

Advocating for Greater Awareness of Duchenne Muscular Dystrophy (DMD) – A Call to Action

Dear Her Excellency Dame Barbara Woodward,

We are writing to you regarding the UN advocating for greater awareness of Duchenne muscular dystrophy (DMD).

My name is Florence Boulton, I am the Chief Executive Officer of Action Duchenne. Action Duchenne was founded as a patient-led charity in 2001, the first national charity dedicated to supporting children, young people, and adults living with DMD.

We would like to bring to your attention the urgent need for increased awareness and support for those living with DMD. We admire your mission in representing the United Kingdom at the United Nations and wish to align our mission to improve the lives of those who are going through a challenging and untreatable health condition.

Duchenne Muscular Dystrophy is a rare and devastating genetic disease that primarily affects young boys. It is characterised by progressive muscle degeneration and weakness, leading to severe mobility limitations, including loss of ability to walk, and life-threatening complications. Individuals with Duchenne usually start using a wheelchair around age of ten due to increased muscle weakness. Most individuals with DMD experience serious respiratory, orthopaedic, and cardiac complications. By the age of 18, the majority of patients require ventilation support at night. Respiratory complications and cardiomyopathy are common causes of death. There have been a range of estimates of life expectancy with one recent study identifying median life expectancy as 22.0 years, with patients born after 1990 having a median life expectancy of 28.1 years.

We wish to share a personal account that provides insight into the challenges faced by families living with Duchenne and emphasises the transformative impact that awareness can have.

As a charity which focuses on supporting families, we have witnessed the profound impact of Duchenne Muscular Dystrophy on the lives of the whole family. The journey has been marked by physical, psycho-social, and emotional hurdles, from the initial diagnosis with overwhelming scientific medical complexities to everyday living. Simple tasks like climbing stairs or brushing teeth become unbearable challenges. Furthermore, the emotional toll on every member of the family is immeasurable.

The lack of awareness in different communities across the countries is adding another layer of difficulty. Therefore, awareness about the condition plays a pivotal role in fostering understanding, empathy, and better standards of care. A more informed society can contribute to a supportive environment that nurtures social inclusion and mental well-being.

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As representatives of the Duchenne community in the United Kingdom, we implore you to leverage your influence to advocate for increased awareness of Duchenne Muscular Dystrophy within the United Nations and the broader UK community. By raising awareness, you contribute to the creation of a more empathetic environment and transform the lives of those living with Duchenne. Together, we can make a meaningful difference in the lives of families facing this devastating condition.

In conclusion, we appreciate your time and consideration of this critical matter. Thank you for your dedication to making a positive impact on the lives of those affected by Duchenne Muscular Dystrophy.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Florence Boulton', written in a cursive style.

Florence Boulton

Chief Executive Officer of Action Duchenne

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