



Case Study

Duchenne Muscular Dystrophy

Study Overview

Illingworth Research Group Limited provided home nursing support 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.

For one of the studies the clients struggled with children dropping out of the study as the protocol required them to attend weekly hospital visits leading 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 $\frac{3}{4}$ of all visits within the child's home, rather than them having to attend the hospital.

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

Our research nurses visited the children in their homes 3 out of every 4 weeks for a 2-year treatment period and 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.

What our nurses were responsible for

One of the children lived on the Isle of Man. This involved the nurse collecting the study drug from the centre of London, transported 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 injection, venepuncture (where venous access was often very difficult), centrifugation, separation, and courier of the samples, maintaining cold chain throughout.

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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 was marvellous, they were trained to follow all the protocols exactly as they were carried out in the hospital. The nurses were more than giving injections and taking urine and blood samples.

I found the nurses friendly, professional, energetic and caring towards my son. It was like having a ray of sunshine helping us all. James said “the nurses make me feel happy and I miss school.” Although James missed more school when we travelled to London, with the research nurses it was only half a day.

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