



# Link

NEWSLETTER SPRING 2013

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

Please let me know if you have anything that you would like to share with other members.

We particularly would like to continue with the 'Member Spotlight' feature that appeared in the Christmas Edition.

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NEW FEATURE  
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### Editor's Note

As Spring is on it's way we look forward to another year supporting you, our members. I hope this year's Family Day will be another success and I look forward to seeing you there.

In this edition we have made several references to the "Give as you Live" scheme, which I have signed up for myself just recently. It is certainly worth doing for those who like to shop online.

I hope you have a great Easter, see you in the summer!



Nicki Turley





## From the Chair

Where does the time go?  
I expect all your children are growing up fast!

There has been lots of talk about changes to the welfare system over the next coming years. Good news is for your children under the age of 16, the DLA (Disability Living Allowance) remains untouched. I have had an increase in concerned parents worried about their children's future. The good news is the Support Group is here to help you through the minefield of getting the correct support for your child.

It's been a good year for the WDS Support Group. Our fundraising activities have gone well. This has enabled us to provide you with another fun packed day at Thames Valley Adventure Playground in Berkshire.

Mark Mayer



## From the Treasurer

I must apologise to you all as I have been most remiss. I have only just signed up for "Give as you live" where about 1% of what I spend on line with shops like Amazon, Ebay, John Lewis, Sainsbury's and many more is donation to the support group at no cost to you.

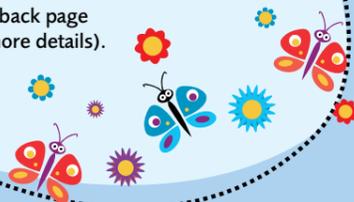
I'm a convert now and have just signed up the wife Vanessa. As a convert I implore you all to sign up and download the App that is installed in your web browser, so you too can raise money for the group.

All the best and hope to see you at this year's Family Day.

John Butt



(See back page for more details).



# Don't forget...

## Our Family Day is on Sunday 23rd June.

The agenda this year is very informal so we can get to know one another and the children can play. Throughout the day members of the committee will be available if you have any questions.

**10.00 - 10.15am** Registration and Refreshments

**10.15 - 10.30am** AGM  
Meet and talk with other members and their families whilst enjoying the facilities

**12.00 - 1.30pm** LUNCH  
Meet and talk with other members and their families whilst enjoying the facilities.

**3.30pm** Tea and Coffee - Goodbyes

There will be facilities for tea and coffee making throughout the day but please remember to bring a packed lunch.

We have all of the facilities at our disposal so we can wander where we wish and enjoy the relaxed setting. We hope that you will come and enjoy an informal day with us.

There are indoor facilities, offering an opportunity for creativity and imaginative play.

Outside activities include a castle, accessible for all abilities, Crazy Golf, a Toddlers Area with swings and climbing tunnels, built into a sand pit and for the more adventurous, there is a Tree Top Trail which is suitable for wheelchair users. There is also a music structure with huge oil drums, sound pipes, bell clangors' and gongs.

We are sure that you and your family will find some activity to enjoy.

To find out more about the facilities then please look at:

[www.tvap.co.uk](http://www.tvap.co.uk)

Thames Valley Adventure Playground  
Bath Road, Taplow, Nr. Maidenhead,  
Berkshire, SL6 0PR

Don't forget to return your registration forms

PLEASE NOTE  
You will need to put  
SL6 0PR  
into your SAT NAV  
to find them



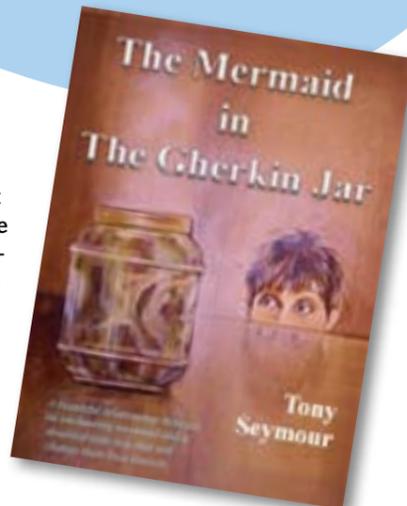
## The Mermaid in the Gherkin Jar

This book has really captured the essence of growing up dealing with a disability.

When Christopher, a young boy with cerebral palsy, attends school for the first time, he suddenly realises how different he is from the other children. His disability embarrasses him and also makes him an easy target for the school bully. Confused and uncertain, Christopher seeks solace in Azalea, an enchanting mermaid with a disability of her own. Little do they know, their relationship will change them both forever.

### About The Author

Tony Seymour is a new author. He was diagnosed with mild cerebral palsy at birth. 'The Mermaid in The Gherkin Jar' is an enchanting children's story, which highlights the challenges Tony faced as a young child growing up with the condition. Tony lives in Manchester



"I was bullied a lot at primary school, so to read something like this as a child would have helped me feel much better. It also gives parents a chance to read a story at bedtime, that means something."

Mark Mayer

[www.themermaidinthegherkinjar.com](http://www.themermaidinthegherkinjar.com)

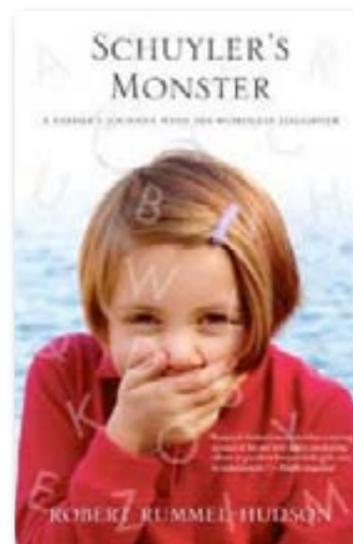


kindle amazon.co.uk

## Schuyler's Monster

A Father's Journey with His Wordless Daughter is a book by Robert Rummel-Hudson.

When Schuyler Rummel-Hudson was eighteen months old, a question about her lack of speech by her pediatrician set in motion a journey that continues today. When she was diagnosed with bilateral perisylvian polymicrogyria, (an extremely rare neurological disorder), her parents were given a name for the monster that has been stalking them from doctor to doctor, and from despair to hope, and back again.



Once they knew why Schuyler couldn't speak, they needed to determine how to help her learn. They took on educators and society to give their beautiful daughter a

voice, and in the process learned a thing or two about fearlessness, tenacity, and joy.

More than a memoir of a parent dealing with his child's ability, Schuyler's Monster is a tale of a little girl who silently teaches a man filled with self-doubt, how to be the father she needs.

An honest, funny and heart-wrenching story of a family who won't give up when faced with a monster that steals their daughter's voice but can't crush her spirit.

### About The Author

Robert Rummel-Hudson has been writing online since 1995 and has a parenting blog called Fighting Monsters with Rubber Swords. Both book and blog concern the author and his wife's parenting of their daughter who was born with a brain disorder that made her unable to speak.

More of Robert's observations on life with Schuyler can be found on his blog at:

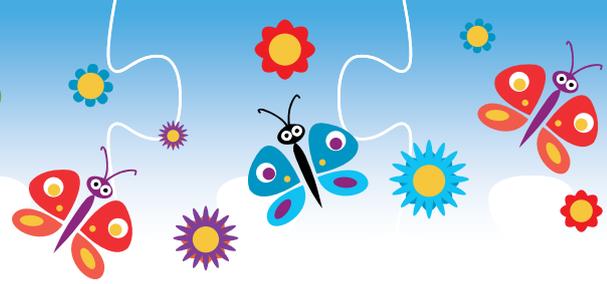
[www.schuylersmonsterblog.com](http://www.schuylersmonsterblog.com)

amazon.co.uk

BOOKS WE LOVE X



# Money Matters



## What is out there at the moment?

Working Tax Credit

Benefits for people who cannot work

Employment and Support Allowance

Incapacity Benefit

Severe Disablement Allowance

Benefits for the extra costs of disability

Disability Living Allowance

Attendance Allowance

Disablement Benefit

Benefits for carers

## Useful links

For questions you may have:

[www.dwp.gov.uk/docs/universal-credit-faqs](http://www.dwp.gov.uk/docs/universal-credit-faqs)

To work out what benefits you can get:

[www.gov.uk/benefits-adviser](http://www.gov.uk/benefits-adviser)

Universal Credit will help claimants and their families to become more independent and will simplify the benefits system by bringing together a range of working-age benefits into a single streamlined payment.

## The new Universal Credit system aims to:

- ▷ improve work incentives
- ▷ smooth the transitions into and out of work, supporting a dynamic labour market
- ▷ simplify the system, making it easier for people to understand, and easier and cheaper for staff to administer
- ▷ reduce in-work poverty
- ▷ cut back on fraud and error.

## It will be launched in 2013 and will replace:

- ▷ income-based Jobseeker's Allowance
- ▷ income-related Employment and Support Allowance
- ▷ Income Support
- ▷ Child Tax Credits
- ▷ Working Tax Credits
- ▷ Housing Benefit.

## Just Walking again!

Mark Mayer is signed up and ready to go for a second year on a 10km walk at Goodward Racecourse in West Sussex on Saturday 11th May.



We wish him lots of luck and hope he has a great day. If you wish to support him please go to his Just Giving page:

[justgiving.com/WDSwalk](http://justgiving.com/WDSwalk)  
or text code WDSW50 £1 to 70070

You are welcome to sign up too, or do something else to help raise money for our group!

Discover Give as you Live

With Give as you Live™ you can shop online with thousands of stores and raise money for our support group with every purchase - at no cost to you.

- ✓ Start now - it takes seconds!
- ✓ It costs nothing
- ✓ 100% secure

[www.giveasyoulive.com](http://www.giveasyoulive.com)

**GIVE IT A TRY**

Affiliated to Contact a Family and Rare Diseases UK

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