

W.O.R.D.S Issue 2

The news sheet of the Worster Drought Syndrome Support Group

Welcome

Welcome to our second group newsletter, I hope you find it useful. Please don't be afraid to comment or maybe send in a piece of information which we can print and pass on to everyone. It may have been two years since the first family day, but things are really on the move. The volunteer committee members have all taken their roles very seriously, and have been hard at work developing the support group in all sorts of ways. As you will read later in the newsletter the group can already boast; an Internet WEB site, fundraising activities, a second family day, links with the Rare Disorders Alliance - UK, and of course the second newsletter which is twice as big as the first. Hopefully with these additions and other things in the pipe line the group can spread its' information and support as widely as possible. The rub to all of this good work is that it all costs money, to print literature, put on events, and so forth. Therefore the committee has decided to work towards 'charitable status' in this way we can make very clear what the groups aims are, how we intend to achieve them, and also will give safe guards and accountability in the management of funds. One of the first steps will be to create a Constitution which can be checked and ratified by all the members. Contact a Family have been a continuing help in starting us off with a pre-prepared draft Constitution which we have adapted for our needs. Copies of the Constitution will be available for viewing at the family day, or upon request (please send a large SAE) from the secretary Karen Hinks. (Address on the back page)

Andrew Hinks, Newsletter Editor.

A welcome to our new committee member Monique Lauder (Fundraiser/Coordinator)

I am married to Jonathan and we have two children. Our daughter Jamie who is 8 years old and our son Zachary aged 5, who has Worster-Drought Syndrome. Zachary has No speech, global delay & behavioural problems. He attends a special school for moderate learning difficulties in Harrow and is very happy there. He communications by using Makaton & gestures. He is generally a very happy child.

Donations

The group's thanks have been sent to Banana Split Productions Limited in London who have very kindly donated £250 to the group.

The Melin Crythan Ladies Choir

in West Glamorgan South Wales held a concert entitled "Sunset Trail" on the 21st of March 1998. In all £714 was raised and has been given to the Worster-Drought Syndrome support

group. The picture shows Alice Whiteway receiving the cheque on behalf of the group from Mrs. Mair Heale. A letter has been sent to the choir thanking them for the tremendous donation

WDS on the WEB

If you have access to the Internet you have probably tried searching for information on Worster-Drought and found very little. To correct this lack of information John Butt has produced a full web site giving all sorts of information on the syndrome, you can try out the new WDS web site at this address <http://www.btinternet.com/~w.d.s.p.g/>

Don't worry if you can't get on the Internet all information will be printed in our newsletter first.

The Rare Disorders Alliance-UK

The Following is my report on the RDA-UK and the meeting attended by Des Nutter on Thursday, 30th July. The Rare Disorders Alliance-UK was formed to further the work performed by Contact a Family in the support of groups who themselves support families of children affected by a rare disorder. The consultant tells many families of newly diagnosed children, that they could be the only case in the country. The first lesson learned by Contact a Family twelve years ago, was that some medical professionals were less than thrilled at the idea of contact between families

Many families and support groups were concerned with the rarity of diagnosis rather than the specific diagnosis, but their concerns could be attributed to the other factors; Rare disorders are seen so infrequently that they may be confused with another disorder, or be unidentifiable to the consultant.

- Experts in rare disorders are few and far between. They tend to become the "expert" just because they have seen one or two more cases than any other professional and therefore the centres of excellence for rare disorders can be placed haphazardly around the country.
- Lack of information or access to relevant information on the condition.
- Research may or may not be going on anywhere in the world.
- Families may have to become proficient at many medical procedures, often with little or no community pediatric nursing support.

The RDA-UK aims to assist support groups that deal with rare disorders in these areas in a more intensive manner than it currently assists the more common disorder support groups

The committee meeting.

A meeting of the RDA-UK committee was held in the CaF HQ in Tottenham Court Road on Thursday 30th July 1998 at 2:30pm. I was invited to attend as Chairperson of the WDS-SG, and because I work close to CaF HQ. Those present at the meeting included several CaF people who will be doing the majority of the alliance's development and organizational work, as well as representatives of support groups affiliated to RDA-UK who will become the steering group for the alliance.

An update was given on the current state of the alliance, with regard to funding for the proposed staff. The initial application for funds for one of those staff had been returned with a request for further information, the Chairman was hopeful that this would be approved upon resubmittal. The alliance was currently attempting to obtain funding for a second member of staff (assistant to first member of staff).

Membership of RDA-UK currently stood at 154, ranging from support groups, and parent contacts, to individuals with a specific rare disorder. It was suggested that some decision should be reached to determine how many representatives would be on the committee, and whether or not some roles should be reserved for those representing smaller groups or individuals. The required commitment from those on the committee was that they should be prepared to attend 4 meetings per year.

The steering group suggested that important issues that should be definite objectives for RDA-UK included;

- standardisation of care received on a National basis.
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- education.
- earlier diagnosis.
- greater media awareness.
- data collection and warehousing.
- greater access to rare disorder specialists.

There will be a "Rare Disorders Awareness" week this year between 23-29 November. A RDA-UK information pack will go out to all affiliated contacts in Aug/Sep. Groups were asked to identify typical families who would be able to represent the condition and be prepared to speak to the press, etc. The chosen families will typically fit the following criteria; family with child affected by rare disorder nnnn, lives in nnnn, contacted by CaF/RDA-UK (who will be present during interview) for story to press, talk about self and group and how the support they have received has been of benefit.

There will be a tea party in the House of Commons on the 24/25 Nov at 4:30pm (until 6:00pm) after Prime Ministers Question Time. Those attending will be asked to invite their MP to the tea party for tea, a bun, and an ear bending. Some parents will be invited to speak to those gathered. Last year approximately 80 MPs managed to attend, but it was pointed out that they often get called away at short notice, and that families shouldn't become disheartened if it happens to be their MP.

Des Nutter.

Evening Primrose Oil (Not just for PMT!)

Over the years, I have become very interested in alternative medicine, so when I read an article about the positive effect of Evening Primrose Oil, it stuck a cord.

The Article was about a young child who was hypo active and had a learning disability he was not achieving at school and was quite a handful, the mother had tried Evening Primrose Oil and was praising the positive effect it had on her child.

Martin has Worster-Drought Syndrome, he is very hypoactive and has a severe learning difficulty, and he just can't concentrate on one thing for more than a few minutes.

Armed with this article I went to our local health food shop and asked their advice, the only warning was if you suffer from epilepsy consult your Doctor, also they advised me to give Martin a general multi-vitamin as well.

Before I started Martin on Evening Primrose oil, I consulted our Doctor, but he could not see any problem with Martin trying it. I bought capsules for him which I cut open and put in his first drink in the morning with his breakfast, the effect was not immediate but within a few weeks, he was achieving at school and bringing home certificates for his work, first time ever. I found that it was better to give Martin one dose in the morning and one when he got home from school. It seemed he needed topping up if I gave it in the morning.

I kept Martin on them for nine months, when I stopped he was a changed boy, as he is calmer and he is learning more. He is still active, but more manageable than he was before we started, and now he can concentrate for a full lesson rather than flit from one activity to another.

We have just had his annual review and for the first time he is concentrating for the full lesson, which is such an improvement, so was it Evening Primrose Oil?

Vanessa Butt

Family Day

The family day preparations are well in hand.

This is entirely due to the hard work of Julie Glass organising the venue, rooms, creche, speakers, and so forth.

An invite and booking form will be with you any time now. If you would like to join us please do send your booking form back as soon as you can, as places especially in the crèche are limited to maximum numbers. Closing date for replies is October 1st.

Family day - 14th November 1988
Coventry Hill Hotel
Rye Hill, Allesley
Coventry.
West Midlands
CV5 9PH
Tel 01203 402151

Anyone wanting to stay overnight may book directly with the Hotel, the rates are below.
Leisure Rate @ £29.00 BB per person
Dinner B&B £41.00 per person
Children staying in room with parents eat free from the children's menu or half price from the adults menu.

Speakers

Dr Lucinda Carr (Consultant Paediatric Neurologist)
Dr Sheena Reilly (from the Dysphagia Clinic, a specialist in feeding difficulties)
Katie Price (Specialist speech therapist)

Proposed Agenda

10.30 Registration

Tea/ Coffee
Children to the crèche
10.00 Welcome (conference room)
Introduction to the Committee members
Details of the day agenda
11.15 Presentation by Lucinda Carr.
Brief question and answer session
12.30 Buffet lunch
(Children collected from the crèche)
1.50 Children returned to the crèche
2.00 Conference room
Presentation / talk by Katie Price and DR Sheena Rilly
4.00 Close
Tea/Coffee

WELCOME TO HOLLAND

I am often asked to describe the experience of raising a child with a disability to try and help people who have not shared that unique experience to understand it - to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip to Italy, you buy a bunch of guide books, make wonderful plans, the Coliseum, Michael Angelo's David, the Gondolas in Venice, you may even learn some handy phrases in Italian, it's all very exciting.

After months of eager anticipation, the day finally arrives, you pack your bags and off you go, several hours later the plane lands, a flight attendant comes in and says, "Welcome to Holland".

"Holland" you say, "What do you mean Holland? I signed up for Italy, all my life I've dreamed of going to Italy".

But there's been a change of flight plan, they've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease, it's just a different place.

So you must go out and buy new guidebooks and you must learn a whole new language and you meet a whole new group of people who you would never have met. It's just a different place. It's slower paced than Italy, less flashy than Italy but after you've been there for a while and you catch your breath, you look around you and notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy and they're bragging about what a wonderful time they had there. For the rest of your life you will say "Yes, that's where I was supposed to go, that's what I had planned". And the pain of that will never, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, very lovely things about Holland.

Emily Pearl Kingsley

Dr. Michael A. Patton,

Consultant Clinical Geneticist & Reader in Medical Genetics

I find it difficult to believe that it is a couple of years since I talked to your Group. I am afraid that the trail for a genetic link seems to have gone cold. When I was over in Numegeen in Holland, speaking to collaborators on one of our other research projects, I did try and follow up the lead that I had suggested at the meeting. They had what they called 'Familial Moebius syndrome and had linked this to a particular chromosome location. I thought, on the clinical photograph, that it looked more like the upper motor neurone palsies in Worster-Drought but I am told by the Neurologists that this is not correct and therefore I think we cannot take this lead further.

The situation at the meeting was interesting because although my own experience with Worster Drought had suggested that there might be quite a number with family histories, that did not seem to be the case in the majority of members of your Support Group.

I am sorry not to have had more positive news for you, but I wish you well in your next meeting, and for the future development of your Group.

Did You Know

Dr Cecil Charles Worster-Drought became a member of the Royal College of Surgeons in 1911. Most of his work on the syndrome was published in the mid fifties. In 1974 a monograph reviewing 200 cases who he had seen over a 20 year period was published posthumously by a T.T.S. Ingram.

Dr Worster-Drought died on 27 October 1971.