



Link

NEWSLETTER SPRING 2012

Don't forget to send your articles or any news that you would like to see in future issues to: secretary@wdssg.org.uk

We are particularly looking to write a future article on your experiences with drooling.

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

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Editor's Note

Welcome to this year's Spring Edition. What an exciting year we have ahead! Not only do Mark and I reach our big 40 this year, but we are also looking forward to taking part in our sponsored walk in the South Downs, where we can raise money for our group. I am very proud to be supporting my fellow committee member in reaching both his personal and financial goal for our charity.

The Family Day will also be great too as it looks to be both informative and entertaining. See you there!

Nicki Turley





From the Chair

Easter is upon us again, it doesn't seem to long ago I put on those bunny ears last year and wished you all a happy easter!

We have lots happening this year, it's been a busy few months getting things ready for the family day in June. I am looking forward to meeting you all, new and old faces. We are delighted to be able to use St Peter's again this year. For those who came last year I am sure you would agree what a fun packed day it was.

As you will also see in the newsletter, I have set myself the challenge of doing a 10km sponsored walk. I am delighted to have fellow committee members Nicki & Rik Turley aswell as a good friend of mine Rory Broughan, joining me on the walk for support. Please feel free to spread the word around so we can gather as many sponsors as we can.

Mark Mayer

Facebook and the WDS Support Group



As a newbie to Facebook, (I'm so new I only have one friend and she is a guide dog call Oddie). I asked our Chairman, Mark, about the group's presence on Facebook and this is the position.

- ✓✓ The group now has a 'Fan' page that is administered by Mark and he, and only he, updates it with news and events about the group.
www.facebook.com/wdssg
- ✓ The group also has a 'Member Lead Group' page that you can register for access to. On this page members can post questions, answers or just have a bit of a rant when they have had a bad day.
www.facebook.com/groups/wdssg
- ✗ All other pages or groups are run by other people and are not associated with the Worster-Drought Syndrome Support Group.

So I now need to get into all this social networking stuff and maybe get a few more on-line friends!

All the best,

Johnny one friend, who is the Suffolk cousin of Billy no mates!



But remember that what we read are on the member page are other member's opinions and because all our children are very different, we should also always consult our child's GP, consultant or specialist for any medical advice.



Family Day

Saturday 30th June

10.00 - 3.30pm

This years event is to be held once again at St. Peters Heritage Centre in Vauxhall.



Don't forget to return your registration forms

Agenda

- 10am AGM
- 10.30am Singing Hands
- 11.30 I-Can
- 12.30 Lunch
- 1.30pm Visit City Farm
- 2.15pm A demonstration from MyChoicePad
- 2.45pm Group Discussions
 1. MyChoicePad
 2. Communication Aids
 3. Mary on Low Tech
 4. Welfare & Benefits
- 3.30pm Teas, coffees & goodbyes

Also on the day...

Name the Teddy
Arts & Crafts
Suggestions Line



Bring someone extra to help you if you wish, as there will be no childcare

Presentations from...

This year we have some very informative presentations. I-Can will be talking to us about education, a subject I am sure a lot of you will be interested in. MyChoicePad will be presenting their exciting new software for the I-Pad, offering a Q&A session and a chance to try it for yourselves too.



I CAN's mission is to ensure that no child who struggles to communicate is left out or left behind.

With the end of the Spring Term just around the corner many parents will be taking a look back at the year so far and having a think about how their son or daughter is getting on at school. For children who have got speech, language and communication needs (SLCN) there may be even more questions to ask. Has she made any friends this year? How is he getting on in the classroom? Why can he never remember what his homework is? It can be very difficult for parents to get the information they want, or even know the right questions to ask.

You might find it helpful to try and see if you can get a meeting with your child's teacher and the SENCO if possible, to talk specifically about how your child is getting on. Prepare a list of question in advance, and maybe even bring some examples of things that you have noticed or that your child has told you about school. Why not get in touch with other people that work with your child, for example their speech and language therapist if they see one. You could ask for an update on how they feel your child is getting on, and see if you can get some ideas of things you could be doing at home to help them.

If you have any queries or concerns about your child, or would like some more information about ways to support SLCN in school, why not call the I CAN Help Enquiry Service? You can have the opportunity to talk to a friendly and impartial speech and language therapist about SLCN, what we know about how it can affect a child at school, and possibly get some information about help and support.

Call **0207 843 2544**
to book your free call back.

www.ican.org.uk

How is my child with SLCN getting on at school?
Posted on: 03-2-2012 Posted in: Parents, Teachers



Available on the
App Store

MyChoicePad is a new educational iPad

app to aid choice and communication for people with learning and communication difficulties. The app uses Makaton® symbols, signs and video with real sounding speech.

- 450 Makaton Core Vocabulary symbols and signs with video
- Synchronised UK accent speech and record own voice
- Option to purchase over 3000 additional Makaton symbols and sign graphics via in-app purchase
- Quick and easy search access to signs and symbols

FREE version MyChoicePad Lite.
MyChoicePad with the Makaton Core Vocabulary is available for £74.99

Visit

www.mychoicepad.com

to find out more.



Entertainment from... Singing Hands

"We are Suzanne and Tracy, co-founders of Singing Hands and we introduce you to the amazing world of signs through songs, rhymes, stories and games."



Singing Hands have kindly agreed to join us again for this years Family Day. Some of you may remember the last time they came to Coram Fields when it was a huge success. They will be doing a signed story and a singalong, for both the children and adults to join in. They have also agreed to stay afterwards for a chat with any members who wish to ask them anything about signing.

as seen on
CBeebies'
Something Special

FABULOUS FUNDRAISING

Just Walk 2012 Saturday 12th May 2012

Just Walk is an exciting sponsored UK charity walk for anyone wanting to fundraise for the charity of their choice. This fundraising walk is open to charities and anyone who is keen to get their walking boots on and hike for charity - you can choose either 10km, 20km, 40km or 60km routes - so something for everybody. This charity walk offers enthusiastic walkers the chance to experience a breathtaking charity walk over the picturesque South Downs in West Sussex and generate funds for their chosen charity. Now in its 6th year!

Our very own Chairman Mark Mayer, Nicki and Rik Turley and a friend of Mark's, Rory Broughan, are proud to be taking part in this walk to raise money and awareness for our Support Group.

People can either donate by **text** by sending a SMS to 70070 with the message WDSG99 and the amount they wish to donate,

or check out the **donation page** at www.justgiving.com/WDS-walk

Sponsorship forms are also available on the WDS website for those who wish to donate the old fashioned way!

You can also follow us on Facebook to find at how much we are raising. Go to <http://apps.facebook.com/jgdonation/WDS-walk/on-facebook>

For more information on the event, see their website:

www.acrossthedivide.com/just-walk

We all hope to achieve our target and raise £1,000 in total!

Thanks...

TO ALL MEMBERS WHO HAVE SET UP STANDING ORDERS

To Sally Woods and her shop on the farm which has raised £206.36 in their collection boxes.

TO WEALD PARK LTD WHO DONATED £500



JUST WALK
ACROSS THE DIVIDE

JUST WALK 2012

Fundraise for the charity of your choice

Saturday 12th May

Just Walk is an annual charity walking event at **Goodwood Racecourse**, West Sussex on Saturday **12th May**. Why not come along with friends and family and walk either the 10, 20, 40 or 60km routes along the beautiful South Downs. **Raising money for the charity of your choice.**



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.