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NEWSLETTER CHRISTMAS 09

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Don't forget to send your articles or any news that you would like to see in future issues to:
secretary@wdssg.org.uk



From the Chair

Dear Members,

I would like to welcome you all to the new look and feel of the Worster-Drought Syndrome Support Group. I feel a great privilege to represent the group as the new Chairperson. Having WDS myself I am sure that I will be able to help you all and my email box is always open to you all. I would also like to welcome you all to the new trustees of the group and I know we have some great ideas lined up for the group this year. I am very keen to get feedback from you all on what support we can offer you, so do feel free to contact me or any of the trustees.

Having WDS my communication is limited and having a hearing loss makes it a little hard for me but I am open to any ideas on ways I can help you all. I also wanted to tell you a little about my own WDS so you can have some idea on how it affects me and how I can help you.

I was diagnosed with WDS at an early age and attending primary school was not possible for me. It wasn't until I was 8 my parents managed to get me into a special needs school in Surrey. Communication was always hard and making myself understood was problematic at the best of times. I learnt a form of sign language which was likely to be Makaton but I didn't know this at the time as Makaton was not as well known as it is now. I have always been a keen supporter of sign language and for those who have met me know that it hasn't affected my ability to learn to speak. Speech is still hard for me as well as eating. I get tired very quickly and throat infections are common in my life. I have been lucky with being able to learn sign language as I have had a number of jobs working within the deaf community and I am currently a life skills assistant helping people out in the community get the most from life. I am currently 37 and live semi-independently in a flat in Surrey. I have found the internet a great resource for me and it's enabled me to feel part of my community. I use many social networking sites like facebook and twitter. Do feel free to check out our facebook page: <http://www.facebook.com/group.php?gid=4764084892>

I believe that by sharing our experiences we are able to help each other deal with the effects of the WDS more. I am on many campaigns myself fighting for rights of people with speech impairments. Communication aids are costly and a lot of families just cannot afford to buy one. For those who have seen my posts on the WDS Forum, I have been fighting trying to get a new law passed at the House of Commons to allow people with speech impairments, the right to have a voice. Sign language is ok for some people who have the ability to learn it, but the importance of AAC devices allow people to communicate much more effectively. As your chairperson I am here to support each and every one of our members.

Mark Mayer

Introducing..

Monique Lauder (Family day Co-ordinator and Committee Member)



My son Zachary (16) suffers from Worster-Drought Syndrome and Autism and resides at Sunfield School for children with Severe Complex Learning Difficulties in Birmingham on a full time basis. He comes home every other weekend. I am pleased to have been elected again onto the WDSSG Committee.

I am looking forward to the challenges it will bring and being able to support families and to keep the group continuing. I am 44 years old & have been married for nearly 24 years to a wonderful man called Jonathan, we have three gorgeous children of 19, 16 & 10 years I work full time as a manager for a Jigsaw Nursery School in Harrow. I have also run a support group for several years called Special Families which meet 6 times a year, I organise speakers of areas of interest to our families, i.e. Transition, Personal Centred Planning, the list is endless & social's. We have a very active e-group as well which is used on a daily basis.

I hope to offer support to families affected by WDS, raise awareness of WDS and support and promote research.

Nicki Turley (Secretary and Newsletter Editor)



My son Callum (7) has suspected Worster-Drought Syndrome but we have not been given an actual diagnosis. My husband Rik and I decided to join the group 2 years ago to find out more and meet people with similar experiences.

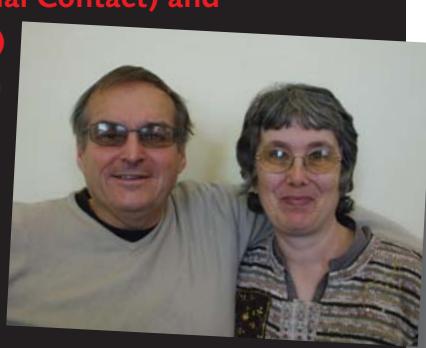
I hope that my having an active role on the committee will enable me to help the group continue and to both give and receive support for other members.

your new committee...

elected at the AGM in London on 25th October 2009

Vanessa Butt (National Contact) and John Butt (Treasurer)

After a two year break from the committee I am feeling refreshed and ready to take on the role again and hope that I can offer help to families who have been diagnosed with Worster-Drought Syndrome and if I can't, to point you in the right direction. Also I hope to liaise with professionals who are researching WDS.



I would like to introduce my husband John, we have been married for 32 years and have two grown up sons, our youngest son Martin has WDS and is living independently in a supported living house very close to us and Paul is a graphic designer who looks after the group's web site. I have been re-elected as National Contact and John the newbie as Treasurer so you could say we are a family package.

Carl and Sally Woods (Committee Members)

Hi, we just wanted to introduce ourselves, we are Carl and Sally Woods and we have just joined the committee for the WDSSG at this years AGM.

Our daughter Bethany (7) was diagnosed with WDS back in February 2006 and we have regularly turned to the support group and its members to guide us along our way.



As new committee members we hope to be able to support the group and also hope to be able to offer advice to new families being given this diagnosis.



No Voice, No Choice

On 25th November Mark attended the parliamentary reception in the House of Commons. On Wednesday 19 November 2008 Scope launched the latest No Voice, No Choice which is a three-year project looking at the provision and support of AAC in the UK and is supported by BT, as part of the BT Better World Campaign. This year the campaign has been looking at the state of Alternative and Augmentative Communication (AAC) services through the experiences of professionals working in the field. The reception was hosted by Dr Roger Berry MP, a long-standing advocate for the rights of disabled people and is currently the secretary of the All Party Parliamentary Disability Group. Over 100 professionals, organisation representatives, people who use communication equipment and their families attended the event.

Dr Alice Maynard, Scope's chair of trustees, discussed the report's findings and highlighted the postcode lottery of support that professionals experience across the country. The report calls on the Government to deliver a commitment to children and young people who use AAC through the implementation of the forthcoming Child Health Strategy and the Bercow Implementation Plan. The report further highlights the need for the Government to focus on support for adults who have speech, language and communication needs. The report concludes by making 10 recommendations to Government, calling on them to take action to ensure all disabled people enjoy their fundamental human right to communication.

John Bercow MP, who recently reported on his independent review of children, young people, speech, language and communication, responded to our report and urged the Government to commit to delivering measures which would ensure the effective provision of AAC services and the support of the workforce. He further noted that his report acknowledged that speech, language and communication needs continued beyond the age of 19 years and therefore the Government should endeavour to look at the needs of adults, particularly during and post transition.

The final speech was delivered by Peter Zein, who is an independent AAC consultant, a No Voice, No Choice Steering Group Member and someone who uses AAC himself. He reminded us that the lack of specific AAC knowledge in health, education and social care resulted in poor or non-provision. He further discussed the acute need for policies in these authorities on how best to meet the needs of adults who use AAC. Lastly, Peter highlighted that best practice occurred when the voices of people who use AAC were at the heart of these policies.

Anyone wanting a copy of the full report contact Mark on chairman@wdssg.org.uk

Save our Date 26th June 2010 ☀

We are in the process of planning next years AGM/Family Day for June 26th 2010: date yet to confirmed subject to venue availability.

Can you help us with the content of the day we already have approached doctors to update us on the syndrome and also input from Professor Hammond who is available to update us on his research, he would like to do more scans of our children's faces? So if you missed this in 2007 then this is an ideal time to get included in the study.

We have a few ideas but have not got the time to fit them all into the day so please help us by choosing from the following topics?

- Makaton workshop
- Behavior management
- Autism -Something about Autism yet to be arranged
- Person Centred Planning. Why it is so important?

Please reply to Monique and Vanessa at national.contact@wdssg.org.uk as soon as possible so we can arrange the day and send you the details of the day

Vanessa Butt National Contact

web links

Here are some websites which may be of interest to you:-

www.widgit.com

www.makaton.org

www.ican.org.uk

www.communicationmatters.org.uk

for younger members:-

www.singinghands.co.uk

www.bbc.co.uk/cbeebies/somethingspecial

and don't forget you can always go on to our website www.wdssg.org.uk for news and updates and chat with other members on the forum.

member links

Our trip to London



After the AGM Carl, Sally and Beth invited us to join them to have a look around all the sights in London before we headed back home to the Midlands. It was very much a "spur of the moment thing" and we had not realised how accessible we were to everything.

"I will push you round Beth"

Callum decided he wouldn't be pushed around in his buggy all day and decided to push Beth in her wheelchair instead. This must have taken it out of him because he suddenly decided that his hands were tired, but he didn't let anyone else know this and subsequently let go of the wheelchair and off it went.

"It's my turn now Callum!"

Closely followed by Carl chasing it as Beth headed in the direction of some passers by and a small fence by the lakeside ahead! Visions of her being catapulted into it came to mind, but we did laugh. As we headed to Trafalgar Square later that day Beth decided it was her turn for revenge and promptly let go of him whilst having their photo taken. We had to smile. It was lovely to get together again after first meeting at last years AGM and it shows how important it is for members to get together and just have fun!

Nicki Turley



Time for farewell hugs and kisses X

What a great day together!!

Affiliated to Contact a Family and Rare Diseases UK

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