

## **DMD Care UK Q+A from 10<sup>th</sup> Jan 2023: Clinician focus**

### **Nutrition – Dr Jarod Wong**

*Comment 1: Weight management and nutritional advice should be highly prioritised as this has numerous implications on physical and mental health*

Recent publications have suggested that non-alcoholic fatty liver disease may be common in boys with DMD which might be as a result of weight. Monitoring for this health issue is not currently addressed in the 2018 international standards of care. The identification of non-alcoholic fatty liver disease may be a determining factor to initiate medication (such as metformin). Dr Anne Marie Childs in Leeds is developing pilot research into this with liver colleagues which may include:

1. A more comprehensive look at North Star data to see how many cases are reported
2. A prospective study using liver fibro-scan – a much more sensitive way of detecting fibrosis in the liver and early signs of non-alcoholic fatty liver disease

Understanding lipid abnormalities in DMD is also important as there are increasing number of older men with DMD

*Question 1: Should we include speech and language in the nutrition WG?*

It is likely that the nutrition WG will focus on weight management issues in the first phase. Subsequently, addressing feeding issues and weight loss, an issue in older adolescents and adults with DMD is important and therefore the need to link in with speech and language therapists in the WG. The overall plans of this WG will be discussed in further detail with the steering committee of DMD Care UK

*Comment 2: It would also be very important to look at issues for people with DMD who become very controlling or restricted with their eating. This highlights an important link with the psychosocial WG.*

*Comment 3: We hear from families that they see a dietician who does not tell them anything they do not already know but putting it into practice is very difficult. The behavioural issues around diet need addressing as well as giving specific, specialist dietary advice. Again, this links with psychosocial and physiotherapy and the WG will connect with these groups.*

*Comment 4: Fluid intake is also an issue for some boys particularly older boys and will be addressed with guidance from the working group.*