



# Wolfram Syndrome Family Coordinator

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**A bit about me**

**How I can help**

**How you can help**

the national charity for sick children



Welcome to the WS Support and Information Day, it's the first conference we've organised so we're hoping it's going to be a really good day, and give you a chance to learn more about Wolfram Syndrome, and meet each other and share experiences and generally have a productive day. We would really appreciate your feedback on how you've found the day, so if you could fill in the evaluation form in your conference folder and hand it into one of us before you leave this afternoon, we'd be very grateful.

I'm Rachel Bates, and I'm the Wolfram Syndrome Family Coordinator.

The purpose of this very short presentation is to give you an overview of my role, how I can help families with children and young people with WS, and how you can help me and each other. I'm not going to go into too much detail, I just want to give you an idea of what I do, but if you want to find out more you can come and find me anytime today.

if you have any questions please feel free to ask them during the presentation, I'll try to answer them!

## A bit about me...

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Funded by NHS Specialist Commissioning Team



Started in post January 2012

Employed by WellChild

My background

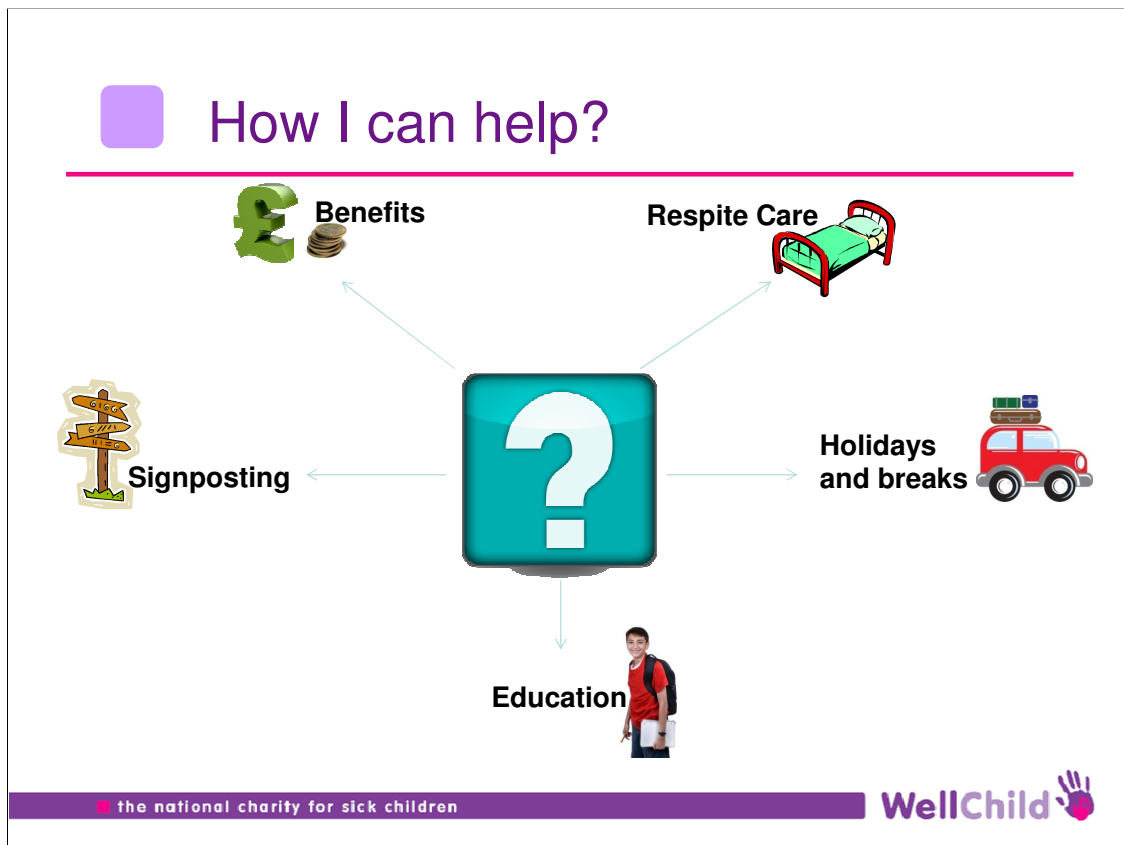
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Last year Professor tim Barrett and WellChild, the national charity for sick children, were successful in applying for a grant for a Wolfram Syndrome Family Coordinator, to work with families with children and young people under the age of 18 with the condition. The grant was provided by the NHS Specialist Commissioning Team who commission over 60 specialised services on a national basis, two of these being the children's wolfram clinic at BCH and the adults clinic at QEH.

I started in January 2012 and I'm employed by WellChild, based in Cheltenham in Gloucestershire, although I spend a large proportion of my time working with the team at Birmingham Children's Hospital.

Before beginning this job I worked in Children's Occupational Therapy, with children with physical and learning disabilities. I did things like provide strategies and equipment to help them access the curriculum at school, and to increase their independence at home and I developed therapy programmes to improve muscle tone, core stability, handwriting, things they were having difficulty with.



So, how can I help families like you....

Very often families are not receiving the benefits that they are entitled to, either because they don't realise they're entitled or they don't have the time or energy to sit down and fill out endless forms. There are agencies in your local area who will sit down with you and help you fill them in, to make sure you get the help and support you're entitled to.

If a child is quite poorly, and needs a lot of care, the family may be entitled to respite care. Accessing respite care can be a long and complex process, which either I can help with, or perhaps put you in touch with another parent who has already gone through the process and so knows what needs to be done.

There are lots of charities out there who offer holidays as a family and breaks for affected children – I can point you in the right direction.

If you're struggling to get the right support for your child at school, I can help by talking to the school on your behalf, or digging out the information you need to approach the school from an informed point of view.

I may know of an organisation in your local area that can help with providing specialist equipment, or have social events that your child can go along to and make new friends.

If for whatever reason I can't help you myself, I'll signpost you to another organisation that can.

These are all things that I can help you with, and make sure that you're aware of all the help that's out there for you and your family.

This is a two way process – I'm learning all the time from talking to you too!!

## How I can help?

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### **Children's WS NHS Clinics:**

**Journey there**

**Hotel and accommodation**

**Answer questions**

**On the day**

**Feedback your experience**



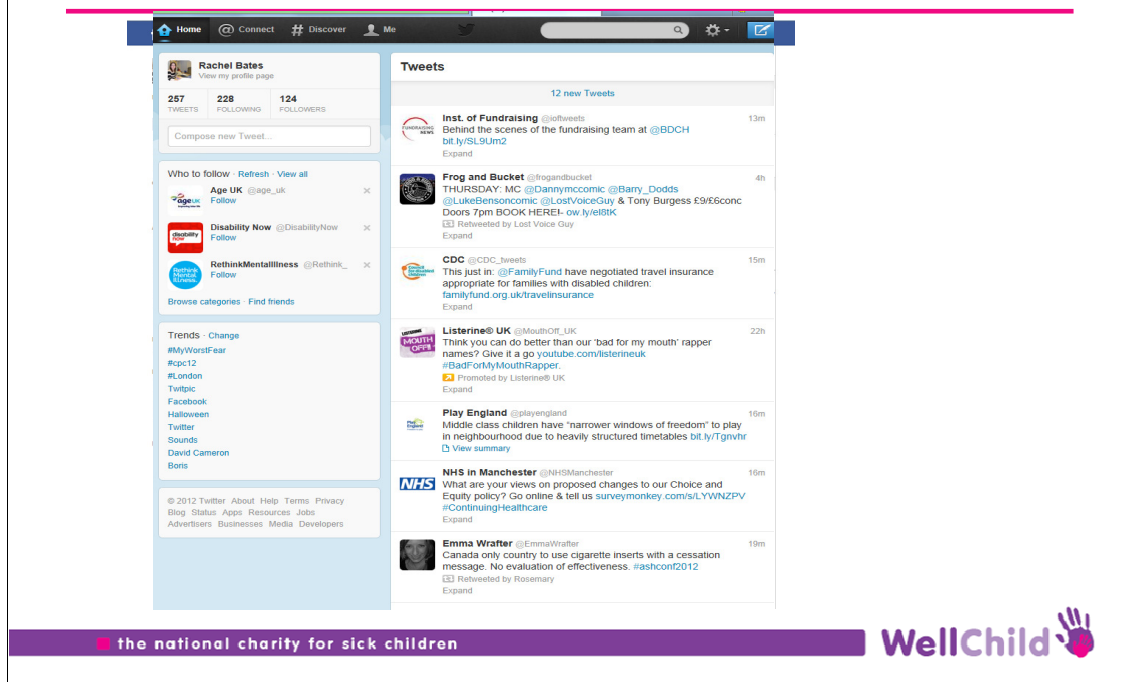
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I work with the team at Birmingham Children's Hospital to help deliver the children's WS clinic. When your child is offered an appointment at the clinic, your details will be passed to me and I'll contact you to give you all the information you need to attend the clinic, and make the process as stress free as possible. I'll send you details about where to park and the hotel you'll be staying in, I'll answer any questions you may have about the clinic, either beforehand or on the day, and I'll be there on the day to help the day go as smoothly as possible for you. It's also a chance for me to meet you, get to know more about your family and find out if there's anything I can do to help outside of the clinic.

Another important part of my job is to make sure that the service you receive at the clinic is right for you and your child. So all the feedback I get from families through the evaluation form they fill in at the end of the clinic day, or through the informal feedback that I get when I call a few days after clinic are fed back to the team at the hospital and used to influence how the clinic is delivered. In response to the feedback we've had so far about the children's clinics, we've changed the format of the day, from being run over one day to running over two days – meaning it's less exhausting and stressful for families.

## How I can help?



A lot of the work we do is aimed at raising awareness of the support that's available, and reaching the hidden families that we don't know about yet, and that don't know about us.

We're doing this through the use of social media like twitter and facebook, and by developing links with key organisations to reach their audiences. Organisations we've worked with so far include Rare Disease UK, SENSE, Contact a Family, Swan UK, and the National Blind children's Society. We'll continue to develop links with these organisations to get the message out to their audiences, and look at ways of working together in the future to support families and people with WS.

We've put a Wolfram families Section on the Wellchild website which we regularly update, and we're working with the UK Wolfram Syndrome Support Group to develop their website and give families up to date, medically endorsed information.

## How can YOU help?

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### Evaluation Forms



### Informal feedback

### Parent Panel



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It's not just about how I can help you, it's also about how you can help me – by providing good quality information on the clinic evaluation forms or during informal telephone calls, and by taking part in our parent panel, which I'll tell you a bit more about. The Parent Panel is made up of a number of parents who commit a small amount of time to meet up, usually via a conference call, to overview the work of the Family Coordinator; to make sure we're doing the right thing for families with children with WS. The Parent Panel can also provide feedback on their experience of the children's clinic, and help decide what really needs to be done to help and support Wolfram families. There's more information about the Parent Panel in your conference folder.

## How can YOU help?

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**Talk to each other....**

**Facebook and  
Twitter**



**Parent Panel**



**Forums**



**Conferences**



**Family Days**



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You can also help by talking to each other...using the forum on the UK Support Group website, chatting on facebook and twitter, becoming involved in the parent panel, coming along to conferences like this one and attending the family days when they're organised in your area. These are all opportunities for you to meet each other, either virtually or for real! They also give your children an opportunity to socialise with each other and swap experiences. These are all really important ways that you can support each other.

**Thank you for listening!**  
**Any questions?**

[www.wellchild.org.uk](http://www.wellchild.org.uk)

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