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NEWSLETTER XMAS 2014

Editor's Note

Welcome to our Christmas edition of the newsletter.
I hope you enjoy our committee members introductions page, which I hope will re-aquaint you with existing members and welcome our new ones.
I hope you all have an enjoyable festive period and look forward to a brand new year with the group moving forward with some fresh ideas.
See you all in the new year!

Nicki Turley

In this issue...

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.

"We thought it would be nice, as we have some new people on the committee, if we could write a little something about ourselves. Looking back over the last 5 years so much has changed since I wrote about myself in a newsletter. There is so much we can do to raise awareness of Worster-Drought Syndrome.

Technology has opened up a new avenue to affordable communication aids enabling children to communicate in ways I could have never dreamed off when I was a child. On a personal note a lot has changed since I joined the committee back in 2006. It seems a life time away now.

I hope you find the information useful and pass this newsletter on to any one who you think may like to join. Membership is free and helps us when raising funds for the group and to show that we have a growing membership.

The Support group is open up to all. Parents, teachers, friends, family and to anyone who knows someone with WDS and wants to know more. It also helps us, when planning family days, to know where those that have an interest in WDS are, so we can locate where to hold the family days. We have a high number of members in the south but would like to reach out to those who are more isolated. If you have any ideas on where you would like us to hold a family day then do get in touch. If you can be specific about where, that would be helpful, instead of just saying up north, this would be really helpful. Venues need to be large enough for us to hold an AGM and have something for the younger children as well as for the older ones."

Mark Mayer

Mark Mayer
Chairman

When I decided to write this I went back through the newsletters to see what I had written last time. I couldn't believe it's been 5 years since I wrote anything about myself.

I am now the grand age of 42, where does the time go? For someone who doctors said wouldn't amount to much, I surely proved them wrong. I am now currently living in Surrey next to Box Hill, which some of you may know held the cycling events for the Olympics. Moving down here from Nottingham was a huge challenge for me and one I have struggled to manage.

After years of trying to manage in a new job and environment I was asked to leave due to my communication issues. I haven't let this stop me and I am currently volunteering for an electronics charity that helped me when I was younger. The charity makes equipment to enable children lead a more inclusive life. They really make me feel part of the team.

I have also recently been diagnosed as Dyspraxic. This was a real awareness for me because I knew I struggled with some tasks like the order I put words in and organising my day, but I thought this was the same for everyone. To have a diagnosis means I can stop beating myself up for not getting things right.

I don't know what the future holds for me but one thing I do know is I will make the most of each day.

Nicki Turley
Secretary / Editor

I have been secretary for the committee for 6 years now and I still love it! I have a husband, Rik and a son Callum, who is 12 now. Despite my involvement with the support group for many years, we only had a formal diagnosis of WDS last year at Great Ormond Street. Callum has difficulties with speech and eating and so he is fed via PEG, but he loves school and has made many friends. He has a wonderful way of communicating with people and making them smile. He has used Makaton since he was two years old, inspired by the BBC programme Something Special, which, fortunately for us, had just been released as a pilot series back then. Since then he has never looked back and, although we have tried communiction aids in the past, he always seems to prefer this method of communication - alongside his ability to 'act out' the rest! He is my inspiration and continually brightens up our lives.

Being on the committee, I have found some wonderful friends, who have been a great support over the years. We work as a team! Due to my graphic design background, I also had the opportunity to utilise my skills to provide the group with its re-branding and produce colourful and hopefully informative, newsletters to all our members. I am so pleased to welcome our new committee members - James and Sarah and hope they get as much satisfaction out of it as I have. I look forward to fresh ideas and approaches to move the group forward, as I myself hoped to do many years ago when I joined.

John Butt
Treasurer

Hi, I have been the treasurer of the group for a number of years. My background is that of a telephone engineer with BT, then I retrained to become a computer software engineer. I have now retired from BT.

I now spend my time making and flying model aircraft, volunteering with Tools with a Mission (TWAM) renovating old PC's before they are sent to third world countries, two mornings a week and commissioning IPADS to be used as communication aids for Suffolk Communication Aid Resource Centre (SCARC).

My youngest son Martin was diagnosed with WDS when he was 11 at the Wolfson Institute. Martin is now nearly 31 and lives in a L'Arche community here in Ipswich about 2 miles from where Vanessa (my wife) and I live.

As treasurer my main role it to look after the group's money by keeping accounts of all income and expenditure, producing the necessary reports for the AGM and the Charities Commission and claiming back any tax refunds the group is entitled to.

Vanessa Butt
National Contact

Hi, I have been married to John for 37 years and we have two son's, our youngest Martin has WDS. Martin was diagnosed aged 11 at the Wolfson Institute where we were given a hand written sheet of A4 with a description of the syndrome. Armed with this description I took this to Martin's GP who said he would find out more information for us. Within a few days he was back in touch asking for a copy of the medical information that we were given as he could not find any other information.This experience has been my motivation to be part of the support group as I do not want other parents to be in a similar position.

As well as being part of the support Group I work with adults with learning disabilities, running a community café as a social enterprise. I also volunteer at Martin's old school, where I help make communication books and logging equipment to go out to children in Suffolk who require specialist communication equipment.

As National Contact, my role is to be the first point of contact responding to enquiries from parents, family members, doctors, social workers, carers… I send information packs to new families and where possible link families together. I maintain the official list of members. I also maintain links with medical professionals working in the field of WDS.

This summer John and I undertook training on Data Protection in Newmarket so our skills are being updated.

Being part of the committee means I do a little of everything, sharing the load with all the committee to make a team.

Sarah Sugden

I'm 37 and married with two boys. I live in Cumbria.I was born with a congenital heart defect known as fallots tetrology – basically I had a hole in my heart and a narrowed pulmonary artery. I had this repaired when I was 5 and have led a normal life since.

As a child I knew I was different to other kids with regards to my speech, drooling and my left side is weaker than my right. Over the years I saw many different paediatricians but I wasn't diagnosed with WDS until I was 13 - but at that point I was told it was something the doctor had made up! It wasn't until I got internet access in 2002 that I googled WDS and to my surprise there was others with it! It was such a relief I cried! My first contact was with a lady in Australia called Anne-marie, who put me in contact with Mark – who is now one of my best friends.

I'm new on the WDSSG committee so I'm just getting to grips with how it all works. I've been a member of the group for approximately 12 years now.

I found the WDSSG to be a fabulous support over the recent years. I've made many friends and we can share ideas/ experiences. Its a nice feeling to know that you are not alone. I always try to make the effort go to the family days as it is such a great opportunity to meet others with WDS. I get so much out of chatting to others to see how they cope. I think a lot of parents that have younger children with WDS are pleased to see the older people with WDS and how we cope with life.

For me without the internet I wouldn't be able to communicate as freely as I do. I love facebook and have just taken part in my first Skype call to the committee.

James Marygold

Hello everyone, I am 21 years old, and my sister has WDS, and her name is Kathryn. Kathryn was diagnosed in 2004, so I have been aware of the syndrome since then and been able to experience it from a siblings point of view. Recently, I have been helping with Kathryn's transition from post 16 to post 19.

I wanted to join the committee to offer a new perspective on things and bring new ideas to the table, and hopefully improve on what has already been achieved. I look forward to getting to know everyone, and take everyone's views and ideas on board and put these forward to help the charity move forward.

Monique Lander

Hi, I have been married to Jonathan for over 38 years. I have three children. Zachy is 21, and has WDS and autism, Jamie 24 and Jacob 14. I am a manager of a Pre School plus. I have recently achieved a degree and BA in Child Care and Young People in my late forty's.

Fab Fun Fundraising

How about a weekend away?

We pose this question as a number of members have suggested that we have an informal meeting where the younger members can have a good time and us older ones can chew the fat, eat, drink and go for a stroll. The staff of Café 66, a social enterprise Vanessa helps to run, have organised a trip to Haven at Caister and I suggest that we could do something similar.

So we proposed that we have a get together at a location like Centre Parcs, a Haven Holiday Park or somewhere, where there is lots to do for a weekend.

The ground rules would have to be that those attending would have to pay their way and would be responsible for those that need care in their group. The support group would try and rent a meeting room where we could meet up, chat and plan what to do.

Are you interested in coming, where would you like this event to be held, what time of the year do you think we should hold such an event?

Answers please to:
John & Vanessa Butt
212 Ashcroft Road, Ipswich, Suffolk IP1 6AF

or **national.contact@wdssg.org.uk**

Looking forward to hearing from you.

John & Vanessa

Our Christmas Cards go down a storm this Christmas!

£3.00 per pack + postage*

Lots of you ordered your Christmas cards from us this year and we would just like to thank you for all your support.

These cards will hopefully help to raise money and awareness for our support group at the same time as enabling you to send your good wishes to friends and family.

There may still be time to order some in time for Christmas if you are quick (subject to Christmas post and time of ordering) so don't miss out!

All order details are on the order forms that you should have received in the post.

If not email:
Nicki Turley
secretary@wdssg.org.uk
for more details.

You can pay by **cheque**, **Paypal** or **BACS transfer**. We are also selling them on **Ebay** if you wish to order packs directly.

* 1 pack £2.60 - add 30p for each extra pack ordered.

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