

CASE STUDY

Duchenne Muscular Dystrophy

STUDY OVERVIEW

Illingworth Research Group Limited provided research nursing support in the home for 2 studies in Duchenne muscular dystrophy (DMD), one with a global pharmaceutical company and the other a small European biotech.

In both studies, 2 UK sites were involved, 1 in the South of England and 1 in the North, and involved children aged 5 and over.

The Sponsors struggled with children dropping out of the study. The protocol required children to attend weekly hospital visits. This can lead to a major loss of time at school, loss of earnings for their parents due to lost time from work and general inconvenience.

The client contracted Illingworth Research Group to conduct 75% of all visits within the child's home, rather than them having to attend the hospital.

Our research nurses visited the children in their homes 3 out of every 4 weeks for a 2-year treatment period. After the 2 years, not one child had dropped out of the study. Parents and their children were delighted with the rapport built up, and it meant the loss of school time, loss of earnings of parents, and general inconvenience was reduced to a minimum.



After initiating the home research nursing service for 2 years there was a ZERO drop out.

PATIENT FOCUS

One of the children lived on the Isle of Man. This involved the nurse collecting the study drug from the site in central London. Then transporting it under cold chain custody the day prior to the visit and flying to the patient to conduct the home visit the next day. Other tasks included administration of a sub-cutaneous injections, venepuncture (where venous access was often very difficult), centrifugation, separation, and courier of the samples, maintaining cold chain throughout.



0.5 hrs drive to ferry from home



4 hrs ferry ride to Heysham



4.5 hrs drive to Great Ormond Street



9 hours from home to hospital, 18hr round trip

Quote from a Patient (James)

"The nurses make me feel happy and I don't miss too much school." Travelling to London meant James missed an awful lot of school. Using Illingworth's mobile Research Nurses reduced this significantly.

Quote from a Parent

"My son, James was on a clinical trial for 3 years. We live on the Isle of Man and on a weekly basis we travelled to Great Ormond Street Hospital in London. When we were told that our visits to London would change to a monthly basis, the whole family were delighted. James still received his injection weekly but research nurses came to our home. It is marvellous, they were trained to follow all the protocols exactly as they were carried out at the Hospital. The nurses were more than giving the injections and taking urine and blood samples. I found the research nurses friendly, professional, energetic and extremely caring towards my son. It was like having a ray of sunshine helping us all."