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NEWSLETTER SPRING 2010

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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



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PRIZES
include

passes for
LEGOLAND
WINDSOR

child pass for
Twycross Zoo
The World Primate Centre

YOUR
M&S
vouchers

Dr Maria Clarke
Professor Brian Neville
Nicole Jolleff
Mark Mayer

Editor's Note

Welcome to the Spring Edition of our 'new look' newsletter.

What an exciting year it's going to be, with the Family Day plans well under way. Things have finally started to get going again and both myself and the committee are very much looking forward to seeing lots of you there. I myself am very much looking forward to meeting "Singing Hands". I have no doubt we will all have both a sociable and informative day.

See you there!

Nicki Turley



From the Chair

Hello and welcome to our Spring newsletter. We, the committee, have been working very hard on this year's Family Day, an exciting and informative day for those who can attend. Budgets have been limited this year so we are looking at some ways to raise funds so we can carry on giving you as much support as we can. I have setup my own donation page on the Just Giving web site:

www.justgiving.com/wds-sg.

This site is easy and quick for anyone to donate money to the group so if you have any ideas on fundraising please contact us or, alternatively, you can setup your own Just Giving page by going to www.justgiving.com/wdssg/Raisemoney.

We are really looking forward to meeting many of you at the Family Day this year. As you can see from our line up for the day we have lots of things for the children to do as well as information for parents. We would also like your feedback on how we can improve support to you all and are hoping that the day will give you more insight into WDS and how we can offer support to children and adults with the condition, and their parents and carers.

Finally, I am really pleased to see that our membership database is building up again and many of you have taken the time to fill out the membership forms so we can keep our information on people with WDS up to date.

Thank you very much for this, and if you know anyone who would benefit from joining us, do get them to contact Vanessa at:

nationalcontact@wdssg.org.uk.

I have also set up a map of towns that our members are located so you can find out whether or not someone is local to you. This map can be found at <http://tinyurl.com/WDS-SG>, so if you wish to make contact with a member, then ask Vanessa to pass on your details so you can make contact. If you find your own location is not on this map then let me know and I will add you to it. Similarly, if you would like your location removed then contact me also and I will remove you from the map.

Mark Mayer



Family Day Format

10 - 10.30am - Registration

Teas and Coffees

Settling in children with log cabin staff

10.30am - AGM and Guest Speakers
Dr Maria Clark and Katie Price

11.40 - Presentation of two young people's journey with WDS

12 noon - Q & A Session with Guest Panel

12.30pm - Picnic Lunch (bring your own) and collect children

1.30pm - Singing Hands perform

3.00pm - Person Centred Planning

Why so important?

3.45pm - Chat time

4.30pm - Goodbyes

Don't forget 26th June

We will be also
be holding a
Raffle on the
day

You should have
received and
returned your
acceptance forms
by 9th April

Children's Dental Care



It is not clear yet if children with WDS have any particular dental problems related to this condition. There maybe issues with feeding which can make following an "ideal" diet difficult. Children with WDS may also have a typical appearance with prominent upper front teeth and a high, arched roof of mouth.

Some general tips follow:

1. TOOTHBRUSHING AND TOOTHPASTE

Toothbrushing should be started as soon as teeth appear. In young children, think of toothbrushing as a way of getting fluoride toothpaste into the mouth. In older children plaque removal becomes more important. If you are finding toothbrushing a struggle then make sure you are at least smearing some toothpaste on the teeth. Children can't brush their teeth by themselves so an adult needs to help and supervise them.

Use only a smear of toothpaste containing no less than 1,000 ppm fluoride.

Use the right sized toothbrush for your child's mouth.

Brush twice a day last thing at night and one other time.

Encourage your child to spit out after brushing - try and avoid rinsing as this washes the fluoride toothpaste away.

2. SENSIBLE EATING

This can be difficult with WDS children as often this syndrome is associated with feeding problems. The health of your child is most important so make sure you are followed dietary advice from your doctor

first. Some simple guidelines you can think about following.

From six months of age babies should be introduced to drinking from a cup, and from one year onwards try and stop feeding from a bottle.

If your child has teeth, don't let them go to sleep at night with a bottle containing anything other than water.

Don't add sugar to weaning foods.

Try and avoid giving babies or infants sugary drinks - water or milk should be sufficient.

Try and avoid giving your child sugary food and drinks more than four times per day and try and give them with mealtimes if possible.

3. SEEING YOUR DENTIST

It's important they get used to going to the dentist, so set them a good example by making sure you attend for regular check ups and letting them watch. Once they start to get teeth of their own, make sure the dentist checks these regularly as well. Encourage your dentist to apply fluoride varnish regularly and to think about plastic coatings (fissure sealants) on the adult back teeth. If you are worried about the appearance of your child's teeth then orthodontics (braces) is a possibility. This will depend on your child's cooperation.

Speakers

Assistive Technology Communication Support for Children with WDS

by Katie Price Speech and Language Therapist
Augmentative Communication Service
Wolfson Neurodisability Service

PCP - Person Centred Planning by Vanessa and John Butt

As part of this year's Family Day we will be running a session titled "Person Centred Planning and why it's important to you and your child". Vanessa and John are both trained facilitators in Person Centred Planning.

The session will start off with a talk on why we think it's so important followed by a couple of exercises which you are likely to perform as part of a PCP session. This is so that you all get a feel for what is involved, with no pressure, as it can all be thrown away afterwards if you wish. It's just for fun!

Featuring 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."



The two of us met through the Project for Children with Special Needs (now the Three Wings Trust) in Richmond, Surrey back in early 2000. Our eldest children were born in 1999 and have additional needs. Because of our own children's difficulties, we both learnt to sign when they were about 8-9 months' old. Signing for us was a necessity, not something we were doing for fun. It was something we were told we would have to do by our children's speech and language therapists little did we know where it would lead us.

We both attended our first Makaton course and, as a way of revising and utilising the signs we had learnt, we soon began running signed storytime and sing-a-longs at the weekly toy library session at the Project. Instinctively, we felt that reinforcing this early vocabulary through stories and songs was such a great way to support our children's early language development.

We both had another baby quite soon after and we began signing with them as well – primarily to communicate with their older siblings. Tracy's eldest son has Down's Syndrome and my eldest daughter had a tracheostomy at the time (plus other additional needs) so signing was going to be a long-term investment in both of our families.

Initially, signing was a merely a necessity but it soon became one of the most enjoyable and rewarding things that we did. It opened a whole new world of communication between us and our children. Later we saw that our second babies were having a great time signing too. Therapists who came to our home to visit Ella and Miles would frequently comment on our other children's verbal skills too. Both of us were sure this was linked to their early exposure to signing in conjunction with speech. Here we were doing therapy for one of our children but in actual fact it was beneficial to all our children. Not surprisingly, neither of us had the time to read the literature about this back then and the whole concept of 'baby signing' was not the phenomenon it is now. Obviously, academic research that we've read since supports what we both experienced.

New series of
Something Special
showing on CBeebies
Monday - Friday
8th- 26th March at
9.45am and 1.35pm



Ella and Miles were due to start nursery in 2003, so from 2002 we set off on a mission to raise our community's awareness about different ways to communicate. Our children were going into mainstream nurseries and we just felt we wanted to foster an inclusive environment so that everyone around them needed to be exposed to, or using, some signs. Fortunately, we both found nurseries which were already signing with the children in their settings and this gave us further encouragement to pursue what we were doing. We ran free drop-in sessions across the borough - at libraries, nurseries, schools, clinics - in fact, anywhere that would listen! Such was the response, we soon established our 'Singing Hands' baby signing classes. This has now grown to include our toddler sessions and all the other schools, nurseries and professional workshop sessions too.

We both went on to complete our Makaton Foundation and Enhancement courses and then qualified as Makaton Regional Tutors in November 2005. We continue to do lots of work with children with learning difficulties who use Makaton signs, symbols and software at home and at school.

In my case, because Ella's trachy had stayed in longer than anticipated (nearly 3 years), I began using BSL with her to meet the needs of her phenomenal vocabulary. I passed BSL Level 1 and 2 and at some point very much hope to do Level 3.

We soon decided to start work on creating signing resources as, when our children were little, there had been hardly any Early Years' signing materials available. How times have changed! Can you imagine a life before Something Special was around? We started by publishing our two signed songbooks with accompanying CDs (in conjunction with the Makaton Charity). More recently, we have added a signing DVD to our collection. These items are all available from our online shop. It is our goal to have everyone singing and signing everywhere! We hope that parents, carers and professionals will be able to use these resources to make that happen.

We have also been lucky enough to work with the BBC on both Tikkabilla and Something Special. This was the icing on the cake. Our Nursery Rhymes episodes are available as part of the series of Something Special DVDs - see the online shop at www.makaton.org for more information.

The past 10 years have been such an amazing journey for the both of us - and one that we would not have made had Miles and Ella not come into our lives in 1999. Big thanks to them, plus Dominic, Florence & Oscar for joining in with this signing lark too!

as seen on
BBC's Something Special

EXTRA CHILD TRUST FUND PAYMENTS FOR DISABLED CHILDREN

From April 2010 the government will start to make extra payments into the Child Trust Fund accounts of disabled children. The extra payment will be £100 per year, or £200 per year if a child is on the care component of Disability Living Allowance at the highest rate.

Q. Will all disabled children receive these extra payments?

A. No. In order to qualify for an additional payment from the government your child must have been in receipt of Disability Living Allowance (DLA) at some point in the previous year. In addition, only children born on or after 1st September 2002 have Child Trust Fund accounts.

Q. My child gets DLA. What steps do I need to take to ensure my child receives these extra payments into their account?

A. The government expects to automatically identify those children who have both DLA and a child trust fund and will then make a payment directly into each child's account. Parents will receive a letter telling them once a payment has been made.

Q. When will my child be able to get the money in their account?

A. A child must normally wait until they reach 18 years of age to access the money in their account. However if your child has a terminal illness and their death could be reasonably expected within six months,

THE SAVINGS GATEWAY - GOVERNMENT HELP TO BOOST YOUR SAVINGS

Later this year a new government backed savings scheme called the Savings Gateway is to be introduced. Aimed at people of working age who are on lower incomes, the government will give you 50 pence for each £1 you save into your Savings Gateway account.

Q. Am I eligible for a savings gateway account?

A. You will qualify for an account if you getting one of the following benefits or tax credits: Income Support; Incapacity Benefit; Severe Disablement Allowance; Employment and Support Allowance; Job Seekers Allowance; Child Tax Credit (your income must be below £16,040 - this limit may increase after April) or Carers Allowance (you must actually get this, not just have an underlying entitlement)

Q. How do I apply for an account?

A. When the scheme launches later this year, Her Majesty's Revenue and Customs (HMRC) will write to everyone who is eligible, inviting them to apply for an account and telling them how to go about doing this. Savings Gateway accounts will be offered by a range of banks, building societies and credit unions. You can only open one savings gateway account during the course of your lifetime – so you need to think about when would be the best time for you to do so.

Q. How much can I save into my account?

A. You can save whatever you like - up to a maximum of £25 a month. At the end of the two years the government will then add a reward of 50 pence for each £1 you've saved.

Q. When will I be able to open an account?

A. At the time of writing no launch date has been announced. However it is unlikely to be before April 2010. More detailed information on the Savings Gateway should be available shortly. Telephone for an update.

Ring Contact a Family on their Free Helpline on 0808 808 3555.

NEW BENEFITS RULES – CHILD MAINTENANCE PAYMENTS IGNORED FROM APRIL 2010

From 12th April, child maintenance payments will no longer be treated as income when working out if you are entitled to means tested benefits such as income support, income based job seekers allowance or income related Employment and Support Allowance. These payments are already ignored as income for housing and council tax benefit and for tax credits.

If you receive child maintenance payments and were told in the past that your income was too high to receive a means tested benefit, you may find that these new rules allow you to qualify for the first time. To find out whether this applies to you seek further advice. If you care for a child with a disability or illness you can get detailed advice from the helpline.

CARER'S ALLOWANCE EARNINGS LIMIT TO INCREASE FROM APRIL

Carer's Allowance is the only state benefit specifically aimed at carers. However in order to get Carer's Allowance one of the rules is that your earnings must be no more than £95 per week. This earnings limit has been unchanged since October 2007. However from 6th April 2010 the government is to increase this figure to £100 per week.

Q. How are my earnings calculated for Carer's Allowance?

A. In working out your weekly earnings certain deductions can be made from your gross wages. For instance any tax and national insurance you pay is deducted, alongside half of any pension contributions you make.

Q. What about if I have to pay someone to look after my children while I am at work?

A. If because of your work you have to pay someone else to care for the person you look after, or to look after your children, you may also be able to deduct these costs from your earnings. However the maximum amount that you can deduct for alternative care costs is 50% of what would otherwise have been your earnings. No deduction is allowed if the person you pay is a close relative.

These rules may allow some carers to qualify for Carer's Allowance even though they are earning slightly more than £100 per week.

Q. What are the other Carers Allowance rules?

A. You must be at least 16 to claim and you can only get Carer's Allowance if the person you look after is in receipt of the care component of Disability Living Allowance at the middle or highest rate or Attendance Allowance (a benefit for elderly people). You cannot claim if you are a student involved in 21 hours or more supervised study.

If you are looking after a disabled adult then in certain circumstances an award of Carer's Allowance could lead to a reduction in that disabled person's benefits.

Parents with disabled children who are working and who want to know if the change in the earnings rule will help them claim Carer's Allowance should ring the helpline.



Affiliated to Contact a Family and Rare Diseases UK

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