



The Charity Roadtrippers started their challenge at Worthing Hospital and were seen off by Worthing mayor Vic Walker and mayoress Rosemary Walker

# Roadtrippers tackle endurance challenge

A TEAM of seasoned 'charity roadtrippers' took on a new challenge spanning four countries and 40 counties, to raise awareness of a rare genetic condition.

Starting at Worthing Hospital, 12 experienced drivers visited 26 major children's hospitals across the United Kingdom, covering 1,600 miles in 52 hours and 35 minutes – smashing their 60 hour target.

The aim of the trip was to present senior hospital managers at every location, with medical information packs specifically written for the many departments that may treat a child with Wolfram Syndrome.

Tracy Lynch, chief executive of Wolfram Syndrome UK, praised the efforts of the team.

She said: "They did really

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well, it's been a huge success.

"We had a very positive response from a lot of the hospitals, with clinicians and consultants coming out to meet the teams when the packs were dropped off.

"It was a lot of hard work and organisation."

Tracy added that the trip had been 18 months in the making.

Tracy's daughter, Jennifer, 12, suffers from Wolfram Syndrome.

Worthing High School student Jennifer, 12, was diagnosed with the condition at the age of eight, following four tormenting years of misdiagnosis.

The condition causes diabetes, blindness and

deafness, as well as a slowly degenerating brain disease. It affects about one in 500,000 children in the UK and there is currently no cure or treatment to stop or slow down the course of the disorder. The disease is also life-limiting.

Tracy, 44, of Church Way, Tarring, said: "Jennifer is doing very well. She's just started at Worthing High School so it's all very different now.

"I'm there all day every day at the moment while teaching assistants are trained medically.

"It is a very lonely and distressing time when you or a loved one first receive the diagnosis of Wolfram syndrome. Imagine if your child was blind, deaf, or had diabetes – or all three for years and no one could tell you why. Then, one day you finally get a diagnosis so you can start to manage the condition, and there is little to no information available – you don't know where to start or who to turn to.

"My husband and I looked on the internet to find out as much information as we could, but there wasn't a great deal – and what we did find was very technical and in medical jargon which was not easy to understand."

The information packs were authored by Professor Tim Barrett of Birmingham University and Birmingham's Children's Hospital, who has researched

Wolfram syndrome for more than 20 years.

Professor Barrett said: "Currently, many children and families have to wait five years or more before the diagnosis is made, as doctors and the public do not recognise the condition.

"We desperately need to find a drug that attacks Wolfram syndrome and I am determined to discover a treatment.

"Realistically, clinical trials might start in the next three years but a definitive treatment for the disease may take years."

Over the last eight years, Charity Roadtrippers has raised more than £50,000 for both local and national charities.

While the aim of this challenge was awareness-based, the roadtrippers managed to raise £5,000, which will be put towards research into Wolfram Syndrome.

Alan Nye, Charity Roadtrippers chairman, said: "Our drivers are no strangers to charity fundraising for many good causes – but this time it was personal. Having met 13-year-old Jennifer Lynch, who is living with Wolfram Syndrome, we did not hesitate to offer our services to help this fledgling charity promote itself."

For more information about the condition and for an online version of the information pack, visit [www.wolframsyndrome.co.uk](http://www.wolframsyndrome.co.uk)



Mayoress Rosemary Walker met Jennifer Lynch at the launch, who suffers from Wolfram Syndrome