NutrInD: Nutrition In Duchenne Study

Assessing Energy Expenditure, Dietary Intake and Body Composition in People with Duchenne Muscular Dystrophy.

Hub Summary

The purpose of this study is to collect information about the nutritional needs of people with Duchenne Muscular Dystrophy (DMD).

Proper nutrition is very important for children, adolescents, and young adults with DMD. Excessive weight gain is a very common problem which leads to obesity. Many factors contribute to weight gain. These include steroid treatment, excess calorie consumption, less physical activity, and lower muscle mass. Extra weight can make walking and transferring more challenging. Obesity may lead to high blood pressure, and affect heart and lung function. Adequate eating habits are also valuable in supporting growth, bone and gut health, and helping the body process nutrients from food.

A better understanding of the nutritional needs of young people with DMD can help improve their overall well-being. So far, very little is known about this.

We hope that the findings of this study will help us create specific nutrition-related guidance for young people with DMD.

Study Number: University of Glasgow MVLS College Ethics Committee Project No: 200230415

Description by Duchenne UK

Participation in the study involves 1 visit to the Metabolic Research Unit in the New Lister Building, Glasgow Royal Infirmary for:
1. Weight, height, and length of forearm measurements.
2. Body fat and muscle stores measurements.
3. Consumption of a special type of water (like tap water - totally safe) and provision of 3 saliva samples.
4. Measurements of the number of calories the body burns at rest and during different activities.
5. Completion of questionnaires about health & medication, usual food intake, and physical activity.

Following the visit, participants will need to:
1. Wear a heart rate monitor on the wrist (like a watch) for 7 days.
2. Record food and drink consumption for 4 days.

We are looking for participants from across the UK. Study-related travel expenses and overnight accommodation (if traveling from outside Glasgow) will be reimbursed. Compensation for participants' time will be offered upon study completion.

To find out more about this study and to register your interest in taking part, please contact the study team:

Phone: 07484 536272 (call or text)

Email: med-sch-nutrind@glasgow.ac.uk

Primary Outcome Measures

- Total Energy Expenditure (How much energy the body needs in a day).
- Physical Activity Level (How many calories the body burns with physical activity) & Habitual Physical Activity Patterns.
- Habitual Energy Intake & Diet (How much, how often, and what type of food is consumed).
- Body Composition (What is the percentage of fat and muscle in the body).

Can I take part?

Inclusion Criteria

Ambulant males with DMD
- Ambulant males (defined as able to walk around the house independently without assistance) with DMD
- Aged 5 to 16 years (inclusive of 16 years)
- On daily corticosteroid therapy (Prednisolone, Deflazacort, or Vamorolone) for at least 12 months

Non-ambulant males with DMD
- Non-ambulant males (defined as unable to walk around the house independently without

Trial Status
Fully recruited

UK Locations
Glasgow, Fully recruited

Trial Sponsor
Duchenne UK

Length Of Participation
1 study visit, 7 days of home recordings

Recruitment Target
40 (20 ambulant and 20 non-ambulant)

Ambulatory
Ambulant and non-ambulant

Therapeutic Category
Observational

Age
5-21

Mutation Specific
All treatment types

Muscle Biopsy
No Muscle Biopsy Required

MRI
No

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assistance) with DMD
- Aged 10 to 21 years (inclusive of 21 years)
- On daily corticosteroid therapy (Prednisolone, Deflazacort, or Vamorolone) for at least 12 months

Exclusion Criteria

Ambulant males with DMD
- A secondary major chronic or genetic medical diagnosis (other than DMD)
- Unable to provide informed consent

Non-ambulant males with DMD
- A secondary major chronic or genetic medical diagnosis (other than DMD)
- Need for the use of day-time assisted ventilation
- Presence of severe nutritional problems (e.g., gastrostomy feeding)
- Unable to provide informed consent

For contact details and to find out more, please refer to dmdhub.org.

Duchenne UK

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