

Authors' Response to Commentary

We thank Bach and colleagues for their detailed commentary on our article in which we describe the results of a survey in which families report their use of therapies outside a paediatric tertiary health care centre in Melbourne, Australia. The aim of the survey appears to have been misunderstood by Bach et al. We aimed to *record the use and perceived benefits of community-based mainstream allied health services and complementary therapies in a paediatric population of males with Duchenne (DMD) or Becker muscular dystrophy (BMD) as opposed to the aim presented by Bach et al. in their commentary: "Its objectives were to present mainstream and alternative therapies to maintain people with DMD and BMDs as active as possible"*. In essence, this survey was about what therapies families' access outside of the hospital, not about the efficacy of treatments to delay disease progression or prolong life. The therapies surveyed fell into two categories: mainstream therapies (PT, OT, Dietetics, Speech Therapy, Psychology, etc.) and complementary therapies (massage, naturopathy, chiropractic, etc.). In Australia complementary therapies are considered 'alternative' therapies and are not sanctioned or provided within the mainstream healthcare system. However individual patients and their families may choose to independently access complementary therapies in addition to 'conventional' treatments.

Respiratory care *is* a critically important element of the care of boys and adolescents who have DMD who attend the paediatric Neuromuscular Clinic at The Royal Children's Hospital. This respiratory care is provided through tertiary hospital clinics, and is regarded as 'core', rather than complementary. It was therefore

not specifically addressed in this survey of *community-based services*. Australian physiotherapists teach airway clearance, lung volume recruitment, manually and mechanically assisted coughing as well as prescribing muscle stretches, exercises and equipment. They work with respiratory physicians, nurses and technicians to provide comprehensive respiratory care as a vital part of management of children with neuromuscular disorders. The physiotherapy alluded to by this paper was not the subject of this study, and was therefore not discussed in any detail.

The authors of the commentary state, in respect to the means of respiratory support they provide to their patient population; "All of these therapies are at least as important, indeed more so, than stretching skeletal muscles, nutrition, speech therapy, and psychological support for people who are unnecessarily made to think that they will die as teenagers". There is no mention in our paper of any prognostic counselling provided to patients. We regard this statement as unwarranted and disrespectful. We provide holistic care addressing all aspects of patients' medical and psychological needs, and reject the suggestion of Dr. Bach and his colleagues that respiratory management is the only intervention with significant impact upon medical outcomes and quality of life for patients with Duchenne muscular dystrophy.

Katy L. de Valle, Zoe E. Davidson,
Rachel A. Kennedy, Monique M. Ryan,
Kate M. Carroll
E-mail: katy.devalle@rch.org.au