

Duchenne Muscular Dystrophy: Double-Blind Randomized Trial to Find Optimum Steroid Regimen (FOR DMD study)

Patient information sheet for children aged four to five years

This Information Sheet should be used in conjunction with the Parent Information and Consent Form for full details before explaining it to the child. At this age, children are not normally asked to give assent.

Guidance notes for the person explaining the FOR DMD study to patients aged four to five years:

Picture 1 - Explain to the child that they will have to come to the hospital with Mum and/or Dad twice a year during the course of the study.

Picture 2 - The doctor will explain the study to the child and will answer any question they child might have

Picture 3 - The doctor will examine the child to check that everything is working properly. The doctor will listen to the child's heart, and measure his blood pressure, pulse rate, height, weight and waist circumference. These examinations will take place every time the child visits the hospital. The child will be asked to provide a urine sample when they come to the hospital at some visits.

Picture 4 - At some visits, a doctors or nurse will take a small amount of blood from the child's arm with a small needle. The person taking the sample will use some cream to make the area numb, so that it should not hurt. These samples are for routine health checks to make sure that the child is well, and for bone biomarker testing.

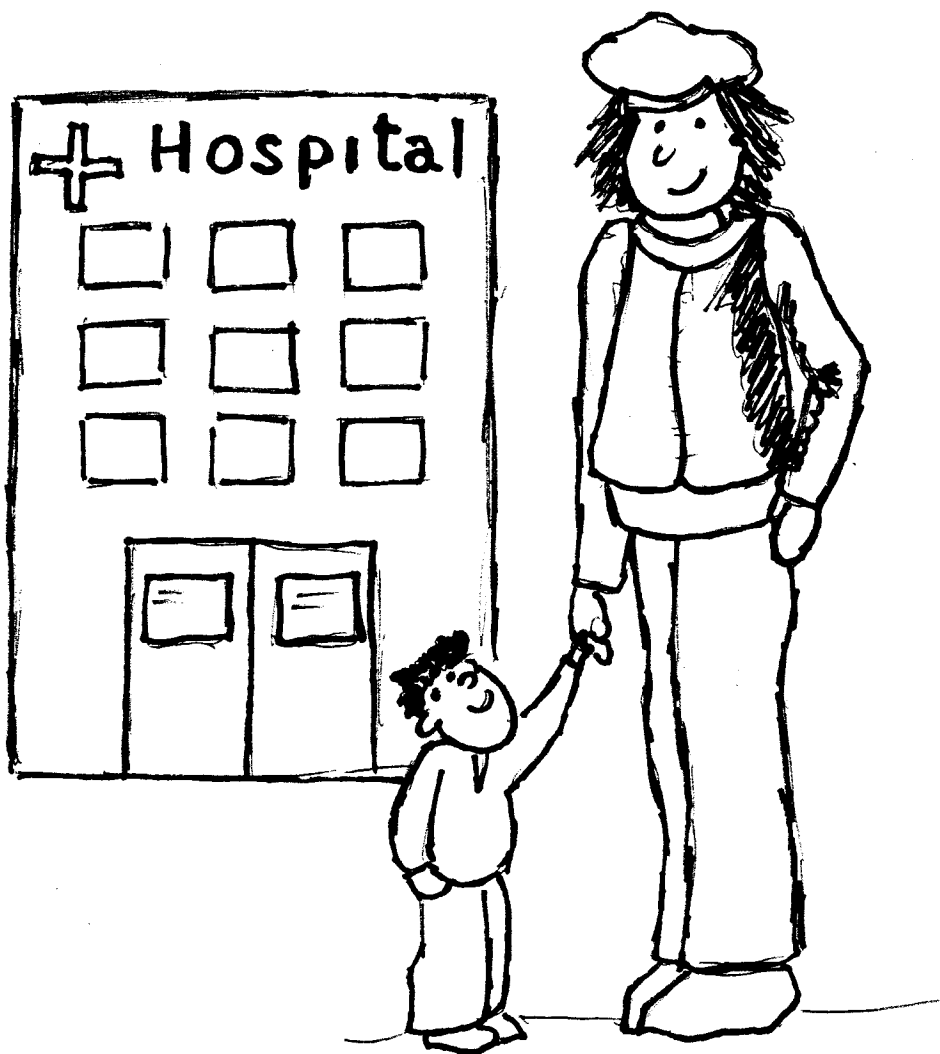
Picture 5 - At each visit, the doctor will ask the child to do different activities like jumping, hopping and lying down and then standing up. The child will be asked to walk up and down the corridor for six minutes to see how far he can walk.

Picture 6 - Pictures of the heart, called ECGs and Echocardiograms, will be taken at some visits. Other tests that the doctor will ask the child to have at some visits include an x-ray (like a picture) of his wrist and spine, and an x-ray of his whole body to see how good his bones are.

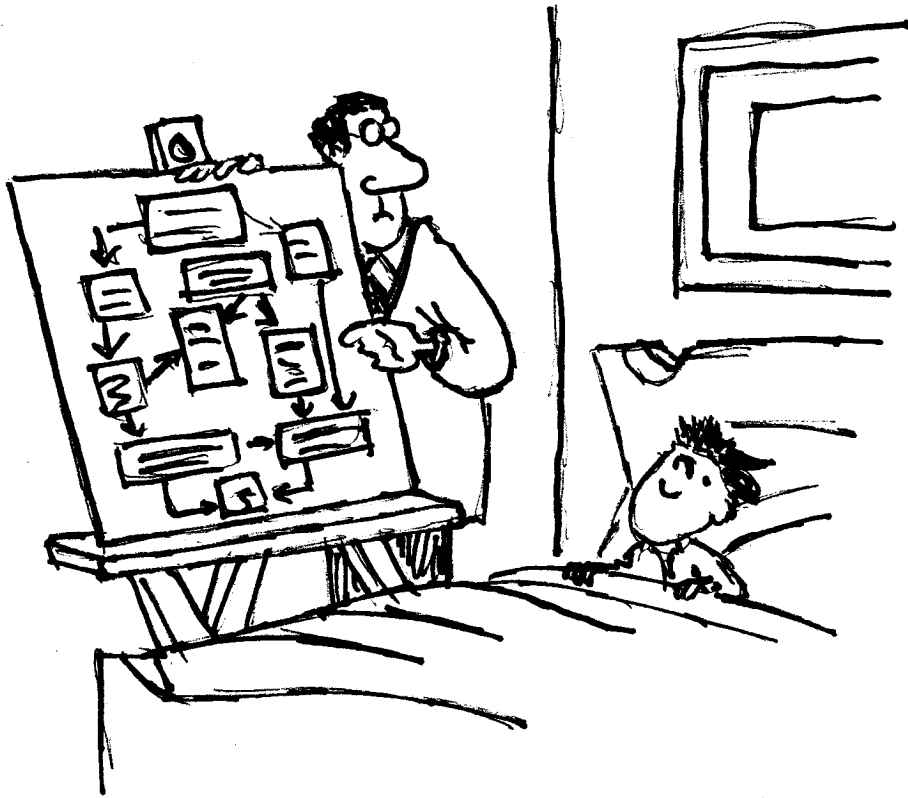
Picture 7 - At some visits Mum and/or Dad will be asked to fill in a questionnaire about how their child is feeling.

Picture 8 - The child will need to take the medicine every day with his breakfast.

Hospital



Picture 1



Picture 2



Picture 3



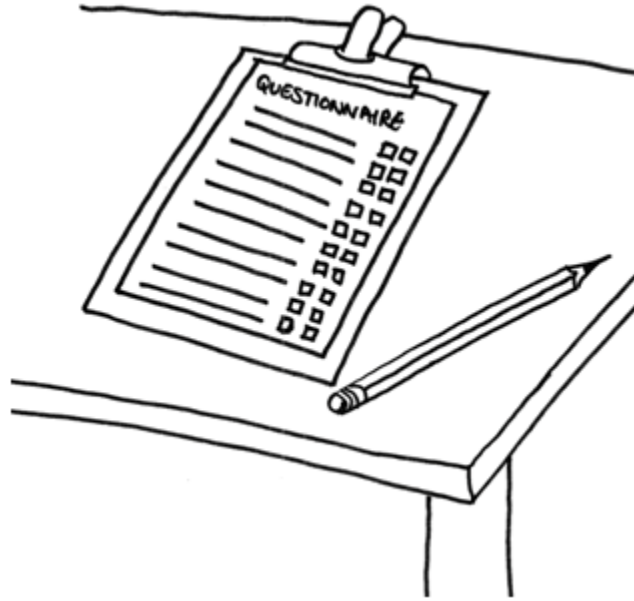
Picture 4



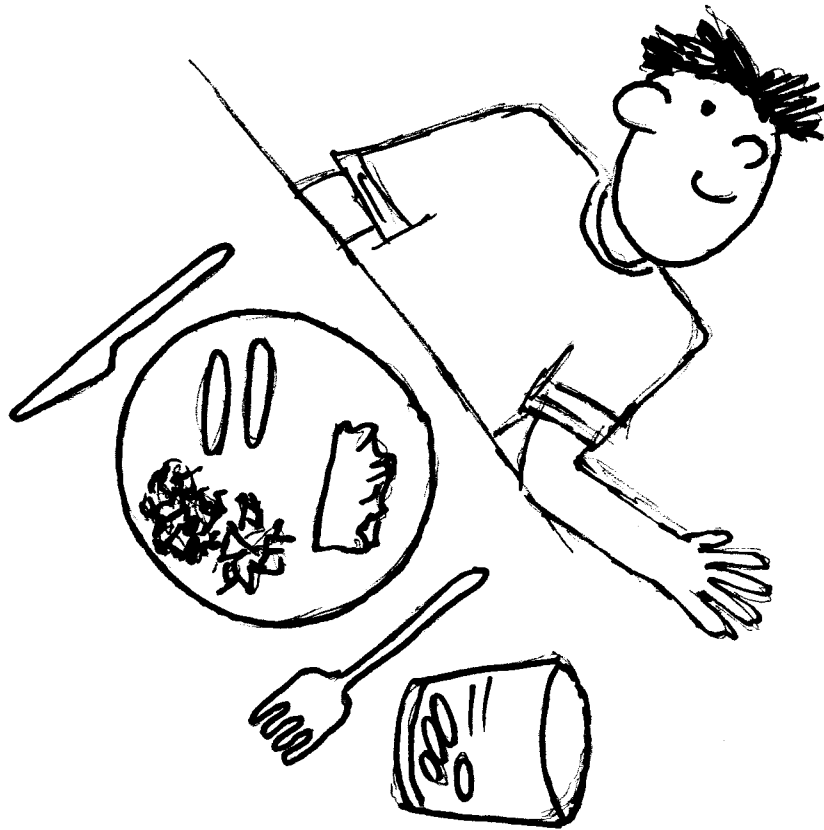
Picture 5



Picture 6



Picture 7



Picture 8