

Issue 4

Words

The newsletter of the Worster-Drought Syndrome Support group

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Launch of the on-line edition of the CaF Directory....

The date; 12th May 1999. The place; the Grand Committee Room, House of Commons. The occasion; the launch of the on-line edition of the CaF Directory of Specific Conditions and Rare Disorders, hosted by the Rt. Hon. Harriet Harman MP.

The printed edition of the CaF Directory has long been regarded as the source for information on specific conditions and rare disorders, not just, by anxious parents, but by professionals too. It contains over 200 entries on over 800 conditions affecting children from Abdominal Exstrophies to Worster-Drought Syndrome, and each one gives medical information and details of available support groups.

Running to over 500 A5 pages contained within a sturdy ring binder, the CaF Directory is a sizeable piece of invaluable literature to carry around, and to keep it up to date receives up-dates every six months.

So what's changed? Well, the content is still the same rich source of information that proves so invaluable to so many; the biggest difference is the cost.

Whereas the printed edition retails at £56 + £4 p7p, the on-line edition comes for free! Add to that the ability to frequently update the contents, and surely CaF must be mad, giving away such a valuable revenue earner!

Well research shows that the free provision of an on-line edition of does not in fact detract from sales of the printed edition, but can in some cases enhance sales!

The cost of developing the on-line edition was met by a grant from the Association of British Pharmaceutical Industry.

Speakers at the launch included Michael Bailey (president of the ABPI), Nigel Barrett (trustee of Unique, the Rare Chromosome Disorder Support Group), Professor Michael Patton (consultant Clinical Geneticist, St George's Hospital Medical School) and Harry Marsh (director of Contact a Family).

Carol Youngs and Dean Casswell (assistant directors, CaF0 provided a demonstration of the on-line CaF Directory and featured Worster-Drought Syndrome entry. From this point a simple click on the hyperlink will take you on the home page of the Worster-Drought Syndrome Support Group. If you'd like to try the on-line directory out for yourself go to www.cafamily.org.uk and the home page for the Worster-Drought Syndrome Support Group can be found at www.wdspg@btinternet

Family Fun Day

The next Family Day is going to be a chance for families to get together and talk about current issues while the children get to know each other and have fun playing in a safe environment. The event is going to be on Sunday 3rd October 1999, from 12-5pm.

The centre in Maidenhead, Berkshire offers; massive indoor and out door safe environments, a huge interactive soft play room, helpful trained play staff, a large sand play area, splash pool, arts and craft area, videos and computers, and covered picnic areas.

The adventure playground began in 1978 when the toy library went to a workshop on adventure playgrounds for children with special needs. After several years of fund raising Terry Wogan opened the doors to the Thames Valley Adventure.

Over fifteen years later and the centre has gone from strength to strength to become the place it is today, and it is visited by over 200 children and adults with special needs each week.

The centre is a registered charity (#278336) and relies almost completely on donations and fund raising events to meet annual running costs of £150,000.

The centre makes a small charge as a contribution towards the running costs, but this is kept to a minimum

The centre has been booked for our exclusive use on Saturday 3rd October, and the cost of the day is going to be met from funds. It will cost about £4 per child, so if you feel able to make a contribution please do so on the day.

Rare Disorders Alliance-UK

The Rare Disorders Alliance- UK (RDA-UK) aims to bring together groups, families and individuals affected by Rare Disorders.

Many individuals have grown up to adulthood living with such a rare disorder that they have never met another person with the same condition. Families are devastated when they are told that a child has any disorder but when it is a very rare condition they face added problems such as difficulties of diagnosis, lack of clear information and variation of advice and treatment around the country.

Jamie is four. He was born with a condition called Epidermolysis Bullosa, which results in him having incurable skin blisters. Sadly this means that his family cannot cuddle him and he has to endure the daily application of painful dressings.

Anne is now 48 and for many years she has had a potentially life threatening condition whereby large blisters develop in her mouth and throat. Unless she gets to hospital quickly she could face suffocation. She has searched for both a diagnoses and the possibility of talking with another similarly affected person. She was given a possible diagnosis of Stephans Johnson Syndrome and searched in vain for good information. At last she now has a confirmed diagnosis of Angina Bullosa Haemorrhagica but still cannot identify much information and has yet to find a link with another person.

To raise awareness of the issues facing individuals and families with a diagnosis of a very rare disorder, the RDA-UK is holding a Rare Disorders Awareness Week from November 23-30 1999. The need for research into rare disorders and the sharing of information across the world will be highlighted. Contact a Family will be coordinating the week and a House of Commons Tea Party will take place on November 25 when concerned individuals and families will meet their MP's to discuss living with a rare disorder in the family

After a lengthy research process producing very encouraging results, this new Alliance was launched on the 20th November 1997 in London. There was an overwhelming response in favour of the proposed Alliance, but it was not felt necessary to set up another completely separate organisation.. As a result RDA-UK will be run from Contact a Family but it has a wider remit i.e., it also deals with conditions affecting adults.

With over 5,000 differing rare disorders the Alliance recognises that many of the problems experienced by families and individuals are due to the rarity of the conditions rather than the specific diagnosis.

It is hoped that Contact a Family together, with an advisory group made up from members, will be successful in trying to redress some of the inequity felt by these families in every aspect of their care. The Alliance will represent all those affected by rare conditions of any age, including those with late onset conditions.

The launch programme included a talk by Professor Michael Patton, Clinical Geneticist, who has been a very good friend to Contact a Family for many years and acted as an advisor for the CaF Directory. The other speaker was Stephanie Korsia, Executive Director of a comparatively new

European organisation for rare disorders called EURORDIS. Together with EURORDIS this new UK Alliance hope to improve the quality of life for all those affected by rare disorders.

Mr Des Nutter was invited to join the advisory group and attends regular meetings in London.

Items currently under discussion include the seeking of funding, and the consideration of independent (from CaF) membership of EURORDIS (to minimise any possible conflict of interests with regard to sponsors).

London Marathon

Karen Hinks (secretary) took part in the London Marathon and raised over £1.000 for the support group.

Karen completed the marathon in 4hours and 24 minutes and 52 seconds, which is good going by anyone's standards, although it took a good 48 hours for her legs to recover.

Flora will be sponsoring the London Marathon again next year on the 16th April 2000 as part of their intention to promote a healthier Britain.

If you are connected to the Internet and want to find out more, or if you are even considering entering, then you can check out the official web site at the URL shown below.

www.london.marathon.co.uk

Well Done Karen

Lock, stock & two smoking turntables

A charity disco in Luton was a great success raising £1.3000 for the WDS-SG and £500 for Great Ormond Street Hospital.

The Disco was called "lock, stock & two smoking turntable" with Mod and Punk music from the 60's 70's and 80's (and the odd bit of 90's music for the trendy folk).

The event was organised by two friends of the Donlon Family

Many Thanks for a wonderful donation to our group.

Research in WDS

Just recently Karen Hinks (the support group secretary) received a letter from the Wolfson Centre at Great Ormond Street Hospital. The letter text is included below

“ I am writing to let you know that we have been successful in our application to SPARKS (Sport Aided medical Research for Kids)for our study, which will investigate the range of feeding and speech problems in children who have been diagnosed with Worster-Drought Syndrome. We are hoping to involve 40 children in this project, which will start in August of this year and last for 12 months. Our aim is to document the clinical and diagnosis features of Worster-Drought Syndrome, and thus establish a set of clinical criteria, which will enable paediatricians and speech and language therapists to diagnose WDS accurately and early. In this way we are hoping that appropriate management strategies for feeding and communication can be instigated as early as possible, and disability arising from WDS minimised.

The SPARKS organisation and indeed the press office at the hospital are hoping that it will also be possible to raise the profile of the needs of children with Worster-Drought Syndrome through some publicity in connection with this project. I would very much like to involve your association in any discussion of the form that this publicity should take in order to make best use of the opportunity.

I wonder if I could ask for your recommendation for the best telephone contact in order to discuss this further. Please call me with any questions about the study.

I look forward to meeting again with members of the group.

Yours sincerely

Katie Price
Specialist Speech Therapist”

Obviously this is exciting news, and you will be kept up to date as soon as we know any further information. If anyone has any comments please feel free to mail them to myself (for publication in the newsletter) or Karen Hinks.

All Change Please

Some of the committee have changed roles

Andrew Hinks has become chairperson instead of Des Nutter, and Des has taken over as editor of the newsletter from Andrew Hinks.

Vanessa Butt has taken over from Jane Thorpe as the current National Contact; we wish Jane a speedy recovery.

Donna Donlon who recently joined the committee is using her financial skills in the position of treasurer

Contact Information

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Raffle

As some of you may remember we were busy selling raffle tickets earlier in the year. Well the draw did eventually take place at Des Nutter's office in London and the prizes have been presented to the winners.

1st prize (a weekend break for 2 at any Stakis Hotel) was won by S MacManus of Luton.

2nd prize (Maddame Tussards tickets) was won by T Bentely of Loughton, Essex

3rd prize (£10 C&A voucher) was won by D Young of Writtle

Even if you didn't win a prize you deserve a pat on the back as the raffle raised £320.50 Well Done!

Letters to the Editor

This is the bit where you come in. If you have any information that you would like to pass on to other families who receive this newsletter then please write in to me at the address above. Alternatively you can e-mail me.

Did you know you can get a reduction in your Council Tax, or that you (or your child) may be eligible for Disability Living Allowance? For more information visit your Post Office where you should be able to find copies of the necessary forms.

Many Theme Parks offer a fast lane for people with a disability. Next time you are going, ring ahead and check. It could save you a lot of time!

