

Please Help

I would like to take this opportunity to ask for any volunteers to provide me with something to fill the space that sometimes appears in the newsletter. If you feel that you'd like to write something to share with other readers, please send it to me at the usual address.
Des Nutter
34 Liberty Gardens

More inside...

Yes, there's more on the inside...
In this lightweight winter issue of WORDS you can read a reminder about the Research Party and how Monique and Vanessa are working tirelessly to ensure that it's a huge success (there's another copy of the invitation just in case your other one went missing), hear news from all around the world, and you can hear about recent contributions to the group funds.

Contact a Family launches freephone helpline

Some of you may be aware that in June of this year Contact a Family launched a freephone helpline for parents. This was made possible by a substantial grant from the Department of Health. The following is a letter from Contact a Family about the new service.

A much-needed national helpline for families and carers of children with disabilities, rare disorders or a special need has been launched by the charity.

The new national helpline number is 0808 808 3555. Opening hours will be 10.00am - 4.00pm, Monday to Friday.

Made possible as a result of a £1.5 million grant from the Department of Health, the new freephone service will act as a one-stop information and advice centre.

It has several aims:

- to provide information on disabling and medical conditions, together with advice on many of the key issues facing parents such as benefits, special educational needs and respite. All medical information produced by Contact a Family is written by leading doctors and paediatricians, specifically for parents and families.
- to put parents in touch with local information services and support groups and other specialist voluntary organisations.
- to put families in touch on a one-to-one basis. Many parents want to speak individually with families. This is particularly important for families caring for a child with a rare condition where there may not be a support network.
- to provide a sympathetic listening ear. Many parents, particularly when they have just received a diagnosis for their child, wish to talk things through.

A team of five Parent Advisers has been put in place under new Helpline Manager, Mark Robertson. By the end of its third year, Contact a Family expects to be e-

sponding to 21,000 enquiries a year.

"Being told your child has a disability, rare disorder or life-threatening condition is devastating", says Mark. "The first thing you want is information and advice. We know there is a vital need out there. We now have the resources to deal with that need; to point people in the right direction and to put people in touch with each other."

"This is yet another groundbreaking step for Contact a Family" says Francine Bates, Chief Executive. "Over these last

months the charity has made huge progress in moving its agenda forward. Currently, families of children with disabilities and special needs are a deeply disadvantaged sector of society, denied services, access and opportunities. We intend to continue with our efforts to ensure they have a better deal. Our helpline is just one way of helping them with their difficulties and problems."



The logo of Contact a Family

News from down-under: New Zealand

One of the frustrating things about living in New Zealand is that medical information is quite difficult to access. This is particularly true if the information is about something as little known as Worster Drought Syndrome. This has prevented our son from being formally diagnosed with the condition; instead we have had a range of responses from "it might be" to "it isn't" to "maybe a forme fruste (atypical) type" to "he is absolutely typical". We have found this to be true for the Childs family as well; no one here in little old New Zealand knows enough to be able to diagnose the condition. To this end Jackie Childs and myself have decided to fundraise to get ourselves to the UK in time for the London Zoo Party. We want to meet with the other families we have met through the internet and people that we haven't met yet as well. We want to find out what the



researchers have to say about the condition, and most of all WE WANT TO SEE THE TEAM AT G.O.S.H. AND GET OUR KIDS FORMALLY DIAGNOSED! While in the UK we would also like to visit some of your specialist Speech and Language Schools as in New Zealand we do not have the population to support this type of school. In cahoots with my workmates I organised a "Sponsored Wax", we asked people to volunteer to get their legs, chests, bikini line or armpits waxed. They were sponsored to do so and on the 3rd of November we held a fundraiser to publicly rip the hair from the poor volun-

teers! Also in attendance were members of Kiwifire, a male strip review in the style of the Chippendales offering massages or leg waxes to the ladies, as well as a local radio personality who had his chest waxed! (OUCH)

Our first fundraising effort has raised over \$2000 towards the expected cost of \$10,000 for the airfares; we will need extra on top of this to meet additional expenses of travel etc. Currently we have the Manawatu Trotting Club doing some fundraising for us on Friday the 23rd November, they are going to give us the gate takings from their Christmas meeting. The bank we have our mortgage with is organising a mufti day for the local branches to raise funds also. And in Rotorua Jackie is planning a competitive mufti day fundraiser for local schools with the winning school getting their principal arrested and thrown in the cells for the

day!

All in all a busy time is ahead for us but we are determined to get to the Research Party on the 19th of May 2002.

Hope to see you all there!

[update: Annemarie and Jackie have been very successful in their fundraising attempts. Since writing this letter for WORDS they have almost completed their money raising efforts. – Des Nutter]

Goodbye Linda, and thank you for all your help

Dear Friends

I am writing to let you know that after 10 years I will be leaving CaF at the end of February. You will however be pleased to hear that I will be staying within the field of rare disorders, as my new post will be The Neurofibromatosis Association. This is a very good career move for me and I am very much looking forward to some new challenges and the fact that the new office is within walking distance of home makes it even more attractive!

Over the years I have had the privilege of working very closely with many of you and have seen your groups grow and develop, often with a lot of time and hard work. In return many of you have been willing to help me, mainly in my quest for families for the media and I would like to say a huge thank you. Many of you have also become more like friends and I have always been pleased to hear from you how things are going.

Anna King who some of you will already have had contact with, will be taking over the UK group work and so I am leaving things in very safe hands. She can be contacted on her direct line 020 7608 8715 or by e-mail anna@cafamil.org.uk

With very best wishes

Linda

Linda Partridge
Senior Development Officer (Rare Disorders)

[Many heartfelt thanks go to Linda who has been responsible in so many ways for seeing the group make it's way to what it is now. Des Nutter]

THE RESEARCH PARTY

LONDON ZOO

The party to thank the children who took part in the research into Worster-Drought Syndrome at the Wolfson Institute and Great Ormond Street Hospital is being organised and funded as I type this. To allow time for us to prepare adequately we have scheduled the party to take place on Sunday 19 May 2002, so don't say we gave you too short notice.

We are holding the day at London Zoo so there should be plenty to see and do for young and old alike. If you haven't been to London Zoo before, or even if you have it is well worth a visit. London Zoo also features excellent conference facilities, which we will be using to update all the parents with the findings of the research in a morning of presentations by Dr Maria Clarke, and Katie Price and her team. After that there will a brief presentation from the committee to update you with our activities and seek your approval for our constitution and committee members. We have taken on board suggestions from past events, so there will be plenty of opportunity to meet and talk with other parents during (picnic) lunch and in the informal afternoon enjoying the facilities of the zoo. To close the day we will meet for afternoon tea before saying goodbye and wishing you a safe journey home.

Details of timings and our special access to London Zoo are attached, we would appreciate it if you would take the time to complete the reply slip and return it to us as soon as possible.

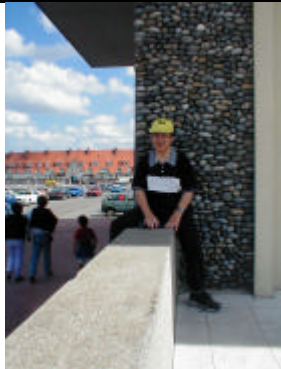
To find out more about London Zoo, you can phone them on 020 7449 6260/6235 or visit their website at www.londonzoo.co.uk



London Zoo is an integral part of the Zoological Society of London, a worldwide conservation, scientific and educational charity. Charity number 208728

Happy 18th Birthday Martin

Many happy 18th birthday returns go to Martin Butt who celebrated his 18th birthday on the 6th of January. Thanks Vanessa for sending in this photo of Martin. If you would like to see your child (or even yourself) in an issue of WORDS then send your photo and an accompanying letter to the newsletter editor (me) at the usual address.



Golden Wedding Anniversary Celebrations



Jim and Eve Staley celebrated their Golden Wedding Anniversary at a party on the 23rd of September. Guests at the party in Henley upon Thames were asked to donate money to the Worster-Drought Syndrome Support Group rather than bring presents. Jim and Eve are grandparents to Sam Melunsky who has WDS. A grand total of £550 was raised for the group. Jim Staley contacted me directly and told me of The Exel Foundation. The foundation match the funds raised for charitable purposes with money raised through their own fund raising activities. The foundation normally insists that the receiving organisation is a registered charity, but as the Worster-Drought Syndrome Support Group is moving towards that goal the foundation made an exception.

[well done and thank you - Des Nutter]

CONTACT

Communication Matters is a UK national voluntary organisation of members concerned with the Augmentative and Alternative Communication (AAC) needs of people with severe communication difficulties. <http://www.communicationmatters.org.uk/>



**British Educational
Communications
and Technology agency**

As the Government's lead agency on the use of ICT in education, Becta plays a crucial role in helping to maximise the benefits to all teachers and learners that using ICT can bring. <http://www.becta.org.uk/>

Network 81 is a national network of parents working towards properly resourced inclusive education for children with special needs. Tel: 0870 770 3306 <http://www.network81.co.uk/>

IPSEA offer advice to parents of children with special needs having problems with their education. Tel: 0800 0184016 <http://www.ipsea.org.uk/>
[more in the next issue... Des Nutter]

Invitation to the Family Day

We would like to invite you and your family to our Fun and Conference Day, our 3rd Worster-Drought Support Group Event on Sunday 19th May 2002 at London Zoo in the Huxley Centre at 10.00am.

This event has been kindly sponsored by the Children No 1 Foundation. In sharing this wonderful day with us it will enable us to socialise with other families in an informal atmosphere and gain more knowledge on the WDS syndrome.

The format of the day is the following:

10 - 10.50am	REGISTRATION Hand out of Presentation Pack Children to be taken to creche facility run by The Log Cabin
11.00am	Introduction by Des Nutter – Acting Chairman
11.10am	Annual General Meeting (AGM)
11.30am	Presentation by Dr Maria Clark
11.40am	Question & Answer Time with a panel of Specialists in the field of WDS
13.00pm	LUNCH - Families free time to look around the Zoo
15.00pm	Coffee/Tea - a chance to meet other parents and committee members in an informal atmosphere
5.00pm	Goodbyes

Please complete the attached acceptance form which we need signed and returned back to us, as soon as possible. Unfortunately creche facilities are now fully booked and we are unable to offer any more spaces.

If you require any further information please contact Monique Lauder on 0208 428 6706.

We look forward to sharing this special day with you.

FURTHER DETAILS OF THE DAY

The Children No 1 Foundation

The day has kindly been fully funded by the Children No 1 Foundation. The only stipulation they have, as discussed in the acceptance form, is that they video and photograph the event. In addition the foundation will be supplying t-shirts with the charity's logo on it for the children to wear. This is to promote their charity and help raise more funds, helping more children with special needs. Should you need further information please email your comments to Vanessa.butt@btinternet.com.

Creche

The Creche employees are being provided by **The Log Cabin**, Adventure Play for Children, who are all qualified in playwork in NVQ, Teachers and Classroom Assistants. They are all police checked and the majority of them have First Aid training, although First Aid is provided by the Zoo as well.

Creche facilities will be provided for approximately **60 children**, older children will be able to go around the Zoo with the Log Cabin Staff. If you require this facility please fill in the Acceptance Form attached as well as the Childcare Form and send it back to us ASAP.

Parking Facilities

There is pay and display parking on the outer circle road of Regent's Park near the Zoo, or the cheaper option is the Zoo's own car park as shown on the map enclosed.

Food

Please note that lunch IS NOT being provided by us. We highly recommend that you bring a packed lunch as the Restaurant queues in the Zoo are long and tedious. There are picnic areas around the Zoo for your comfort. Under no circumstances must food be eaten in the conference rooms.

ACCEPTANCE FORM

Name(s), in full, of Adults attending		
Names of child/children with WDS		Age Age
Names of other child/children attending		
Do you require creche facilities?	Yes	No
If yes, please fill out the Child Registration Form attached and send it in the stamped addressed envelope attached		
In order to update our records thoroughly please could you supply the following information (if applicable)		
Amendments to address (if any)		
Mobile Number:		
Fax Number:		
E-mail address:		
<p>The day has kindly been fully funded by the Children No 1 Foundation. The only stipulation they have is that they video and photograph the event and that all the children wear t-shirts with their charity logo on it. Thus enabling them to promote their charity which in turn raises more money to help children with special needs. If you have any questions please e-mail Vanessa.butt@btinternet.com</p>		
If this is not a problem please circle yes.	Yes	No
<p>If you would like to send a question to the panel in our Question and Answer Session please fill in the space below:</p> 		