

Issue 3

Words

The newsletter of the Worster-Drought Syndrome Support Group

In this Issue

The Family Day
New Group Logo
London Marathon
Tea for two
Raffle
Communication Aids

The Family Day

The Family Day in November was attended by 27 Families and 30 children..

The day's guest speakers, Lucinda Carr, Dr Sheena Reilly and Katie Price, gave in-depth and detailed talks, which gave everyone a wider insight into the range of difficulties faced by both parents and children.

Our thanks must go to children in need for supporting our family day.

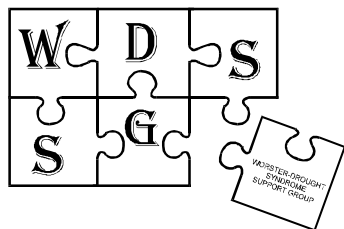
By helping to fund the day they helped to make it so successful.

These events are expensive to stage and without their assistance we would not have able to have such a successful day.

Group Logo

Another activity at the family day was to "Choose A Logo"

Here is the winning Logo



London Marathon

The secretary of the WDS group is running in the London marathon on April 18th.

Karen has been training very hard and not down the pub either. She has run for just over 3 hours on her longest training session so far and is planning to do a 22-mile run prior to the marathon. Karen she is running for the group and of course donations and sponsorship will be gratefully received.....

Tea for two

The WDS group's affiliation with Contact a Family gives the group an opportunity to be involved with the Rare Disorders Alliance. This involves mostly committee meetings, but occasionally more high profile events come along, such as the recent tea party at the House of Commons, hosted by Dafydd Wigley for the Rare Disorders Alliance.

In November Donna Donlon and her husband represented the WDS group at the tea party and was able to speak to MP's and in doing so raise the awareness of Worster-Drought Syndrome.

Also Prof. Brian Neville and Dr Micheal Patton were there at the tea party and they were both interested to hear how the group was doing.

Raffle

Thank you to everyone who has supported the group by buying raffle tickets

Good Luck

Living with a AAC user (A Parents Perspective)

Martin is our second child; at the age that children babble Martin was so quite. He didn't make any attempt to communicate with us although he gave us a lovely smile when we talked to him. As Martin had numerous problems he attended CHAMP (our local child assessment clinic) where it was suggested that we sign to him, I will always remember the response I got, he thought it was so funny that he laughed at me this did not help with my self confidence.

We persevered, and it was not long before we had a few signs, this was good, as he so wanted to communicate with us. As parents we were keen for Martin to talk to talk and we have never given up hope that he will, but we have tried to give him other methods of communication as well (total Communication)

When Martin started school we had our biggest break, Martin was introduced to symbols he could use these to put across his feelings and we soon realised how frustrated he was, and we didn't have the constant guessing game with him. As Martin could say the first letter of many words it was confusing for him and us. Martin started with a single A4 sheet of symbols; this was great for Martin as now he could communicate with anyone.

Living with Martin is different to our other son, you have to have time to stop and look at what he is pointing to in his book, if you carry with a task he gets cross with us, the same as if we do not pay attention

Another difficulty is when driving the car, Martin sits in the back and he is signing away (not to other road users) and getting all steamed up because we can't see.

Phone calls are interesting as he signs at the receiver expecting the phone to answer but Nana does not see, we look forward to the day when video phones are the norm.

Three years ago Martin was introduced to ORAC an electronic Aid. This Aid has really helped him he is using it at school, home and socially at church and Boy's Brigade.

The number one question is do these aids stop speech, well without a Martin double it's difficult to be sure but we are getting a few words, and he still tries to use verbal communication, as it is still the most readily available method.

The last few years, Martin has made great progress, he is at present trailing, a smaller communication aid. Over the last year we have forgotten that Martin talk with us because he uses his book and his beloved ORAC this is a giant step since the early days when all we wanted was Martin to Talk.

John and Vanessa Butt.