

# **PRESS RELEASE**

For Immediate Release - 10:00am Tuesday 7 September 2021

## **Lottery backs 'All-through Support' for Duchenne**

**Young people, adults and families affected by Duchenne muscular dystrophy to gain life-long support in Lottery-supported project.**

Action Duchenne will offer Duchenne patients and their families across England emotional and practical support through their entire Duchenne journey giving families access to essential support through diagnosis, transition to adulthood and living independently.

Duchenne is a progressive condition, but improvements in care have increased life expectancy and with more adults living with Duchenne than ever before, support services have struggled to keep up. Supporting adults to live as independent a life as they wish is a vital part of Action Duchenne's vision.

The funding from the National Lottery will also support parents and families. Often, the first time a parent hears "Duchenne" is when their child is diagnosed with the life-limiting, muscle-wasting condition. This project will help them come to terms with the diagnosis, changes in ability and changes to their lifestyle and plans.

Professor James Ker-Lindsay, whose son has Duchenne said: "When John was diagnosed it made a huge difference to have people we could talk to, who understood what we were going through, and helped us cope with the emotional stress of the diagnosis, loss of the ability to walk and education, and thinking about employment and end-of-life care."

A spokesperson for the National Lottery Community Fund said: "We are delighted to be providing funding to Action Duchenne to deliver their 'All Through Support' project. This will make an immediate and lasting difference to the Duchenne community, ensuring that support is available throughout all stages of the Duchenne journey. "

Together with partner organisations, Action Duchenne will provide direct and peer-to-peer support to patients and their families to help them live as independent a life as they wish, and to meet their aspirations.

Florence Boulton, National Director at Action Duchenne said, "I am thrilled that The National Lottery is supporting this vital area of our work. We aim to support people throughout their Duchenne journey, bringing people together physically and emotionally to address the day-to-day challenges that affect our families and building foundations for improving families' lives into the future."

**ENDS**

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## Notes to Editors

### **About Duchenne muscular dystrophy**

Duchenne muscular dystrophy is a rare genetic **muscle-wasting disease** that can occur unexpectedly in any family. The condition is usually diagnosed in early childhood and mainly affects males. In the UK approximately 2,500 people live with the condition.

Duchenne is progressive, and muscle-wasting means those living with Duchenne typically need to use a powered wheelchair from their early teens. The heart and breathing muscles are affected and most will require a ventilator and 24 hour care in their twenties.

Until recently, children with Duchenne did not often live beyond their teens. However, improvements in care mean that life expectancy is increasing, with many Duchenne patients reaching their 30s, and some living into their 40s and 50s.

**There is no cure and treatment options are limited.**

### **About the 'All-through support' project**

The National Lottery will sponsor Action Duchenne's 'All-through Support' project with almost half a million pounds over two years. The project will fill gaps in the support available and will build on the charity's pioneering work over the past two years. It will include supporting:

- Parents through diagnosis - one-to-one immediate and seamless support for every family diagnosed with Duchenne;
- Families to make informed decisions about their child or young person's care and participation in clinical trials;
- Whole families through online peer-to-peer support groups, regional support groups and access to free professional counselling;
- Young people transitioning to adulthood - professional-led residential and online skills training;
- Through end of life and bereavement - giving parents a safe place and helping parents retain their place in the Duchenne community.

Action Duchenne is led by families' feedback and involved the whole community in designing the 'All-through Support' project. The project will be delivered alongside partner organisations in the Duchenne, rare disease and wider fields.

### **About Action Duchenne**

Formed in 2001, Action Duchenne was the first national charity dedicated to supporting those living with Duchenne muscular dystrophy. We have a clear vision: a world where lives are no longer limited by Duchenne muscular dystrophy.

Our work to date has seen over £10m invested in research, educational programmes and campaigns.

We are delivering our vision through three core objectives:

- Developing effective treatments for all by funding research, educating clinicians and researchers, supporting clinical trials and campaigning for access.
- Building a community by uniting families, educating about Duchenne and raising the profile of the condition to a wider audience.
- Striving for a more inclusive society by promoting the importance of human equality, day-to-day acceptance of disability and accessibility for those with Duchenne.