

Case Study - Jack

Jack is thirteen years old and has Moebius Syndrome, a rare condition that affects his life in many ways. Jack is also blind in one eye and has dual hearing aids for moderate hearing loss in both ears, and a lack of cerebellum which drastically affects his balance and co-ordination. Jack's legs have also been severely affected with problems in his hips, knees and feet and he has had to undergo numerous operations on his legs, eyes, ears and mouth. He is now at St John's Catholic School for the deaf at Boston Spa, however he accessed and graduated from the MOVE Programme whilst at St. Luke's Special School.

Before starting on the MOVE Programme, Jack was unable to move independently for himself and was reliant on a wheelchair for any movement outside the confines of his house or school. Jack hated his wheelchair as it emphasised his disabilities and differences to other children, however, without it he was limited to having to roll or crawl in order to move around his home and school.



Jack started on the MOVE Programme when he joined St Luke's nursery. With his family, Jack set his own personal goals which were then broken down into steps and worked on by his care team and family at every opportunity of the day. Through Jack's hard work and determination, and that of the whole team around him, he gradually began to make steady improvements whilst gaining new skills. Jack was able to learn how to sit in a standard classroom chair, to walk around his schools and home with ease, even managing to walk up and down steps. Eventually the only equipment Jack needed was a reverse rollator for extra long distances, which provides minimal support.



Jack's new skills enabled him to go on errands for his teachers and he was always first to volunteer for classroom jobs. Jack loved moving around the school to talk to all his friends and developed a great sense of humour. Alison Harland, the Profound and Multiple Learning Disability Coordinator at St Luke's, comments, *"It never ceased to give me great pleasure when I saw Jack in the corridor, he was quick to offer me the latest 'gossip' and was so positive in his approach to life. He has a wonderful sense of humour and fun, determination and courage..... he is a true MOVER and we are all very proud of his achievements"*.

At 8 years old Jack graduated from the MOVE Programme as an independent and confident boy. Since then Jack has never looked back and he has further learnt how to run, kick a ball, jump, and although still unsteady due to his cerebellum, he has learnt to balance, which are all huge achievements for someone with Jack's condition.

Though Jack had been faced with major surgery on both hips and knees, through the benefits of being active and mobile after starting on the MOVE Programme, he now only requires surgery on one leg.

After attending a special school for 5 years, with the help of his new skills Jack was able to MOVE on to enjoy two days a week in a local mainstream Primary School, allowing him to

become more independent both emotionally and socially. Eventually at the age of 10 he became a full time student at the mainstream school, and in two academic years Jack was awarded the James Jones' trophy for being the hardest working pupil in the school overcoming diversity.

After graduating from the MOVE Programme, Jack decided he would like to fundraise for other children – mainly for MOVE Europe. To date, along with his sister Jaimie, Jack has completed many walks and runs, and through his fundraising efforts he now sponsors a child on the MOVE Programme.

Jack in typical fashion says of his achievements, *“I was 8 years old before I could walk and I still remember how good it felt. If it hadn't been for MOVE I wouldn't be on my feet and I wouldn't be able to do take part in any of the runs that I do. They have enabled me to reach my maximum potential as far as physical movement is concerned and I use my new found skills to try and raise money to enable other children to benefit from the MOVE Programme. I want each and every child to achieve their own personal maximum potential and have fun doing it. I am trying to pay MOVE back for my mobility by fundraising so that they can keep helping other children in the hope that one day they will feel as good I did.”*



Now with his independent mobility Jack does not consider himself to be disabled in any way at all, he is just living his life to the full and doing what he enjoys doing most, which is helping others.

Jack and Jaimie are now Young Person Ambassadors for the MOVE Programme and through their commitment to fundraising and raising the profile of the charity they are proving to be fantastic supporters and spokespeople.

Jaimie comments *“It's thanks to the MOVE Programme that Jack's wheelchair stays empty. Without MOVE I do not know where Jack would be today and I thank you for making Jack mobile, I hope his achievements can inspire people to support the MOVE Programme in any way that they can to enable others to achieve their own dream of mobility”.*

