

## NEWS FOCUS

## HEALTH

## Health e

# Teenager's family fight for awareness of rare disease

THE family of a teenager with an exceptionally rare disease are raising awareness in a bid to find a cure.

Jennifer Lynch, 14, from Worthing, has Wolfram Syndrome, which can cause diabetes, visual impairment, coordination, breathing, deafness, bladder and neurological problems.

Wolfram Syndrome (WS) affects one in 500,000 children, and there is currently no cure for the condition. Charity Wolfram Syndrome UK is fundraising to support research in to a drug that has been identified as showing signs of slowing down or stopping the progression of the condition.

The charity said a minimum of £600,000 is needed for the first stage – getting to clinical trials in the next five years.

Tracey Lynch, Jennifer's mum, said: "As a small child Jennifer was always uncomfortable in new surroundings, with new people and particularly shy with men, including her grandfathers. This was put down to her personality; it was only once she was diagnosed with Wolfram Syndrome that it was found out that being anxious, upset and easily agitated was all part of the condition."

After being in and out of hospitals for years, Jennifer was eventually diagnosed in 2010. But since then, she underwent a tracheostomy, after her lung collapsed after she choked.

Tracey said: "The decision was made for her to have a tracheostomy, hopefully a temporary measure.

"She was on PICU for four



Jennifer Lynch

weeks and then a further week and two days on a general ward in London before being transferred back to our hospital in Worthing for a further three weeks."

Jennifer has blossomed at her secondary school – and is joining in sports lessons where she had previously been excluded.

Tracey added: "Jennifer doesn't live a normal social life like any other 14 year old does. She has to be accompanied everywhere she goes; not just because of the vision issues but also and

more importantly because of the tracheostomy.

"You can never tell when this might require suctioning. At the moment only her dad and I are trained in the care of this and it obviously isn't cool to be out with parents all the time."

Tracey said WS is a life-limiting condition, although she said Jennifer isn't fully aware of the long-term health implications.

Jennifer's family started the Wolfram Syndrome support group in 2010, after finding there was no support

in the UK for anyone else affected by the condition.

The group holds fundraising events throughout the year and is appealing for a celebrity to become an ambassador for the charity.

"Raising awareness of such a rare syndrome among the public and especially among the medical profession is very important to us. Many doctors have never heard of the condition or are likely to ever come across a person affected by the syndrome," said Tracey.

Professor Tim Lead Wolfram researcher in the "At the end of the world of big pharma and medical research, incredibly competitive very money driven number of groups this research and find a life changing for Wolfram Syndrome."

"I know that with a cup of a cure the children like Jennifer need someone to lead."

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