

Every week around 2 boys are being born with Duchenne Muscular Dystrophy. Although there has been a gradual improvement in the management of the condition boys are still dying in the UK at 19 years. DMD is a devastating genetic severe muscle wasting disease for which there is no cure. About one third of new cases are new mutations of the gene that occur out of the blue and can affect anyone, having no regard of background or race.

The Government funding into neuromuscular conditions prior to 2004 has been quoted from between £1 million and £2 million. However, it is believed much of this was not specifically on neuromuscular conditions, rather associated research with considerably less than £1 million actually being spent on Duchenne Muscular Dystrophy research. The Department of Health's funding of the MDEX exon skipping project in 2004 of £1.6m has been groundbreaking in developing one of the first clinical trials for a potential gene therapy for DMD in the world. The subsequent grant of £600,000 from the MRC will help to develop this research project for other exons and for multiple administrations of the Antisense Oligonucleotides.

We would like congratulate the Government on these recent initiatives despite the woeful record of previous administrations. However we would like to ask why the MDEX consortium has had both its original grant applications cut for this project? What strategic planning and funding is in place to ensure that any successful clinical trial will lead to the rapid development of treatments for boys with DMD?

Gordon Brown, the Chancellor of the Exchequer, announced a Review of Government spending on Health Research in this year's budget. He is proposing to pool together current Department of Health and Medical Research Council (MRC) spending on health research and create funding for 2007/8 of about £1.3bn with the possibility of new money. Pooling the budgets in this way could give a much more focussed way to stimulate more research for DMD. A pooled budget could and desperately needs to provide a significant strategic budget for a devastating neuromuscular disease like DMD.

We would like to propose to the Government that Duchenne Muscular Dystrophy research is granted £20m of ring fenced funding from this new proposed budget structure. Only earmarking funding in this way can we

ensure that research of the highest international calibre like the MDEX consortium project is adequately funded to deliver treatments for our sons.

Yours sincerely

Nick Catlin  
CEO Parent Project UK Muscular Dystrophy