



Link

NEWSLETTER CHRISTMAS 2010

Editor's Note

Welcome to another festive edition of our newsletter. I hope you are all looking forward to an exciting Christmas holiday. We have had a very successful year and the group is really moving again thanks to everyone's effort and commitment, so thank you all.

We are looking forward to a prosperous year for 2011 and to continue the hard work. On behalf of the committee I would like to wish you all a very Merry Christmas and we look forward to seeing you all next year.



Nicki Turley

in this issue

From the Chair	1
Member Profile Bethany Woods	2
My Pregnancy + WDS	3
Money Matters	4

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



From the Chair

I am very proud of everyone this year making the WDS Support Group such a special and fantastic group. A very warm welcome to all our new members and I look forward to meeting more of you in 2011. I am very keen to have more regional meetings and would be happy to help people make contact with each other in your local areas. If you have anything you would like the group to do for you please do contact me, even if its just for a chat about the stresses of life with WDS. Merry Christmas!



Mark Mayer





Member Profile

Bethany Woods

Our daughter Bethany is now eight and a half and has WDS. She was given her diagnosis in February 2006, just a couple of months before her fourth birthday. All the usually things had happened before then, we had been referred to just about everyone

possible (speech therapist, occupational therapist, physio, portage, ears, nose and throat, orthoptist, orthopedic, community paediatric and finally a neurologist) It was the neurologist who finally told us Beth had WDS after doing a clinical diagnosis.

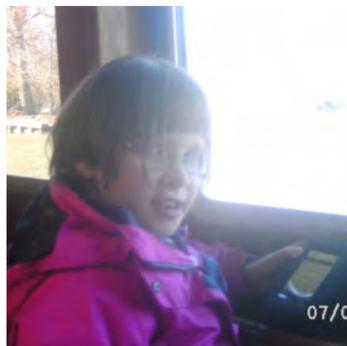
The diagnosis was a shock as we had expected the neurologist to do lots of tests, not just tell us straight away that this was the problem. We, like any other family were desperate to know more about the condition and immediately got in touch with the support group for advice and of course information. With WDS being so rare the future is obviously not clear for Beth or indeed for the others with this condition, but we do find now that we are able to work with the condition and are no longer trying to push Beth to do things that just aren't going to be possible for her. Beth's speech is very limited, she can say Mummy, Daddy and KoKo (her little dog) but does need encouragement, although odd words do slip out when she gets excited! She uses Makaton and is great with it, she doesn't mind telling us if we do a sign wrong!

In December 2009 we decided, after several meetings with our speech therapist, that the type of communication aids Beth was being offered just were not acceptable, so we looked at other options for her. We bought her an iPod touch, downloaded some software called Proloquo2go and bought a portable speaker case. What a great move this was for Beth.

This is a handheld portable device which in the speaker case is also quite hard wearing so when it gets dropped it survives! The software is made to be customised so you can literally put anything on it and say what you want. Beth has actually come so far with the iPod that along with her Makaton she can now communicate with anyone really. She will sign something to me and then push her iPod at me so that I programme what she wants on to the iPod. Beth now has a device that she enjoys using, its modern so she doesn't feel like the only one, and she is actually proud of her communication aid!

For more information see their website:

www.proloquo2go.com



Singing Hands New Resources

"It's a Christmas Cracker" DVD ,
"It's a Christmas Cracker CD"
and "It's Signing Time 2" DVD

Please visit the Singing Hands website www.singinghands.co.uk for more information about our new resources.

"It's a Christmas Cracker" DVD has a collection of some of our favourite Christmas Carols alongside fun festive songs about reindeer and snowmen! As always, the DVD features Makaton signs and symbols. We also have "It's a Christmas Cracker CD" so that you sing along with us every-

where. "It's Signing Time 2" is another brand new resource which has great new songs to build your signing repertoire - including our Pirate song, Wheels on the Bus, Little Peter Rabbit, I Hear Thunder and so much more.

Our original signing DVD "It's Signing Time" and our ever-popular signed songbooks and

CDs are still available as well as other resources featuring Makaton signs and symbols.

Come and visit our website soon!
Happy Signing!

Festive best wishes from *Suzanne & Tracy*



www.easyfundraising.org.uk/causes/wdssg

This website has now been registered and active for easy fundraising. This allows you to buy things online and the companies donate a percentage to the group. They will send any donations to us by cheque. This service is free at no cost to you the customer.

Regional Meetings

As requested by some of our members we arranged a regional meeting in the South East of England with little success. We aim to try again, but this time in the Central and Northern area. We will be asking members for feedback so watch this space!

If you would like to express an interest or have an ideal venue please contact secretary@wdssg.org.uk





My Pregnancy + WDS

Sarah Sugden



Andy and I got married in August 2008 and had discussed having a baby together. I already had a son Dion, now 11, to a previous relationship. When pregnant with Dion I knew very little about WDS other than that it was a rare form of cerebral palsy. Years later I found out that the main cause of WDS/cerebral palsy happens in pregnancy during the first trimester due to an abnormality of the brain forming.

Andy and I thought long and hard about having a baby, not only was I born with WDS, I also had a serious heart defect called fallots tetralogy, I had a hole in my heart and a narrowed pulmonary artery which was repaired when I was 5 years old. We had a lot to think about as WDS and my heart problems could be hereditary.

We found out I was pregnant we were happy but nervous that our child could inherit my conditions. We only told close family until I had my first scan. We were so relieved to hear our little miracle's heartbeat and found out I was further on in my pregnancy than we first thought.

My consultant was concerned about my heart condition and she recommended that I had a more in depth scan of the baby's heart, and my heart was to be closely monitored. This meant going to RVI hospital in Newcastle and St Mary's hospital in Manchester. I also had more scans at the local hospital to keep an eye on the baby's growth etc. Everything was showing up 'normal'.

Due to complications I was frequently assessed in fetal assessment at my local hospital and it was then I expressed my concerns about being in hospital taking medicine. I also felt that I wanted my own privacy rather than being in a 4 bedded ward after delivery. I felt paranoid about eating in front of strangers and making polite conversation. The

midwife made a note in my hospital notes that all medication was to be in medicine form and that I wanted my own private room.

As my pregnancy progressed I was worrying about labour and Andy making it to hospital in time. As I had delivered Dion very quickly I was advised to dial 999 as soon as I went into labour and get an ambulance - not easy when you have a speech impediment! We decided I'd phone Andy and he would phone an ambulance for me. I have a friend who is a paramedic and she advised my to get a printout of my medical history so the paramedics would have the information at hand.

After all this planning and Andy worrying himself silly that he wasn't going to make it in time for the delivery, I went 6 days over due. I knew something was wrong and that baby wasn't going to come out on his own, it was then that I requested a caesarean. The consultant wasn't happy about me having one due to my heart problems but I insisted it was what I wanted. I was booked in for 2 days later. I am so glad I trusted my instinct as the cord was wrapped around baby Jack's neck 5 times, there was no way he could have come out. Jack Bruthen Sugden was born at 12.37pm on Thursday 30th September weighing 8lb 7oz.

Upon going back to the ward I was placed in a single bedded room, I felt so much more relaxed. The staff were very understanding regarding my medication.

I think doing a bit of forward planning and mentioning to the midwife about WDS and my speech problem they were able to prepare themselves and them doing that made me feel more relaxed.

Jack is now nearly 3 months old and is such a content baby. Even though he appears 'OK' it will always be at the back of our minds that he could have WDS.

NetBuddy

Netbuddy is full of handy tips and bright ideas from parents, carers, teachers and therapists with experience of learning disability.

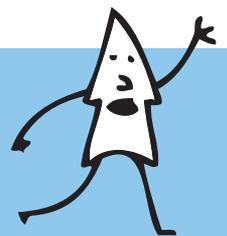
Netbuddy began – as so many good ideas do – over a cup of coffee between friends. Deborah Gundle and Linda Goldberg met through Deborah's son,

Zach who has learning disabilities. Linda was then CEO of Cosgrove Care, an award-winning charity that supports people with special needs.

The original idea was to create a handbook of tips and helpful hints for parents, carers, teachers and therapists of people with learning disabilities. It would be a 'by you, for you' resource, offering practical solutions to everyday issues.

Eventually, after lots more coffee, the book became a website and Netbuddy was born. Go to www.netbuddy.org.uk to get and give tips, chat on the forum or obtain information packs.

Netbuddy is registered as a charity no. 1127905



Money Matters

We would like to thank everyone, including our members, for their contributions and support throughout the year. We hope to have a prosperous 2011 and wish all our members a Happy New Year.



Directgov
Public services all in one place

Direct payments arranging your own care and services

These are made by councils to people receiving

social care services, instead of the council providing the service directly. Find out whether you can get direct payments, what you can and cannot use them for, and how to apply for them. They are local council payments for people who have been assessed as needing help from social services, and who would like to arrange and pay for their own care and support services instead of receiving them directly from the local council. A person must be able to give their consent to receiving direct payments and be able to manage them even if they need help to do this on a day-to-day basis.

Eligibility

If you already receive social services your local council must offer you the option of direct payments in place of the services you currently receive. There are some limited circumstances where you are not given this choice. Your council will be able to tell you about these.

If you are not receiving social services - to get direct payments, you need to contact your local council to ask them to assess your needs. Social services - and therefore direct payments - are normally available if you are:

- disabled and aged 16 or over
- a carer aged 16 or over, including people with parental responsibility for a disabled child
- an older person

If you have been refused social services

If your local council has decided that you do not need social care services, it will not offer you direct payments. If you think your needs or circumstances have now changed, ask your council for a new assessment.

How much you can get

The amount you receive will depend on the assessment your council makes of your needs.

How it is paid

Direct payments are made directly into your bank, building society, Post Office or National Savings account. If you need someone who cares for you to collect your money, or you are registered blind, payment can be made by sending a cheque which can be cashed at the Post Office.

How to apply for direct payments

If you already get services, ask your local council about direct payments. If you are applying for services for the first time, your social worker should discuss the direct payments option with you when they assess your care needs. Search for your local council website where you can find out more or apply online. Please note that this service is only available for English councils.

What you can use direct payments for

The money is for you to use to pay for the services and equipment which will meet the needs the local council has assessed you as having. As a general principle, councils should let you to choose how best to meet your assessed needs as long as they are satisfied that agreed support arrangements are being met.

What you cannot use direct payments for

To pay for permanent residential accommodation - but you may be able to use direct payments to pay for occasional short periods in residential

NEWS

accommodation, if your council agrees that is what you need. Unless your council decides that exceptional circumstances make it necessary, you cannot use direct payments to pay for a service from:

- your spouse (husband or wife)
- your civil partner
- a partner with whom you live as a couple
- a close relative with whom you live, or the spouse or partner of that close relative.

Record keeping

If you receive direct payments, you will need to account for the money you spend. Your council will tell you what records you need to keep and what information you will be expected to provide. Examples include timesheets signed by personal assistants, or receipts for services from agencies. The council has to be satisfied that the needs for which it is giving you direct payments are being met. They should tell you how they will go about this. This may involve a visit to your home.

Carers and direct payments

If you are a carer aged 16 or over, you may be eligible for direct payments for yourself. You cannot use direct payments to buy services for the person you care for. They can only be spent on getting the support you, as a carer, have been assessed as needing.

Effect on other benefits

Direct payments are not a replacement of income and therefore do not affect any other benefits you may be receiving.

What to do if your circumstances change

If your social services needs change. If your needs change, contact your local council as soon as possible so that they can reassess the level of payments you require. It does not matter whether the changes are long- or short-term. e.g. if you do not need to spend the full amount because your condition improves temporarily, or you go into hospital, they may need to adjust your payments. If you do not want to continue with direct payments. If you decide you do not want to continue, your council will arrange services instead. If the council decides you cannot manage with direct payments, it might decide to stop making direct payments and provide services instead. www.directgov.org.uk

You can also download information from the Department of Health at www.dh.gov.uk/prod



Thanks to...

Freemasons, Anthony Pulley, Sally Woods for collection boxes and Callum Turley. He raised £10 for WDS by collecting money 'trick-or-treating' instead of sweets.

JustGiving

WAITROSE

eBay

(He unable to eat them and wanted to do his bit!)



Affiliated to Contact a Family and Rare Diseases UK

This newsletter is presented by the Worster-Drought Syndrome Support group (WDSSG) as a service and may be used for informational purposes only. WDSSG believes that this information is accurate and reliable, but does not guarantee its accuracy or completeness. WDSSG makes no warranties express or implied, with respect to this information, including but not limited to that of fitness for a particular purpose.

© 2006 Worster-Drought Syndrome Support Group

Registered Charity: 1095290

IR Charities Charity Ref. XR67990