

## Thank You

"On May 12<sup>th</sup> Andy and I attended our last committee meeting, we are both standing down from the committee due to other commitments. Andy has been involved with the committee from the start and myself for about 3 years, the group has come along way in that time.

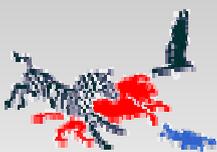
Thank you to all the people we have

## More

Yes, there's lots more inside...

In this issue of WORDS you can get all the information on the recent changes to the committee, who's on the committee, what do they plan to do, and how you can get involved.

You can read two articles written for us



## The Research

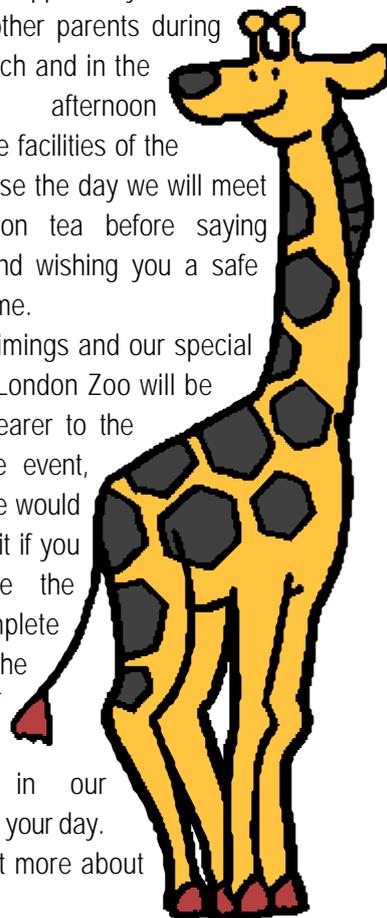


Big news – the party to thank the children who took part in the research into Worster-Drought Syndrome at the Wolfson Institute and Great Ormond Street Hospital is being planned as I type this. We had originally hoped that SPARKS – the charity that funded the research would organise the party, however the agreement was never formalised, and so we have assumed responsibility. 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 will be provided nearer to the date of the event, however we would appreciate it if you would take the time to complete the slip at the bottom of page 4 to help us in our planning for your day. To find out more about



## Sam: Diet &

The following has been written by Sam's mum Judith Melunsky. Please feel free to send any comments back to us for publication in a future issue of WORDS.

"My son Sam is 11 years old and was diagnosed with WDS about 18 months ago. We met many other children at the family day at Thames Valley Adventure Playground and shared lots of information. One area that I am very interested in is diet and food intolerances and I completely forgot to ask about this. Sam has been found to have very low levels of iron previously and testing has suggested he may be intolerant to dairy and wheat products. I would be very interested to know if anybody has had similar problems, looked at diet and what sort of benefits have been achieved. Tiredness is a big factor with Sam, he sleeps for 12 hours a night and can still be tired during the day and I don't know whether his diet could be contributing to his energy level. Any

## All Change...

A lot has happened since the last newsletter, Andrew and Karen Hinks have resigned from the committee and we have started to have an influx of new members taking on some of the work that the committee does. Andrew has been involved with the committee since the start, and Karen for about 3 years. During that time Andrew took over as chair and Karen secretary. Owing to an increased workload at home both Andrew and Karen feel that they are no longer able to give the committee the level of support they feel it requires, although they intend to keep in touch and take an active role in all activities we organise.

Some of you will be aware that I was chair when the committee was first formed, and I am now acting as chair again. In my role as chair I would like to thank Andrew and Karen for all their hard work, and wish them well in all that they choose to do in the future. At the last meeting of the committee (12/5/01) we were fortunate enough to be joined by the Rumbold family, Mick and Mary, and their son Elliott. As part of their initiation into the committee, they have produced an article about Elliott, which appears later on in this newsletter.



Des



Vanessa



Gavin



Monique



Stephen

It doesn't stop there – at the meeting on 14/7/01, we

## What Next?

Well, those on the committee believe that it would be in the group's best interests to become a registered charity. Their reasons for this being that it would lend an air of legitimacy to the group and assist us when seeking funding from corporate sources. Another reason why the transition has become more attractive is the changes that Linda Partridge of Contact-a-Family has been working on with the Charities Commission to produce a fast-track method by which small groups can become registered charities. What this basically means is that if we agree to accept the standard constitution offered by the Commission, we will avoid most of the problems encountered when groups try to get their own constitutions accepted by the Commission. This isn't a significant restriction as in the past we had been using a "standard" constitution (provided by CaF) as our working document for the production of our own constitution.

Our main stumbling points had been in trying to agree the criteria for membership in a fair and legal way. None of us are

legal experts (are you, and if so would you like to help?) and so as you can imagine this was not a smooth process. The terms for membership in the Charities Commission constitution require no amendment at all. The only items we have to consider are the numbers of members who are required in order for a committee decision to be valid.

Once we have agreed on this at committee level we can then present it to the general membership of the support group (all of you in the UK) at

## What Does This Mean For Those On The

What this means is that there will have to be a number of trustees who will have certain legal obligations and responsibilities, which are determined by the Charities Commission. These changes may influence whether or not people choose to serve on the committee, but we must bear in mind that there are many people out there who are willing to do good work but don't want the responsibility of being a trustee.

This is catered for by the inclusion of co-opted members. These are people

who feel that they are able to offer some time or other attribute to the committee, but don't want to have a permanent or fixed role on the committee. These people are just as valuable as the trustees, and in many cases provide services that the committee otherwise would not be able to offer. What this means is that there will have to be a number of trustees who will have certain legal obligations and responsibilities, which are determined by the Charities Commission. These changes may influence whether or not people choose to serve on the committee, but we must bear in mind that there are many people out there who are willing to do good work but don't want the responsibility of being a trustee.

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## What Does This Mean For

Well, one of the changes that were agreed at the committee meeting in May was registration for the group with the Data Protection Act (DPA). The reasons behind this were to enable us to provide another service to you – the members.

We have a number of aims as a group, and one of them is to provide you with access to information about the condition. So far we have been doing this as regards the overall syndrome, but we have been unable to offer much more in the line of personal enquiries. What we would like to do (with your help) is gather some information from you about how



Worster-

Drought Syndrome affects you and your child. We don't plan to ask a hundred questions, just a handful of questions that should take the minimum of your time to complete. Of course this information can only be requested, it is up to you to decide if you want to provide it or not.

What happens next depends upon how much response we get back, but we plan to put the information into a database. The database will not be available online, no one will have access to your information save for a few key people on the committee. One of those people will have responsibility for maintaining this database – adding new members to it, etc. The other

will be the Vanessa – the National Contact. She will use the information as a means of helping her when she gets requests to link families together. At the moment Vanessa has to rely on a card index system with minimal personal information, some of which could be out of date. She often gets requests to put families in touch who are affected by similar problems, something that is often extremely hard to do. When she receives these requests she writes to families who she thinks might be an appropriate match to ask if they would like to be put in contact with another family. As the size of the group grows this task becomes more difficult to perform adequately, and the requirement for a database becomes more understandable.

Over the next few months we will be looking into the restrictions imposed upon us as a group by the DPA, and consider the best way forwards. Once we have successfully registered we will be contacting you with the questionnaires. As well as the collection of data regarding how WDS affects you, we will also be using the questionnaires as a means of ensuring that we only have current contact information in

Elliot is a happy, popular although somewhat sensitive boy. At the age of 3 he didn't have any speech, he didn't even make sounds when playing with his cars. Around this time he had a high resolution MRI scan that showed a muddled brain picture, or neuronal migration disorder. Basically some of the cells in his brain formed in the wrong places. Elliot started having regular speech therapy, occupational therapy, and physiotherapy. He has progressed in all areas. When school began we managed to get him into a school for physically handicapped children in Bristol, and he is still there now. He gets a lot of support from therapists that he wouldn't necessarily get in a mainstream setting, however we do feel that he misses out socially sometimes as most of his peers have greater physical handicaps, and can't run around the way he can. Over the years everything has improved. Elliot walks, runs, jumps etc. but put alongside another child his age he can look clumsy and awkward, especially in a playground with climbing frames, open steps on slides etc., but give him a football and he's well away! Even now though, he still comes downstairs with one foot leading all the way. Elliot's fine motor skills improve all the time, but slowly. He can't completely dress himself; buttons, zips, jackets, jumpers, all prove a problem, and he hasn't got enough control to manage to write -although he loves painting and colouring,- so at present he is having key-boarding lessons, so that for the foreseeable future anyway he can do his written work on a laptop computer. The greatest problems though are addressed by the speech and language Therapist. Elliot still dribbles, and we are currently trying to work on maintaining lip closure for between 10 to 30 seconds at a time. For over two years now he has been able to drink from a cup without a lid, and for about 18 months he has managed to start using a straw,

## Elliot's Story

although this can sometimes be hard work. Even so, when eating and drinking Elliot needs a bib, as it can be a very messy business. He has no side-to-side movement of his tongue at all, so he tends to put food to the side of his mouth with his fingers in order to chew it. He used to choke, not so much on food but drinks on a daily basis, but this hardly ever happens now. Elliot's speech and language therapist decided that the best approach would be to give him as many ways of communicating as possible. So Elliot uses signs that are based on English sign language, - although of course his fingers aren't as dexterous as the average deaf signers would be. He also uses Rebus symbols; these come from a dictionary of symbols and pictures, He has a combination of these and words on an electronic speech aid called a 'message mate' & he also has a mixture of the symbols and words in a book which has different sections in it that he is familiar with, so he just locates the page/s that he wants and points at the word/s, symbol/s. In addition to this of course, Elliot's speech is being worked on, he is now extremely vocal, and several words have over time become quite clear. He can make all of the vowel sounds, and he now easily says 'K', he also says a fairly good 'G', and we are currently working on 'M', and 'B', which he finds more difficult, but he's getting there. He also has trouble combining sounds, so for example 'K' followed by 'EE' is kept separate as 'K-EE'. What Elliot does do though is talk in sentences, so he will normally attempt to say anything you ask him to repeat. He uses the correct intonation, word order, and amount of syllables per word, it just all sounds 'vowelly'. However if you are a familiar listener, or are maybe looking at him, it is quite clear what he is saying.  
Mick & Mary Rumbold

That's all for this issue of the newsletter, please feel free to write to me and let me know what you think, your articles and stories are always appreciated. Send your stories to; Des Nutter, [REDACTED]

E-mail: [nutsoft@hotmail.com](mailto:nutsoft@hotmail.com)

Please complete this slip and return to the secretary, Gavin Leech, [REDACTED]

Family Name

Number in Group

Address

Yes, we plan to attend the Research Party at London Zoo

No, we don't plan to