

WORDS

The Newsletter of the Worster-Drought Syndrome Support Group

ISSUE 11

A Message from the Chairman

Welcome to the first edition of our newsletter in 2003. May I take this opportunity to wish you all a belated Happy New Year on behalf of our management committee.

2002 was a fantastic year for WDS-SG. The family day in May at London Zoo was a huge success and I look forward to meeting many of you again later this year at our AGM and family picnic.

Amongst the many things I have done in my life I have always wanted to shout HOLD THE FRONT PAGE. Well at last I can.

This edition of Words was in the process of being proof-read when we received a letter at home.

We did, as you are aware, apply for status as a registered charity in May 2002. This

process, we were told would take approximately 6 to 8 weeks and should be a formality. This, however, was not the case. The initial application can take up to 8 weeks and then the real work begins.

Each trustee is checked. Organisations such as GOSH and The Wolfson Centre are contacted to ensure our integrity. Research is conducted to check our condition is real, even though we are affiliated to The Rare Disorders Group and Contact a Family. This all takes time and add to this, our case file being sent to the Liverpool office, as London was too busy, via the Taunton office!!

The good news is that, some 9 or so months since the initial application, we have been granted charity status. Our charity registration number is

1095290, which will be added to all our stationary as soon as possible. Now we can forge ahead, raise some money and help with research into this condition, which affects all our lives.

Before I sign off I must thank Graham for gathering the content of this newsletter, Paul for setting it out and Vanessa for checking the spellings.

Also, a big thank you to MFI who sent us a donation cheque for £200. This was gratefully received.

Once again I wish you all a happy New Year and look forward to meeting many of you soon.

Gavin Leech

Chairman

Workshops

We would be very interested in setting up workshops in and around your area. Workshops would be run by a professional speaker, well versed in his chosen topic. They would be run informally and would be a wonderful way in gaining a better understanding, increasing your knowledge, aiding your education and getting to know other parents in and around your area who have a child with WDS. The subjects can be as diverse as you want them to be. Already we have a number of educators lined up to talk about

IT, Communications, Education, Behaviour and Movement.

Obviously these workshops cannot work without you the parents. We would therefore be very interested in knowing whether this sort of service would be of any interest to you? Please let us know your thoughts either by email: Haymarcons@aol.com re: Workshops, or by sending us the cut off (on the last page of this newsletter) in the post. We look forward to your speedy reply.

In this issue of WORDS:

[Page 1] - Message from the Chairman / Workshops.

[Page 2] - Links / Communication Aid Suppliers Consortium

[Page 3] - Family Day June 2003

[Page 4] - Family Day Accommodation

[Page 5] - Zachary, His Personal Journey.

[Page 6] - Zachary, His Personal Journey - continued.

[Page 7] - A Message from Contact A Family / Workshops reply form.

Links

Publications

A lot to say by Jenny Morris. A free copy can be obtained by emailing

Information@scope.org.uk

Software

Writing with symbols 2000 from Widget creates makaton signs from Words. More information is available on their website at

http://www.widgit.com/html/products/s_wws2k.htm

Support services

Anyone wanting free independent advice and guidance with the statmenting process for special educational needs. There is help available from :

Network 81

<http://www.network81.co.uk/>

Telephone: 0870 7703306

Advisory centre for education (ACE)

<http://www.ace-ed.org.uk>

Telephone: 0808 800 5793

Independent panel for special education advice (IPSEA)

<http://www.ipsea.org.uk/>

Telephone: 0800 0184016

Rathbone

Can be contacted by emailing:

advice@rathbone-ci.co.uk

Telephone 0800 9176790

Communication Aid Suppliers Consortium

For anyone looking into getting a communication aid for their child, a good place to start is to attend a Communication Aid Suppliers Consortium Roadshow.

There they have demonstrations and information on products currently available on the market by most of the leading manufacturers.

Its an informal event where you choose which Communications Aids your interested in and sit in on any of the workshops you wish to attend.

You get the chance to try out the equipment and ask any questions you may have.

Some useful information about upcoming events can be found on the communication matters website at:

www.communicationmatters.org.uk

There may also be help with funding available through different channels.

Anyone wanting any further information, please contact the news sheet editor through the WDSSG website.

Want a message or a useful link published on the WDSSG website news page? Send an email along to news@wdssg.org.uk and we'll see what we can do!

AGM 2003 and Family Day

Sunday 22 June 2003

This year's Family Day and AGM will be very informal, so families can have fun together, have a chat, swap ideas and enable us to hold the groups AGM. All of which will take place at a wonderful venue in the Sunfield School, Clent Grove, Woodman Lane, Clent, Stourbridge West Midlands DY9 9PB..The school caters for children with severe complex learning needs.

To keep costs for the day to a minimum there will be no creche available but we are booking childrens entertainment.

Please note that parent supervision will be required at all times

Unfortunately this year we will need to ask you for a donation of £10 per family to cover some of the costs for the day

Full details of the day are not yet available but the following is rough outline for the day, we will confirm the final running for the day nearer the date.

Start 11 am

Teas and coffees will be served between 11-12 pm

12 noon AGM

During the AGM there will be activities for the children,

1 pm Teddy bears picnic (Lunch)

So young and old bring your teddies and picnic lunch and join in the fun.

After lunch we will have access to the

Soft play area- maximum of 10 at a time

Outdoor special needs area.

Look at the animals the school is very fortunate to have animals that we can see.

Art and crafts

Walk around the grounds

Chat to others and swap ideas etc

3-4 pm

Teas and coffee

Goodbyes

Invitations to the event will be sent to all the group in March.

We hope that you will be able to join us, at what hopes to be a very enjoyable day, if you need any further details then please phone Monique on 020 8428 6706.

Places providing overnight accommodation are listed overleaf.

Family Day Accommodation

For anyone with a long way to travel who might be thinking of making their journey on the Saturday and staying overnight, we've contacted some hotels and B&B's in the area and secured some preferential rates.

The Hilton Bromsgrove
Birmingham Road
Bromsgrove
Worcestershire
B61 0JB

Telephone: 0121 447 7888

B & B - Single Occupancy	£45
B & B - Double Occupancy	£60

Children under 5 are completely free of charge.
 Children between 5 - 15 years old are free when sharing a room with an adult (only breakfast is charged at £6.50)

This is a special deal organised for WDS parents so quote WDS Weekend c/o Carlie Orme, reservation co-ordinator.

The Mount Hotel
Mount Lane
Clent
Stourbridge
West Midlands
DY9 9PR

Telephone 01562 885904 / 886482

Single Room - Single Occupancy	£40
Double Room - 2 Adults	£50
Twin Room - 2 Sharing	£52
3 Bedded Room - 2 Adults 1 Child	£55
3 Bedded Room - 3 Adults	£60
4 Bedded Room - 2 Adults 2 Children	£65

St Elisabeth's Cottage
Woodman Lane
Clent
Stourbridge
DY9 9PX

Telephone: 01562 883883
C/O Mrs Sheila Blankstone

1 Room	Twin	With en suite
2 Rooms	Double	With en suite

£30 per person per night Bed & Breakfast

This cottage is next door to the school.

Travel Inn
The Badgers Sett
Birmingham Road
Hagley
West Midlands
DY9 1JS

Telephone: 01562 883120

1 Room en suite	2 Adults 2 Children	£42
-----------------	---------------------	-----

1 Room	£40
--------	-----

Breakfast not included, There is a Beefeater next door

The French Hen
Bromsgrove Road
Clent
Worcestershire

Telephone: 01562 883040

3 Rooms Only

2 People	£48.50
1 Person	£35

Articles for the next newsletter

Does anybody have any articles they would like to appear in the next newsletter, any information they could share with everyone, personal experiences, their story. We would like to hear.

Please email the news sheet editor through the WDSSG website under contact us.

Zachary - His Personal Journey

Zachary's Diagnosis -

Whilst at the Alexandra School in 1997, at the age of 4, we got a referral, through our constant insistence, to see Professor Neville, Neurologist at Great Ormond Street Hospital where he diagnosed Zach with WDS (Worster-Drought Syndrome). After years of wondering and speculating we finally found out what was wrong with Zach and our initial reaction was not what I expected after waiting so long to find out. We expected to feel relief that we finally had a diagnosis instead we felt very numb and empty. There was no cure, there was no apparent help and we were left in a wilderness and didn't quite know how to get out of it. We were concerned about his future, our future, our children's future and whether it could happen again, should we decide to have another child or indeed whether our daughter, Jamie aged 7, would be affected by this. As time went by we realised that Zach was the person we needed to worry about and really our feelings, however important, needed to be dealt with but our son's needs had to be dealt with first.

The Family

We decided for many reasons that we wanted to have another child. We sought genetic counselling and felt that we would take a chance. However, my husband stipulated that if on any of the scans they're showed an abnormality we were to have an abortion. We felt that our family was not complete because we both came from a big, warm and close family and wanted to emulate that into ours. The pregnancy was a huge burden for my husband, my daughter, our families and myself. I became obsessed with eating well, living well, and the general looking after myself because as a mother I had always felt a little to blame for the way Zach is. I know this is ridiculous but one cannot help one's feelings. I went through 9 months of pretence with everyone.

I told everyone I was feeling wonderful but mentally I was petrified especially when I found out in the early stages that it was another boy. Thank G-d Jacob turned three in November; he is a wonderfully happy, healthy child who has brought a huge amount of love and happiness to our home.

How Zachary affected the family as a whole?

When Jacob was coming up for one year old the problems with Zachary escalated. Zachary became even more obsessed with Jacob; he wanted everything he wanted including food and/or toys. With no malice intended Zachary pushed, shoved, prodded and pulled Jacob about on a regular basis causing bumps and bruises (thank goodness for Arnica!). We couldn't leave them alone in a room for one second unsupervised.

Jamie our daughter reached crisis point during the summer of 2000. We took her to see a psychologist, as she seemed very unhappy both at school and at home. She was phoning home from school saying she was ill and asking to be collected. She had undergone a change in her personality by becoming aggressive and snappy at home, and was experiencing mood swings which were not normal in a girl of 10 years of age. The psychologist recommended a change in school partly to keep her busier after school and away from Zachary more. We moved her from her local state school and placed her in a small private school. The repercussions of this for Zachary were disturbing. Both Jacob and Zachary had to come with me to pick up Jamie from school which was a 20-minute drive causing Zachary great distress. He didn't want to leave the house; he became very vicious towards us and constantly attacked us in the car. The result of all this for Jamie was that she became solitary, rarely requested to have friends over, and spent long hours on her own in her room from her return journey from school. We

found this situation heartbreaking.

Our Reasons for Residential school

As Zachary needed constant adult supervision it became completely impossible for us to go out and do normal family things. The simple act of going to a friend's house for tea became impossible. Zachary didn't cope well with a change of environment and this caused him to be more aggressive and prone to tantrums. His obsessive behaviour was getting worse and he was getting more and more physical with all of us. His poor sleep patterns meant that we were sleep deprived and along with his special needs and demands it caused many arguments in the home, particularly between his parents. His lack of comprehension was particularly difficult to deal with, as was the situation with his bowels. All our family time was spent meeting Zachary's needs at the expense of our other children and us.

At the age of 8 he was still at the Alexandra School. Until then it had served him very well, but the school felt that he needed the input of a school designed and run for children with severe learning difficulties. After various visits from the Health Team in Harrow they too felt that he would be best placed in a residential school, as did our social worker, Paediatrician and the Educational Department in Harrow. After extensive soul searching at home, we too concluded that the best provision for Zachary would be in a 52-week provision enabling him to benefit from the advantages of a 24-hour curriculum, essential to develop his self help skills and to give a consistent approach to his challenging behaviour. This was the most difficult decision we have ever had to face as parents. We had to think about our family and how it could survive if Zachary was to stay at home and we honestly felt that it would have destroyed our home life, our children's sanity and our marriage.

Zachary - His Personal Journey (cont.)

This is where the process of looking for an appropriate school for Zachary began. Once you start the process you then realise that there are limited 52-week schools with varying stipulations of special needs. We had to get books from organisations i.e. Rathbone, Network 81, Norwood Ravenswood and ask friends. We couldn't believe that there wasn't a central organisation or book that had all the details you needed in it, but we live to learn! After months of searching through loads of books for suitable schools we selected just three schools which we felt would possibly be suitable for Zachary's needs. All schools selected were out of our borough which involved funding.

We visited Sunfield School in Stourbridge, near Birmingham. The school runs as a 52-week provision. It had a very caring atmosphere and uses the TEACCH method, which we felt would benefit Zachary. The educational level seemed to us to be the right pitch for Zachary as it was a very visual system and we knew it was used extensively and successfully for children/adults with autism and autistic spectrum disorders. The school assists in giving order in a world of confusion. Here they use a visual daily personal timetable, both at school and in residence.

The residential part of the school was very attractive with each child having their own bedroom, which was done to your specification making the transition as easy and homely as possible. The school also took the approach of looking at each child as an individual and decided, as a group of professionals, with many years experience with challenging young people, how best to meet the needs of that individual child. They also seemed willing to work with the family as a whole, not just the child. The family could visit the children at school and stay at a family centre specially created for parent and siblings. We were impressed with the staff's level of commitment and

care towards the children.

The whole school appeared clean, friendly and inviting, something which was lacking in the other residential schools we saw. Here Zachary would receive 1:1 support and stimulation during all his waking hours and that was essential for a child with his level of disability. We felt absolutely certain that a 24-hour curriculum was best for Zachary. We felt just as certain that a 52-week provision was best for us as a family.

Let the Battle Commence

Sunfield had a place available for Zachary after the school met and assessed him. The next stage was to get the local authority to fund his education and well being. To simplify matters you needed to get the actual name of the school you wanted your child to attend on the statement to cover yourself legally. This involved the social worker going to see the school on more than one occasion to see if he felt the school was suitable, on behalf of the local borough council. He then had to convince a panel of experts along with the various reports from the Health Team in Harrow, our social worker, paediatrician and the Educational Department etc in Harrow in order to confirm funding. Please be assured this is not a quick process and can cause stress! Funding was eventually agreed and Zach had a place to start in August 2001 at the age of 8.

The Outcome

We made regular visits to the school before he started so that he could get used to his surroundings and prepare him as much as you possibly could but he had very little understanding of it. We felt absolutely certain that this school was going to be the best place for him but this didn't seem to help us feel any better about the situation. On the weekend he started the school, myself, my husband and

Jamie our daughter stayed over night in the family centre and Zachary had a good night and settled in well. We spent a little time with him in the morning and then we had to leave which was awful for all of us. We were all crying and upset.

Zachary, on the other hand, seemed fine. He settled in very well and his room was like his home from home with all his 'stuff' around him. He obviously misses us because he still carries around photos of us and watches videos of family events everyday. We have recently had a visual conference computer put into his room so he can see us every day, which confused him at the beginning, but now he looks forward to our calls. We see Zach every other week, which entails going to Birmingham and him coming home once a month. Zach was confused, in the beginning, when he came back home to visit as he didn't want to leave but as time goes by he is enthusiastic about returning to Sunfield and has accepted the situation with great ease. His overall behaviour has improved tremendously and he seems happy and content with his life.

Seeing Zach happy helps us to know that he is being looked after and cared for and that he is getting the best care and support he can get. As we have explained previously, the decision to send Zachary to Sunfield was not an easy one. It has involved much sole searching and tremendous heartache. We have always had wonderful family support, which hasn't gone away, and this has helped us tremendously. However the pain of the situation is with us on a daily basis and we never kid ourselves that it will be any easier as time goes by.

A Message from Contact A Family

Dear Group Chair / Secretary

Contact a Family has been approached by the Human Genetics Commission(HGC). This is the government's advisory body on how new developments in genetics will impact on people and health care. The HGC are planning to conduct future research work on the impact of human genetics on decisions about reproduction. This will include some of the scientific and ethical aspects of advances in genetics and the choices faced by people before and during pregnancy. As part of this study they have invited us to give a list of what we believe are the key issues for them to consider.

We would be very interested in your thoughts, feelings and suggestions about this and would be grateful to receive any contribution which you would like to make to the discussion. Please feel free to contribute as little or as much as you like. Everything will be of value and we will incorporate this into the Contact a Family response which is due by the 31st January. We would therefore appreciate your response by 23 Jan 2003. Please feel free to contact either Lucy Arnold, Directory Researcher or Liz Ranger, Development Officer, if you would like to discuss to discuss this or for any further information.

Many thanks

Lucy Arnold
lucy@cafamily.org.uk
Direct line: 020 7608 8712

Liz Ranger
liz@cafamily.org.uk
Direct Line: 020 7608 8715

-
Contact a Family - <http://www.cafamily.org.uk>
For families with disabled children

Helpline 0808 808 3555 - free for parents and carers (10am - 4pm
Mon-Fri)
Minicom 020 7608 8702
General e-mail: info@cafamily.org.uk

209-211 City Rd, London. EC1V 1JN
Tel: 020 7608 8700
Fax: 020 7608 8701

Registered Charity No 284912
Company Limited by guarantee No. 1633333
Registered Office: 209-211 City Rd, London. EC1V 1JN

RE: Workshops

Name: _____

Address: _____

Name of Child(s) with WDS: _____

I would/wouldn't be interested in workshops in and around my area.

I think the subject matters the committee have chosen are excellent but I feel I require a better understanding of the following subjects:

Reply to: Hayley Herman, Secretary WDS, 40 Hilfield Lane,
Aldenham, Herts, WD25 8AJ