



Link

NEWSLETTER SPRING 2014

Don't forget to send your articles or any news that you would like to see in future issues to:

secretary@wdssg.org.uk

Please let me know if you have anything that you would like to share with other members.

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Editor's Note

As Spring is now upon us, we can look forward to another great year for us and our members.

I am sure this year's Family Day will be another success and I look forward to seeing a lot of you there. We will have a wonderful opportunity to hear our Guest Speakers answer some of your questions, which I think will be very interesting.

I hope you all have a great Easter and we will see you in the summer!



Nicki Turley



Don't forget...

Our Family Day is on Sunday 22nd June.



Reg. Charity No. 278336
THAMES VALLEY ADVENTURE PLAYGROUND
for children & adults with special needs

Bath Road, Taplow, Nr. Maidenhead, Berkshire, SL6 6PR
Tel: 01628 628599 E-mail: theplayground@tvap.co.uk

The agenda this year is a little less informal, so we can not only chat to each other but also acquire some useful information from some of our guest speakers. Throughout the day members of the committee will also be available if you have any questions.

- 10.00 - 10.30am Registration and Refreshments
10.30am Presentations from
Dr Maria Clark and Professor Neville
12.30pm-1.30pm LUNCH
Meet and talk with other members
and their families whilst enjoying
the facilities.
2.00pm AGM
2.30pm-3.30pm Tea and Coffee and a chat

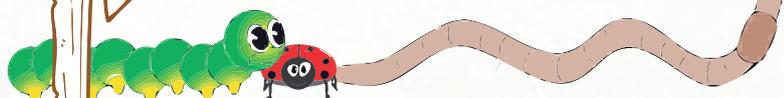
There will be facilities for tea and coffee making throughout the day but please remember to bring a packed lunch.



ANIMAL ENCOUNTER



The zoo that comes to you. Meet the animals, insects and creepy crawlies, with a chance for some hands on if you dare!!



Make up a team or be a spectator and join in the fun in ...

our version of

FAMILY FORTUNES

Don't forget
to return your
registration
forms

Our Speakers

Our speakers are coming to the Family Day to speak about progress on the WDS genetics research project and Epilepsy and WDS.

They will also be responding to questions asked by members that have been prepared beforehand, so please make sure that you have sent your questions in to Vanessa, our National Contact, on the sheet provided with your invitation. Alternatively you can email them to her at:

national.contact@wdssg.org.uk

Maria Clark

Dr Maria Clark is an expert in developmental aspects of paediatric epilepsy. She has worked as a consultant at Great Ormond Street Hospital (GOSH) for five years, running the Developmental Epilepsy Clinic and prior to that did much of her training and research at GOSH.

Dr Clark leads a multidisciplinary team that provides specialist assessment and management of the interaction between complex epilepsy and development.

Specialisms

Developmental aspects of childhood epilepsy (including learning, language and behaviour),
Landau-Kleffner syndrome (acquired epileptic aphasia), Worster Drought Syndrome (congenital pseudobulbar palsy)

Professor Neville

Professor Brian Neville was the first Prince of Wales's Chair of Childhood Epilepsy, stepping aside from this post only to continue with research in December 2007. He was the first Professor of Paediatric Neurology in the UK appointed in 1989, and developed the unit at Great Ormond Street Hospital to become the largest combined clinical and academic department in the country, with collaborative links across Africa and India. He was also key to the development of the epilepsy surgery programme.

He was appointed to the Prince of Wales's Chair of Epilepsy in 2004, with a vision to considerably expand the academic research between UCL, GOSH and Young Epilepsy.

His research interests involve the early onset epilepsies, with a focus on mechanisms involved in the comorbidities of cognitive and behaviour impairment, and interventions available to minimise these.

He has been a principal driver in highlighting the possible extent of problems encountered by these children in education, and is developing research to determine the true extent of the problem as well as the possible role of intervention in the community.

Emeritus Professor of Paediatric Neurology at University College London
Professor of childhood epilepsy at UCL Institute of Child Health



The Venue

We have all of the facilities at our disposal so we can wander where we wish and enjoy the relaxed setting. We hope that you will come and enjoy an informal day with us.

There are indoor facilities, offering an opportunity for creativity and imaginative play.

Outside activities include a castle, accessible for all abilities, Crazy Golf, a Toddlers Area with swings and climbing tunnels, built into a sand pit and for the more adventurous, there is a Tree Top Trail which is suitable for wheelchair users. There is also a music structure with huge oil drums, sound pipes, bell clangors' and gongs.

We are sure that you and your family will find some activity to enjoy.

PLEASE NOTE
You will need to put
SL6 0EF
into your SAT NAV
to find them

To find out more about the facilities then please look at:

www.tvap.co.uk

Thames Valley
Adventure Playground
Bath Road,
Taplow,
Nr. Maidenhead,
Berkshire,
SL6 0PR



www.thesupercarevent.com

You are welcome to join us
on 21st June 9am - 4.30pm
at Dunsfold Park, Compass Gate,
Dunsfold Road, Surrey GU6 8HY



From
the
Chair

It's hard to believe where does the time go? As I get older my Worster-Drought presents new challenges, I have been suffering from a ongoing set of throat infections but glad to say that I believe they are all cleared up now. I expect many of your children find it a challenge over the winter months and it's been a very wet winter this year. I am so glad the spring is with us again and we can all look forward to the longer and warmer days. I have now done my second 3 year term as Chairman which means I will have to stand down again. Its hard to believe I have been Chairman for such an awesome and supportive charity for 6 years now, I believe this is the longest that anyone has been Chairman. I would of course be delighted if I get voted back into representing you all and raising awareness of WDS.

I am really looking forward to the family day this year as I missed it last year the first time ever that I have not been able to attend. I was however supporting another Charity close to my heart at Glastonbury last year but this year I will be here.

Talking of which I am also looking forward to seeing those who can come to the Top Gear track on the 21st June, we can make a whole weekend packed of fun.

I have noticed that my mail box has been quiet the last few months so I wanted to remind you all if you ever need someone to talk too I am always here with a ear to bend.

Mark Mayer

Pictures:
Mark at
Top Gear Day 2013



We need your help!



John Butt Treasurer

I have been then treasurer of the group for a number of years. My background is that of a telephone engineer with BT then I retrained to become a computer software engineer and I still work for BT looking after some of BT's older computer systems.

My youngest son Martin was diagnosed with WDS when he was 11 at the Wolfson Institute. Martin is now 30 and lives in a L'Arche community here in Ipswich.

As treasurer my main role it to look after the group's money by keeping accounts of all income and expenditure, producing the necessary reports for the AGM and the Charities Commission and claiming back any tax refunds the group is entitled to.

Nicki Turley Secretary and Editor/ Designer (Newsletter)

I have been secretary of the group for a number of years now and I am still enjoying it. My main role is to minute meetings and organise paperwork associated with it.



Due to my design and print background I have been able to utilise my skills to not only provide a fresh logo for the charity but also to design and create interesting newsletters for our members to enjoy receiving.

I came into this role with no confidence or experience with this type of thing and thought that all I would be able to bring to the committee were my existing skills. I did not realise that it would turn into much more than that. I have met some wonderful people over the years and gained a lot more from it than I have put in. Seeing the progress that my son Callum has made alongside that of the charity has made me immensely proud to be part of it.

Can anyone help me?

I need suggestions regarding Apple Ipad apps for 2-4 year olds about colours, shapes, numbers, letters and animals etc.

Please email monique.lauder@btinternet.com

Become a Committee Member it's easier than you might think!

Being a committee member means:

- ▷ Having the satisfaction of supporting others using your own experiences
- ▷ Getting involved in seeing how the charity operates
- ▷ Being part of the team to help steer the way the group should go
- ▷ Bringing new thoughts and ideas to the committee
- ▷ Learning what to do, start as a general member to learn the ropes and then step up to a key role if you wish.
- ▷ Attending a few meetings a year and/or a small number of conference calls

and does NOT mean:

- ▷ Attending every meeting held
- ▷ Spending lots of precious hours doing it
- ▷ Pressure! You do what you can to help, that's all that will be asked
- ▷ Doing it alone - we try to share the work load

If you think you might be interested contact us on: committee@wdssg.org.uk



Vanessa Butt National Contact

Hi I am the National Contact for the WDS support group I have been performing this role off and on for the last seventeen years. I am also part of the founding group who worked with Contact a family to set the group up 20 years ago



As National Contact my main jobs are:-

- To be the first point of contact for anybody with questions about WDS and or the group
- Sending out information packs to new families
- Answering questions from parents, relatives and professionals
- Linking members together
- Maintaining the official list of members
- Liaising with Gt Ormond Street over matters that may impact our members like the current research project
- Signposting parents to other agencies that may be able to help
- Finding out events that may be useful to our families

Affiliated to Contact a Family and Rare Diseases UK

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All information in this leaflet is correct at time of going to press.