



I am going to talk to you today about why we set up the UK website/support group & about the fundraising that we have been doing for research into Wolfram Syndrome.

After receiving the Wolfram Syndrome diagnosis in March 2010, my husband Paul & I did what most of you probably did – looked on the internet to find out as much information as we could, but there wasn't a great deal. We came across the worldwide site & joined that & started to have some contact with other families, mainly in America. The information that we did find was quite difficult for a non-medical person to understand & seemed to be contradictory between sites.

We then decided that perhaps we should try to develop a UK support group & website. We found Professor Barrett's name in amongst the search information, as the researcher here in the UK, so we decided to contact him about what we wanted to do. His response was very positive & he told us then that he was in the process of applying for NHS funding for the Multidisciplinary Clinics. He also asked us to have a look at his application to see if we thought there was anything missing that should be included. He also gave us the details of Linda Partridge at WellChild who was also involved with this. The process began & with the help of a friend we had the website ready in 5 months. We asked Prof Barrett to look at the website before it went live to ensure that all the information about WS was correct. We had decided to put it into layman's words to make it easier for everyone to understand. Our thinking was that when you first receive a diagnosis the last thing you want is to be bamboozled by long technical words. Everything was fine so the site then went live. A month later the support forum went live. I then emailed the UK families that were listed on the worldwide site as a starting point. We try to get new information & any stories/achievements onto the site as soon as we can after receiving them. Only members of the forum can read stories posted on there & contact other members. Forum members are not only sufferers & their families but family friends & professionals working with WS sufferers.

If you haven't yet joined then please do as you will then receive updates & news as I get them. We are also hoping that we can start organising regular chances to meet up with each other. We have done this, meeting up with another family twice now whose daughter is 8 years older than Jennifer. It has been great for both of them & the families, just spending the day together chatting & comparing problems & care.

On the website we have the following pages – home, resources, contact us, about us, fundraising & forum. There are going to be some new pages & information added to the site over the next few weeks so please keep looking. If you have any news or events that you would like put on the site then please send them to me. At the bottom of the fundraising page is a link to our fundraising group 'The Charity Roadtrip'. The charity road trippers have previously raised about £40,000 for a local hospice by organising & taking part in 3 roadtrips from our hometown, Worthing, to the Nurburgring & back – travelling to 5 countries in 5 days. During the last roadtrip a decision was made by all to fundraise for research into WS as obviously priorities had hanged. This is when our involvement with WellChild really started & it was agreed with them that all the money we raise goes specifically to WS research. It was decided that for the 1st roadtrip it would be done on a slightly smaller scale as a test run.

While this was being planned our younger son & 3 of his friends, all children of members of the roadtrip team, approached their headteacher & asked if they could hold a purple mufti day, where each person in school including teachers would make a donation of £1 to wear at least one item of purple clothing to school for the day. Elaborately decorated cupcakes were also sold to staff on the day. The 4 of them then held 4 assemblies to each of the school houses talking about WellChild, Wolfram Syndrome & for Marcus what it is like to live with a sibling with the condition, this was done as a Q&A session. He found the 1st one rather difficult as his younger sister, who has WS, was in ICU in London at the time on a ventilator with both Paul & myself there with her, but he managed it. The 'purple' day raised £885.01 which was sent to WellChild & put into the WS/roadtrip account. The school sent the details of this to the local paper, who then came & did an interview about Jennifer & her story which they ran at the same time. The school also ran the purple day story in their Easter end of term newsletter & again at the end of the school year.

A collection day was held in April at one of the Argos stores in Worthing, organised by one of the road trippers who worked there. This day with the guys dressed in fancy dress & a decorated van, gave the theme for the roadtrip & also raised over £700. The roadtrip plans were now well under way with the route planned around Wales including the main challenge of all the participants walking up Mount Snowdon in fancy dress as children's cartoon characters & also with Nessa the Nurse, Wellchild's mascot.

In between the Argos collection & the roadtrip, one of the local football teams held a charity match of players v managers & raised £250 for us. Nessa was spotted on CCTV & encouraged to take part for some of the match.

On Monday 28th May, 4 cars & 7 roadtrippers all departed for Wales having to solve various clues to get to their destination. A presenter from a local radio station, which had also been promoting the trip & the reason why it was happening including interviews from myself, one of the roadtrippers, Rachel & Prof Barrett & a sound bite from Slash, was with them on the trip & was broadcasting live updates daily, when telephone signals allowed. Each day the teams were set a challenge to complete, failure meant a forfeit at the end of the day. There are always lots of pranks played on each other on a roadtrip which makes it a lot of fun. On the Wednesday they all faced the toughest challenge of the trip, climbing Snowdon. They managed to complete the walk up in 2 hours 40 minutes, even "Nessa"! Apparently coming down was harder than going up. £70 was raised on the mountain with the roadtrip itself raising about £6500. After the mountain climb that evening was silly night which involved making & sampling new cocktails. The next day they set off for a hill climb in one of the more worn out cars & their final night end of roadtrip meal. Day 5, the last day they travelled to the WellChild offices in Cheltenham to return Nessa & to meet all the staff there & a bit of a photo shoot with Rachel & Miranda, who is the Director of Fundraising. Then it was back to Arundel to be met by family, friends & supporters.

Our next event was a family fundraiser day in one of the pubs in town. We had a hog roast, a children's entertainer, and activities for the children, raffles, live music & an auction at the end of the day. We thankfully had lovely weather & managed to raise about £1050.

Last month a 20/20 cricket match & BBQ postponed from July due to weather was held. We also held a raffle & auction with lots of fabulous things to bid on. This raised £1500.00.

We have 2 more fundraisers happening before the end of this year, one of which is happening this evening. A local mature male choir are holding a concert in aid of us & are allowing us to have buckets there for collecting as people leave.

Next month there is a Charity Boxing match being held in our home town that are having us as their nominated charity for the event. If this proves successful there may be the opportunity for this to become an annual event.

There are a few smaller things going on such as selling silicone wristbands, which I have with me today that you can purchase & also commission to come from selling chocolates & cards for friends via their books. It doesn't raise great sums but every penny counts. If anyone would like to take some bands to sell to friends, family etc then please come & see me later.

A new magazine is about to be launched near us called "Sussex Style" & we have done an interview for that which we hope will help raise more awareness about WS.

More fundraising plans are in progress for next year but have not yet been finalised. As a support group we are trying to raise awareness of the syndrome as well as raising funds for research into finding out more about the condition & ways to try & slow down or even halt the progression. I hope that things will really start to take off for us as a Charity group after this year.

I would like to thank you for listening to me & would now like to present a cheque for £11,600, the total monies raised so far to Professor Barrett & Rachel from WellChild.