

WORDS

ISSUE 17
August 2005

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Letter From The Chairman

Welcome to this latest edition of WORDS, the newsletter of the Worster-Drought Syndrome Support Group.

Firstly a big thank you to all of you who came along to our family day last month. It was disappointing that the professionals day didn't get off the ground as expected but I have had lots of positive feedback from families that were there. I also send my thanks to Monique, Hayley, Vanessa and all the other members who made the day happen. Unfortunately I was unable to attend due to work commitments but I'm glad all had a good day.

There were a few things that came out of the AGM which need mentioning. Donna, who has been our treasurer for several years now, decided to step down. I send her our best wishes and thanks from the rest of the committee for her sterling work. I would also like to thank Mary Rumbold for agreeing to step into Donna's shoes and take over the reins. It was suggested at the AGM that Jacqui, my wife, would like to take over the role of treasurer but the charities ommission don't allow related people to both be in senior committee positions and cheque signatories. It is OK for related people to both be committee members, but only one of them can have a senior role.

On the subject of senior committee roles and as announced at the AGM this year will be my last as chairman. There are many reasons for making this decision but first and foremost I feel it is time to bring some new blood into the committee. So here is the challenge. Who out there can take over from me at the next AGM and help, with the rest of our first class committee, drive this group forward, to take it, if you like, to the next level. We have done fantastically well over the last few years but now need to go that bit further. If the role is of interest to you then feel free to give me a call.

We are now steaming towards summer, which holds horrors for some families. I know that our Christopher becomes somewhat "difficult" in the heat. I wish I could wave a magic wand and make it all better but I ask that you do your best to try and enjoy the summer holidays.

Take care and I'll see you soon.

Gavin Leech.



Giving a helping hand to the London Fire Brigade.

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Family Day 2005

We hope you agree that the family day was a great success and we would like to thank the following people and organisations who helped.

Institute of Child Health

Coram Fields

Phabulous Club

Log Cabin

Professor Brian Neville

Dr Maria Clark

Dr Linda Soutter

Katie Price

Nicola Jolloff

John Butt

Jonathan Lauder

London Fire Brigade

London Police

Saul Eisenberg

Julian Mogiliner Coram's cafe

David and Amanda Pampel

Marc Herman

Tara Roerig



We hope that we have not forgotten anyone , we appreciate all the work that so many people did to make this day memorable.

And to the families who allowed us to do profiles of the children we featured in our presentation .

Look forward to seeing you all next year!!

AGM Coram's Field

It was agreed that everyone really enjoyed their day at our AGM/Fun Day 2005. We were obviously a little frustrated that the Conference run on behalf of GOSH the day before our event, was cancelled, but that didn't seem to dampen our spirits. The Venues were brilliant. Whilst our children were all having an incredible morning of fun and entertainment at Coram's Field accompanied by The Log Cabin, our members were able to hear the quickest AGM on the planet!

We heard a wonderful presentation from Jonathan Lauder in reference to 7 children who suffer with the WDS condition. We had a presentation from Dr Linda Soutter, Community Paediatrician, Kingston Hospital, Department of Paediatrics which was extremely informative. Our panel of experts for the Question and Answers Panel all showed up again and didn't disappoint. Our speakers included Professor Neville, Katie Price MA DipCST, Nicola Jolleff from the Wolfson Centre, and Linda Soutter. All of whom, I'm sure you will agree, were informative. We really appreciated the fact that they gave up their time to help us.

We all went back to our families at Coram's Field and had a lovely picnic with all the members of the WDSSG sitting together and we really felt like we got to know people, some for the first time. Even the weather held up for us this year, although there were specks of rain which no one seemed to let bother them.

An enormous thanks goes out to our emergency services who came to our event and showed the kids how to use the fire hoses and what it was like to be carried in stretchers and what the police cars/bikes could really do. They were amazing with the kids and the adults quite enjoyed the experience as well!

On behalf of the committee I would like to thank the Co-ordinators for the day, Monique Lauder, Vanessa Butt and Hayley Herman who helped to make this special family day so memorable.

Next Years Family Day

We are in the process of planning and organising next years family day and so far we have a few ideas.

What we would like to do is give everybody the opportunity to make a suggestion as to what they would like to do.

So if you have any ideas or venues that we could use we would really like to hear from you.

There's a feedback form at the back of the newsletter where we would welcome your thoughts about this years event and space to put down any suggestions you may have for next years.

Coram's Fields

Katie Price and Rebecca Harris, Speech and Language Therapists,
Great Ormond Street Hospital for Children (NHS Trust)

Communication skills

2(i) Children's skills in *communication* develop throughout their life. The contrast will be made here between *speech* and *language* and *communication*: for many children with Worster-Drought Syndrome, *speech* is one of the most difficult skills for them to achieve. This is because the muscles of the mouth/tongue/palate are often the most severely affected, and because speech is a very rapid, very precise motor skill where even the slightest difficulty in co-ordinating movements can produce significant changes in speech intelligibility. So..for all children with cerebral palsy, *speech* in itself probably reaches best intelligibility levels towards the end of primary school years (age 10): again, we are very short of studies in this area, but this statement is made on pooled clinical evidence from specialists in the field.

Language (understanding sentences, producing more complex phrase, learning new vocabulary) continues through life, although into secondary years this process can be seen to slow down, and such progress may be very slow.

Communication (ability to interact/participate/enjoy conversation/contribute in class) can be promoted throughout life, and many children will benefit from additional, non-speech, methods of communication (signing, gesture, use of printed symbols, voice output communication aids). There IS some evidence that these methods can improve functional communication, and our team are keen to contribute to the discussion about the role of these methods for children with WDS.

(ii) Prioritisation of resources is part of caseload management, and the patterns of development as described above determines that younger children have more access to speech and language therapy monitoring and evaluation. We would argue that children in secondary school should have at least annual review of speech intelligibility (measured with an instrument such as the *Children's Speech Intelligibility Measure*), and review of the relevance of alternative/augmentative methods of communication to support their speech.

(iii) See (i) above for "does speech therapy work?" ! A recent review of ALL (11 in total) the scientifically sound papers they could find on this subject (for all children with cerebral palsy) had to conclude the following:

Firm evidence of the positive effects of SLT for children with cerebral palsy has not been demonstrated by this review. However, positive trends in communication change were shown. No change in practice is recommended from this review. Further research is needed to describe this client group, and its possible clinical subgroups, and the methods of treatment currently used in SLT. Research is also needed to investigate the effectiveness of new and established interventions and their acceptability to families. Rigour in research practice needs to be extended to enable firm associations between therapy and communication change to be made.

The “something extra” may be a concentration on the child’s total communication, and would include, as we have said, a discussion about the relevance of other non-speech methods (signing/symbol use etc).

Eating and drinking:

1. The range of difficulties around mealtimes for children with Worster-Drought Syndrome does vary enormously. Some children will have relatively few problems with chewing and swallowing, some more significant difficulties, and some will have such poor co-ordination/strength of muscles that it will actually be safe for them to continue to take food orally. It is this last group of children for whom gastrostomy feeding may be considered an option.

There are different reasons for a gastrostomy to be considered. In addition to safety reasons (to reduce the risk of children inhaling food/drink particles into the lungs), gastrostomy may be considered where children are failing to gain enough weight to keep healthy and for their brain and body to develop. It is becoming increasingly recognised, both clinically and through studies, that children’s development can benefit greatly if additional methods of feeding are used where there is inadequate oral intake for good nutrition.

2. As in other areas of therapy intervention, there is a lack of research study evidence around the interventions for feeding and their results. There is no proven method of improving a child’s chewing patterns. A speech and language therapist can advise on many aspects of feeding, including the promotion of tongue movements, but any progress will depend much more on the neurological basis of the motor pattern, and the extent of the neurological damage identified. Most children make some spontaneous progress, even slowly, with their muscle patterns as they grow, simply with neurological maturation. It is not clear if speech and language therapy can accelerate this process, and claims that intensive/expenseive methods can accelerate “natural” progress should be examined carefully.

3. Supplemental feeding recommendations need input from a dietician. Full supplemental feeding (through gastrostomy tube feeding, or naso-gastric tube) have all the nutritional requirements that will be needed, including vitamins and minerals. Sometimes dieticians will recommend calorie-adding supplements for a child who is eating orally, but requires “top-up” intake (eg *Duocal/Calogen*).

Is WDS genetic?

WDS is not one condition, but a group conditions that share common clinical characteristics. It is likely that there are several causes, including in some cases genetic defects in the development of the perisylvian region (area of brain that controls movement of the mouth and throat) and others sporadic injury to the developing perisylvian region, particularly toward the end of the first trimester of pregnancy. It is not always possible for a given child, to identify the cause.

WDS is a clinical diagnosis, and there is no 'test' that detects it. In some children, a brain scan will show an abnormality in both perisylvian areas (also known as congenital bilateral perisylvian syndrome). In other children, the abnormality may only be seen on one side. For the majority, no abnormality can be seen with the current imaging techniques. When present, the perisylvian abnormality is consistent with polymicrogyria, which is an abnormality in brain development that occurs early in pregnancy, around 16-20 weeks after conception. The presence of the perisylvian abnormality does not signify a particular cause, and may be found in genetic and non-genetic cases.

Family groups, where more than one person is affected by WDS are well recognised, and represent a significant minority of people affected. They can occur with or without imaging changes, and for some families, affected members have different imaging findings. Several different patterns have been seen within the family groups, suggesting that there is more than one gene or pattern of genetic inheritance at work.

When families have one child with WDS, they would be given an approximate recurrence risk of 1 in 10 that WDS might affect subsequent children. This is similar to the level of recurrence risk given in other cases of unexplained cerebral palsy. However, these families will be a mixture of some families who in fact have a high risk and others who have a low risk (as at present we cannot identify those cases that are genetic until there is a second affected person). In general the risks for siblings of a child with Worster-Drought syndrome, of having children of their own affected by the syndrome, is lower than the above risk and for many it will be no increased risk. However, the current evidence suggests more than one pattern of inheritance, including an 'x' linked pattern in which the sister of a boy with Worster-Drought syndrome would need specific genetic counselling as it may be inherited through the female line.

It is our hope that the genetics will become much clearer over the next 5-10 years so that much more precise genetic counselling can be offered. We hope to work with the WDS Support Group, and a Genetics Research Group in USA, to begin to address these questions. WDS is undoubtedly under diagnosed. No prevalence studies have been done. Cerebral palsy is known to occur in around 3 in 1000 in the general population, and WDS is probably around 10% of this rate.

How is the behaviour of a child with WDS affected by the condition?

From studies to date, we know that around 40% of children with WDS have significant behavioural difficulties, particularly in areas such as hyperactivity, poor attention span and social communication. There is no specific behavioural pattern associated with Worsler Drought. Many of the behaviours are seen in other children with learning difficulties, in particular, those with epilepsy and social communication disorders. It is important to undertake a clear analysis of any difficulties, as they may require specific treatment, behavioural or educational approaches. A Clinical Psychologist can undertake an analysis and it will be important to determine what has triggered a tantrum for 'no apparent reason'. This may be due to a sudden loud noise, proximity or change of expected routine, as well as the more obvious reasons like not having their needs met quickly enough. It will be important to identify what rewards the child is gaining from the behaviour and think about how this may be changed. There are many techniques which may be useful, particularly those used with children who have an autistic spectrum disorder.

Useful references are:

1-2-3 Magic: Effective Discipline for Children 2-12 by Thomas Phelen

ISBN 0-9633861-9-0

Challenging Behaviour and Autism – Making Sense, Making Progress

Published by the National Autistic Society

It is also increasingly recognised that having a neurological impairment brings out the genetic behavioural pattern which may be present in the family. This can be helpful to know in terms of family coping strategies.

The majority of children with WDS (>90%) have difficulties with feeding at some stage. Feeding difficulties are most common in infants and younger children, and there is a distinct improvement in feeding abilities for most children with time, although many will always need a modified diet (e.g. avoiding particular textures such as apple skins or crisps). Around a quarter of children will need tube feeds at some stage, most commonly as infants. However about 10% will require long term tube feeding, and this is often provided for by a gastrostomy. An important aspect of feeding difficulties is to know that although they may show steady improvement they may be very difficult to manage without a gastrostomy for the first one to two years of life and that it is not just a matter of physical survival during that time but of keeping relationships going, including during feeding, and not creating massive negativity related to it.

Is it necessary for a child with WDS to have an MRI scan?

WDS is a clinical diagnosis, and the scan result (presence or absence of perisylvian polymicrogyria) will not change the child's management. However it may provide a more complete understanding of the individual child and help to exclude alternative diagnoses. It does not however separate genetic from non-genetic varieties of WDS though the presence of the typical abnormality does seem to increase the chances of epilepsy. It may also be informative for future studies of causation. This must be weighed up against the fact that many children will need sedation or even a general anaesthetic to have a scan.

Some children with WDS drool constantly. Why is this?

The majority of children with WDS have some problem with drooling, although this may improve with age. Drooling is caused by the lips being open, lack of regular swallowing and sometimes by the mouth being tilted forwards. Simple positioning techniques, with a head-up posture, keeping the activities in front of a child as high as possible so that gravity assists their swallowing is important. Attempts to train people to swallow more frequently (e.g. attempted habituation to noises every 20 seconds) require an extraordinary degree of compliance, and have not been very successful. Drugs can be used to dry up the secretions, but carry a risk of dental caries and gum disease, as well as side effects such as constipation, irritability and sometimes blurred vision. Glycopyrrolate is the most commonly used drug for this, and is successful in significantly reducing drooling in most people. However, at least a third of people discontinue it because of the side-effects⁸. Hyoscine patches have also been used.

Botox has been used, particularly in adults with other neurological diseases, to control drooling. It dries up secretions, and therefore also has the risk of increased dental and gum disease. It involves injections which need to be repeated every 3-4 months, which is not usually acceptable for a chronic condition such as Worster-Drought syndrome.

Some surgical techniques involve removal of salivary gland tissue or tying off of the salivary ducts to dry the mouth, and will need extra care of teeth and gums because of the dry mouth. Where dribbling persists beyond the age of 5-6years, transplantation of the salivary ducts can be very helpful (i.e. redirection of the salivary ducts backwards to divert the saliva towards the back of the throat so that it is swallowed rather than dribbled). Children will need careful assessment before such surgery, since for some children who are unable to swallow safely or who cannot deal with the increased saliva volume, this procedure can be dangerous as they cannot protect their airway and may be at risk of aspiration (e.g. swallowing the saliva onto their lungs). Surgery should always be combined with speech and language therapy input to maximise its efficacy. Some research papers on this subject are enclosed.

GOSH is, rightfully, considered to be the centre of excellence for WDS, however not everyone has access to the expertise offered there. Are there any other centres nationwide that can offer the same service as GOSH?

Appropriate services for children with Worster-Drought syndrome should be available nationwide. All regional level centres should be able to provide comprehensive assessment and management for children with complex neurological diagnoses, communication impairments, dysphagia, epilepsy and behavioural impairments. These centres should have a network that links with the local child development services and schools to provide for the needs of most children.

Both specialist and general child development / neurodisability services have been relatively slow to develop in the UK. Resources might be best invested in a family care worker who knows the facilities that should be available in the UK, can assist families in accessing appropriate local services and can monitor progress and facilitate implementation. This, of course, assumes that the child has been identified as having Worster-Drought syndrome. In many areas of the country, children go undiagnosed and are therefore unable to access the comprehensive services they require. We hope to address this with targeted professional training and heightened awareness, and will liaise with the WDS Support Group over this.

Circles of Support

A circle of support is a group of people who agree to meet on a regular basis to help a friend or family member who needs some extra support. The person who is the focus of this support asks a number of people to work with him or her to overcome difficulties and these people then form the Circle. The basis of the support offered is the simple idea of pooling skills and resources and sharing tasks. The difference from other approaches is that the focus person (or the closest if more appropriate) are in control and the goals are determined from information about the person's dreams and aspirations.

How does a circle work in practise?

The focus person and the circle invest time and effort in defining what the fuller life should include and how it can be achieved. The obstacles and difficulties are discussed and ways of overcoming them are worked out. Solutions almost always require members of the circle sharing their talents and resources and taking actions together.

Regularly the circle, at the focus person's invitation, meet again to discuss what progress was made, what needs to be done next and by whom. Everyone involved learns and benefits from the experience. As they develop skills, attitudes and experiences, so they influence the wider community, challenging discrimination and fostering 'can do' attitudes.

Person Centred Planning

Person centred planning is a process of life planning for individuals, founded on the principles of inclusion. Derived mainly from early work in building circles of support, these tools should be available for us all. Person centred planning tools are alive and active, always ensuring the focus person is central and in control. They are flexible, setting no limits to the persons wants, needs and dreams for their life.

Person centred planning is:

Process of planning for individuals which is alive and active enabling the person to be central and take control
Founded on the principles of inclusion and social model of disability

Creates a comprehensive portrait of who the person is and what they want to do with their life
Not a set of tick boxes or checklists and are completely individual

This process can help beyond to dream beyond current constraints and set targets for a present and a future, which is based on who they are, what they want and where they want to be.

If you want to know more about setting up a circle of support or developing a person centred plan then contact Circles Network on 01788 816671 or visit the website on

www.circlesnetwork.org.uk

Re drooling questionnaire

Hi,

I want to start by thanking everyone who replied to my recent questionnaire regarding drooling and its management. Many of you did, and your contributions were gratefully received. I promised at the time that once my study had been assessed, I would post an abstract on the Words web site, but I thought it might also be useful if details were given in the newsletter, so here goes.

Incidence

A total of 83 questionnaires were distributed and 55 (66.3%) of you responded. Data revealed a high incidence of drooling within the survey group. A total of 48 (87%) of our children/young adults either currently experienced problems with drooling, or had previously experienced such problems. In those over 6 years of age - *the approximate age up to which improvements are thought to continue in those with neurological impairments (Vaughn & Brown, 2003)*, 37 (74%) continued to drool. However, interestingly 3 respondents reported instances where drooling ceased at 7 years, and a further 3 highlighted cases where drooling ceased at the ages of 10, 13 and 14 years.

Awareness and use of techniques

The techniques aimed at management of drooling that parents were most aware of were – chin wipe/dap, the use of verbal prompts, oral exercises, drugs and surgical techniques. It is perhaps not surprising that use of techniques followed a similar pattern to this, although understandably fewer parents chose to use the more invasive techniques such as drugs or surgery with their children. Less well-known techniques included – palatal training appliances (only used with 1 child), botox (no reported use), and use of beeps or buzzers to prompt a swallow (only used with 1 child). Only a few parents were aware of point percussion therapy (acupressure), vestibular screens (an oral appliance), acupuncture and herbal medications, and none of these had been used. Some of these less well-known techniques however are relatively new, such as the use of botox, while some have been used more widely abroad, as in the case of palatal training appliances. In many instances to date there has been little or no scientific research into the use of techniques e.g. in the cases of complementary medicine, acupuncture and point percussion therapy.

Two parents highlighted additional sensory stimulation techniques that had been used with their children with varying levels of success. One of these involved the introduction of strong tastes for oral stimulation as part of a holistic programme.

Effectiveness

A huge variation was found in the effectiveness of the techniques used with the WDS group. Where any of the techniques used were rated by more than 1 respondent, ratings varied e.g. in the case of use of verbal prompts (VP) a total of 14 ratings were given, and in 3 instances (VP) were found to be ineffective, while in 2 instances (VP) were rated as very effective. The remainder of the ratings fell between these two extremes.

Context of use of techniques

A child's age when a technique was used was considered, along with their level of cooperation and the source(s) of supervision for techniques. Results indicated that the key factor in successful use of a technique was a child's cooperation.

More general comments from parents

An equal amount of positive and negative comments were made – Positively, parents reported being pleased with advice given; pleased with the success of techniques or the motivation of their children. Negatively, many parents felt that they didn't have a complete picture of the techniques available; some indicated that they had received conflicting or inappropriate advice; others found implementation of techniques or motivating their children difficult.

Overall

- Incidence of drooling is high in the group.
- Techniques stemming from medical, surgical, therapeutic or behavioural backgrounds are generally better known than those from orthodontic, or complementary medicine.
- Use of techniques, *unsurprisingly* follows knowledge of them, however, where techniques are more invasive, there is less use.
- There is a great deal of variation in the effectiveness of techniques across the group.

A child's cooperation appears to be a key factor in the successful use of many techniques.

The findings largely correspond with those generally found in the literature looking at other groups. In most cases where research is carried out specific techniques are found to have variable results. While this highlights the uniqueness of each individual and their particular problems, and the complex nature of drooling (which is not fully understood) it also appears to suggest that more detailed knowledge of *exactly* how techniques are being used may offer valuable insights.

In a review of drooling management in cerebral palsy, Harris & Purdy, (1987) - in addition to acknowledging the serious health issues that can be associated with drooling - note that the anguish and social stigma attached to constant drooling means that many individuals consider it to be their worst affliction. Despite this, others, including Scott & Johnson, (2004) recognise that drooling management remains an area where the evidence base is seriously lacking, they suggest that there is a need for more interest from the medical community.

Harris, S. R. and Purdy, A. H. (1987) Drooling and its Management in Cerebral Palsy. Developmental Medicine and Child Neurology, 29, 805-814.

Scott, A. and Johnson, H. (2004) A Practical Approach to the Management of Saliva, (2nd edition) USA: Pro-ed.

Vaughn, T. L. and Brown, K. R. (2003) (accessed 29.01.2005) Drooling. [Online].

Available URL <http://www.emedicine.com/ent/topic629.htm>

This subject is one that is of personal interest to me; as I am very aware of the effect that drooling has on my son Elliot's life, and on the lives of others I have worked with. We have been using scopolamine patches with Elliot, but they have gradually become less effective over time, and we feel that we would rather not use them long term. However, we are now faced with the problem that Elliot wants to keep using them because he is concerned that his drooling will be even worse if we stop! Therefore, we are trying to use a 'beeper' attached to his clothes twice daily for 15minute periods to encourage him to close his mouth and swallow more often. We have found that he can usually manage to keep his chin dry during this time. although I have to admit that we are also using a chart and financial reward for extra incentive! I will have to report later how well we are getting on.

If any of you are interested in reading more about drooling and its remediation, the Scott & Johnson book (see refs above) is the one that inspired me to do this project. It is expensive, but it is possible that it could be ordered through a library service I am told.

Mary Rumbold



The National **A**ttention **D**eficit **D**isorder **I**nformation and **S**upport **S**ervice.

Provides people-friendly information and resources about Attention Deficit Hyperactivity Disorder to anyone who needs assistance - parents, sufferers, teachers or health professionals. Whatever you're looking for in ADHD, they'll do their best to help.

CONTACTING ADDISS

Phone: 020 8906 9068
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FEEDBACK FORM

WDS - 6th AGM/CONFERENCE FAMILY DAY

SATURDAY 25TH JUNE 2005

CORAM'S FIELD

Thank you to you and your family for coming to our Worster-Drought Support Group AGM/Conference Family Day event. We hope the event fulfilled your expectations in both a social and educational basis. The support group involved would appreciate hearing any comments you have with regards to the day's events whether good or bad.

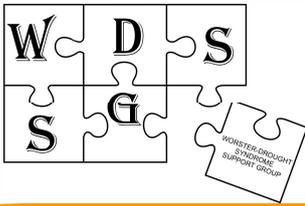
Name of Child(ren) with WDS:

Name of Parent/Carer:

Contact No:

Your Comments:

If you cannot fill out the form on the day please send it back to:
Monique Lauder, 4 Hallam Gardens, Hatch End, Pinner, Middlesex, HA5 4PR.
Telephone: 0208 428 6706 or Email: monique.lauder@btopenworld.com



Chairman: Gavin Leech
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Ipswich, Suffolk, IP1 6AF

*Worster Drought Syndrome
Support Group*

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

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.

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

The cut off date for the next newsletter will be mid January 2006

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.

Thanks for all the contributors of this issue of the newsletter especially

Professor Neville, Katie Price, Nicola Jolleff, Rebecca Harris, Mary Rumbold.

WDS Family Day Presentation Disk 2005

On the 25th June at our Family Day the group presented a power point presentation titled "Our Children." This CD shows the profiles of some of the children with WDS. If you were unable to attend the family day and would like your personal copy .

Please send a self-addressed C5 envelope with a first class stamp to

Presentation Disk
Mrs Vanessa Butt
212 Ashcroft Road
Ipswich
Suffolk
IP1 6AF