

Letter From The Chairman

Welcome to the 19th issue of Words.

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Thank you for voting me on as chairman, I hope to continue the good work of my predecessor Gavin Leech along with the other W.D.S committee members.

We had our first meeting on Saturday 9th September 2006. Everyone was incredibly enthusiastic and is dedicated to continuing the work we have been doing.

We will, in the not to distant future, be publishing an

article which we hope will be placed in Magazines that we feel WDS will best be represented, making the medical communities more aware of W.D.S. We hope that this will be a useful vehicle in our quest to get WDS diagnosed more speedily. Next years family day will be on Saturday 30th June 2007, so please put this in your dairy's as we are planning a great family event at a London venue and workshops. Details to follow.

Hope you all have a great Christmas and a happy healthy New Year. Don't forget we have set up our own W.D.S.S.G forum to enable you to talk to other parents or let us know if you have something to help others with their children's families.

<http://www.wdssg.org.uk/forums>

take care, Best Wishes

Monique Lauder

Worster Drought Syndrome Support GroupCommittee Members

Monique
Lauder
Chairman

I am Monique, I have a wonderful husband Jonathan who I have been married to for 20 years. I have three children, Jamie who is 16, Zachary 13 who has W.D.S and Jacob who is 6 years old. I am in the process of doing my N.V.Q level 4 and I am a Supervisor of a Pre- School Nursery. In my spare time (that is a joke!) I run two other support groups in my area and have been doing this for many years, Zachary is at a residential school in Birmingham for Complex Learning difficulties and comes home every other week.



Secretary

Hi I'm Jacqueline Leech, I have taken on the role of Secretary this year and am married to Gavin the groups previous Chairman. I have 3 wonderful children, Peter, Christopher (who has WDS) and Maria. Christopher is going through lots of upheaval at the moment at school so it makes for interesting times for all, especially after reading his statementing review form!



Vanessa
Butt
National
Contact

I am married to John and we have two sons, my youngest son Martin has WDS and has been a student at Portland College for the last three years.

In August he moved into a new L'Arche community house very near where we live and studying in our local college for three days a week.

I hope that being National Contact for the group I can help new parents get the information on the syndrome and help to get WDS more commonly known.



Hayley
Herman
Committee-
Member

hi my name is Hayley Herman - i am Monique lauders sister. I have been on the committee for several years and am really enjoying the challenges it brings my way. My nephew, Zachary, suffers with WDS and is at Sunfield School in Birmingham. He is doing really well and is improving all the time. I am married to Marc who is wonderful nearly all the time and have three children, Rafi aged 9, Ellie aged 8 and Mia aged 3.



Newsletter Editor

Hi, I'm Graham and I'm the newsletter editor and have been a member of the committee since June 2002.

I'm married to Karen and we have 2 children, Olivia 8 and Charlie 7.

Olivia has WDS and this prompted me into getting involved with the group to find out as much as I can about the condition to be able to help her and be able to pass that information on to others.



Mary Rumbold Treasurer



Micheal Rumbold Committee Member

Mick & Mary Rumbold.

When our son Elliot (13) was diagnosed with WDS we naturally contacted the WDSSG and soon after became members. We have recently moved to Sandhurst in Berkshire and Elliot now attends a special needs school in Bracknell.

As parents of a WDS child we felt it was important to support the group and help raise awareness of the condition. We are now both committee members and Mary is Group Treasurer.



Rene Fullerton Committee Member

Rene Fullerton, 35 years old, parent of Jack who has WDS aged 9 and Charlie aged 4. Lives with husband Adam in Hindon, we both work from home.

Adam is an Embedded Systems engineer and I design and make clothing as well as look after the financial side of the business. I am back at college studying Pattern Cutting.

We live in a lovely village where we are able to keep or own livestock. I am a governor at our local school and also assist with a number of fund raising projects in the village.



Mark Mayer Committee Member

Mark Mayer, 34 years old, I live in Nottinghamshire. I have been a member of the WDS group for 3 years. I became a member because growing up with WDS I found I could give a lot of support to other WDS members and parents. I am now glad I am a committee member

I work as a Learning Support Assistant in a College that specialities helping people with psychical disabilities. I have worked there now for 2 years.



Anita brown Committee Member

My name is Anita Brown i have been a committee member for 5 years. I Have 3 children 2 girls and 1 boy and it is my son who has worster-drought-syndrome he was diagnosed in 1996 when he was 4yrs old his main area has been his speech but over the years has improved, he attends a special needs school. Thomas loves going to the family days that the committee arranges.

Positive Aspects is a new **free** bi-monthly email newsletter for anybody who has an interest in any disability and/or mental health issue from anywhere in England*. To subscribe, all you need to do is return this email and put 'subscribe' and the county you live/work in, in the message of the email. Please read on for more information about Positive Aspects and me.

Positive Aspects is full of useful information:

- Campaigns
- Computer Hints & Tips
- Contacts and Penfriends
- Law and Order
- Leisure and Fun
- Real life stories by parents who have a child who has a disability/Mental Health Issue
- Stories and articles from people themselves who have a disability/Mental Health Issue
- Medical and Research
- Poetry and Prose
- Books/Downloads/DVD's/Report and Resources
- Support
- Things to make your life easier
- Useful Information
- Useful Websites
- A separate supplement entitled '**diary dates**' – dates for conferences, exhibitions, events etc., for all England.

As the main **Positive Aspects** newsletter contains information on a national level, there is Positive Aspects '**Newsflash**' for information on a local level: i.e. A new support group in Surrey wants to get word out about themselves and what they offer – they send me their info and I send it to all who are subscribed in Surrey - A brilliant idea to get the word out, plus Newsflashes can be sent out at anytime.

Anybody who wants to put something/advert in **Positive Aspects** or to go out in **Newsflash** can do so **free of charge**.

If you want to see what Positive Aspects is like, visit: <http://www.pinonline.org.uk/16.html>

Finally, here's a bit more personal information about me:

I have 4 children, 2 of whom who have disabilities. Nicholas, who is 12 years old, has Williams Syndrome and Alice who is 8 years old has Down's syndrome. I myself have Obsessive Compulsive Disorder and have a history of depression and self-harm, with suicidal tendencies (all currently under control). My father who is disabled through Polio bought up my brother, my sister and me. I live in Ipswich, Suffolk, and am married to Tim. I am 38 years old.

If you would like to receive Positive Aspects, please email me with 'subscribe' in the subject and make sure you let me know which county you live/work in, so you can receive the 'newsflash' articles.

I look forward to hearing from you.

Trudy Ransome
trudy.1@ntlworld.com

Jack Fullerton's Story

Our first child, Jack was born on October 16th 1997 in Salisbury, Wiltshire. A slightly complicated arrival in as much as Jack was delivered by 'Ventousse Extraction'. Jack did not latch on and had to be fed by bottle. This isn't uncommon, so I didn't worry about it at all. Jack was a happy little baby from the beginning and didn't give us any cause for concern. At around three months, after a spate of colds it was discovered that Jack did have a heart murmur which in turn meant he had a 'wet chest' so he was vulnerable to coughs and colds.

Developmentally Jack was a little behind schedule which didn't cause us too much concern until it was very noticeable that the bottom shuffling he was doing was proving to much more successful than any attempt to walk. In fact, he went so fast he wore a lot of his clothes out! I did have concerns about this but was assured that Boys take longer to do things and all should iron itself out. However when we added up that Jack didn't seem to be able to chew up his food properly and I was still mashing it up and giving him soups when his friends were tucking into a fairly normal lunch I started to ask more questions. Jack was still dribbling and not really talking, just Mum & Dad and No.

Then Jack had a spate of illness and got Bronchilitis at 18 months. This was considered unusual as this would be an ailment for a child of less than 12 months. He was hospitalised for four weeks, I mentioned that he had a heart murmur. The doctors could not hear it so we were sent to Southampton where a large hole was detected and Jack's heart was enlarged. It was decided that a heart operation was the answer to the problem, but the doctors wanted to delay it for as long as possible to avoid Jack unnecessary discomfort. The doctors at Southampton felt Jack was delayed too and made a few enquiries. Given the diagnosis of a Heart abnormality I didn't concern myself with the delay in development too much. This is because I just wanted him to be healthy and to get the heart operation out of the way and concentrate on the rest later.

After numerous hospital stays for every imaginable chest infection or cold Jack got A typical Pneumonia and was given his operation.

In August 2000 Jack had his op and was changed boy. At nearly three years old he started to walk and tried to say more. Even the eating started to improve. I enrolled him at a Montessori nursery which he really enjoyed. However, the sudden changes did not continue and no further improvement was made. Having said that, Jack did get himself dry and using the toilet very quickly at around 3 and a half.

The Nursery head teacher referred us to an ICAN nursery in Salisbury and we began to use Makaton and Pecs.

This went rather well and I was encouraged by Jack's progress. The dribbling continued and we became aware that Jack's co ordination and balance was poor. Jack could not grip a pencil very well and seemed to have a squint. I was beginning to think it would never end. There seemed to be something wrong all the time. We pressed on with Nursery and got referred to a Paediatrician at Salisbury who felt Jack may have Dyspraxia and we started the whole speech therapy/physio roundabout. This went on for about 18 months and we got Jack statemented for a school with a speech and language unit. This was a bit of a mistake as they did not have a clue! It took me 18 months to get him out of there.

So, Jack by this time is making very little progress and we really were at a loss as what we should do next. At our next visit to the Paediatrician, Dr Lwin at Salisbury I told him I was unhappy with how Jack was getting on and he did agree that Jack's progress was not as he expected it to be with the help he was getting and felt that maybe a different diagnosis was needed. He showed me some literature on Worster – Drought Syndrome and said he would like to refer us to see Professor Neville at Great Ormond Street. I was quite shocked, I didn't think Jack fit the information Dr Lwin gave me. Needless to say we went to see Professor Neville and he diagnosed WDS. Since the diagnosis Jack has been moved to a better school. In fact he's very lucky because he attends two. One is the mainstream school in our village, three days a week and two days a week he goes on the bus to a special school for children with SLD. He loves it! He's also got a little brother, Charlie, who he dotes on. Charlie understands Jack perfectly and they share a very special bond.

We still have trouble with balance and he can't use a pen very well, so he's got a lap top. Jack's school work is behind the others, but he's catching up. He's just turned nine and now does up his buttons on his polo shirt, packs his bags for school and goes away on trips with his friends. He's becoming a very independent young man. The speech is still a problem and always will be but he's improved so much and improves every day. We're blessed to have a little boy like Jack.

ABOUT BDF NEWLIFE

BDF Newlife is the UK's leading charity focussing on inborn conditions.

BDF Newlife funds medical research into all inborn conditions (Birth Defects) and has had success in improving diagnosis, understanding conditions and helping with treatment and care. In the last financial year the charity committed around £1 million to medical research.

BDF Newlife also campaigns to raise awareness on the impact of these conditions and prevention. BDF Newlife started as the Birth Defects Foundation in 1991 and is celebrating 15 years helping children and families.

Every day in the UK, BDF estimates that as many as 124 babies are born with some sort of inborn condition. That's five every hour. Sadly, 25 of the babies born every day may not live beyond the age of seven.

BDF Newlife funds a national nurse helpline which offers information and support to those affected or awaiting test results on inborn conditions. The professionally manned service is available on 08700 70 70 20 or info@bdfnewlife.co.uk

Child and family grants are also available to families in need and more information is available at our website www.bdfnewlife.co.uk

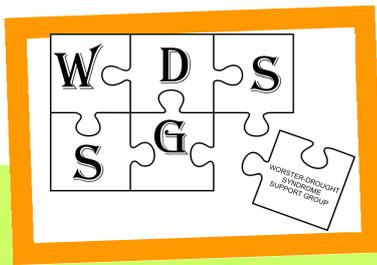
The charity's CEO and co-founder Sheila Brown was awarded the OBE for Services to Child Health – she is the mother of a son with a genetic disorder and autism.

PLEASE KEEP SATURDAY 30TH JUNE FREE FOR THE WDSSG AGM

The Worster-Drought Syndrome Support Groups' AGM and Family Fun Day is going to be on Saturday 30th June 2007 at Coram's Fields, a wonderful park reserved for children with organised childcare from The Log Cabin. Whilst your children are taken care of, the parents will be taken to another location, near Coram's, where our AGM will be taking place.

We have a wonderful, special TV personality with us this year called Lorraine Marer, Behaviour Specialist. Lorraine will be running a workshop on behaviour, ADHD and anger management. She has starred in two programmes on prime time TV. The first was 'Families Behaving Badly' and 'Teen Tamer' both on Channel 5.

We are so excited to have Lorraine Marer join us and hope that you can come and support the WDSSG. Both venues are in Guilford Street, Central London. We are asking that each adult member of WDSSG pay a voluntary fee of £5.00 per family and non members pay a voluntary fee of £10.00 per family. If you are interested in joining us please contact Monique at monique.lauder@btopenworld.com



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Worster Drought Syndrome
Support Group

www.wdssg.org.uk

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• We are always looking for articles for the newsletters so
• please email them to the editor at
• words@wdssg.org.uk

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• We would gratefully receive short stories, personal in-
• sights, poems, funny stories or indeed anything that you
• might consider useful. Generally we keep the articles as
• sent but sometimes it may be necessary to edit them
• slightly for various reasons.

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• The Editor and The Worster Drought Syndrome Support
• Group do not accept any responsibility for the views of
• contributors expressed in this newsletter.

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• The cut off date for the next newsletter will be mid Janu-
• ary 2007

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• From the next issue, we hope to send the newsletter by
• email so it is very important that you send us your correct
• email address on the registration form.

•
• Don't worry if you are not on email we will send you the
• newsletter through the post as normal.

We are struggling and we need your help!

Dear Newsletter readers,

We (the committee) are finding it more and more difficult to find articles to include in the newsletter and we are desperate for articles about **your** children. Over the years we have written a great deal about our own children and while we can give updates, we really don't want to just re-hash what has gone before. So any new articles or ideas would be most welcome. Please don't put this off to another day, sit down this weekend for an hour or so and just start putting something together. We all need to do this in order for us to all benefit from each other's experiences and to keep the newsletter fresh, interesting and informative.

WEB SITES THAT MAY BE OF INTEREST

<http://www.ncype.org.uk/> (The National Centre for Young People with Epilepsy)

www.communicationmatters.org.uk/

www.makaton.org/

www.widgit.com/

www.symbolworld.org/

www.talkingpoint.org.uk/

www.btinternet.com/~black.ice/addnet/statmnt.html