

Family's fund-raising for brave Jennifer...

THE plight of one little girl from Worthing with an exceptionally rare disease has triggered a spurt of fund-raising for sick children, led by her family.

Jennifer Lynch, 10, has Wolfram Syndrome, a very rare genetic disorder which can cause diabetes, visual impairment, deafness, and both bladder and neurological problems.

Wolfram Syndrome affects one in 500,000 children, and there is currently no cure for the condition.

Jennifer's condition means she finds it difficult to do many normal things with her friends, such as going to the park, and must schedule her day around her insulin injections and snack times.

Jennifer, who lives in Church Way, is also registered blind, and has recently undergone a tracheostomy, after her lung collapsed following a choking incident.

Jennifer's mum, Tracey, said the tracheostomy was a result of her daughter's condition.

She said: "Jennifer has a slight narrowing of the throat, which we have since found is common in people who have Wolfram Syndrome. She is now fed through a gastric nasal tube, which will be the way for the foreseeable future."

Tracey, 42, said Jennifer was diagnosed

by **Catrin Shi**

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in 2010, after three years of tests to determine her condition.

"It started with a simple trip to the opticians, where they noticed her irises were very slow to react," she said. "Then she was diagnosed with diabetes and she started becoming more disorientated. It took three years to get the final diagnosis, which was a relief, because we finally knew what we were dealing with."

Tracey added: "Jennifer cannot go anywhere alone as her eyesight is so poor and she needs to be reassured in new places - she gets very disorientated and upset. We have, however, had lots of support from WellChild - a charity for sick children - they are one of the handful of charities which support research into Wolfram Syndrome."

Since Jennifer's diagnosis, the Lynch family has set up a Wolfram Syndrome support group, and had its first meet-up in Birmingham in January.

Tracey said: "It was nice to meet other sufferers and their families there. One man said to me: 'It's so nice to know I'm not alone', and it's true - because this condition is so rare, it can be very isolating, even for the families."

Jennifer's dad, Paul, is also set to bring in some funds for the charity with his road trip to Snowdonia in May. The event will see Paul and a group of friends scale the mountain dressed as children's cartoon characters to raise awareness of Wolfram Syndrome.

Paul, 40, said: "WellChild has said it will direct all of the money we raise into research into Wolfram Syndrome, which is great. I have done road trip fund-raising before for St Barnabas and Chestnut Tree House, but obviously now my priorities have changed. It should be a great event and I hope people will support us."

For more information on Wolfram Syndrome, visit www.wolframsyndrome.co.uk, and to sponsor Paul in his road trip, visit www.charityroadtrip.co.uk



Jennifer Lynch

Brother's school assembly idea

WORTHING High School also played its part in raising money, after Jennifer's brother Marcus gave a series of assemblies to raise awareness about Wolfram Syndrome.

Marcus, 14, stood up and gave an assembly to each community in the school about his sister and her condition, and proposed a "purple day", where pupils came into school in their purple best, with the result raising more than £800 for the charity.

Marcus said: "My dad



Staff and pupils on the purple day

assembly a bit of a kick. to explain Jennifer's condition sometimes."



Jennifer's brothers Marcus and Iain Lynch

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