

From the Chair



Hello All

As you may know I stood down as Chairperson at the last AGM. It has been a difficult few years for me, with my health slowly getting worse brought on from what I can tell are seizures this is pretty hard to tell as I live alone so only really know what is going on after they have happened.

I have been struggling with getting carers to understand me when I am tired which means I end up trying to do stuff on my own. I have and always will be an optimistic person so I like to make each day count, this however makes it really hard for me to plan things ahead as I don't always understand things afterwards. I really didn't want to stand down as Chairperson because the Worster-Drought Support Group is very important to me, making sure that your children and adults with Worster-Drought get the help and support from the group they need. With no one being nominated for the position of Chairperson at the AGM I have decided to remain as acting chair for the time being until someone comes forward, of course I will support that person as much as I can. I thank the committee for helping me over the last year or so while I have been trying to get my health under control. I have found things a little easier the last few months but travelling is still hard for me as it takes a great deal of concentration.

I think as a group we have achieved some awesome things over the years and I see this to continue as we grow. It has been nice to see new families join us over the last 12 months. I see so many things we all have in common yet we all have our own characters and personalities. As always I am open to suggestions and ideas from you all for things we can do to help, even if that is just someone to talk too. I am aware that it may help others for me to share more of what it has been like growing up with WDS but I struggle to do this so publicly but as some of you know writing is my main form of communication as it gives me time to reply to you. I am hoping with more responsibility taken off me I am able to do this more but as always do feel free to contact me even if that is to say hi. :-)

Mark Mayer

We had a lovely time at the family day this year which was held in the pretty village of Dunchurch in Warwickshire. As a contrast to previous years it was not only away from the hustle and bustle of London but it was also a much more intimate and quiet gathering.

Members got to really chat together and have a 'cuppa' whilst some of the children had fun on the inflatable slide and toys or played 'beat the goalie'. We welcomed some new members as well as meeting up with familiar faces to share our thoughts and experiences.

Nicki Turley



you might like to look at...

Scope
About disability

End The Awkward

"Research shows that a whopping two-thirds of people say they feel awkward when they meet disabled people. We know that this awkwardness is often because people are worried about saying or doing the wrong thing, so they avoid disabled people all together.

We want to make sure this isn't happening, so we've got some handy tips to help everyone feel more confident around disability."

Go to www.scope.org.uk/end-the-awkward to read more

On 31st October the Government launched "Improving Lives", a consultation on proposals around disability, health and work.

Tell the Government what you think about support in and out of work.

The consultation is open from 31 October 2016 until Friday 17 February 2017.

Go to www.scope.org.uk to learn more

Scope

disability
HORIZONS
GIVING YOU A VOICE

Disability Horizons is an online lifestyle magazine designed to enable you to live your life to the fullest.

Go to disabilityhorizons.com or find them on Facebook

Please offer me a seat

From Monday 12 September, London transport are trialling a new badge and card on all their services to help their customers who are less able to stand get a seat when they need one. They need your help to support the campaign. Learn more on

tfl.gov.uk/campaign/please-offer-me-a-seat?

Unfortunately the badge and card are not yet available to the public.



Also, don't forget to check out our website www.wdssg.org for up to date information. It now brings you a much more streamlined and integrated website for you to use.

There you will find:-

- a direct member sign up area where you can download a membership form or complete one online.
- an area allowing you to donate directly to us via Charity Checkout. We rely solely on donations to keep us running. If you are thinking of doing a sponsored event please let us know.
- you can get in touch with us. We really value your feedback.

member contact

NEW
for
members

You should have all received your letters about the two new facilities we have introduced to help members contact each other directly.

Please remember the details sent will be used if you have not opted out or revised the information by 1st December 2016.

In a nutshell there will be:

a list of members comprising of name, area and email address only which will be distributed to all those members who have not opted out of being on this list.

an email distribution list which will enable you to share information and questions to a single address which can be seen by all members on this list.

If you have not received yours and you wish to join please contact John on johnb@buttsco.co.uk

Fab Fun Fundraising



Link



NEWSLETTER XMAS 2016

the 'potalottery' taya heywood has been raising funds for the wds support group

Taya Heywood (aged 9) from Leicestershire has been raising funds this summer for the WDS Support Group, as her younger brother Alfie is likely to have the condition.

Taya ran three 'Potalotteries' (potato lotteries), which involved drilling holes into black plastic buckets, filling with compost, and planting during spring with four to five new seed potatoes. Every two weeks during the summer, family and friends would guess how many potatoes would grow in each bucket. Each ticket cost a pound to guess a number between 30 and 70, the number of potatoes ranged for 38 to 62. Taya decided that qualifying potatoes need to be larger than a one pence coin.

The winners were as follows:

1st Potalottery - Winner, Adam Heywood, winning a small cash prize.

2nd Potalottery - Bali Kaur-Haswell, winning an exotic fruit and vegetable box.

3rd Potalottery - Alana Turnbull-Heywood, winning an exotic fruit and vegetable box.

Runner up Carol Barnes, winning a Del Monte Pineapple.

The delicious new potatoes were shared between anyone who had bought a potalottery ticket

give yourselves a break! ...

Would you be interested in an adventure weekend organised by WDSSG, at a venue experienced with the disabled and their carers?

The weekend would be organised by a member of the committee and would require a deposit to secure a place.

This would equate to being a mini holiday for those members interested, so therefore it would be a personal cost commitment.

If you have an interest in participating in this exciting opportunity and would like to get together with others in the group who enjoy the outdoors, or simply to try something new then please contact:

Nicki Turley secretary@wdssg.org.uk for more details
Looking forward to hearing from you.

... next years agm

For 2017 we thought we would try a new format as a replacement for the Family Day and AGM. What we are proposing to do is split the day into two parts as follows.

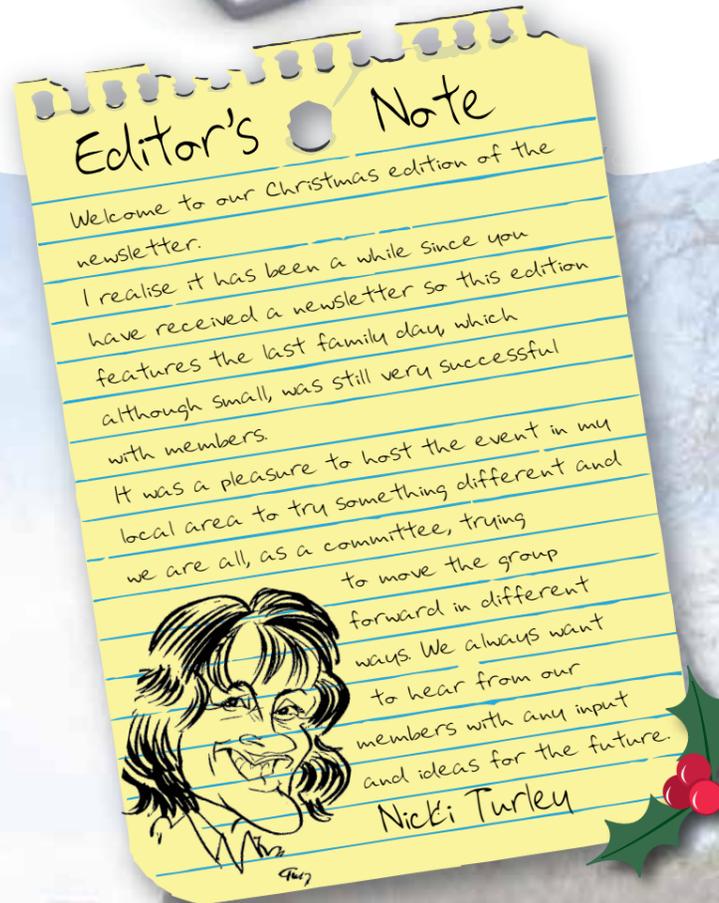
Firstly the AGM and a general discussion with other parents and carers, this will take place in London at a date, time and location still to be finalised.

We suggest you come alone to give you a chance to concentrate on the discussions without having to keep an eye out for young children.

Why not make a "Weekend Break" of it, take in a show, visit a museum or art gallery, book a ride on the "EYE", fly on "Emirate cable car" or just see the sights.



(Picture from left to right) Carol Barnes (Taya's Grandmother) and Alana Turnbull-Heywood (aged 15), Taya Heywood (aged 9).



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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.

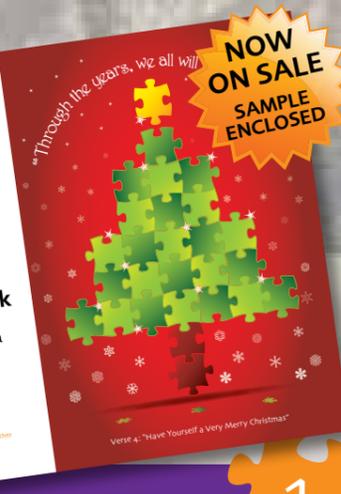


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You can pay by cheque, Paypal or BACS transfer. See our website for more details and an order form or contact Nicki at secretary@wdssg.org.uk

* 1 pack £2.60 - add 30p for each extra pack ordered

£3.00 per pack + postage*



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.

linking members together

www.wdssg.org.uk