

## **W.O.R.D.S            Issue 1**

The news sheet of the Worster-Drought Syndrome Support Group

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### **Welcome**

to the first newsletter of the Worster-Drought Syndrome Support Group, hopefully we can use the newsletter to keep everyone informed, pass on tips or just socialize. First a brief history, although the syndrome was documented by Dr. Worster-Drought in the fifties it was only last year when the very first meeting of families from around the country took place. Until this time national family support was being offered single handed by Jane Thorpe via the Contact-a-Family organisation. The decision was taken at the family day to form a support group for the families run by the families. So a formative group committee has now formed in order to focus the group activities and develop ways to promote awareness of the syndrome and allow easy access to information. The Newsletter is the first visible activity but we are planning an information leaflet, an Internet WEB site, another family day which could be some time in November 98 and ways in which to support the group activities financially.

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### **Feedback**

One very important point, is that what we are planning is designed to help you the families like ourselves living with Worster-Drought. We do need feedback, about the planned activities, are they a good idea are there better ideas out there? Please tell us so we can best support you. There are committee members phone numbers listed elsewhere in the newsletter.

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### **London Marathon**

Our thanks go to Yvonne Phelan who ran in the 1997 London Marathon and raised £280 for the WDS group. Yvonne from Sheffield, is the friend of one of the grandparents who came to the family day in 1996.

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### **Who's Who in the Committee**

Simone Whiteway (Information leaflets)

I am married to Alastair and we have a two year old little girl, Alice, with Worster-Drought Syndrome. She has very severe feeding and speech difficulties, but, despite this is an extremely bright and cheerful little girl. My current role within the group is to produce information leaflets for parents and professionals, in collaboration with the other members of the committee.

Des Nutter (Chairman)

I am married to Anita and we have a five year old son, Thomas who has Worster-Drought Syndrome. His major difficulties at present seem to be speech and fine motor skills, with a good degree of clumsiness thrown in for good measure, although he is a very loving and affectionate child. He has two sisters, Chloe aged seven, and Megan aged 14 months. My current role within the group is to act as chairperson/co-ordinator and generally to provide help and assistance to the others on the committee in their activities.

Vanessa Butt (web site)

I am married to John who is a software Engineer and works for a well known telephone company. We have two sons, Paul who is just sixteen and is busy doing work for his GCSE's and then there is Martin who is thirteen. Martin has Worster-Drought Syndrome. Martin is a happy child who loves life he is a member of our local Boys Brigade, and has a busy social life. His major difficulties are with speech, he has a Communication Aid (ORAC ) which talks for him. He also uses a symbol book and limited signs, this might sound daunting but he makes himself understood. My role within the group at present, is with the aid of my son and husband to create a Web page for the group.

Andrew Hinks (Newsletter Editor)

I'm married to Karen (Group Secretary) , our six year old son Thomas has mild symptoms of Worster-Drought Syndrome, we also have two other children Alex aged three and Clare who was born in October 97. Thomas has difficulty with speech and understanding but with the help from a support assistant in class he is coping well with main stream school, probably helped by his friendly personality. His tip toe walking has yet to be tackled. Karen and I found getting information on Worster-drought difficult, probably because there's so little of it, so the opportunity to talk with other families has helped so we now don't feel alone with the problem. I am the editor of the newsletter.

Jane Thorpe. (National contact)

I am married to Richard and we have two sons, Oliver aged 13 and Sam aged 10. Sam has Worster-Drought Syndrome and it was our desperate search to find relevant information and speak to another family in a similar situation which encouraged me to form the WDS support Group.

Julie Glass. (Family day coordinator)

I am married to Ray and we have two children. Nathan aged 6 who has Worster-Drought Syndrome and Rachel aged 3. Although Nathan's major difficulties are fine/gross motor co-ordination and speech/Language, he still has a great desire to communicate, and does this very effectively by a combination of Makaton, eye contact and oral language. He is a very happy and loving child who is developing an artistic flair. Nathan's needs are currently being re-assessed after a successful SEN Tribunal Appeal. My first role within the group is to arrange the next family day.

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## **Family Day**

After the success of the first family day, we are trying to arrange another day where we can get together. The provisional date is 14th November 98. The location, Coventry, hopefully this central location gives everyone an opportunity to reach the meeting. The Room is being offered to us free of charge by the Hotel, and we will be applying for a grant from Children-In-Need to fund the days activities. Booking information for the day will be sent out with the next newsletter in August.

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## **Contact-A-Family**

We would like to acknowledge the support from Linda Partridge, Senior National Development Officer at Contact a Family. Without the help of the Contact-a-family organisation its unlikely our group would have been able to start.

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## **Green Paper**

More support for parents of children with special needs and developing special schools as centres of excellence are included in the most far-reaching review of special education for almost twenty years launched by Education and Employment Secretary David Blunkett. A Green Paper - Excellence for all children - meeting special educational needs - begins a process of consultation on how to achieve high quality provision for all children with special educational needs (SEN). The 99 page Green Paper and its summary version are available on the Internet. The address is <http://www.open.gov.uk/dfee/dfeehome.htm>. Comments can be e-mailed to [fee.sen@gtnet.gov.uk](mailto:fee.sen@gtnet.gov.uk).

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## **W.O.R.D.S**

The Title for the newsletter came about from a discussion at the first committee meeting about the newsletter and what to call it. With a flash of inspiration Julie Glass thought up "W.O.R.D.S" which is the first three letters of Worster the "D" of Drought and the "S" of Syndrome. "WORDS" seems to be very apt as after all, words are what we want from our children.

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## **Help!**

Although we have made a start at bringing the group together we do still need additional help. We still need a volunteer to act as group treasurer. This is an important job, but it wouldn't take much time as our funds are quite small. Also fund raising is important for things like the newsletter and the family day. If anyone has skills in fund raising or may be running the odd marathon then any support would be very welcome. Contact Des Nutter for details.

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## **Next Newsletter**

Newsletter number 2 will be printed in August with all the details for the Family day.

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- *WEB Page created from issue 1 of the news sheets on 13-May-1998.*