WORDS

The Newsletter of the Worster-Drought Syndrome Support Group

ISSUE 10

A Message from the Chairman

Dear Member

Worster-Drought Syndrome is a condition that affects us all. Like many others, we knew our son Christopher was in some way different from his peers but didn't know how or why. His older brother was very bright and did everything earlier than he should have and we thought Christopher was just a little slow off the mark. At each developmental assessment any concerns we had were brushed aside.

We then moved to back to Essex after spending four years in Surrey and finally found someone who listened to us. During the first routine visit by our health visitor, following the birth of our daughter, we mentioned our concerns over Christopher's lack of progress to her. Within six weeks we had an appointment arranged to see the community paediatrician, who then arranged an urgent appointment with the paediatric consultant at our local children's centre. Our consultant Dr Bridgeman mentioned numerous conditions, Worster-Drought Syndrome being one of them. HELP, we had never heard of this condition, the children's centre didn't have much info, where could we turn, who could we turn to. Then a lifeline appeared whilst searching the net for info, we came across the WDSSG website and communication with the national contact, Vanessa Butt was established. Following confirmation of the diagnosis we were put in touch with another family who had a child with WDS and who had some similar problems to Christopher. At last, a group of people who understood. We could chat to like minded families, meet other children with the same condition and generally find out more information. Our GP knew nothing about WDS, everything he now knows he learnt from us (nothing new there as we have since found out).

The point I am making is I am now in a position to offer something in return. The WDSSG was a huge help to me and my family. My first task was to register the group with the data protection act. Which is important when you are holding information on people on a computer. Then it was to apply for status as a registered charity.

The group had been asked to help raise money to fund further research into WDS. Brian Neville, Professor of Paediatric Neurology at Great Ormond Street Hospital, asked for our help in raising £150,000.00. Being a registered charity makes this sort of task easier. Companies and individuals are more likely to give to or sponsor the group if we have charity status. The paperwork was duly filled in, financial statements included and documents signed by the management committee. This is currently with the charities commission as I write.

Then came the Family Fun Day at London Zoo. The next thing I knew was, I was standing in front of a hundred plus parents talking about WDS. What a fantastic day, I must at this point thank Monique, Hayley and Vanessa for taking 10 months to organise the day. It was a huge success!

So here we are. The structure is in place to help raise the money needed to improve all our lives in relation to WDS. Fresh faces on the management committee with new ideas working alongside established members who have a wealth of knowledge. And an exiting future for all involved with the Worster-Drought Syndrome Support Group.

In This Issue:

WDSSG Fun and Conference Day

All those who attended the third WDS Fun and Conference Day at London Zoo on the 19th May will agree that the children went away happy and parents/carers went away with a better understanding. Over fifty families attended the event from all over England and people travelled from as far a field as New Zealand and Norway to learn more about this little-known syndrome.

Thanks to the Children's No 1 Foundation, who funded the event, the support group was able to offer the families excellent crèche facilities. This was organised and run by a wonderful group of professionals from the Log Cabin and New Games UK.

Families were given bright yellow presentation packs which included useful information and the children were given specially printed T-shirts to mark the occasion as well as a London Zoo Lion for a leaving present. This event wasn't just about having fun, it was to enable us to hold our inaugural general meeting, talk about our constitution, and discuss our financial concerns for the coming year. All this was done and we all agreed it was a resounding success. Chairman, Mr. Gavin Leech commenced the proceedings by thanking everyone for their continued support. He talked about the reasons for being a registered charity and the greater need for more research and support to be available. He also discussed raising funds amounting to £150,000, for a three-year research project into WDS.

We held a successful Question and Answers session lead by a panel of highly qualified individuals. They all share the same dreams of more research and the need for a better understanding of the syndrome. Professor Brian Neville headed the panel along with Paediatric Neurologist Professor Renzo Guerrini, and Senior Specialists in Speech and Language Therapy Katie Price and Nicola Jollef. The session was very important as it answered many of their queries on the Syndrome.

Our primary goal as a group is to support families whose children are affected by WDS, many of who had never met, and share information on its treatment, care management and early diagnosis. I think those that attended will agree that this was definitely achieved.

Question & Answer Session

Question by: Susan and Allan Garcia
Could WDS be hereditary and does genetics play a part?
Answer: Yes, in a number of families it is, but has not yet been well researched.

Question by: John Butt
Do the research team have any contact with the original study that Dr Worster-Drought did in the 50's to see how they have developed and also if they have had children with WDS?
Answer: Yes I have seen a member of one of the original families.

Question by: Joanne O'Doherty
Can the panel please advise why a child's ability to process and retain information is affected by WDS and whether short-term memory is affected more severely?
Answer: This is usually because of learning and attention problems

Question by: Martina and Paul Savill
By what age/stage is it obvious the WDS child will definitely not speak?
Answer: 6-7 years

If a submandibular Duct Transposition operation is necessary to ease drooling, before what age it is not advised to do so or does the panel recommend the continuing use of drugs (e.g. Atropine or Robinul) for life?
Answer: No they dry the mouth. Surgery after 6-7 years usually i.e. to wait to see if there is natural improvement

If a WDS/CBPS child regularly chokes on food, is this something that they will grow out of with maturity or just learn to deal with the choking as and when it occurs?
Answer: this needs careful and specialist advice.

In Brief

A research update by Dr Maria Clark. This was taken from an indepth research project undertaken on behalf of 100 cases of WDS known to Great Ormond Street and 40 children involved in an ongoing study.

What is WDS and how does it show itself?

- Congenital Pseudobulbar Paresis
- Facial Features are varied
- Expressive speech problems occur
- Dribbling is common place
- Glue Ear
- Gastro-Oesophagael reflux
- Aspiration
- Poor Nutrition
- Movement can be a problem
- Learning difficulties
- Birth anomalies
- Behaviour problems
- Epilepsy
- Eye movements
- Feeding difficulties

How to look out for WDS

- Condition often not recognised / more awareness is needed
- Unlike other children's major speech and feeding problems
- Multiple needs can compound difficulties
- Long term difficulties
- Complex multi-disciplinary support

Understanding of Causes

- Oral features
- Other impairments
- Birth anomalies
- Genetics (20%)
- Rarely underlying chromosomal abnormalities

How do we investigate WDS?

- Brina imaging
- Muscle
- Eye movements

Question & Answer Session

Continued from Page 2

Question by: Vanessa Butt
When teaching a child sign language is it best to go for a system that teaches grammar? Or go for a symbol-based system?
Answer: It depends upon the child's stage of communication

With the changes in technology, communication aids are being increasing used for our children, the down side of this is the waiting time for the aid, and the funding process. Have the panel any advice that would help parents get the aid sooner rather than have a very long wait.
Answer: There is a new nationwide scheme, which should speed things.

Question by: Deborah and Richard Holroyd
Have any triggers been suggested for WDS such as drugs e.g. Larium. As opposed to environmental triggers or infection during pregnancy?
Answer: NO

Question by: David Melunsky and Judith Melunsky
Accepting that there are differences in WDS children's abilities, what happens to adults with WDS?
Answer: Very Little is documented but no dramatic change after teens

Question by: Monique Lauder
As our children are getting older the genetics of WDS is becoming more important especially to older siblings who are thinking about children of their own. Is research getting closer to finding an answer regarding the genetic link to WDS?
Answer: I think it will be better in 5-10 years

Question by: Vanessa Butt
One of our families in Europe is being helped to improve tongue movements by having a plate fitted with a metal ball on it to stimulate the tongue. Have the panel heard of this?
Answer: No experience

Question by: Jame and Richard Thorpe
Why do some WDS children who clearly have epilepsy have 'normal' (negative) EEG results?

Answer: Common in epilepsy generally and less likely if have sleep deprived/sleep record

Professor Brian Neville has very briefly answered our questions The group would suggest that if you have any medical concerns that you seek advice from your child's doctors

Meet the Committee!

Donna Donlon
Treasurer

We have two children, Jake and Ruby both with WDS. Jake is a boisterous 7 years old, he has several words and communicates well with Makaton. Ruby is a quite placid 5 year old, she has not started to sign, but looks like she will given time. They both attend a wonderful special school, which has been a huge help. My husband runs his own Carpentry Company, whilst I do some part time work as an accountant. Jake was diagnosed at 3 years 4 months, the WDS group was a wonderful help with so little information available. Ruby was diagnosed at one year.

Hayley Herman
Secretary

My name is Hayley Herman. I am happily married to Marc and we have two children called Rafi, 5, and Ellie, 4, who continue to amaze and delight us.

My role on the WDS support group is that of secretary. I collate, debate, relate, and do all sorts of other office duties. My nephew, Zachary Lauder suffers from this dreadful condition and my sister Monique managed to get me involved with your group. I worked on the London Zoo event and whilst the work was demanding, it made it all the sweeter when I saw all the children's happy faces during the event, making the day the success it was. I look forward to the challenges this role will bring and am honored to be working for such a dedicated support group.

Vanessa Butt
National Contact

I joined the group when Jane Thorpe asked for help to form a national support group seven years ago. I am very happy to still be here and am looking forward to working with the newly elected members of the committee.

We have achieved a great deal over the last seven years and I hope that any family whose child is diagnosed with WDS today, will be able to find information on the syndrome. When Martin was diagnosed, all we were given was an A4 piece on the syndrome and when looking for more, we found nothing.

I thank you for voting for me and over the coming months I will continue to strive to help any new parents who contact the group, to link families together but also try to make more professionals aware of Worster-Drought syndrome.

Monique Lauder
Fund-raising

My name is Monique Lauder, My son Zachary (9) suffers from Worster-Drought Syndrome and now lives at Sunfield, Birmingham on a full time basis. I am thrilled to have been elected onto the Worster-Drought Syndrome Support Group Committee. I am looking forward to the challenges it will bring and am delighted at the thought of being in the thick of things again. As you know the WDS support group offers support to families affected by WDS, raises awareness of WDS and supports and promotes research. We will be following the progress of the research project and will keep you informed of any developments that occur. Thanks again for electing me

Graham Spencer
Committee member

My name is Graham Spencer, I am married to Karen and we have 2 children Olivia aged 4 and Charlie aged 3. Olivia has WDS, which mainly affects her speech.

Up until recently she had no real words only vocalisations backed up by Makaton signing, but we are thrilled that she has started saying Mummy and Daddy.

I am involved with the WDSSG as a committee member to help out in anyway I can and also to gain as much knowledge as possible about WDS for Olivia. For anyone who may wish to contact me, I will always be available to offer support and information, just as we have been helped in the past. I am keen to help with fund-raising and look forward to any new research for the answers and understanding it may bring.

Anita Brown
Committee member

Hi I am Anita Brown, I live in Nailsea, Bristol in the south west, with my three children Chloe (12) Thomas (10) and Megan (5).

Thomas has WDS and was diagnosed with it in 1996 and has come along way since then. I've been involved with the group actives since then, and I felt it was time for me to get more involved and try and help the group as much as I can down in the west country.

Thomas is my big friendly giant, he always has a smile and who ever he meets, just loves him. His speech is the main problem, but he lets you know what he wants and will not give up until he makes you understand him. He goes to a special needs school and he loves it and he has blossomed since going there.

Jacqui Leech
Committee member

I was asked to write an introduction about myself, so here it is. My name is Jacqueline Leech and for my sins I'm married to the groups chairman. I'm mum to Peter 9 1/2, Christopher 5 1/2 and Maria 2. Christopher has WDS, he has a beautiful personality most of the time but then all the behavioural issues kick in and boy is he hard work.

I became involved with the support group because I wanted to help other families as I was helped when Christopher was first diagnosed.

Michael Rumbold
Committee member

See News from the Rumbold family Page 7.

News from Norway

Stian (5) was a very happy baby. He was breast-fed until he was 11 months, the only worry we had was that he hardly made sounds, he just smiled and laughed all the time. At 6 months he was quite chubby. When he turned 18 months we started getting worried about his speech. I contacted the local health center but they just blew me off. I had a feeling that they thought I was another hysterical mother. We had to wait until the 2-year control. After going through the system a few times Stian started with speech therapy when he was 3. The therapist believed Stian was stubborn and not willing to speak, his theory was to break down Stian's stubbornness... (only made things worse!). We discussed with the speech therapist several times about having a clinical examination. He got quite angry each time we brought the subject up. We were un-comfortable with the situation. Luckily we have had great help in Stian's pedagogue at daycare, (she helps Stian with eating, communication, stimulation etc). The pedagogue also understood that maybe the problem lay somewhere else and she helped us to get in contact with one of Norway's best child neurologists. It took the doctor 15 minutes to give us a diagnosis!

Once we had a diagnosis and we got into the hospital system we could stop fighting. We were offered great help and understanding. Stians MR convinced the doctors that it was WDS. The first EEG showed some un-normal activities, but the next two showed none. Stian has never had any seizures. The hospital that examined our child had no knowledge of other children in Norway with WDS at this point. We have found out that there are at least two other boys in Norway with WDS, but we are not in contact with them yet. We have found all information about WDS on the Internet.

We understood pretty early that Stian has a mild form of WDS. This was verified when we met other children in London in May. Stian has good fine motor skills, but he has a slight hand tremor (especially early in the morning - he seems to warm-up during the day though…!). He has chewing/drooling problems because of his tongue. He eats everything though, and his favorite food is sushi!

Stian is very intelligent and will be attending a normal school. His speech is improving and people who know him understand 90% of his language. The main problems are K,G,R,S,F and V's. We have been through lots of tests to find out which difficulties we need working with. He doesn't hold a pen with enough strength, but he is good at all sports (especially ball sports). In September we are going to get a plate fitted to the roof of his mouth with a small "bead" attached to it, to help stimulate his tongue and swallowing. His tongue movements are slowly improving - before he couldn't pull his tongue out at all but now he can. There are no side movements, and he cannot point it. This autumn he will receive speech therapy. We hope this will help him even more.

I have contacted the Swedish and Danish seldom syndrome groups to try and find help in Scandinavia but neither had heard of WDS.

The whole family attended the fun day in London to try and find out more and to meet others with WDS. This was a great experience. We learned more about the syndrome, and met lots of lovely and friendly people. It was a little peculiar to be able to examine other handicapped children without feeling rude. Usually you tell your children not to stare! We wished afterwards that we had more time to meet other parents as we traveled from abroad. We had spare time, but we understand that others were eager to get home. Maybe this could be arranged next time? ;))

Two weeks ago Stian received a personal computer (one for home and one for daycare!) He's getting quite good at the games bit.... After the holidays he will get Boardmaker installed (a picture based program). He will also be getting a digital camera so that he can take pictures to use at daycare. The specialists think that this will help stimulate his language. (He's a bit lazy about giving any information away for free, but if he gets excited you can hardly stop him!). Stian will be attending school next year (they start at 6 here) so he has got a full year to manage the computer stuff. He will be attending a mainstream school. His big brother Erik (7) will be good to have then!

Hope this information can help others in (small) countries where WDS is not acknowledged yet. What kept me going until Stian got a diagnosis was that I knew my child better then anyone else and the doubt/feeling that something wasn't right kept coming back. If we had done as advised from many and waited until he got older Stian would have never been prepared for school.

Ole and Marie Gundersen

Sensory Integration Dysfunction (SID or DSI)

For the last few years we have 'put up' with Christopher becoming unbearable behaviour-wise during the summer months. There became a point when good weather was dreaded in our household as this meant our lives would be turned upside down for a few months.

We requested help with controlling Christopher's tantrums and also asked for a sensory assessment to see what if any of his behavioural problems were sensory related. After months of badgering, Christopher finally had his sensory assessment, undertaken over 6 weeks. The findings that came back were certainly a revelation to us not least because most of Christopher's behavioural problems were sensory related the rest of them were typical behaviours associated with a child of his 'mental' age.

A Sensory Assessment looks at the following areas of a child's everyday life;

Auditory Processing - what noises do they like or dislike, do they seek or hide from noise?

Visual Processing - Do they seek or hide from different types of light?

Vestibular Processing (ability to control movement of body and direction of movement) - How active is the child do they seek or hide from activities that involve movement?

Touch Processing - What type of objects does a child like touching, do they seek or hide from physical touch?

Oral Processing - What if anything will they put in their mouth?

There are other observations carried out by the OT, but they are quite hard to simplify into everyday language, such as Modulation of Arousal Level.

One specific question we asked our OT was about heat and Christopher's apparent change in personality during the summer months. The reply we got back was eye-opening to say the least!

Christopher needs to have constant movement in his life to get the sensory input he needs to function at a normal level; this has a lot of ramifications in hot weather.

During warm/hot weather a 'normal' person will slow down when hot, children like Christopher who cannot function without movement in their lives 'switch' off the messages from the brain saying 'it's hot please slow down.' They continue to crave and seek out movement making them appear 'hyper', couple this with Autistic spectrum disorder and ADHD etc. and you have a recipe for disaster. Children like Christopher may then suffer sensory overload whilst trying to function in warmer temperatures leading to sensory shutdown which can manifest itself in numerous ways. With Christopher firstly he becomes 'unbearable' then he hides away from everyone, but other signs can be unexplained nausea or dizziness, or the child may fall asleep suddenly

At the moment Christopher is undergoing a 'sensory diet' with the OT, she is showing us what activities we can do with him that give him the sensory input he needs and calm him down. She has said she can't promise that the 'diet' will help all the summer related problems because like us she has no control over the ambient temperature, but at least it's a start. Whilst still dreading high temperatures at least we now know why Christopher is so 'HYPER' during this time and we can prepare ourselves a little better mentally to cope and before anyone suggests using a fan, that only works short term with Christopher, typical!

The above is only a small part of Christopher's sensory problems, but I am aware that there are some families out there who like us have problems during the summer, so I hope it helps you in some way. The specific 'sensory diet' Christopher is undergoing may not help another child with similar problems which is why I haven't listed them, what I can suggest is that you ask, badger or scream for an sensory assessment. There are some very good OT's out there trained to undertake such an assessment and your paediatrician should be able to help you with this.

If anyone want's more information about SID either visit the website at **http://www.wdssg.org.uk** or contact us

Jacqueline and Gavin Leech
01376 348948

News from the Rumbold Family

Hi, Mary Rumbold here. It's been a while since I last wrote a piece about Elliot for the newsletter, and so I figured it must be our turn to contribute once more. I have to start by saying how much we enjoyed the W.D.S. conference at London zoo. It's great to see the group growing and becoming more and more organised, and it's good to see so many new faces. I think the highlight of the day for me was having 'neuronal migration disorders' explained in an accessible way.

Some of you might be aware that Elliot was sponsored to climb Snowdon in June. I have to say he was just great, we were so proud of him. The weather was fine as we started out, but about 2/3rds of the way up it changed completely, and we had driving rain for some time. However, once he reached the top there was no dampening his spirits, he was so pleased with himself. Many thanks to those of you who sponsored Elliot; the money raised will be equally divided between his school, which is a special school for children with severe speech and language difficulties, and W.D.S. Research.

Elliot is 9 now, and just coming to the end of his first year at his new school in Cardiff. Changing schools was a bit of a gamble but it seems to be paying off as he is progressing in all areas. Number work though, still remains a big problem. Elliot has difficulty with co-ordinating his counting, e.g. he might point at objects on a page one at a time, whilst counting numbers out loud, but the pointing will often be at a faster pace than the speech sounds. His teacher also recently discovered that he has never got to grips with rhyming language, he just doesn't seem to be able to consistently identify words that rhyme.

At his old school Elliot was easily one of the most able children, whereas now he is the least able in many respects. Our hope was that if he was surrounded by a more able peer group this would encourage his own development both academically and socially. This certainly seems to be the case. Elliot loves his school and socialises well, and despite the fact that he is in a class a year younger than his age, and still with children who are academically higher achievers than he is, we have been pleased with his progress so far.

We are still waiting for assessments from the educational psychologist and the communication aids centre. Here in Cardiff, seeing an occupational therapist, even with a referral can take 12 months, which is a frustratingly long time when you have a child of Elliot's age who needs a dedicated computer in order to be able to fully access the curriculum.

For a long time Elliot has worn a sweat band around his wrist to help deal with his dribbling, but this has never been completely satisfactory and is now becoming a bit more of an issue as far as he is concerned. So we are trying 'hyocine patches'. They are quite effective and he likes using them, but they do leave him with a dry mouth over night and we wonder if this may disturb his sleep. Elliot has recently seen a specialist Speech and Language Therapist, and she has developed a series of exercises that we use to try and help him gain more control over his tongue and lips. I have definitely seen improvement in him, albeit slight, and we have only been doing them for about ½ a term.

At the moment Elliot's speech often seems to be more of a problem than at any time before, purely because it can be so frustrating trying to figure out what he is saying in ever longer utterances. His speech mostly consists of vowel like sounds, but his syllable lengths and intonation patterns are usually correct, and often offer the best clues. He uses signing to supplement his speech, a combination of Makaton which he used at his old school and Paget Gorman, which is used at his new school. Unfortunately though, many Paget signs are difficult to make for those with poor fine motor control. One thing we are sure of though, is that Elliot is a great one for communicating, and we can't wait until he has the 'right' communication aid, so that we don't always have to be available to interpret for listeners. Especially when the conversation is about Power Rangers, cars, heavy plant machinery or other such riveting topics!!!

I look forward to a time when as a group member it will be easier to contact other families within the group, especially when their child shares similar problems to your own, so that we can discuss strategies for dealing with specific problems.

Hope you all have hot and happy summer holidays.

Mary, Mick and Elliot Rumbold.

And Finally...

Can you Help?

Dear Parents

Those of you, who like me have gone through the process of obtaining a Statement of Special Educational Needs know what a minefield it is.

The Support Group is looking at ways it can help parents with this in the future, in order to do this we need your help.

Please reply to the questions below adding any other comments you may feel are relevant to the process:

- Did anyone in the LEA know of WDS?
- Did the lack of info on WDS mean you weren't offered the appropriate help for your child?
- Have you had to get any 'extra' diagnosis to get the help you need, e.g. Autistic Spectrum Disorder, behavioural problems etc.?
- Anything else you think might help other families

If you can help me could you please write, email or phone

Jacqui Leech, 10 St Vincent Chase, Braintree, Essex. CM7 9UJ, Email: gleech@lineone.net , Tel. 01376 348948

Thank you in advance for your help

Jacqui Leech, WDS-SG Committee Member

Attention all Non Internet ready members.

For families who were not at the family day and have no access to the Groups Internet Site we have an article about “The role of augmentative communication to support unclear speech”. If you would like to receive a copy please send an A4 stamped addressed envelope to Mrs Vanessa Butt, 212 Ashcroft Road, Ipswich, Suffolk IP1 6AF who will be happy to send you a copy.

Thank you

Mike and Mary Rumbold would just like to say a very big thank you to everyone who sponsored Elliot Rumbold to climb Snowdon this June, we have been overwhelmed by peoples generosity.

Despite driving rain, and as it turned out 'leaky' waterproof climbing boots, Elliot managed very well, much better than we thought he would, and we were very proud of him. Elliot himself was so pleased with his achievement that on the journey back down he just wouldn't /couldn't shut up! In fact he was on such a high, that once he'd got back to the hotel and had a bath, he was ready for a game of ping-pong! Later that evening, we joined the rest of the climbing party, who of course all congratulated Elliot on his climb - as did his school friends and teachers when he got back to school - so he is still riding high on the crest of a wave at the moment or should that be mountain?

Elliot's climb has managed to raise about £1000 which, as stated in the sponsorship forms is to be divided equally between Meadowbank school for children with severe speech and language difficulties, and the Worster Drought Syndrome research project, which is looking into the genetics of the syndrome. Both parties can put the money raised to very good use, so once again thank you all.

STOP PRESS

The next AGM/Picnic Day will be on June 22 2003 from 11.00am to start at 12.00 noon. The venue decided on is called Sunfield in Birmingham, which is a magnificant boarding school for children with special needs. The details are sketchy at the moment but we will let you know more when we can. In the meantime please put the date in your diaries.

To give us some indication of numbers can you send this slip to Mrs Monique Lauder, 4 Hallam Gardens, Hatch End, Pinner, Middlesex HA 5 4PR

or Email details to HaymarCons@aol.com for the attention of Monique Lauder.

Invitation and directions will be sent out nearer the date.

Monique I/we are interested in attending the next WDSSG AGM/Picnic Day on 22nd of June 2003.

Name:……..

Address:…….

……...

……

Post code:……...

Number Likely to attend: …… Adults

…… Children