



Member Memories

Sarah Sudgen and Mark Mayer met in the summer of 2003 at Lake Windermere in the Lake District. Both of them had never met anyone with Worster-Drought Syndrome before. The excitement of actually meeting someone and realising that they were not alone in the world, was a dream they didn't think could come true.

Mark says "The internet has opened up a whole new world to me and I was so excited to meet Sarah for the first time".

"Meeting Mark for the first time was amazing. They had been chatting on Yahoo groups for a while, and to see how WDS affected us both was both really exciting and nerve-racking at the same time" Sarah comments. They both felt it was so nice to meet someone with WDS at last.

Despite living at the other ends of the country, Mark and Sarah kept in touch via email. It was always nice when the family days came round when they got to chat about the things they had been doing over the last year. The WDS group has given them the strength to carry on when things were getting hard or getting on top of them. They had someone to talk to who understood. Equally Sarah said "When I got married to my husband Andy we were delighted that Mark could come and celebrate the day with us". Mark was equally delighted that Sarah, as well as other members of the WDS group, came to celebrate his 40th birthday party. Having that connection has made their friendships remain strong. In the summer of 2013 Mark and Sarah met up at Lake Windermere for a drink to celebrate 10 years of friendship, here's to another 10 years!

The WDS support group has been so much more than just learning about WDS. The most valuable thing they have received from the group is just knowing they can achieve things that, as a child, neither one of them were told it may be possible. Together they have achieved so much more than people believed.

From the Chair



It's soon to be 2014, where does the time go? It only seems like yesterday when I first joined the Worster-Drought Support Group.

Ten years later, its gone from strength to strength and I am delighted to have met so many wonderful people.

I do hope you enjoy reading this Christmas newsletter and find it interesting. If you have any stories you would like us to feature then do get in touch.

Mark Mayer



Genetic Research Project

WDS is an umbrella diagnosis and does not imply a particular cause. Indeed it is likely that as medical knowledge increases, we will find that there are several causes of WDS. There is clearly a genetic cause for some people and in around 15%, several family members are affected.

DNA is the alphabet or language of our genetic information. Genes are the instructions that our bodies use to develop and function. DNA and genes are packaged into structures called chromosomes, which are inherited from parent to child. If there is a mistake in the genetic code such as a misspelling of the DNA or a chromosome abnormality, this can cause problems with growth, development or functioning.

A genetic abnormality has recently been identified in a patient with WDS by Professor Michael Patton at St George's, University of London. We would like to see if this is also found in other people with WDS, as it may lead to a genetic test for some types of WDS. Therefore Great Ormond Street Hospital (GOSH) and St George's are undertaking a joint project to look at the genetics of WDS. GOSH will be largely responsible for identifying and recruiting patients and the laboratory analysis will take place at St George's.

People involved in the study:

Great Ormond Street Hospital:

- Paediatric Neurology/Neurodisability: Brian Neville, Maria Clark
- Clinical Genetics: Maria Bitner-Glindzicz

St George's, University of London

- Clinical Genetics: Michael Patton, Kate Everett, Research Fellow

What will happen in the project?

Initial phase

People known to Great Ormond Street Hospital who already have DNA stored, will be approached to ask if we can use the existing sample to look for this deletion. We will use the latest contact details we have, and also try to trace people via GP records where necessary. If we are unsuccessful in contacting people, we have been given permission to analyse samples using linked-anonymised techniques so that we can use the samples anonymously, but have the ability to link them to a specific person should they contact us at a later date.

New patients presenting to Great Ormond Street or to genetics at St Georges under Professor Patton, will be invited to join the project and have a new blood sample for DNA taken.

The initial phase is planned to last a year and we hope to have some information by the end of summer 2014. Once it is complete, participants will receive a written report, telling them if we have identified a gene that could be responsible for some cases of WDS. In this case, we will arrange to feedback to them individually about their results.

Next steps

If this initial phase has found useful results such as a gene that might be responsible for some types of WDS, we would like to continue with the research and arrange to collect samples from more people with WDS and possibly also consider studies that would look at gene function. We may need to look for specific funding for the project at that stage.

The results of the research will be published in scientific and medical journals so that the information is publically available to improve our understanding of WDS. Participants will not be personally identified in any report or publication. There will also be teaching presentations to groups who are interested in WDS, arranged jointly with the WDS support group.

Maria Clarke

MORE INFORMATION WILL BE AVAILABLE AT NEXT YEARS FAMILY DAY

EXACT DATE & VENUE TO BE CONFIRMED
LOOK OUT FOR MORE DETAILS IN OUR FAMILY DAY FEATURE IN THE SPRING EDITION 2014

Tell us your experiences, good or bad, so we can share them with our members.

Out & About

We are going places with our disabilities...

NEW FEATURE

“ I would like to share our travel experiences on our family holiday to Portugal.

I booked the flights with British Airways and thought little more about this until a few weeks before departure when Martin indicated that he wanted a window seat. So I went back online to see if I could book the seats in advance which you can but at a cost of about £7 per seat per flight. Then I saw the disabled link so I clicked there and was instructed to ring a number. This I did and spoke to a very helpful lady who booked Martin his window seats along with Vanessa's and mine all at no cost.

Our tickets were marked as disabled and we received very good service and were asked at several key times if they could help us.

Many thanks British Airways and we had a great holiday with wall to wall the sun ever day!

No doubt most airlines would offer a similar service so the moral of this story is that there is help out there for you to use, even with internet booking you just need to find the right link or contact them direct.

John Butt

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“ Zachary has just come back from the trip of a lifetime.

The trip, organised by a charity called Birthright, sends young jewish adults to Israel who can't otherwise go for whatever reason - whether it be financial or just bad timing.

Birthright had never taken young adults with learning difficulties to Israel before, so this was a chance for Zach and eight other young people to take part in a life-changing experience. The trip was a wonderful way to celebrate his Jewish identity in a new and exciting way.

The eight young participants had complex learning disabilities and additional physical disabilities. They were accompanied with twelve support staff, a specialist manager that came from Norwood (a Jewish organisation specializing in young people with moderate to severe difficulties), plus two tour leaders and a tour guide. They did a special, tailored version of the traditional Birthright itinerary, geared to the participants' educational and physical needs.

In the pictures are Nick, Zach's carer and Zach at Massada (don't ask how they got up there!). They both floated in the Dead Sea too. Zach and his carer Nick had the experience of a lifetime. They all said that Zach was the life and sole of the party and that made us very proud. This was something that would have been logistically impossible let alone unaffordable!

Birthright is a Jewish organisation BUT there are organisation's in the vast majority of your communities and many religions run amazing, fully funded holidays for your children. As you can see in the pictures it was a holiday of a lifetime and we are so grateful to Norwood and Birthright for giving Zach the opportunity of experiencing it.

Hayley Herman

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Link

NEWSLETTER CHRISTMAS 2013

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NEW FEATURE

Editor's Note

Welcome to another Christmas edition. The group has had yet another successful year and a warm welcome to all our new members. We have a new Out and About feature in this issue and I hope more of you will want to share your stories for future editions. The Member Spotlight is on Mark and Sarah this time and their lovely story so read on and I look forward to seeing you next year! Wishing you all a Merry Christmas and a Happy New Year.



Nicki Turley

Don't forget to send your articles or any news that you would like to see in future issues to:

secretary@wdssg.org.uk

Please let me know if you have anything that you would like to share with other members.



TRY OUR NEW QR CODE



linking members together

www.wdssg.org.uk

All information in this leaflet is correct at time of going to press.

Affiliated to Contact a Family and Rare Diseases UK
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