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NEWSLETTER SUMMER 2012

Editor's Note

Welcome to another bumper summer edition. We had a wonderful time at the Family Day again this year and it was both informative and entertaining. Thanks to all of you that joined us and for those of you that couldn't make it, there are some articles that cover some of what you missed. It is always wonderful to meet other members and share their experiences. Apart from the Family Day my personal highlight has been the



sponsored walk that I thoroughly enjoyed taking part in. You can read about it on the back page. See you soon!
Nicki Turley

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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





From the Chair

I am delighted to say this year's family day was a huge success. Thank you to everyone who came and I hope you found the day useful and enjoyed it as much as I did. I am glad to see that there has been lots of positive feedback on the Facebook pages, do feel free to come and join into the discussions.

It's been a road of up's and down's for me this year so far with completing a personal goal of walking 10km, to getting attacked, causing me to have two cracked disc's in my back and leaving me struggling a little more than I normally would. This hasn't stopped me I have returned to work since and I am delighted to be Chairman for the group another year.

I am still looking for more ideas of raising money for the group so we can make our family days bigger and better. I will, more than likely, be doing the walk again in West Sussex next year so for those who want to join me feel free to contact me for details.

Lastly but by no means the least, I reach the big 40 this year, a massive achievement for me and surely proves that doctors don't know everything. If you were to ask anyone when I was the age of many of your children, would I have achieved what I have at the age of 40 they would have probably said not likely. I am not one for recognizing my own achievements and always push myself to achieve more but getting to 40 and still able to work is something I was not convinced I could do, but I have.

Mark Mayer



Singing Hands

We had a wonderful start to the Family Day when Singing Hands got us all warmed up with a

sing-a-long which was enjoyed by all. We would like to thank Suzanne and Tracy for joining us again. It helped to make the day a huge success.

Singing Hands started back in early 2005, when they filmed a little segment for the 'arched window' on BBC Cbeebies Tikkabilla. In this slot, they did a signed sing-a-long session (including their favourite song 'Mmm mmm frog') with a group of children. It was a really inclusive session with their own kids plus other children from local schools and nurseries that they visited, some toddlers who had attended their baby signing classes and some friends from the Toy Library for Children with Special Needs.

www.singinghands.co.uk

They were therefore delighted to then be invited by the Producer of Something Special to contribute to this new series.

Singing Hands have now progressed to have their second DVD 'It's Signing Time 2' awarded with a prestigious Gold Practical Pre-School Award 2011 in the Music and Multimedia category. They scored a whopping 97.8%.

They also have other DVD's, books and merchandise that can be purchased via their website.



Your feedback..

We had some great feedback from this years Family Day which was a huge success. Thank you to all of you that joined us and helped to make it another fantastic day.

I really like the venue it works really well
Thank you

A great first WDS day for Mason and us we all enjoyed the experience especially Singing Hands and the friendly atmosphere that we experienced from all the families

We really enjoyed the day - again
At least we managed to see Singing Hands this Time!!!!
We found the talk on Mychoice pad really useful. The venue was once again great Sam enjoyed the horses and cows next door

Good Venue
Really enjoyed Singing Hands
Interesting talk from Mychoice Pad

Excellent Day Thank you we found the talk on My choice pad very useful and informative. The whole family enjoyed taking part in singing and signing. We have decided after today to come along again next year if possible Thank you for all your helpful advice

Another excellent and well planned fun day Singing hands were brilliant for Emily. Great to meet lots of new parents and children and exchange ideas, views and have a good chat in an informal environment

As always the family day has been informative for us and fun for the children. It was good to chat with some other families. The session on lean education was particularly helpful

What do you want next year?

Singing hands Again Also a professional discussion showing how the brain affects the way sound production is delayed and affected with WDS in a way that is simple to understand also a dietary specialist explaining what foods affect the brain or help brain development

Just the same!

Perhaps some discussion on how to work out which is the best school for your child-perhaps led by an educational psychologist Thank you for all your hard work and organization

Much the same please perhaps "Mr Tumble"

We appreciate all your feedback. It helps us to make our Family Days into what YOU want them to be. Please feel free to get in touch with any ideas you have for future events, as your input is greatly appreciated.

Celebrations

We would like to welcome two new committee members who have now joined the team - **Carla Marygold** and **Callum Turley**.

We are delighted that Carla has agreed to join us. She has a lot of experience that she can pass on to other members.



Callum is our youngest new recruit and has been given the very important role of Fundraising Manager. He is only 10 years old but is very keen to help out on our committee and play a part in the group.

"Hi, I have been a member of the group since 2004 when our daughter Kathryn was diagnosed with **Worster Drought Syndrome**. Since then I have spent a lot of my time trying to get Kathryn the support that she so rightly deserves. I am very happy that I have been voted onto the committee and look forward to meeting more of you. I am looking forward to another successful Family Day." **Carla Marygold**



We all would like to congratulate one of our new members, **Mason**, who celebrated her birthday at the Family Day. Singing Hands got us all to join in to sing happy birthday while presenting her with a wonderful hat to wear.

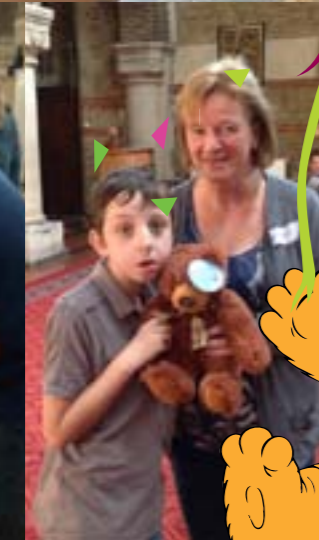
It is also a special birthday year for two of our committee members, **Mark** and **Nicki**, who are both celebrating their 40th this year!



NAME THE TEDDY WINNERS

We had three winners of the Name the Teddy prize.

Mia-Rose Mayhew
Mary Rumbold
and **Emily Riches**



Assessments with



At their Assessment Centre, they can provide assessments for a wide range of levels.

What we do - LOOK AT THE OVERALL PROFILE:

- ✓ **Strengths of the children.**
Not just concentrate on their Speech and Language but Education Psychologists, that are experts with speech difficulties, don't use just speech to assess the child and perform non-verbal assessments.
- ✓ **Motor skills** and how it impacts on their learning
- ✓ **Discriminating sounds.** How they develop strategies and do they persist? Are they resourceful? motivated? Do they accept help?
- ✓ Look at their **understanding** and level of speech and how they put sentences together.
- ✓ **Fine motor skills.** How they use sign especially to assess for use of communication aids.
- ✓ Assess their **visual skills** and how easy it would be to access communication aids.
- ✓ **Attention levels.** Are they easily distracted how they respond and what is a barrier to learning.
- ✓ **Social communication** and how they respond and how are they emotionally.

This is the key to get a clear profile.

How can we help?

Children may have some speech, but the key part is AAC and low tech, ie. communication book. It is not just the aid that is important but assessing what motivates the child and works best for them alongside the help of SALT. It is essential that support and training are given when being introduced to a communication aid. At Meath School they have actually taken a child back to a level of

communication that is more appropriate to the child, instead of going straight to a complicated aid. They introduce the communication aid as part of their lives and all the children in class get involved in the use of it

When signing, everyone must be inclusive and embrace the use of it, as some children may feel different if using it in an isolated way.

What we have found useful for WDS

High visual signs such as **Paget Gorman** are used at Meath School, which have good grammatical variations. They are easier when dealing with phonics.

Cued articulation for sounds – this is a way of marking sounds that children cannot produce, but can actually hear. They can show spelling skills with this for sounds and **finger spelling** for letters. Charts are used aswell **THRASS** - Teaching Handwriting Reading and Spelling Skills - this is quite a complicated system so **SALT** support may be needed.

Symbol software that is colour coded. This is useful to use in lessons.

SALT work for speech and advice for eating and drinking, keeping everyone in the loop, assessing progress and changing the approach as skills develop.

Occupational therapy is very helpful for learning and assessing the educational setting eg. seating, whether handwriting is suitable or using a laptop instead.

Input to develop **motor skills**.

Access to **small group learning** is very appropriate, for pace to be slower to enable children to be able to speak and communicate.

Appropriate peer groups so they feel as included as possible and as close as possible to a total signing environment is of course best.

Visual support is key as they can't show their learning without this. (If the child is in mainstream – find out what are they are going to be learning so they can have a grid in advance and also work with signs prior to a class so they can use the words that they may be using for the lesson).

Being aware of their **social needs** and allowing time for communication. Help with social skills may be needed such as groups of children getting together and working out how to help a child with difficulties.

Celebrate strengths - Meath School hold many award ceremonies including a signing award to boost childrens' self esteem.

IEP's are used for targets and to get feedback from the children to relay back to parents.

Other support may include **Medical and music and play therapy** that explores how they feel and **Psychology support** for increasing awareness as they get older.

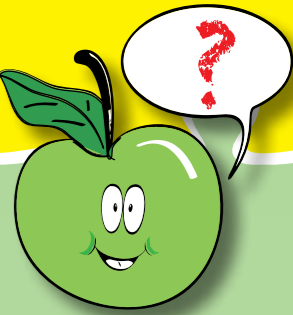
It is crucial to have an up-to-date profile of your child. Check part 2 and 3 of your statement. Part 3 may need to be more specific about what your child's needs are. It can be difficult to get what you need straight away and may require some negotiation. It is important that everyone works together and talks to each other as a whole, after all, it is only one child that you are talking about.



www.ican.org.uk

www.wdssg.org.uk

Some food for thought...



My Daughter, Emily, is 5¹/₂ years old. She has WDS including some mobility and fine motor skill issues. Like the vast majority of WDS children, speech delay is her biggest problem area. I decided to write an article by researching and collecting facts from numerous, credible websites on the subject and have also liaised with an expert in health, so you can be assured that I have really tried to get the most factual and unbiased information.

We know that a 'multi-disciplinary' approach to speech and language helps, using as many different methods as needed from speech therapy to music therapy. To create speech, many parts of the brain are involved, from more than one lobe and the very complicated balance that is needed is easily affected by neurological dysfunction such as WDS. To make correct speech sounds, the lips, tongue, jaw, velum and larynx must make accurate movements at the right time.

So could someone's diet actually have an effect on how their brain functions and develops?

Actually, there is a great deal of evidence that this is the case and since I've found out more about this, I wanted to share it with other parents. What's more, since implementing some changes to my daughter's diet, I have seen a range of improvements with her abilities, including making many new sounds and words, attempting to write words and a general improvement in awareness. It seems more than just a coincidence to me, as this noticeable development happened at the same time as the improved diet and even the speech therapist has similarly commented. Obviously, none of this will fix the neurological problems, but it really helps to do as much as possible to help the brain develop, repair and improve itself.

The initial spark in my interest was a few years ago when I saw an episode of the Jamie Oliver "School Dinners" series where teaching staff were baffled by the children with asthma whose symptoms disappeared when their diet was changed to a healthier one. However, it was not until recently, after talking to another kind parent at school that I gained some more knowledge of this particular subject. She is currently completing a Degree in Health Sciences and with her expertise, she suggested the idea of implementing the use of extra virgin organic coconut oil into Emily's diet, which I will discuss in detail later. Her family eat a diet based around the 'Paleo', or 'Primal' diet.

More information on the concept of this way of eating can be found at <http://perfecthealthdiet.com/the-diet/>

Strangely, I found that there is a similar way of eating being used by some parents of autistic children; there is a growing body of evidence that children anywhere on the autism spectrum could benefit hugely from a casein (a protein found in dairy) free, gluten free diet.

One of the problems with modern foods and cooking is that industrial seed and vegetable oils can produce a variety of toxic chemicals and trans-fats, which when heated up become rancid. These oils are also high in Omega-6, which in excess causes harmful inflammation in the body. Today's diets are massively high in Omega 6, so elimination of these harmful oils where possible is essential. To demonstrate this point, the human species evolved eating a ratio of about 1:1 Omega 3 to Omega 6, where in far contrast, today's diets have a ratio of about 15/1.

See study at <http://www.ncbi.nlm.nih.gov/pubmed/12442909>
Many of them are also genetically modified too. None of this is good news for the brain. However, there are several options, one of them which is extra virgin organic coconut oil (not to be confused with refined coconut oil). This oil is considered one of the best fuels for healthy brain function and is unusually rich in medium chain triglycerides (MCT's) which are treated differently by the body. The MCT's go directly to the liver, converted into ketones which are then immediately released into the bloodstream, where they are transported to the brain as fuel. There are many other unique properties which are excellent for brilliant general health too. Normal oils contain long chain triglycerides which take a lot of work for the body to break down. Another option would be healthy fats like unrefined beef fat, especially from grass fed cows, lamb fat and occasional use of lard and duck or goose fat. Saturated fats are a more stable fat, making them less prone to harmful oxidation than unstable poly-unsaturated fatty acids, (e.g. vegetable oils etc.) and these healthy fats do not tend to go rancid over time, so they do not damage the body and brain.

Correcting the balance - some suggestions for 'Brain Foods'

Sadly organic foods are often more expensive but they will really help because of their higher nutrient levels and no toxic pesticide residues.

Foods with too many carbohydrates should be avoided, especially refined varieties such as white flour and sugar. Over eating carbohydrates results in the body releasing insulin and an enzyme called phospholipase A2 which damages cell membranes and impedes repair of brain nerves.

As previously discussed, extra virgin organic coconut oil can be used instead of the normal cooking oils. This product is packaged in a jar and has a similar consistency to butter, allowing it to be spread or heated as cooking oil. If you wanted to mask the taste of the coconut oil, it can be mixed with organic butter from grass fed cows such as the 'Yeo Valley' brand to help with the taste. Regular 'fake fats', like margarine and hydrogenated fats, enter and damage cell membrane function. Peanuts, cashew nuts and canola oil also have other damaging effects due to their high anti-nutrient content. Plenty of protein in the diet is important as it provides the means for repair and detoxification, with animal protein being the most superior and nutrient dense source. Keeping sufficiently hydrated with water is also important for cell membrane and brain repair.

Omega 3

A good source of Omega 3 fatty acids can be found in salmon, mackerel, trout, sardines and herring. The Omega 3 fat "DHA" (Docosahexaenoic) which is found in rich abundance in fish like salmon is very important and a study showed that as little as one meal per week of oily fish reduced cognitive decline by 12%! Canned salmon and mackerel are readily available in supermarkets, packaged for instant use. Almonds also have a high Omega 3 value and are rich in antioxidants including Vitamin E. They can be bought in a ground powder form in supermarkets, which makes it beneficial to children with swallowing difficulties. Grass fed 'ruminant' animals (such as beef and lamb) are superior sources of Omega 3 and other healthy fats too.

Omega 6

Nuts and seeds are helpful for providing a correct balance of Omega 3 intake with that of Omega 6. The best type of nut for the Omega 3/Omega 6 ratio is the Macadamia, which is available in supermarkets. The essential oils contained are important for membrane and brain repair. You could grate down to make it easier for your child to swallow, if they have trouble with choking. Macadamia nuts do not have a strong taste and can be "hidden" within other foods, without your child knowing! However, because our diets nowadays are so rich in Omega 6, you could get enough Omega 6 through foods like poultry and pork without needing to source it from nuts or elsewhere.

Fruit & Vegetables

It is common knowledge now about getting your '5 a day' fruit and vegetable intake. Fruits and vegetables are excellent sources of antioxidants including Vitamin C, Beta-Carotene and Fibre. Antioxidants help clean up the brain - a bit like rust cleaners that keep rust off our brain matter. Blueberries are one of the best sources of antioxidants, even when frozen. Vegetables in the onion variety provide essential sulphur for repair and detoxification. As a rule, the darker green a vegetable is, the higher is the concentration of antioxidants. A good example of a green vegetable to be included in a diet would be broccoli.

Eggs

Eggs are a rich nutrient dense food which is very good for brain health. Whole free range eggs are high in protein, rich in vitamin E, Omega 3 fatty acids and B Vitamins. B Vitamins help prevent inflammation and aid in new brain cell development.

Dairy

In addition to these "brain" foods, you may want to consider organic dairy products, where the cows are fed on grass - "Grassfed" products are rich in all the fats now proven to be health-enhancing, but low in the fats that have been linked with disease. Yeo Valley is a great British brand for organic "Grassfed" products which are easily available in supermarkets. Also raw dairy is a fantastic option, as by being unpasteurised, it still contains all the life enhancing nutrients that are destroyed during pasteurisation, Raw dairy is a true super food. More information can be found at <http://tinyurl.com/clcr8c>

Phil Riches

Credit: Many thanks to Carly Evans for her help and expert advice



MyChoicePad is an educational iPad app that uses Makaton symbols and signs to enable choice and communication for children and adults with learning or communication difficulties.

Zoe, a former Senior Manager at The Makaton Charity, joined us at the Family Day and gave us a demonstration of how the MyChoice Pad app works.

"MyChoicePad uses the very latest iPad technology to provide a highly intuitive and interactive new teaching and learning solution to support speech, language and communication needs in the home and classroom through the use of photos, symbols, and Makaton signs with video."

Two years ago, Zoe left to build this app for the future for Makaton. It took a year to develop and was released a year ago. She developed it, won a grant and received investment to keep it growing.

It's main features are:

- ✓ It uses a grid system which is at key word level.
- ✓ It builds communication skills and the first steps towards literacy.
- ✓ There is no folder system and works with a side panel.
- ✓ There are not just symbols, there are also images which are important in helping understanding.
- ✓ It can be personalised to the individual user.
- ✓ Sizes of concepts can be altered.
- ✓ Voices can be recorded.
- ✓ Drop box can be used for off site back up so that if the device gets lost, the grids are backed up. This is important for when you get a replacement app, as it won't have all your customised settings.
- ✓ Grids can be edited.
- ✓ User can import personal photos in quickly.
- ✓ Either sign, symbol or a video of the sign can be seen.
- ✓ Lockable grids help to avoid unwanted deletions.

The app costs £74.99 with the Core Vocabulary included. Other vocabulary is available at an extra cost.

There is a free version as well as the full version of MyChoicePad available. There are also iPad packages with everything fully loaded up. Go to their website for full information.

www.mychoicepad.com



FABULOUS FUNDRAISING



Here we go ...



half way up (so we thought!)



what goes up must come down!



and a proud finish.



Not Just a Walk

"It was a very proud moment, walking over the finish line with Mark by our side. He made me extremely proud to be a part of something that would not only help us raise money for WDS, but to see first hand, Mark achieving his own personal goal." Nicki

"I think this is the furthest I have ever walked!" Mark

Committee members Mark, Nicki and Rik accompanied by a friend of Mark's, Rory Broughan, proudly took part in the **Just Walk** 10km walk on Saturday 12th May, to raise money and awareness for our Support Group.

What a fantastic day it was for all of them, and despite the aches and pains they managed to have a giggle too. They were lucky as the cool but sunny weather was perfect for walking and there were some beautiful views over the South Downs to look at along the way.

They are even considering doing it all again next year, so your support would be very much appreciated.

If you think you would like to join them next year then contact Mark or Nicki.

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BETWEEN THEM
THEY MANAGED TO
REACH THEIR
TARGET AND
RAISED

£1000

Affiliated to Contact a Family and Rare Diseases UK

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Registered Charity: 1095290

IR Charities Charity Ref. XR67990