

21st July 2010

Dear

Cough Assist Machines

Cough assist machines are inexpensive cost effective items of equipment which can reduce hospital length of stay and risk of inpatient re-admissions, save money and improve patients' health outcomes and quality of life.

I am writing this letter because the Muscular Dystrophy Association (MDA) believes that all people with impaired or no ability to cough as a result of a neuromuscular condition should have publicly funded access to this technology, irrespective of where they live.

The MDA supports people who may have one of over fifty different neuromuscular conditions, including muscular dystrophy itself. All of those with these conditions experience incurable, irreversible and progressive weakening of their muscles. It is not just their legs and arms that may be affected but also their respiratory muscles that enable them to breathe and cough.

A person who does not have the muscle strength to cough effectively can not clear their lungs. This in turn results in increased risks of repeated respiratory infections, pneumonia and frequent, long and expensive periods of hospitalisation.

A cough assist machine stimulates a natural cough, allows people to clear their lungs, and thereby mitigates these risks. I attach some of the evidence affirming the efficacy of cough assist machines which may be summarised as follows:

- Prolonged survival of patients with Duchenne muscular dystrophy (Gomez-Merino and Bach, June 2002)
- Improved life expectancy for children with spinal muscular atrophy, together with fewer hospitalisations, freedom from daytime ventilator use, and the ability to speak (Bach et al, July 2002)
- Prolonged survival and delayed need for a tracheotomy for patients with amyotrophic lateral sclerosis (Bach, February 2002)
- Improved quality of life and prolonged lifespan for people with neuromuscular diseases (Kang, June 2006)
- Prevention of pulmonary complications (Miske et al, November 2003)
- Avoidance of intubation (Servera et al, November 2005)
- Improved management of airway mucous encumbrance in neuromyopathic patients (Vianello et al, February 2005)
- The higher the cough flow, the more effective the cough and the less likely that airway secretion accumulation will result in respiratory failure (Bach, 2003)
- The only currently available therapy that assists the expulsive phase of coughing, which is critical in airway clearance (Finder, July 2006)

- Physiologic improvement for patients with chronic airway secretion encumbrance associated with both obstructive and restrictive disease, suggesting that patients other than those with neuromuscular conditions may also benefit from this technology (Winck et al September 2004)
- 75% drop in the rate of hospitalisation for pneumonia in Duchenne muscular dystrophy after commencement of use of protocol-based respiratory management (personal communication with Jonathan Finder, MD, Professor of Pediatrics, University of Pittsburgh School of Medicine, July 2010)

It currently costs about \$7500 to purchase a cough assist machine, which is comparable to the cost of treating one person in an intensive care unit for two days, followed by five days in a hospital ward (personal communication, Assoc. Prof Andrew J. Kornberg, Director of Neurology, Royal Children's Hospital, Melbourne, February 2010). The money that would be saved through fewer hospital admissions and reduced length of stay suggests that purchasing cough assist machines would be a good investment for DHBs, and we strongly recommend that you include them in your minor capital expenditure budgets.

International estimates suggest that the number of people in New Zealand with a neuromuscular condition is somewhere between 1200 and 4300. The MDA has about 1000 people with a condition among its membership. It is likely that this population experiences high hospitalisation rates, and that all DHBs will have a continuous need to provide appropriate care and interventions.

Up to now most of the cough assist machines that are used by MDA members have been purchased by the MDA itself. We have seventeen machines, all of which are in use and allocated to people who live in eight DHB catchment areas (two in each of the Auckland, Canterbury, Capital Coast, Waikato and Hawkes Bay DHB areas, three in both the Mid Central and Taranaki DHB areas, and one in Otago). These machines help a number of our members stay within their homes and out of hospital. They maintain their respiratory function and keep their chests clear, allowing them to go to school, go to work and be a part of their community.

However, the demand always outstrips the supply. We are a not for profit organisation and we do not have unlimited resources that allow us to continue to purchase more machines. In any case, we believe that our members are entitled to have this technology routinely available to them through the publicly funded health system.

I acknowledge that some DHBs have already invested in the purchase of cough assist machines, including Counties Manukau, Auckland, Waikato, Nelson Marlborough, Capital and Coast, Hawke's Bay, Canterbury, Bay of Plenty and Mid-Central (through Enable NZ). There is a close correlation between these DHBs and the areas to which MDA's cough assist machines have been allocated. We surmise that clinicians in those DHBs, having seen the benefits to patients of the MDA's machines, have then gone on to successfully make a case for acquisition by their DHBs.

We believe that all of our members are entitled to have the opportunity to benefit from cough assist machines irrespective of where they live, and we strongly recommend that those DHBs which have not yet purchased any do so. Those DHBs which have already purchased their own machines may wish to take the opportunity to review whether they have sufficient numbers.

About three months ago we wrote presenting a case for cough assist machines to all District Health Boards, including your own, via the respiratory services clinical leader

or closest equivalent that we could identify from DHBs' websites. Those letters appear to have received very little interest.

I hope that this revised and hopefully more compelling letter will be received differently. Please let me know if you require further information, or if you'd like to meet with us to discuss further.

I look forward to your response in due course

Yours sincerely

Chris Higgins
Chief Executive