

WORDS

ISSUE 16
April 2005



"Our Christopher"
Defending against some
unseen foe.

Letter From Our Chairman

Welcome to this latest edition of WORDS, the newsletter of the Worster-Drought Syndrome Support Group. Before I tell you about our next family day, I would like to thank everyone who rallied round during August and September last year when I had a bout of illness. It is very pleasing to know there are people you can rely on in times of need and a little bit like this group, there to lend a hand when it's needed.

This year's Family Day looks like being, potentially, the best yet. Saturday the 25th of June is the day to note in your diary when we get together at Coram Fields in London. You should have all received a pack of information about the day including a reply form asking if you would like to attend. Please, please, please, can you let us know if you want to come along? Even drop us a line if you can't come. It is very important to know numbers in advance as the cost of the day to the group is quite high which is why we are asking for a £10 contribution towards the costs. Contact details for the Family Day are later on in this issue.

The Family Day this year follows a Professionals Day at The Institute of Child Health. This day, hosted by Professor Neville and his team is to raise awareness of Worster-Drought and Perisylvian Syndromes within the medical community. It is hoped that a wealth of information will come out of this day which we can pass on to our membership base. We are also planning a presentation to give on the Professionals Day highlighting our group and what our aims are. Jonathon Lauder and myself are going to stand up in front of the assembled medics and tell them about our group. The intention is to let them know we exist and they can then suggest us to families who have come across WDS for the first time. I think we have all been there at some point. The next issue of Words will tell you all about the two days and, if you can't make the Family Day, let you know all the nitty gritty.

There has been a lot of debate over the past few months about what the future holds for our children. We know that some will grow into mature and self-supporting adults whilst the rest may need some kind of emotional and educational support for the foreseeable future. While I fully understand our need as parents to let our children develop and "fit in" as much as possible I also understand that, take our Christopher for instance, it is extremely unlikely that he will ever lead a truly independent adult life. The singularly most important fact about our children is that they are all different. Which is why it is so difficult to diagnose WDS and why we are pushing so hard for recognition in the medical world.

I hope that all of you who can make the Family Day do have a fun and fulfilling day and I can tell you that we have tried to book some decent weather.

Take care and I'll see you soon.

Gavin Leech.

INSIDE THIS ISSUE

Letter from our
Chairman

AGM Announcement

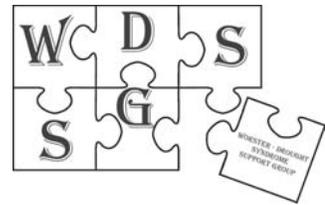
AGM 2004 Minutes

Mark's Story

Useful Information

Family Day 2005

Worster-Drought Syndrome Support Group



Affiliated to Contact a Family and the Rare Disorders Alliance - UK

Monday 18th April 2005

Dear Member

You are all aware, from notification in our news letter WORDS (issue 15), that Saturday June 25th 2005 is not only the Family Fun Day at Coram Fields London, but also the AGM.

In accordance with our constitution I am formally asking for any nominations for committee positions and any topics for discussion under Any Other Business.

The current committee positions are as follows.

Chairman	Gavin Leech		Trustee
Secretary	Hayley Herman		
Treasurer	Donna Donlon		Trustee
Ordinary Member	Vanessa Butt	National Contact	Trustee
Ordinary Member	Monique Lauder	Projects Co-ordinator	Trustee
Ordinary Member	Graham Spencer	WORDS Editor	Trustee
Ordinary Member	Jacqui Leech		
Ordinary Member	Anita Brown		
Ordinary Member	Michael Rumbold		Trustee
Ordinary Member	Mary Rumbold		

Our constitution dictates that committee positions are for three years and as such all the positions are up for election. I can confirm that, with the exception of treasurer, all committee members are willing to stand for another year. I must at this point thank Donna for her sterling work over the last few years.

We have also agreed as a committee to elect a Vice Chairman.

Any nominations for a committee position, or topics for discussion under any other business, please forward these, in writing, to the group secretary (address at the bottom of this page) to be received no later than Monday 6th June 2005.

We will notify all members of any nominations for committee positions received (other than above) seven days prior to the AGM itself. If there are no further nominations the existing committee will be elected on block by show of hands.

If you have any questions regarding the above, feel free to contact me directly on 01376 348948, j.gleech@btopenworld.com or by post to 10 St Vincent Chase, Braintree, Essex, CM7 9UJ.

Thank you.

Yours faithfully

Gavin Leech Chairman.

Chairman:- Mr Gavin Leech, 10 St Vincent Chase, Braintree, Essex, CM7 9UJ.
Secretary:- Mrs Hayley Herman, 40 Hilfield Lane, Aldenham, Herts, WD25 8AJ.
National Contact:- Mrs Vanessa Butt, 212 Ashcroft Road, Ipswich, Suffolk, IP1 6AF.
Charity Registration No. 1095290. WEB SITE www.wdssg.org.uk

Worster-Drought Syndrome Support Group

Minutes from AGM

Saturday 12th June 2004 London Zoo, Huxley Center

1. Introduction by Chairman

Gavin proceeded to welcome everyone to the AGM. This was our 2nd AGM since we became a registered charity. Everyone was asked to sign the attendance list, which was done. He proceeded to tell everyone about the video which was going to be done on behalf of the No 1 Foundation. He told everyone about the emergency exits, the format of the day and where the entrance to the Zoo was for everyone in the WDS group. He talked about gift aid and the importance of this to WDSSG.

2. Minutes of Previous Meeting

Summarized minutes from AGM on Sunday 22nd June 2002 were read by Gavin Leech, Chairman. There were no questions raised from this.

Proposed: John Butt
Seconded Donna Donlon

3. Election of Officers

Executive election committee was voted on a block vote, as we received no more proposals. It was put to a vote and it was unanimous that the committee is to carry on as is. If any other members were interested in joining the committee then they need to let committee members know.

Carried by John Butt

4. Chairman's Report

Gavin Leech, Chairman thanked the committee for all our hard work this year.

A special thanks to Monique Lauder, Vanessa Butt, and Hayley Herman for the organization of this event. He talked about linking families together. He talked about understanding the condition of WDS and he looked forward to more learning opportunities within the group.

5. Secretary's Report

Hayley Herman, Secretary apologized for her new arrival of Mia Herman and that all her work has to be thoroughly checked for spellings as her brain is a little mushy still!

6. Treasurer's Report

Donna Donlon, Treasurer was thanked for all her hard work. In brief we need more money on a day-to-day basis. Donations are fundamental and not that forthcoming. Members accepted the Annual Report and Accounts

Proposed: Hayley Herman
Seconded John Butt

7. National Contact's Report

Vanessa Butt, our National Contact was thanked for all her hard work.

Proposed: John Butt
Seconder: Hayley Herman

8. Any Other Business

No other business was raised.

9. Close of Meeting

A big thank you to Monique Lauder, Vanessa Butt and Hayley Herman for all their hard work in making this event work. They have shown commitment and dedication and we thank them very much. Gavin Leech thanked everyone for coming such a long way and hoped that today was successful for everyone. He finished by saying how amazing it was that we finished the AGM in a record time!

This is Mark's Story,

My name is Mark I am 32 years old I was diagnosed with having WDS when I was 3 years old at Great Ormond Street. My early years were trying for my parents, not knowing what was wrong with me they felt they were fighting a losing battle.

Both my local GP and health visitor didn't have a clue why I couldn't talk, and dribbled like no tomorrow. I remember statements like "he doing it on purpose" I was always frightened as a child as I was different to other children but didn't know just how I could change that. I would always try and fit in with other children from an early age. Some how I kept getting isolated.

My early memories were of nursery and having to do knitting. Yeah knitting! Don't quite know what that was all about? But I was having great tempers because I couldn't do it and I wanted to be able to, but I couldn't get my hands to do what they wanted, no matter how much I tried. I was not able to tell someone that I didn't like it and wanted to do something else they just wouldn't listen. This continued for a number of years before I learnt to control my temper and use it to help me rather than against me.

I started mainstream primary school at the age of 5 and that was one of the most nervous days I had in my life. I think well definitely at that age anyway. I quickly formed a bond with another kid there who had CP we became best friends for a number of years before I lost contact when we moved house. Not being able to communicate that well, most of the teachers in my primary school just made me sit in the library and read books, only problem there is I never learn to read so found myself getting very lonely and ran away from school a number of times.

I think at the time it was more to get attention rather than I didn't like it. Also to see how far I could get away from home before getting caught! Oh just encase your wondering I never did get away from home. Well at the age of 6 both my parents had enough by this point I was having massive tempers at home so my they started a long battle with the LEA to get some special schooling for me.

After a 2-year battle they found me a school, which at the age of 8 I went to visit a few times before hand to see what it was like. It was a residential school that meant I would have to sleep there.

When I was first told about it I wasn't sure but soon after visiting the school I became part of the family there. It was like having a new home and life where people accepted me for who I was rather than what I couldn't do.

My carer was a very nice Nun called Sister Anne I owe a lot of my thanks to her, for who and what I have become now. She gave me the biggest kick up the backside I have ever had in my life, the shocking thing was even at the time I know it was me that had to improve things. I spend 3 years under the care of Sister Anne before moving to a new residential block.

In this time I became more confident about things

and being able to start a new way of life I went to learn more about how to interact with other people and better forms of communication for me. Learning so much about getting about and how to control my dribbling which by now I have managed to control pretty well.

I was able to spend most my time learning speech and language I had 2 sessions a week for an hour each time. Looking back on it now not really sure if it helped me or not, being able to control my temper which sometimes could get really bad.

It was the only time I feel so out of control and the frustration of not being able to do what the speech and language teacher asked me to do was driving me mad. I then started to use sign language a lot that I found to be very useful. At the time I didn't know if it was Makaton or not, most the signs I made up myself and then use the basic alphabet to aid my own speech this was proving to be more positive for me.

Now at the age of 11 I had to start thinking about what I was going to do as a career. Always being fascinated with electronics I wanted to do something along those lines. I did really well in computers, I found they gave me a new way to interact with other people. Plus having note pad on most computers I was able to use this to type to people what I wanted to say. My spelling often let me down but as the years when on this began to improve. Not getting any GCSE's A to C grades at school

I then went on to college where I studied for a Btec course in Telecommunications and electronics. This proved to be a good move for me as on the college open day a family friend came to the college to see what I was doing on the course, as they knew there was vacancy at the company they worked at. They seem to be really impressed and after attending an interview I started working in the field of satellite communications. I was with that company for 8 years. My WDS nearly became a problem a few times regarding communication, as people didn't think I was all too clever. As I got older it never has become a shock to me how narrow minded some people can be. I was stopped going onto many contracts, as the company didn't feel that I would be setting the right impression for them.

It wasn't until much later in my time working for the company that I had a new manager who saw this and took action. It was only then I realised how much I could do myself given the chance. He gave me my biggest break I ever had working on the British Airways contract.

From what I have learnt now, the company never expected the contract to do that well but both my manager and myself knew that the contract had great potential. So after making me contract manager for Heathrow site where I managed over 10,000 locations including setting up the network at the new waterside building the contract was attracting management attention. In the first year we made so much money the contract was sold for a nice little profit, leaving me unfortunately redundant. Being I worked there for 8

**WDS-SG FAMILY DAY
SATURDAY 25TH JUNE 2005
CORAM FIELDS LONDON**

This is the singularly most important day in the WDS-SG calendar.

It is a unique opportunity to gather information and meet like minded parents.

Proffesser Neville will be presenting his findings from the professionals day.

All group members have been sent a pack inviting them to come along and benifit from the day, and it's still not to late to reply.

If you would like to know more please contact
Monique Lauder on 020 8428 6706
monique.lauder@btopenworld.com

Please come along otherwise you will miss out on what will be a fantastic day.

The cost of the day very high and as such WDS-SG are asking for a contribution of £10 towards this per family.
We are unable to contribute towards travel expenses.

We are always looking for articles for the newsletters so please email them to the editor at words@wdssg.org.uk We would gratefully receive short stories, personal insights, poems, funny stories or indeed anything that you might consider useful. Generally we keep the articles as sent but sometimes it may be necessary to edit them slightly for various reasons.

The Editor and The Worster Drought Syndrome Support Group do not accept any responsibility for the views of contributors expressed in this newsletter.

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