abstract. It isn't a listing of services per se, but rather a basic definition of the kinds of things you have a right to. There is a complex structure of committees and subcommittees that deals with more concrete questions about specific services. The highest level committee has members representing the physicians, the hospitals, the health insurance companies as well as 'impartial' members. Representatives of the patients have the right to examine documents and make motions.

The main problem that I see with Germany's system is that it was designed when people first realized that the population was aging and they didn't think much beyond the typical senior. Most are at home and just need a bit of care. Others are in a retirement home and need that to be subsidized because their pensions can't cover the full cost. The designers of the system didn't anticipate the needs of people with chronic conditions which lead to severe disabilities and a need for round the clock care for many years. That's why people with DMD end up needing to get the supplementary financing as well.

The amount of money the long-term care system pays: This depends on two factors. One is the work done by professionals or by friends/family. The other is the severity of the disability, with people being divided into 3 basic classes.

Care done by professional:
Class I: 440 Euro maximum
Class II: 1040 Euro maximum
Class III: 1510 Euro maximum
Class III+: 1918 Euro maximum

A has had class III+ for years. 1918 Euro is nowhere near enough to pay for round the clock care for a month, so the secondary system has to step in. Without the secondary system, we'd be in trouble. With it, everything works fine.

Care done by friend/family
Class I: 225
Class II: 430

Class III: 685
No class III+

As you can see, the family member doing 24/7 care is a cheap alternative.

The systems can be combined. The person with the disability chooses what he/she wants.

A typical trap that people fall into is the following: A parent stays at home to take care of a child with DMD. Either that person is already a single parent, or over time the marriage falls apart and that person becomes a single parent. Initially, life seems manageable with welfare for a parent and child plus 685 Euro tax free which doesn't count when the welfare is being calculated, and payments for the caregiver's retirement pension are also made. So the income plus getting pension benefits later is kind of like having a real job. But, the care needs go up and up and up and eventually the caregiver is overwhelmed. Professional help is needed to keep the caregiver from burning out. But if professional help is brought it, the family loses the 685 Euro that has made life significantly above the poverty line possible, and, the caregiver loses the payments for their retirement pension. The typical caregiver in this situation has been unemployed for so long that most don't have much of a chance to compete in the workplace, at least not initially. People have real trouble breaking out of this. I've spent a lot of time trying to convince people with young kids here to accept professional help early and stay in the workplace. The people I know who have done that are much better off. These are typically people who had good jobs they didn't want to give up anyway. Most people don't see the trap ahead of them when their kids are 10 years old, and they fall head first right into it. The system could use some sort of funding for re-integrating these people into the workforce.

About the point that Doug could use some help in the mornings: Absolutely! It's easier said than done, but try and put a percentage of your energy into getting care for Doug somehow or another.

I've been putting my energy with respect to care into making sure that the system is set up so that A becomes responsible and independent. JM really influenced me early on. I use a family business metaphor. The pedagogical aide and the four home health care aides from the agency are employees of the family business. Right now, I'm running the business, but A is in a sort of apprenticeship. He's learning how to run the business from me. As time goes by, he assumes more and more responsibility. He manages most of the day to day stuff like the schedules. He does most of the training. I supplement him in these areas. The hiring decisions we make together. I do the firing because he just doesn't feel comfortable with that yet. But, if we need to fire someone, I talk to him in detail about it before we do and he is part of the decision. Ultimately, he needs to be able to hire, train, manage and fire his aides. The pedagogical aide is a bit like my lieutenant. He helps me train A to take over the family business.

<end snips>

The Commission is to include an examination of a social insurance model on a no-fault basis, reflecting the shared risk of disability across the population. The Commission should also examine other options that provide incentives to focus investment on early intervention, as an adjunct to, or substitute for, an insurance model.

If motor accident victims can be “no fault” so can persons with genetic diseases. With Duchenne, it affects 1 in 3,500 males in all cultures. It is supposedly hereditary (an x-linked disorder passed through the female line with a possibility of a 50/50 chance of boys being born with Duchenne or girls being born carriers of DMD. But more and more I am not introducing myself to mothers whose brother and uncles succumbed to Duchenne. Women are not selfish or foolhardy and avail themselves of reproductive technologies and genetic counselling. However the incidence rate is not declining. More of our cases result from spontaneous mutation to the biggest target in the body – the dystrophin gene. There is no way anyone then can predict whose son, grandson, brother, uncle, cousin, friend will be affected.

And what will happen to them? Please view our 6 min clinical presentation about the progression of Duchenne. Briefly - walking, moving one's arms, breathing and living are not only compromised but this loss of strength on such a grand scale is almost certainly ensuring that only a handful of adults from making 30yrs of age. Early intervention in terms of respite and care may not be appropriate for our children who begin life normally and treasure this 'honeymoon period' but early intervention in terms of medical care and genetic services is crucial to our children if they are to be maintained with best possible abilities. Early intervention with cognitive and emotional issues too means that they are better educated and in youth and adulthood (which more are reaching lately) they will have the skills and intelligence to contribute to society if they are taught appropriately...so even though our disorder is progressive and becomes physically severe around adolescence, earlier intervention and support can have a great impact on long-term health and fitness.

I don't believe early intervention can be a substitute because what you are doing then is investing in the young and putting youth and adults on the scrap heap – this is ageist. To survive beyond 22 yrs with some dignity, my son is likely to need: a bi-pap (which some need in their mid-teens), an orthotic device to move his arm, environmental controls, a ventilator and a personal cough assist machine that he doesn't have to share with the community. We have had subsidy for an electric wheelchair, provision of hoist and shower chair and a non-profit has given him his electric bed on loan, but physical carers and facilities should be provided so that he can pool these resources with other youths and live independently of his parents as all young men in Denmark do.

The non-physical facets of early intervention must be considered part and parcel of the overall insurance model entitlements, albeit not strictly medical in nature, if the disability has not progressed to a point of needing physical support or if a disability is not a physical disability.

2. The Commission is to consider the following specific design issues of any proposed scheme:

- **eligibility criteria for the scheme, including appropriate age limits, assessment and review processes**
- **coverage and entitlements (benefits)**
- **the choice of care providers including from the public, private and not-for-profit sectors**
- **contribution of, and impact on, informal care**
- **the implications for the health and aged care systems**
- **the interaction with, or inclusion of, employment services and income support**
- **where appropriate, the interaction with:**
- **national and state-based traumatic injury schemes, with particular consideration of the implications for existing compensation arrangements**
- **medical indemnity insurance schemes.**

There are so many service providers already and the solution must be to put the funding with the family so they can decide on the best option for them and have more freedom to hire those who are suitable and not put up with substandard care from those who will not continue as originally trained. Families should have the right to choose between services or find another solution. The continence scheme recently changed its disbursement of funding to this model. Choice is the key. For years we have had little choice about who cares for our children. We know not to complain too much because any criticism could lose the only carer that the SP had been able to find and that a substitute will not be found readily – we are even reminded of this upon occasion. It is particularly dissatisfying when these are not fully funded hours but hours that we ourselves contribute to financially. Our children need training in dealing with carers as much as carers need training to care for children with Duchenne.

I have already suggested that an online employment service for carers and persons' with disabilities be formed – the service itself could be run by those with a disability and those family members who care for them, who do not wish to abandon their dependent to leave home for work.

I also have firsthand experience as a volunteer for my non-profit for a specific disorder (Duchenne Foundation formerly Parent Project Australia), not a general disability organization such as MDA, which caters for 50+ separate disorders and in all fairness must continue to do so, given that they were instituted in a period in history when the scientific paradigm was that all presentations of muscle weakness regardless of age of onset or muscle groups affected or progression, were one single disease.

Duchenne Foundation provides specific up-to-date information through our website, discussion list and through 3 joint national conferences in 7 years with international and national experts, but we struggle to fund specific research and to lead in advocacy for our disorder because volunteers must also fundraise to meet costs. There should be grants available so that advocacy organizations like ourselves can be assisted, not only to raise awareness for the most common muscle pathology of childhood (from which few survive into adulthood) but to continue to provide specific support, advocacy, accurate information (not the misinformation that is posted on sites which are not validated by medical professionals or are only geared at tugging at heart strings for donations) and first world treatment and care standards for Duchenne(& sister disorder Becker) muscular dystrophy through our global support network, the international United Parent Projects Muscular Dystrophy. This network, like ourselves comprised of medical experts and family members (who are necessary to ensure that our agenda is always to strengthen our sons as a first priority) has the history, scientific and medical knowledge and the advocacy experience to guide us. With funding, we can do an even better job, not only for our children who are sidelined but by show casing our humanitarian researchers in Australia who are sidelined along with us. There simply is not enough financial support for the innovative work we do on a voluntary basis for those upon whom Duchenne & Becker impacts. In our volunteering, we suffer and we are overworked but we see the benefits and new knowledge we can bring to our stakeholders and we cannot do otherwise. So groups such as ours, who have proven with the calibre of their national and international activities to be solely motivated to the alleviation of a single disorder, require assistance because all disabilities and all muscle disorders are not the same – science has proven this in the mid 1980's when the biggest gene in the body was first discovered – the dystrophin gene, responsible for the production of a protein missing in children with Duchenne muscular dystrophy.

We should not forget, and my son is a living example of this being fortunate to have top care with MontroseAccess and best physiotherapy practices in the world, that with good care and preventative treatments, a great saving in costs to society can be made. My son may not be an exemplar for his disease, in fact I know he isn't, but it is true that his muscle necrosis and chronological age should have seen him need the following, long before this point in time: back rodding surgery and the follow up care; bi-pap nocturnal ventilation and frequent hospitalizations from bouts of pneumonia. By preventative measures on behalf of this centre of excellence and non-profit, they have saved our society a considerable amount of money because my son has not required these measures in mid-teens. The same principle applies to early and proper concern for all disabled persons – it will amount to a long-term saving in social costs.

The bulk of the inquiry terms seem to focus on logistical solutions. I regret I don’t have many concrete suggestions for the big picture system (s) beyond the general idea or the international examples cited above. I am confident that many in society will supply these alternatives, but it is important that all end users have opportunity to input into the logistical aspects put forward because some carers are so exhausted and those with disabilities so unfamiliar with horizons long reserved for the able-bodied in society, that many of us would only recognize the possibilities if we are made aware of them in discussion; and also because many of our disorders are marginalized and overlooked, we should all contribute to outlining the many practical needs of families living with a disability in this country – needs which deserve to be finally met.

Yours very truly

Deborah Robins

“I am writing to congratulate you for the wonderful work your Foundation has achieved for boys with Duchenne muscular dystrophy. Having children of my own and a young son, this disease is heartbreaking not only for the boys but also for their families" ~ Shane Warne

NB The opinions expressed do not necessarily represent those of Duchenne Foundation