

Fabulous Fundraising

Running for Ronnie

Siobhan Holmes ran the Cambridge Half Marathon this year and she raised £450 for the WDS Support group.

We would like to thank Siobhan on behalf of the committee and all our members for her efforts and to congratulate her on this fantastic achievement!

"It was an honour to run for The Worster Drought Syndrome support group. Being a university student I didn't get as much training in as I would have liked, but I'm so happy that I completed the race. It was a cold, rainy morning the day of the race, which after a mile or so, was very helpful at keeping my temp normal. The support you receive will running is uplifting, from those who are running themselves and all the spectators. I was lucky have some family members and the family I was running for passing me in their cars along the course. The friends and family were all at the finish line cheering and taking photos, and its the most wonderful feeling to receive. I'm looking forward to doing it next year and have managed to talk some friends and my sister into it.

I ran to help support my friend Kerry and her son Ronnie, and Ronnie who suffers with WDS, as she explained that the support group needed to be more recognised, and I felt this was a wonderful opportunity to do just that. It was great to have Kerry, dad Paul and Ronnie at the finish line. After completing the race I was treating to a well deserved burger and (alcoholic) drink.

Here's to the Cambridge Half Marathon 2018!"



The WDS Support Group, the way forward...

At a recent committee meeting we discussed the future of the group and the type of service it should offer to people with WDS and their families and friends in the age of the internet. This discussion was stimulated by the year on year decrease in families attending the Family Day.

Many small support groups like ours are closing or becoming just an internet based information centre rather than a full blown charity with family days, AGMs information days etc. The main discussion was whether we should continue to be a registered UK charity or just become an informal self-help group based on the internet. Being a charity has many advantages with respect to money and fund raising which enables the group to hold family days, presentations, support for research etc. but with an overhead that requires a formally based group with officers, trustees, AGM and returns to the charity commission. The meeting decided to keep going as we currently are for the present and to ask the members what they thought the future of the group should be, what they require of the group and how they can support the group in the future.

To continue as a charity we need new committee members and in the longer term members who are willing to take on the role of trustees. Please could you let us have your views on the above, how you would like to see the group go forward and how you can help us in the future?

Please send your answers, needs and feelings to committee@wdssg.org.uk or John Butt 212 Ashcroft Road, Ipswich, Suffolk IP1 6AF

Affiliated to Contact a Family and Rare Diseases UK

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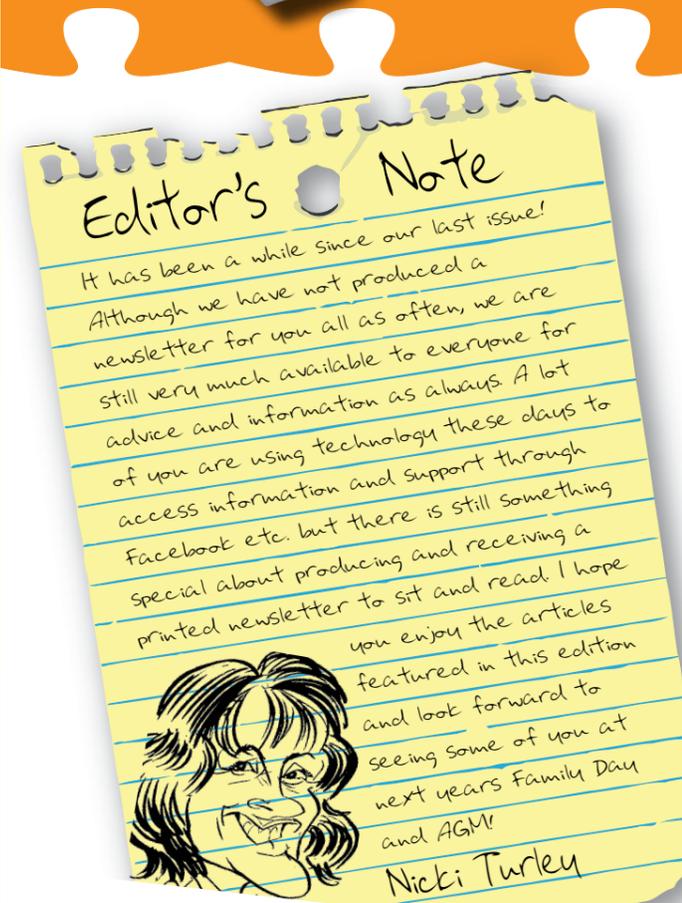
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All information in this leaflet is correct at time of going to press.



Link

NEWSLETTER WINTER 2017



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NEW THIS YEAR

Order your usual pack of Christmas cards and you will also receive an extra design from our new competition winner - Jack Sugden.

NOW ON SALE

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*

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.



linking members together

www.wdssg.org.uk

From the Chair

This year has gone so quickly and I can't believe just how fast the dark nights are coming. Winter is never a good time for me I find the cold really does make my Worster-Drought so much worse. Most people would say that they don't like winter but when you have to deal with it becoming much harder just to walk about it can take its toll on you. Getting enough energy into me still remains a big issue even with having someone help with cooking. This brings me onto a topic I would like to ask you all about. I have been asked a number of times if something is related to the WDS or something else, growing up with Worster-Drought and having met quite a few of the children and now adults with WDS I have noticed some common characteristics. The idea I have is even though it is nice that I am able to do this I don't have any facts to back this up i.e. I couldn't tell you how many children or adults have had epilepsy for example. Since the



group became a charity in 2001 we have had a pot of money set aside for research, as you can imagine funding any research into treating Worster-Drought or research into detection of the condition like genetics costs millions.

We are looking into ways we can better support you and those affected with Worster-Drought with information about how others are affected by WDS and how it

changes over time or not.

There are ways we could conduct our own research and produce database or something to see how the condition changes over time or we could employ a research company that would maybe more effective but this would cost.

Before we conduct anything like this I would like to ask you the members first if you feel this would be something you would be interested in participating in?

To give you a bit of an idea what the information could be used for and how it may be collected I have listed some points below and would appreciate your feedback.

Ways of collecting the information

We could do this ourselves or ask a 3rd party company to do this for us.

- This could either be done by an online survey.
- A form posted to members .
- Someone ringing up those who have given permission to be contacted.
- Or maybe all of the above

What Questions will be asked

This is a topic that will change over time and needs to be something each person to feel comfortable with and willing to share. I wouldn't suggest something that I wouldn't be comfortable doing it myself and this applies to all of these suggestion.

I feel that all information should be given anomalously or an option to provide the information anomalously.

The sort of questions asked would be:-

- Persons current age
- Gender
- Types of symptoms.
- Do they have epilepsy
- Feeding issues.
- Speech

Plus more detailed information like what age did they start talking, what age did the epilepsy start or stop etc..

Like I said earlier these questions could grow over time and whatever way we gather this information and store it needs to be easy for you all to make changes over time.,

What will happen with this information?

Although the data collected would be anonymised we will have to be careful that individual cannot be identified with the use of other secondary information.

Simple basic data could be published on our web site as it would be completely anonymous, for example:-

- A% of members with WDS also have epilepsy.
- B% of members with WDS also have speech impairments.
- C% of members with WDS also have mobility issues.
- D% of members with WDS also have fine motor control issues
- E% of members with WDS also have eating difficulties.

- F% of members with WDS also have been or are being tube fed.
- ETC.
- W% of members are impacted by 2 of the above.
- X% of members are impacted by 3 of the above.
- Y% of members are impacted by 4 or more of the above.

The management and dissemination of more complex views of the data would be more difficult but there are many parts of the WDS that none of us would have known if it were not for this type of information.

For example I never knew that Dyspraxia was common to those who had Worster-Drought and didn't find this out until late into my adulthood. I bet there are many parts of your children's condition growing up that you did not know if it was a common to WDS and other families and now adults growing up may have found ways to deal with it, as I have found with my Dyspraxia. I also think it would be useful for new families who are not sure if their child who may have WDS will be able to ask or look at our website and have a better understanding that their child have many common symptoms and then can ask for their child to be referred to someone for a formal diagnosis.

The other use for this information would be to help those who have an interest into the condition to have a better understanding. I have often been asked even by my own GP how the condition develops over time. It has been my understanding that it doesn't, like most forms over Cerebral Palsy it is only the ability to manage it that changes over time. I am not seeing this to be the case in those who I meet but without the information to back this up who knows?

What we need to know is:-

1. Do you support the group spending some or all of the research money on progressing an information database on WDS.
2. If yes, what type of data do you think we should collect, it would be easier if the questions have 2 or 3 simple answers.
3. Are you willing to include your or your child's data.

Please send you answers and comments to: chairman@wdssg.org.uk or by snail mail to Mark Mayer, 21 Limeway Terrace, Dorking, Surrey RH4 1HZ

Member stories

For new members that do not know me as well as others, I feel it would be nice for you to understand what it is like for me growing up with WDS, as some of your children may not be able to express themselves quite as well as I am able to now. This hasn't always been the case and I have had many ups and downs over the years with speech problems, hearing, epilepsy and anxiety to name a few. The ups have been doing jobs I love, like being a communication support worker, BSL interpreter, teaching and now working for a charity that helped me as a child, making products for disabled children.

I was diagnosed as a child and went to a special needs school at 8 years old. A lot of details I am not able to ask my mum anymore as she sadly passed away 4 years ago and I have difficulty understanding what I was like as a child. From what I understand I was a very difficult but loving child and I always liked to help others but I found my inability to understand things and not being able to express myself to others very frustrating and would often get told off for my tantrums. I found even though I was a sociable child I would always be the child that sat to one side and enjoyed watching others play. I was often found sat with my headphones on listening to music and this is still the case today, even though now I don't have to isolate myself with headphones and enjoy going to festivals. My first big festival was Glastonbury 2013 and I was really nervous about going and when my radio microphone broke for my hearing aids the anxiety really became too much and I really panicked, little did I know at the time this was a blessing because I returned to the one language I have been able to understand and communicate well in - sign language. I never really appreciated just how much more music is enjoyable for me when I am able to communicate with those around me. I found the BSL Zone and explained to them my problem and they were fantastic and for me it reduced my anxiety, especially as this was just after losing mum. So, going to Reading this year I was even more excited that, even though I



have been to the Reading Festival before, now I felt really safe going. The BSL interpreters get as much enjoyment out of signing the songs as I get from them, this has been the beautiful thing I have loved about sign language as it's such an expressive language.

Even with my anxiety I have a sense of adventure and love doing things, growing up this was normally because I was told I can't so I just wanted to do it to prove to people I can. This can however cause a whole number of issues from learning to ride a bike to learning how to write, I think this is why I have embraced technology so much as it has given me the ability to communicate with others. I would so love being a child growing up with all this technology around. I currently work for a charity call MERU, they make equipment for disabled children that cannot be found anywhere else. I mainly make iPad cases with special flexi stands. We have also



found that an important part of a child's learning is being able to interact with their toys but not all toys are accessible so we modify them to work with bigger buttons and switches. This is more important at times like Christmas when there is nothing worse than someone getting a toy they really want and then can't use it due to poor motor control, I speak from experience. This can lead towards many other things like being able to control a powered wheelchair or interacting with a communication aid.

I thought by writing this article you will see that by sharing experiences, it helps others to understand what it is like to grow up with WDS. I want to share my story so you feel able

to share yours. I have seen many children with WDS growing up and now becoming adults and my aim for this group is for you to share their stories, so others can learn from them. What works, what doesn't, what to look out for and how to best prepare for it and most importantly be part of this wonderful family.

If you would like more stories, do get in touch. I would like to make this a feature in our newsletters but don't want it to be all about me. We could write about your experiences with no names mentioned if preferred. There is one thing I can be pretty sure on is not everything is all plain sailing and there must be things you wish could be easy and I am hoping that we as your WDS family could help you.

Mark Mayer



Sunday 1st July 2018

We will be returning to our popular venue for our annual family day and AGM next year.

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

SAVE THE DATE