



Duchenne UK Conference 2024

NewHorizons



## Frequently asked questions

### What is New Horizons?

New Horizons is Duchenne UK's first conference for the Duchenne muscular dystrophy (DMD) community. It will bring together people personally affected by DMD, and those who are working to help DMD patients and their families. There will be presentations from the UK's leading DMD specialists and researchers on the latest developments in research, treatment and care. It is also a chance to meet other members of the DMD community.

### New Horizons 2024

In March 2024, we are delighted to host our inaugural New Horizons conference, which we will hope will become a fixed date in the calendar moving forwards.

### What is the date of the event?

Friday 1<sup>st</sup> – Saturday 2<sup>nd</sup> March 2024

### Where will the event take place?

[Holiday Inn London](#), Bloomsbury, Coram St, London WC1N 1HT

### How do I get to the venue?

**Driving:** There is parking at the venue (see below for more information and costs)

### Public Transport:

- Closest tube station: Russell Square, then a two-minute walk
- Euston station: 10-minute walk
- King's Cross Station: 15-minute walk

### Is there parking at the venue?

- There is a car park at the Holiday Inn London, Bloomsbury. The daily rate is £28 - please use the following link to book: <https://www.yourparkingspace.co.uk/locations/show/4010381010>
- Another car park can be found at: Royal National Hotel underground car park, which is a four-minute walk from the venue. The address is 38-51 Bedford Way, London WC1H 0DG and the daily rate is approximately £20

### How can I register?

Registration will open in September 2023. Due to overwhelming initial interest via the pre-registration, only those who have pre-registered will be invited to register at this stage.

### Reserve guest list

Once registration is full, a reserve list will be in operation. Should anyone drop-out those on the reserve list will be contacted. If you would like to be included on the reserve list please contact the team: [newhorizons@duchenneuk.org](mailto:newhorizons@duchenneuk.org)

## What is the registration fee?

Audience	Cost	Notes
<b>Adult with DMD</b>	<b>Free of charge</b>	Access to all conference sessions on Friday PM and Saturday, plus the Friday night dinner is included in this package
<b>Parent/caregiver to a person with DMD</b>	<b>Free of charge</b>	
<b>Relative to a person with DMD</b>	<b>Free of charge</b>	
<b>Industry professional (non-sponsoring), corporate and other professionals</b>	<b>£800 plus dinner (£70 per person)</b>	Access to all conference sessions on Friday PM and Saturday is included in these packages.  Should you wish to attend the Community Dinner and Social there is a supplementary cost.
<b>Healthcare professional (not employed by the Pharma Industry)</b>	<b>Free of charge plus dinner (£70 per person)</b>	Access to all conference sessions on Friday PM and Saturday is included in these packages.  Should you wish to attend the Community Dinner and Social there is a supplementary cost.
<b>Academic, researcher or student</b>		
<b>Voluntary sector organisation</b>		
<b>Patient Organisation Representative</b>		

## How will I pay for any registration fees or supplementary costs?

One of the Duchenne UK team will be in touch with an invoice for any costs. This will need to be settled by bank transfer.

## Community Dinner and Social – Friday PM

A community friendly dinner will be held on Friday evening.

All conference attendees are invited to attend the dinner.

The supplementary cost for those attending from industry, healthcare and voluntary sectors is £70 per person.

## What is included in registration package?

The registration fee includes access to all sessions provided throughout the 1.5-day conference programme (Friday afternoon and all-day Saturday).

Families and caregivers can also attend the Friday evening Community Dinner and Social event.

Those attending from industry, healthcare and voluntary sectors will be asked to pay a supplementary cost to attend dinner.

## Are meals included in my registration?

- For those attending the conference on Saturday 1<sup>st</sup> March, lunch is included
- A Community Dinner and Social will take place on Friday 1<sup>st</sup> March at 19:30. Families attending the event are invited to attend this at no extra charge

- Those attending from industry, healthcare and voluntary sectors will be asked to pay a supplementary cost to attend the Fright night dinner (see above for more info)

Those attending the DMD Care UK meeting on the morning of Friday 1<sup>st</sup> March will receive lunch.

Coffee and tea will be served throughout the day at the conference

**Please note:** lunch is NOT provided for New Horizons attendees on Friday 1<sup>st</sup> March.

### **What is the cancellation/refund policy?**

We understand that unforeseen circumstances do occur which might prevent you from attending the conference.

For those delegates attending at no cost, we do ask that if your plans change and you can no longer attend, you let us know as quickly as possible. The event is oversubscribed, and we want to ensure that we offer as many people the opportunity to attend as possible.

For paying delegates, the registration fee is non-refundable. If you'd like someone to take your place, please contact the team to discuss this further: [newhorizons@duchenneuk.org](mailto:newhorizons@duchenneuk.org)

### **When does registration close?**

Registration will close on 1<sup>st</sup> February 2024, unless the event sells-out before this date.

### **Can I send someone in my place?**

Yes, this can be arranged. Please email the team to confirm the change and new name as soon as you can: [newhorizons@duchenneuk.org](mailto:newhorizons@duchenneuk.org)

### **Can children attend?**

The event is not designed for children under 12, and the agenda will not include a programme for children. If older children wish to attend (over 12), please register them as normal.

### **Can other family members attend?**

Yes, family members can attend. Due to an overwhelming response to the event, places are limited to two (2) per family

### **What are the timings of the event?\***

#### **Friday 1<sup>st</sup> March**

1:00pm Registration for New Horizons opens, tea and coffee

1:30pm Newly diagnosed introductory session

2:00pm Introduction

2:15pm Sessions commence

5pm: Meeting ends

7pm: Duchenne UK social evening and dinner

#### **Saturday 2<sup>nd</sup> March**

8:30am Registration & welcome tea and coffee

9:30am Introduction

9:45am Sessions commence

Lunch

5:00pm Conference ends

\*Timings are subject to change

**What is the agenda?**

The agenda will be announced in due course.

**Who is speaking at the event?**

The agenda and confirmed speakers will be announced in due course.

**Can I attend certain sessions?**

It will not be possible to pick and choose specific sessions, but it will be possible to attend just day 1 or day 2. You can also step out at any time and have a cup of tea or coffee with a member of the Duchenne UK team.

**Can I attend the event virtually?**

The event will not be live-streamed. But the sessions will be recorded and available to the community after the event. If you'd like to receive this footage, please contact [newhorizons@duchenneuk.org](mailto:newhorizons@duchenneuk.org)

**Do you have a list of hotels in the area?**

Please find below a small selection of hotels in close proximity to the venue. Unfortunately, the Holiday Inn is unable to provide a group rate for our event. We have no affiliation with the other two hotels.

- [Holiday Inn Bloomsbury](#)
- [President Hotel](#)
- [Royal National Hotel](#)

**What are the check in / out times for the Holiday Inn Bloomsbury?**

Check-in at Holiday Inn London - Bloomsbury is from 3pm, and check-out time is 12pm. Contact the hotel directly for options available for early check-in or late check-out.

**Is there anything in particular I should bring to the conference?**

- Pen/notebook to make notes
- Sweater or jacket for the meeting rooms

**What conference materials can I expect to receive?**

In a bid to limit the environmental impact of this event, we will be keeping conference materials to a minimum.

Everyone will receive a New Horizons Conference folders containing:

- Agenda
- Speaker bios
- Duchenne UK information

We will have a selection of other information available throughout the venue including;

- 2023 Impact Report
- Duchenne UK Newly Diagnosed Family Folder
- Duchenne UK DMD Family Folder: Guide to Adolescence and Adulthood
- DMD Care UK guidance and recommendations
- Steroid dependent wristband

The agenda, speaker biographies and speaker presentations will be available for download online.

Furthermore, post-event summaries and key take-aways will be shared with all attendees.

**What is the suggested dress code for attending a conference?**

The dress code is casual, no specific code is in place

**What is the dress code for the Friday evening dinner?**

The dress code is casual, no specific code is in place

**How do I find out the location of the meeting when I arrive on-site?**

Follow the signs for the Duchenne UK New Horizons Conference from the hotel entrance

**What to do in the case of dietary and other additional needs?**

Please email the team to notify them of any specific dietary requirements or additional needs: [newhorizons@duchenneuk.org](mailto:newhorizons@duchenneuk.org)

**Is the venue accessible?**

Yes, the venue is accessible. Read more about accessibility at the venue [here](#). There is also accessible Parking:

- Wheelchair Accessible Parking Spaces: 2
- Parking Drop Off Point is adjacent to entrance
- Please contact to the hotel to reserve these spaces.

**Who is Duchenne UK?**

Duchenne UK is a charity that was set up in 2012 by Emily Reuben and Alex Johnson following both of their sons being diagnosed with DMD.

They set up Duchenne UK to tackle some of the big challenges in drug development in their search to accelerate the development of treatments. In 11 years, Duchenne UK has raised more than £20 million and used this money to:

- Fund clinical trials of medicines that are now showing promise for DMD
- Set up [DMD Care UK](#), a national care programme for patients with DMD. The programme is establishing best practice across all the disciplines involved in DMD care, and works to ensure all medical professionals and parents know exactly what treatment children and adults with DMD need.
- Create a [DMD medical research hub](#) with hospital sites across the country, which has led to more trials for DMD treatments than ever before.
- Develop innovative technologies, [the SMART Suit and Dream Chair](#), to support the independence of people with DMD.

**What is DMD?**

DMD is a genetic disease that is typically diagnosed in childhood between the age of three and six. It causes muscle weakness and wasting. It eventually affects all the muscles in the body, including the heart and lungs.

DMD almost always affects boys and can affect any ethnicity.

**What causes DMD?**

It is caused by a fault, known as a mutation, on the dystrophin gene. Dystrophin is a protein that protects muscles; without it, muscles are easily damaged, and their strength and function is weakened.

**Treatment**

There is currently no cure for Duchenne, but there are treatments and therapies that can slow down DMD progression and improve quality of life.

**Further questions or more information**

Please contact [newhorizons@duchenneuk.org](mailto:newhorizons@duchenneuk.org)