

Freestyle Freedom

Lewis (6), who has Recessive Dystrophic EB, and his mum Kelly give us the inside story on competitive swimming.



Living with EB brings many challenges – for Lewis, surviving was one of the biggest. When he was born the skin was missing from his legs and feet. Doctors thought he would never live to walk or talk, yet here he is six years later – he has never let anything hold him back.

Lewis' daddy Stuart has been involved in swimming most of his life both as a swimmer and now as a coach, and our daughter Georgia followed in his footsteps. From a very young age, while watching Georgia competing, Lewis would say 'I will do that when I get bigger Mummy'. When we introduced Lewis to swimming as a hobby we did worry about how it would affect his skin, but we thought, 'We'll just give it a go and see.'

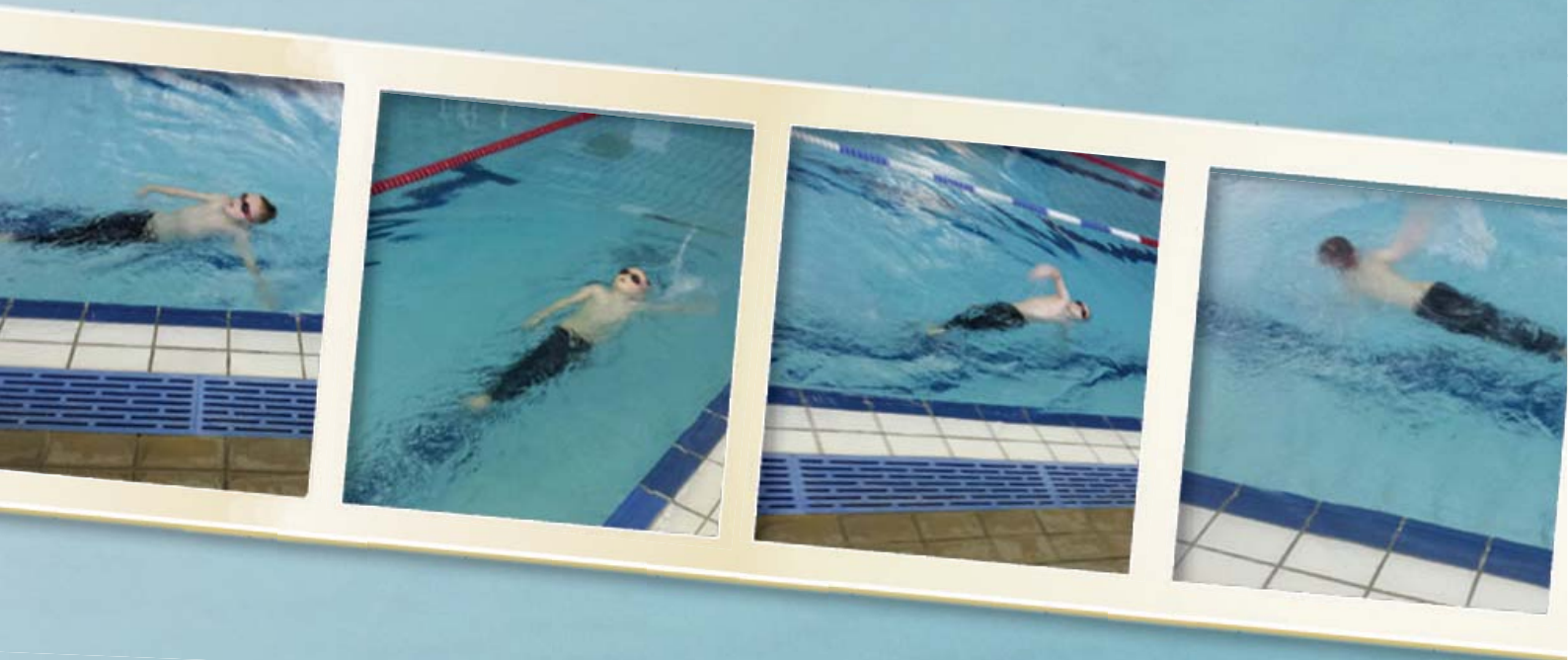
When he first started he wore swimming shorts but we found that his dressings would come off in the water. Apart from anything else, this hindered his progression and knocked his confidence a bit. He needed something long legged to swim in but we found that swim leggings weren't available in small enough sizes. Eventually, I came across a pair of Speedo Pro swim leggings on

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the outlet section of a website. They were only £20 – not too expensive for the job they were going to do. We also took advice from our EB nurse on which dressings were best to use in the water. With these things in hand and with his new leggings holding his dressings securely in place Lewis started to progress and gain confidence in the pool.

Swimming is great whole body exercise – good for your heart and lungs – and the only sport in which Lewis (and other people with EB) will not be in contact with anyone or anything. Lewis does tend to have sores on his legs and the pain of the water on his wounds is sometimes challenging, but he takes it all in his stride.

Rosie Jones, the specialist EB dietitian at Birmingham, has been helping Lewis maintain the good nutrition needed to support his swimming. Lewis eats the same balanced diet as the rest of the family, but he also has a prescribed high energy nutritional supplement with



added vitamins and minerals which helps him to refuel at school and after swimming. It also aids in the healing of wounds.

After 18 months of swimming, Lewis decided he wanted to compete in a gala which the swimming club held. We did have to receive authorisation from the club committee to allow Lewis to compete in a mainstream gala in his leggings – they are no longer considered acceptable swimwear in competitive events due to a change in the rules and regulations, but the club were accommodating of Lewis' needs once the importance of the leggings was explained. He swam the 25m freestyle against eight year old boys. He was the youngest male competitor in that gala, and we were the proudest parents there.

After that, Lewis really wanted to enter another gala so we entered him in the 2013 Club Championships, where he again swam the 25m freestyle. When

he finished he said, 'You just wait 'til I'm six, I'll be faster then!'

That's when we realised just how competitive a nature Lewis has and how deep his passion for swimming runs. But Lewis' future in competitive swimming is uncertain. When we were entering him for in-house galas the club committee explained that we would need to contact the Amateur Swimming Association (ASA), the governing body of swimming, to clarify whether Lewis would be allowed to compete as a disability swimmer or a mainstream competitor in the future. While the club can accommodate Lewis' needs in internal competitions, if he wants to compete in wider competitions when he's older there are national and international rules to be stuck to – wearing swim leggings is currently seen as a breach of these rules and he would not be allowed to compete as an able-bodied swimmer if he wore them in the pool.

So with the help of the EB Community Support team I contacted ASA to see if Lewis would qualify as a disability swimmer under the Equality Act. It was heart-breaking to discover that EB is not on the list of accepted disabilities. In the future I hope we can open disability competitive swimming to all people living with EB, and I hope this article will help other families who are facing similar challenges. Once Lewis is in the water he is free – it's wonderful to watch him achieving his goals.

Kelly and Lewis Holding

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