

# Supporting... Stefan

An award-winning setting in Leicester is helping a boy, and his mother, cope with his rare genetic disorder, reports *Charlotte Goddard*

**F**our-year-old Stefan is a happy bundle of energy, who has been attending Allextion Day Nursery in Leicester since he was two-and-a-half. Stefan has X-linked Chondrodysplasia, a rare genetic disorder which results in malformation of a child's cartilage, and is associated with short stature and learning difficulties.

'There is not a lot he is not involved in here at the nursery,' says Stefan's key worker, nursery practitioner Claire Pratt. 'He is very happy, and eager to explore. As soon as he arrives he is immediately running around, seeing what has been set out to play with. He loves cars, and dressing up – he is often to be seen walking around in high heels!'

Outstanding-rated Allextion, a private day nursery which won *Nursery World's* Inclusive Practice Award in 2016, is located within the West End Children's Centre in Leicester. Currently, 14 children who attend Allextion have special educational needs and involvement from outside professionals, with five of these either having an Education, Health and Care Plan (EHCP) or on the pathway to receiving one. Five staff members have SENCO training.

Stefan has a passport document which sets out the targets he needs to reach. 'Stefan's passport, which outlines his targets, is set up during a passport meeting,' says Katie Lynch, managing director at the nursery. 'These meetings are arranged and set up by the Area SENCO (early years support team), and attended by parents, Stefan's key worker and speech and language therapists, so that relevant and realistic targets are set. On some occasions the educational psychologist and the health visitor will also attend.'

Small-step targets on the passport get reviewed termly, and there are also 12-month targets. 'These meetings tend to happen before an EHCP referral is put in place,' says Ms Lynch. 'If a child is making good progress on their passport then this is taken with them to school and the termly meeting will continue.'

Stefan is supported by the area SENCO, an educational psychologist, speech and language therapist, community paediatrician and a genetics team. Most have come into the nursery to work with Stefan, and practitioners are able to contact them if they have concerns, and to share information. 'If I thought Stefan was regressing, for instance, I would not hesitate to phone for advice and to get him checked,' says Ms Pratt.

The area SENCO and educational psychologist have given the setting ideas on activities they can use to

**Stefan is involved in most activities at the nursery, and a favourite is football**

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## X-LINKED CHONDRODYSPLASIA

- Chondrodysplasia punctata 1, X-linked recessive (CDPX1) is a genetic disorder present from birth that affects bone and cartilage development.
- CDPX1 is caused by mutations in the ARSE gene, located on the X chromosome.
- The condition occurs almost exclusively in males. Females have two X chromosomes, so if they have a gene mutation on one of them, they still have a normal copy on their other X chromosome.
- Although there is no specific treatment or cure, there are ways to manage symptoms.
- The exact number of individuals with CDPX1 is not known. In one study, it was estimated to occur in one in 500,000 people; however, it is suspected to be more common.

Information from <https://rarediseases.info.nih.gov/diseases/1296/chondrodysplasia-punctata-1-x-linked-recessive>.



support Stefan. 'For example, an activity for developing the ability to share with other children, which can be an issue, involves a piece of material which they can take turns to pull on, and can feel the tugs,' says Ms Pratt.

Allextion has been able to obtain 10 hours worth of local authority element 3 funding, also known as top-up funding, for Stefan, which helps to pay for one-on-one work. The setting was also awarded Children in Need funding to provide activities and days out for children and their families, including visits to local theme parks, strawberry picking and picnics in the park.

'From the funding we received we also paid for an outside agency to come in and work with the children, doing sing and sign sessions and football sessions,' says Ms Lynch. 'Stefan has loved participating in the football,' she adds.

## RESEARCH AND STRATEGY

Practitioners have researched Stefan's condition, so they can support his well-being. 'We have been finding out about his needs, because it is not something we have come across in the past, from conversations with his mum because she is knowledgeable about what he is diagnosed with, but it is also important to have the confidence to ask questions of other professionals,' says Ms Pratt.

Stefan's developmental delay means he is behind his peers in



speech and language, literacy and numeracy. 'He is at the level of a 24- to 30-month child, at the stage of using two-word phrases,' explains his key worker. 'We are working with him on basic pre-literacy skills, such as mark-making, giving him a lot of support on a daily basis. His capacity for concentration is very limited so it is challenging to keep him focused throughout an adult-led activity.'

The setting uses a lot of pictures and visual aids to help Stefan maintain his focus. 'He is coming along really well,' says Ms Pratt. 'During circle time he is now able to say what he wants to do, even if it is just using one word, so he can ask for a specific song, for example.'

Stefan also takes part in one-to-one sessions, including use of Tacpac, a sensory communication resource using touch and music to help communication and social skills. 'The resources can be used with children with more complex needs, but Stefan is able to explore the items himself, rolling the hairbrush on his own leg, for example,' says Ms Pratt.

The nursery also supports Stefan with his behaviour, which can be challenging. 'At times Stefan will throw things at people without realising, he's got so much excitement,' says Ms Pratt. 'We keep a close eye on him so we can see it coming and try to calm him down. For example, when he starts walking from one side of the room to the other side,

getting quicker each time, we know we need to calm him down. His mum has shared with us that this is how he is at home as well.'

Socialisation at the nursery has helped Stefan develop his friendships. 'He engages with the other children, and before he was not really bothered,' Ms Pratt explains. 'As we are quite an inclusive setting, we have a lot of children with a lot of different needs, but also a lot of typically developed children, and they are all quite accepting.'

As well as benefiting him, Stefan's attendance at the nursery has helped his mother. 'I think it gives her a support network she didn't have before,' says Ms Pratt. Stefan's mum Bridie agrees wholeheartedly. 'Stefan would not have progressed as he has without going to Allextion,' she says. 'All the different activities they do help so much, and they support me no end. Every parent wants the best for their kid, and when they are born in a difficult way, and you are told there is no magic cure, it can get you down. But the ladies at the nursery always take when I am feeling negative and turn me around to feeling positive.'

Although Allextion has a lot of experience in multi-agency working, aided by its location in a children's centre, the most challenging aspect of supporting Stefan is still chasing up other professionals. 'Trying to get people to come out and see Stefan and make sure things happen in the timescale required is sometimes dif-



## MORE INFORMATION

- [https://en.wikipedia.org/wiki/X-linked\\_recessive\\_chondrodysplasia\\_punctata](https://en.wikipedia.org/wiki/X-linked_recessive_chondrodysplasia_punctata)
- Entries are open for the 2017 Nursery World Awards, including the Inclusive Practice category, [www.nurseryworldawards.com](http://www.nurseryworldawards.com)

ficult,' says Ms Pratt. 'I phoned the educational psychologist every day for a week to try to get information about the school transition.'

## MOVING ON

Stefan will be moving on to Reception in September, a transition which is causing his mother some anxiety. 'What support is he going to have?' she says. 'We have so much communication that goes backwards and forwards from nursery, I am concerned that this will no longer be the case at school. I am aware that departments are understaffed and budgets have been cut, and more and more children are needing help; it is not the fault of the individual professional, but I want to know the plan.'

The nursery is doing all they can to support Stefan and his mother through the upcoming transition. 'We reassured Stefan's mum that we will be involved,' says Ms Pratt. 'We will have the school in for a meeting to share information about Stefan's needs and what has to be done to meet them, and Stefan will make short visits to the school, which will eventually become longer transition visits. If Stefan finds it hard to settle, we would go into the school and support him.'

Although anxious about the future, Stefan's mum has nothing but praise for the practitioners at Allextion. 'I always walk out of there feeling happy,' she says. 'They genuinely want to help Stefan, and look after him like he is their own.' ■