

Myotonic Dystrophy Foundation Chair Jeremy Kelly Awarded OBE by King Charles III

The honor recognizes more than two decades of leadership and service to the global myotonic dystrophy community.

OAKLAND, CA, UNITED STATES, July 17, 2026 /EINPresswire.com/ -- The [Myotonic Dystrophy Foundation](#) (MDF) is proud to announce that its volunteer Board Chair and Lifetime Trustee, [Jeremy Kelly](#), has been appointed an Officer of the Order of the British Empire (OBE) in the 2026 New Year Honours.

Established in 1917, the Order of the British Empire is one of the United Kingdom's highest civilian honors, recognizing individuals whose service has made a lasting and meaningful impact on society. Appointment as an Officer (OBE) is awarded for distinguished national or international achievement and service.

Jeremy received the insignia from His Majesty King Charles III during an investiture ceremony at Windsor Castle in June 2026. The honor recognizes more than two decades of exceptional volunteer service to the global myotonic dystrophy community through his leadership of the Myotonic Dystrophy Foundation.

During Jeremy's tenure, MDF has helped transform the landscape for individuals and families affected by the disease by advancing research, expanding patient care and advocacy, and building a global network that unites researchers, clinicians, industry partners, and the families they serve.



Jeremy Kelly, Board Chair and Lifetime Trustee of the Myotonic Dystrophy Foundation, displays his OBE insignia following his June 2026 investiture at Windsor Castle, recognizing more than two decades of service to the global myotonic dystrophy community.

The award also reflects Jeremy's enduring commitment to accelerating the development of treatments and, ultimately, a cure for myotonic dystrophy while fostering an international community dedicated to improving the lives of everyone affected by the disease.

Jeremy Kelly said:

"The Kelly family's journey with Myotonic Dystrophy began in 2005, when my wife, Erica, and our two sons, Jack and Ben, were diagnosed with the disease. At that pivotal moment, my late father challenged me to step back and take a 35,000-foot view of how we might change the landscape of Myotonic Dystrophy. That challenge became the inspiration and guiding principle for my work with the Myotonic Dystrophy Foundation.



Jeremy Kelly addresses attendees during a Myotonic Dystrophy Foundation conference. His leadership has helped advance research, strengthen global collaboration, and accelerate therapeutic development for people living with myotonic dystrophy.

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Jeremy Kelly, OBE, Board Chair and Lifetime Trustee, MDF

“My father was the greatest influence in my life. Following a distinguished 30-year career in the Royal Navy, he was appointed an Officer of the Order of the British Empire (OBE) by Her Majesty Queen Elizabeth II. To have now received the same honor, in recognition of my service to the Myotonic Dystrophy community, is the greatest privilege of my life.

“I am deeply honored to have received this award from His Majesty. While I am personally grateful for this recognition, I regard it above all as a tribute to the extraordinary

dedication of the volunteers, donors, clinicians, researchers, and staff who have worked tirelessly with the Myotonic Dystrophy Foundation over many years.

“Their unwavering commitment has advanced research, strengthened advocacy, and brought hope to individuals and families affected by Myotonic Dystrophy around the world. I am proud to have been part of their efforts and extend my heartfelt thanks to everyone who has contributed to this important work.”

Dr. Darren Monckton, Professor of Human Genetics at the University of Glasgow, Scotland, said:

"Over the past two decades, the field of myotonic dystrophy research has been transformed. What began as a scientific effort to better understand the disease has evolved into a global endeavor focused on developing meaningful therapies for people living with myotonic dystrophy. Jeremy recognized early that achieving this progress would require sustained investment in research, collaboration across disciplines, and strong partnerships between scientists, clinicians, industry, and the patient community.



Jeremy Kelly stands with his wife, Erica, and sons, Ben and Jack, outside Windsor Castle following his June 2026 investiture as an Officer of the Order of the British Empire (OBE). Their family's journey with myotonic dystrophy inspired his leadership and service.

Through his stewardship of the Myotonic Dystrophy Foundation, Jeremy has helped create the environment that has enabled this remarkable progress. His vision has strengthened the global research community, accelerated therapeutic development, and helped lay the foundation for the treatments and, ultimately, the cure that we are all working toward. His impact on the field will be felt for generations to come."

Dr. Tanya Stevenson, Chief Executive Officer of the Myotonic Dystrophy Foundation, said:

"Jeremy's visionary leadership over the past two decades has helped shape MDF into the world's leading organization dedicated exclusively to Myotonic Dystrophy. Through his vision and unwavering commitment, countless individuals and families have benefited from expanded patient support, world-class scientific conferences, groundbreaking research initiatives, and an increasingly robust [therapeutic development pipeline](#).

"Jeremy combines strategic vision with humility, compassion, and an extraordinary ability to unite people around a common purpose. This well-deserved honor recognizes not only his personal contributions but also the remarkable achievements of the entire MDF community.

"We are immensely proud of Jeremy and grateful for his unwavering dedication to our mission of Community, Care, and a Cure."

About the Myotonic Dystrophy Foundation

The Myotonic Dystrophy Foundation (MDF) is the world's leading nonprofit organization dedicated exclusively to improving the lives of people living with myotonic dystrophy and

accelerating research toward treatments and a cure.

Through patient support, education, advocacy, scientific collaboration, and research investment, MDF brings together patients, families, clinicians, researchers, industry partners, and policymakers to advance meaningful progress for the global myotonic dystrophy community.

Learn more at www.myotonic.org.

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