

**WDS-SG**

# WORDS

ISSUE 20

March 2007

## Letter From The Chairman

INSIDE THIS ISSUE:

Hi Everyone,

Hope all is well with you and your families. Myself, Vanessa and Hayley have been very busy putting together a new concept for our family day on Saturday 30<sup>th</sup> June 2007.

We have decided to change the format and start the day earlier, as well as having Discussions Groups with various professionals on Behavior, Siblings, Transition and Dentistry. We have also employed the Log Cabin staff to look after your children in the morning and the children will also be entertained by music man Saul.

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The day will not only be different but we do however have some very exciting news Paul Ashley who is currently doing research on some of our children's teeth along with Professor Hammond will be doing a short presentation at the A.G.M

Professor Hammond will be setting up at a 3D Face Image Scan for our children on this Saturday. We hope as many children will participate in this exciting study as it's the first one for Worster-Drought Children.

I hope you will support us and other Worster-Drought families in joining us for what promises to be an interesting and fun packed family Day.

See you all soon.

Best wishes

Monique Lauder

## Transition

If you are aged 13 and above and have an Education Statement then by law it is your right to a transition plan. There are lots of people you can help you and make sure that what you say is in your transition plan and help it happen.

Transition is growing from a child and becoming an adult and it is wise to talk with as many people as possible, so you know what is available and it helps going and visiting different places.

There will be a transitional review which will start to build a plan for your future.

Be Prepared

### People who can help

**Your parents, family, carers or friends**

**School staff**

**Teachers Support Workers**

**Special educational needs co-coordinator**

**Head teacher**

### People who work in the Health service

**Your paediatrician**

**GP**

**Therapists Speech and Language and OT**

**Connexions Personal Advisor** your school can put you in touch with your local advisor

**Social Worker**

### Person Centred Plan

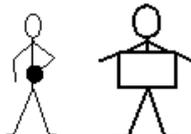
If you have trouble with communication then having a person centred plan can help as this is where you and a group of friends who know you best, get together and help you write down what you would like to do in the future and any dreams you may have.

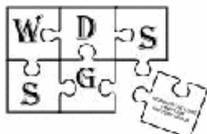
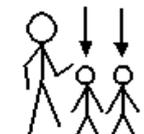
Circles network can help and advise you.

[http://www.circlesnetwork.org.uk/what\\_is\\_person\\_centred\\_planning.htm](http://www.circlesnetwork.org.uk/what_is_person_centred_planning.htm)

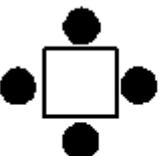
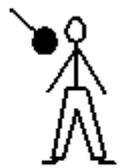
<http://www.after16.org.uk/pages/learn1.html>

[www.skill.org.uk](http://www.skill.org.uk)

     
Hello , my name is Mark

        
Welcome to the WDS children's page of

       
the newsletter Connor sent me his story

       
about going to football and his

    
family. Thanks Connor

## To all our junior readers

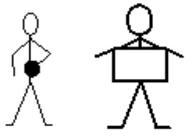
Can you help us design a new logo for the children's page, go on have a try and we will pick a winner in the next issue.

Over the summer if you have some holiday snaps that you would like to share with us then please send them to Mark Mayer

Portland College Nottingham Road Mansfield Nottinghamshire NG18 4TJ

or email [newsletter@Markinsutton.co.uk](mailto:newsletter@Markinsutton.co.uk)

# Children's Page



my name

is

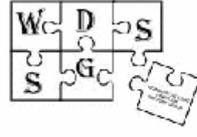


Mark

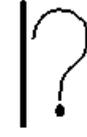
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WDS



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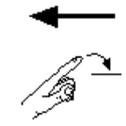


was



small

I



went to

a



special needs



school.

I



am



now



working

at



Portland



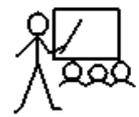
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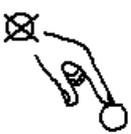
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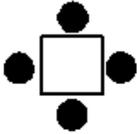
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teach



others



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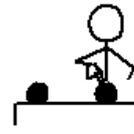
computers.

I

really



enjoy



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like



computers

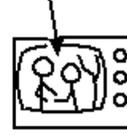
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have



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programmes



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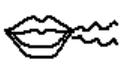
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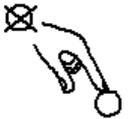
me



talk



with



others.

I

also

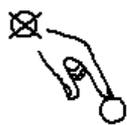


give

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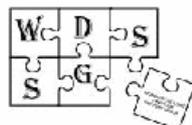
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who



have



WDS



Please



send



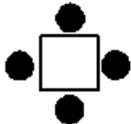
me



your



stories



about



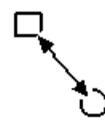
your



school,



friends



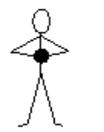
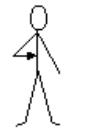
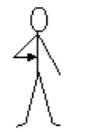
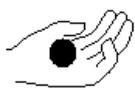
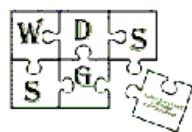
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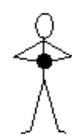
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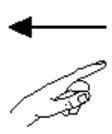
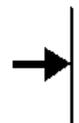
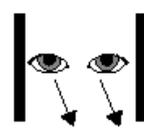
jokes.

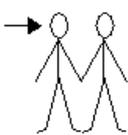
# Connor's Story

 Hello  my name is  Connor  I  age 9.  I  have  WDS

 I  like  Football  my  Favourite  team is

 Manchester United  I  like  Rooney  and  Ronaldo.

 I  went  football  with dad  to  watch  Manchester United

 and  they  won



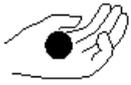
Me and Dad



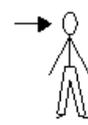
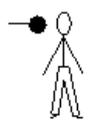
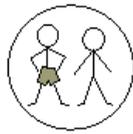
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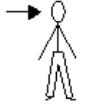
Old Trafford



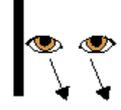
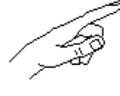
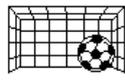
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I have one brother his name Adam he plays



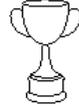
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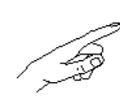
Football he is in goal. I go watch Adam play



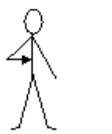
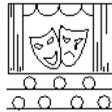
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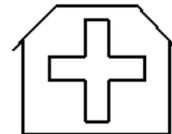
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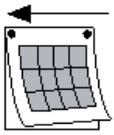
football Adam got lots of Trophies I not go



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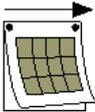
christmas play I was sad go Hospital.



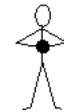
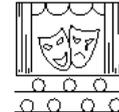
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last year I was shop keeper in Willy Wonkers chocolate Factory.

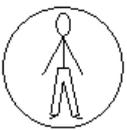


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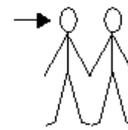


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maybe next year I be in christmas play My Mum and

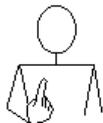
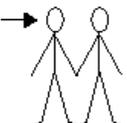


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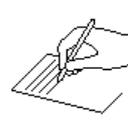


dad name is Gareth + Michelle I love them lots

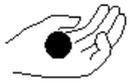
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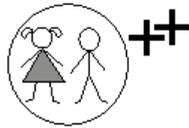
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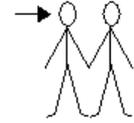
and they help me with reading and Writing



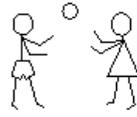
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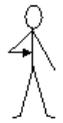
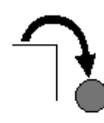
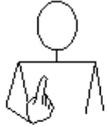
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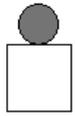
I have two sisters Briany and Abbieleigh they



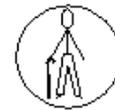
help Me I like playing with my sisters My Dad



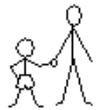
help me ride bike. I fall off sometimes I



+



get on bike again My Nanna and Grandad Going



+



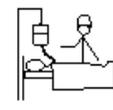
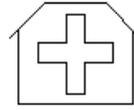
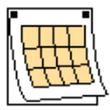
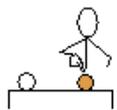
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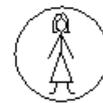
take me swimming with Dolphins I am happy and excited



this year but sad i go hospital again operation my



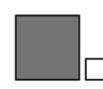
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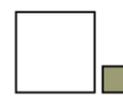
ears and brain scan. I know am ok mum with me I



-



have tablets make me grow. next year I be big boy



Mum and Dad call me little soldier

## Christopher – From Nursery ‘til Now

I was indulging in a spot of reminiscing and came across the Parental Report I wrote when fighting to get Christopher statemented in 2001.

I was amazed at just how ‘naïve’ I was. I wrote that I hoped my son, two or three years into mainstream education, would require very little support from a teaching assistant. In reality he spent 2 years at mainstream, the first year he settled in well but the following year everything that could go wrong, did. Despite numerous meetings with the School, Ed Psych and Specialist Teachers and all the strategies they put in place, nothing helped to keep Christopher integrated.

One problem was the astounding attitude of the Australian supply teacher who thought children with special needs should not be in mainstream school. At one meeting she had nothing positive to say about Christopher and I was so amazed I asked ‘do you have anything nice to say about my son?’ Strangely enough she didn’t. She left all Christopher’s lessons to his LSA and did not include him in the class; this isolated him and led to numerous outbursts. After her departure the damage had been done and Christopher was unable to settle within the class structure that was in place. Within 2 weeks of starting year 2 it became obvious that it was no longer viable for Christopher to continue in mainstream. The turning point for us was the attitude of certain teachers, including the school’s SENCO. The final straw for the school was Christopher hitting out at the SENCO when she confronted him – something she had been told by specialist teachers not to do.

Finding a more suitable school became the focus of our lives for a few weeks. Special Schools by their very nature are unique and a lot of the ones we looked at proved unsuitable. We were very lucky that the best school, in our opinion, was local to us and so didn’t mean long journeys or Christopher having to reside away from home.

Christopher has attended special school for the last 4 years, but even this has not been easy for him. At first he enjoyed the fact that he didn’t ‘stand out’ from his peers as he had in mainstream, but it soon became obvious that too structured a day caused him problems. He still required a lot of one to one interaction, something that both the school and us have been trying to change.

He struggled with writing (due to ataxia) and to this day still does. Christopher’s way of coping with this was to disrupt lessons so he didn’t have to write. To date he now only writes when he wants to otherwise he uses the computer to ‘write’ things out with a lot of help. Christopher can only spell a few words and cannot read due to scanning issues with his eyes.

His concentration span is still very poor for most things, the rule being the more difficult the subject for him the less time he can cope with it and the more ‘time out’ is needed. The Consultant Neurologist has said that children like Christopher will always have lower concentration spans for difficult subjects as the more complex a task for them the more brain irritation they suffer.

Behaviourally things change as often as the seasons do. He can be calm and a pleasure to have around or be the ‘devil incarnate’ often with varying degrees in between. He had previously been diagnosed with challenging behaviour and ADHD, although it has been proved that not every child with ADHD has behavioural problems. He spent six months of the previous school year being taught completely segregated from any other children, something he thoroughly enjoyed. Christopher went through a period of time where he couldn’t cope with anything going on around him and he reacted by wrecking the classroom and constantly threatening ‘violence’ towards others. His neuro consultant wondered if his epilepsy was getting worse and his behaviour was a reaction to this. Unfortunately we were not able to confirm this, as we were unable to get an emergency EEG when he was having an outburst.

This was a trying time for everyone, both at school and home. No one, not even outside agencies were able to come up with the ideal way to help Christopher which was extremely upsetting as no parent wants to see their child isolated from the world around them. Thankfully the specialist teacher that the school employed, taught Christopher to stop, think and assess his actions, with a degree of success.

This enabled Christopher to rejoin a class in September. Last August, Christopher was seen by a new consultant. She sensed something in Christopher and said that she wanted to do a more in depth assessment of his needs.

An appointment was made for November, which lasted nearly 2 hours. Afterwards I felt totally drained, both physically and emotionally. The assessment was hosted by Christopher's Consultant but also included, a Senior Registrar, a Specialist Speech Therapist and a Senior Occupational Therapist. They questioned everything from before his birth to the present day. At the end of the session I was informed that Christopher, on top of WDS, Ataxia, Epilepsy, Complex Learning Needs, Challenging Behaviour and ADHD also has Social Communicative Disorder – Autism to you and me.

It was agreed that Christopher would need a change in the way he was educated and that hopefully this would lead to him being much calmer and more accepting of others and the world around him Whilst not fazed by this new diagnosis I still wept on the way home from the children's centre. I had always thought that Christopher had ASD but now it had been confirmed by a group of professionals it was another hurdle jumped over. Hopefully if everything recommended by the group of specialists is implemented this will lead to a better future for our wonderful little boy.

Yes he can be hard work a lot of the time but with all his 'problems' who wouldn't be. He has the most affectionate nature, a wicked sense of humour and a beautiful smile.

On a happier note his favourite subject is history and this year he finally found someone equally interested, his class teacher. They apparently can talk for ages about history, especially the Romans, much to the amusement of the classes 3 LSA's. This has led to him being much more settled at times during school hours (time out is never required during history lessons – a real bonus) and for the very first time in his life he wants to go to school!

Education for our children whether or not they have a 'disability' is always going to be an emotive subject. All we want is what's best for them. The biggest learning curve for me throughout Christopher's school years has been to trust my own judgement and to know when to challenge the establishment so that he has access to an education suitable for his needs.

Christopher is more than the sum of his numerous diagnoses, he is, as are all our children, unique and deserves to be treated as such.

Jacqueline Leech

PLEASE KEEP

**SATURDAY 30<sup>TH</sup> JUNE 2007**

**FREE**

**FOR THE WDSSG AGM/FAMILY DAY**

The Worster-Drought Syndrome Support Groups' AGM and Family Fun Day is going to be at 10.00am on Saturday 30th June 2007 at Coram's Fields a wonderful park in London, WCI. We have organised childcare with The Log Cabin. There are only 60 places available in the crèche, so please send in your forms quickly as we will be working on a first come first served policy.

Whilst your children are taken care of, the parents will be taken to the School of Pharmacy over the road where our AGM and Discussion Groups will take place. Professor Hammond and Paul Ashley will also be joining us and will be giving a short presentation regarding 3D Scanning and Dentistry at the AGM.

Shortly after this we will be running our discussion groups. We have wonderful guest speakers joining us. Lorraine Marer a Behaviour Specialist who has appeared on her own TV show will lead us on behaviour, ADHD and anger management. One session for early years and one for our older children

Paul Ashley will be talking about Dentistry and the other discussion groups will be about sibling issues, transition, and behaviour for early years and teenagers. We will be heading back to Coram's Fields for our Family Picnic lunch at around 1.15pm.

We are asking that each family pay a £10 contribution to cover administration for the day.

We look forward to seeing you on the day. If you need any further information or would be interested in joining us please contact Monique at [monique.lauder@btopenworld.com](mailto:monique.lauder@btopenworld.com)

## Proposed timetable for the Family Day

10.00-10.30	REGISTRATION for children and adults at Coram's Field Hand out of Presentation Pack Drop off for Childcare run by The Log Cabin Parents to be escorted over to The School of Pharmacy Tea/Coffee in Guild Hall at Coram Fields
10.30 am	Annual General Meeting (AGM) Presentation by Professor Hammond and Paul Ashley about 3D Scanning and Dental Research
11.15–12.00	<b>1<sup>st</sup> Session</b> <ul style="list-style-type: none"><li>- Behaviour for Teenagers</li><li>- Dentistry</li><li>- Siblings</li></ul>
12.10-1.15pm	<b>2<sup>nd</sup> Session</b> Transition Discussion -Behaviour for Early Years
13.15	<b>LUNCH</b> Meet with children at Coram's Fields for picnic lunch.
15.15pm	Coffee/Tea – Coram's Fields
17.00pm	Goodbyes

If you can offer the committee any help on the day then please get in touch with Monique who will be pleased to hear from you.

## Thomas and the Orthodontist

Thomas has always had problems with his teeth the main problem is over crowding, the dentist keeps a watchful eye on Tom's teeth monitoring each baby tooth that fell out and the new teeth that came through.

The dentists decided that Thomas needed to go to the orthodontics because of the overcrowding problem, our appointment arrived and on the date we visited the orthodontist, they looked at his teeth but took no action because he still had one baby tooth left (he was 14) and we should go back after 12 months.

2007 our next appointment arrived and we decided to keep it even though he still had his baby tooth. When we went into the room Thomas got on to the chair the dentist looked into his mouth and was very surprised to see the baby tooth still there saying that it should have come out by now. Thomas was sent for an x-ray of his mouth there were some surprises Thomas still had his baby tooth because there was no adult tooth in the gum to push it out, the x-ray also showed his 2 back teeth are growing at an angle inwards. The next problem more worryingly were the teeth at the top front 2 of the teeth were in the wrong place and one of the teeth was growing behind the other and growing at an angle pushing the very front tooth outwards.

None of this sound very good and the orthodontist decided to refer Thomas on to the hospital where we shall now wait for the appointment..... To be continued!

## Bouquets to Anita and Rene

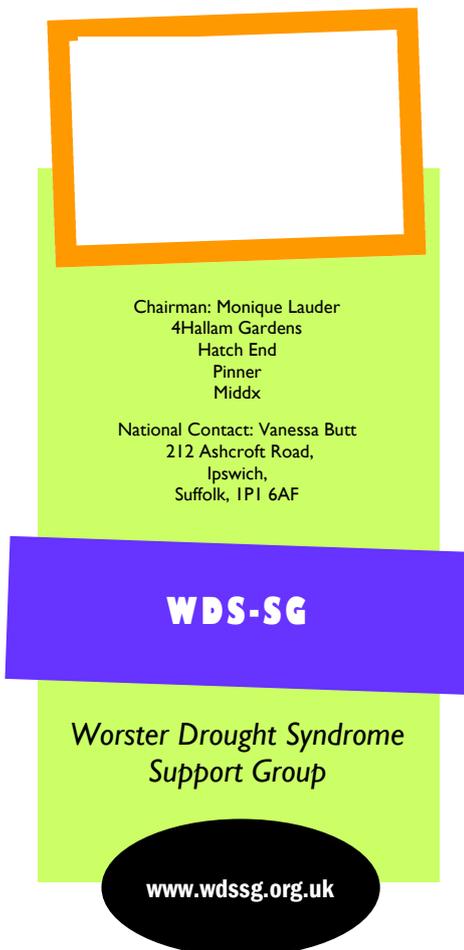


Our thanks go to Anita and Rene, who have both unfortunately had to step down from the committee, we would like to pass on our grateful thanks for all the work that they have done to help the group.

We wish them and their families every good wishes in the future and we hope to see them in the summer at the family day.

## Thanks

The group wishes to thank all the BT staff at Bibb Way in Ipswich who raised a staggering £1.250 for us by holding a Christmas Raffle. We would especially like to thank Rose and Chris who worked so hard in organising this event and thinking of us and East Anglia's Children's Hospice who received a similar amount.



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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](mailto:words@wdssg.org.uk)
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- We would gratefully receive short stories, personal insights, 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 September.
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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.
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- Don't worry if you are not on email we will send you the newsletter through the post as normal.

### Can you help

Have you some spare time to help with the organisation of the group, just a couple of hours a month, if you have, then please get in touch with Jacqui, Monique or Vanessa or any member of the committee.

### Group Updates

If you have had trouble joining the Forum then please get in touch with Vanessa, we are having trouble with spammers so we have stopped automatic joining for a short period

### Address changes

If you have changed your address or email address then please let Vanessa know so we keep our records up to date

### WEB SITES THAT MAY BE OF INTEREST

- <http://www.after16.org.uk/pages/learn1.html>
- [www.skill.org.uk](http://www.skill.org.uk)

Many thanks to all you have contributed to this issue of the newsletter

The Worster-Drought Syndrome Support Group Committee.