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BODY:

In the second week of the Gazette's appeal for the Springboard Nursery Zoe Mills looks at the help it has given one little girl who could now lose her place

HOLLY Williams is an angel. The blonde haired blue eyed three-year-old has a rare condition called Angelman Syndrome which affects every single aspect of her life.

But Holly is one of the children who will lose their place at special needs pre-school Springboard if money is not found to help them.

"It's difficult to put into words how important Springboard is to us " her mum Lesley said this week. "It makes life so much easier."

Last week the Gazette launched the Springboard Appeal to help the pre-school find the £ 40 000 it needs to save these children's places.

Holly was born with part of chromosome 15 on the maternal side missing which means every cell in her body has a bit missing.

She can't walk and probably never will she will most likely only ever speak ten words in her life and she sleeps just four hours a night.

But little Holly is a happy bunny ' it's one of the nicer characteristics of Angelman's.

Speaking from their home in Bentley Grove Calne her dad Richard said: "Genetically she's a very happy child and prone to inappropriate outbursts of laughter.

"When it was first diagnosed in the 1960s it was called Happy Puppet Syndrome but it was renamed in the mid 80s to be slightly more politically correct. The children are now known as angels.

"I wouldn't wish Angelman's on my worst enemy but there are worse things she could have."

Holly was born with a genetic heart defect which was repaired when she was eight months old. At first doctors put Holly's developmental delay down to her heart problems but started to worry when she still couldn't sit up on her own at 18 months.

"She had lots of tests and it became apparent that they had their suspicions it might be Angelman's " said Mr Williams. "Holly has certain physical characteristics related to Angelman's like flapping arms a slightly protruding jaw blonde hair and blue eyes and a flat area at the back of her head."

Things took a turn for the worse when Holly started having fits last Easter. "We weren't sure if they were micro naps or blackouts but they were happening every ten seconds " said Mrs Williams. "She went from being a happy bouncy baby to just lying still all the time. It was frightening."

After several trips to hospital doctors told Mr and Mrs Williams that their daughter had epilepsy on Easter Monday 2004.

"It was a relief to know that the epilepsy could be controlled with medication but we were still waiting for the test results to find out what else was wrong with her " said Mrs Williams. "The next day we had to go back to find out and we braced ourselves.

"They delivered a verdict that it was Angelman's. The doctor was white as a sheet but it couldn't have been nice for him. He had just broken our hearts."

That day marked the start of a long voyage of discovery for the Williams family. Mr Williams said: "As many questions as we had it answered why Holly is like she is. Suddenly someone said this is what it is and this is why your child is doing it.

"We were scared but at least we knew more about what was going on."

Holly's epilepsy is now controlled by daily medication but unfortunately there is no cure for Angelman's.

Holly started going to Springboard before she was diagnosed with Angelman's Syndrome and spends two days a week at the pre-school.

Mrs Williams said Holly had come on no end since starting at Springboard.

"But if Holly lost out now it would be gutting. She loves going and they all love her too."

The Williams hope Holly will attend St Nicholas Special School in Chippenham when she's old enough.

"Springboard was the start of a long and important process for us " said Mr Williams. "The atmosphere has been amazing. Before Springboard we felt we were the only ones but now we know there's help out there."