

Swindon Down's Syndrome Group

June 2010



Further to a recommendation by the Office of the Third Sector in the Cabinet Office, Her Majesty the Queen has agreed to award the

Swindon Down's Syndrome Group

The Queen's Award for Voluntary Service – an MBE for Charities.

In December, our very good friend, Cliff Puffett nominated the Swindon Down's Syndrome Group for the Queen's Award for Voluntary Service. Our patron Howard Taylor wrote a supporting letter. Both letters were full of the kindest, most generous sentiments about the Group and the work that we do to support each other and those that help to care, support or educate our members. We completed a mammoth application form detailing what we do and how what we do impacts the community around us. In January Cliff, Howard, Kim and I met with Patrick Wintour, a deputy Lieutenant of Wiltshire. He observed a speech therapy group and then discussed our application in detail. His recommendation was then presented to the Regional committee who then makes a recommendation to the Cabinet Office. The Cabinet Office then makes a recommendation to the Queen. Awards are announced in the London Gazette on the 2nd June.

This is truly a great honour and is something for the whole Group to be proud of. This is the Group's award and everyone in it has led to it becoming the Charity that it is. You are all so supportive of each other and those that help us and this has been recognised.

The Lord Lieutenant of Wiltshire will present the Award on behalf of The Queen. We will receive an inscribed commemorative crystal and certificate signed by Her Majesty. The citation will read:

Swindon Down's Syndrome Group

Supporting people with Down's syndrome, their families and carers.

We will also be entitled to use the above logo on all our letters and publications.

Four members of the committee were invited to the Queen's garden party at Buckingham Palace on 22nd June as a result of the award so Jo Messenger, Kim West, Julie Thomas and Jenny Williams will be attending. (Terry and I had already had an invitation to attend the same garden party through Nicky Alberry of Swindon Cares, would you believe, so we are also going!)

Congratulations to you all.

Special thanks to Cliff Puffett and Howard Taylor.

Swindon Mayor - David Wren

Swindon Cares was one of the Mayor's chosen charities this last year and on Friday the 14th May David Wren presented the Swindon Down's Syndrome Group with a cheque for **£2,500**. This is an amazing amount of money and we are really grateful to the Mayor for choosing us to be a beneficiary.



Balloon Flight

Nicky Alberry is on the Swindon Cares committee and is also Joint Chairman of GWE Business Southwest. Her company have their own hot air balloon and they have very kindly offered a ride to the Group. So, we have a little competition.

Eligibility Criteria:

- a member with Down's syndrome plus a parent/carer
 - person with Down's syndrome must be of secondary school age or above
- both need to be able to hold on independently with both hands for going up and landing must be available for an evening or weekend flight with 2 -3 days notice.

May also be cancelled at the last minute due to weather conditions but will be re-arranged

must be able to get yourselves to the launch site

The flight would be for about an hour would land some 10 miles from the start point but their vehicle will pick up the balloon and passengers and return you to the launch site

Must send an article and photo for the next newsletter and annual report!!

If you would like the opportunity to win this fantastic prize please send your name and details of those that wish to fly to me

Nicky Parker - n-parker5@sky.com - 28, Whiteman Street, Swindon SN2 1BW by **25th June**. All names will be put into a hat and the winner drawn at the committee meeting on 29th June held at my home. All welcome to attend! The winner will be notified that evening and the name placed on the website the following day. Good luck!

Have you booked your summer outing yet? remember the last date to get details to Kim is **Monday 21st June**

Date of trips

Saturday 3rd July



Thank you

We would like to thank those of you that continue to support us with your kind donations. Thank you.

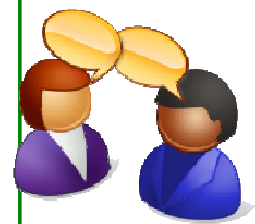


Swimming

We have spaces for the fortnightly swimming lessons on a Monday at the Hydrotherapy Pool in Jefferies Avenue, Swindon. The lessons are 6 - 7pm (including changing time) and cost 50p per child and £1.00 per adult. Children must be accompanied by an adult. Vicky Hunt is the swimming instructor and she attends most term time sessions. The children all work towards nationally recognised qualifications and the session is for all abilities from non-swimmers to those that just want help with technique.

Speech

There are spaces available in the Speech and Language Therapy Groups. The groups are free to children who live or are educated in the SN postcode area but there is an expectation for all to be involved in raising funds for the Group. The Groups are all held during the school day and school teaching assistants are encouraged to attend as well. So far all schools have responded positively to their pupils attending the Groups and most send a teaching assistants every week. If you would like some more information about the Groups please contact Nicky - n-parker5@sky.com - 01793 640234



Please see attached letter for picnic information.

Lydiard Park on the
1st & 29th August 2pm

Come and meet the families and enjoy a great afternoon. (weather permitting)



The Swindon G4S team based at Kembrey Park chose the group as their Charity for the past year and have been busy fundraising under the leadership of Craig Brett. They raised an amazing £1115.00 and G4S matched the figure so Clare Simms - Communications Director and Craig Brett came along to the monthly coffee afternoon on 6th May to present a cheque for £2115.00.

Thank you so much.

Thank You

We would like to thank Jeremy Wray, Adam Wainwright, Chris Tanner and Nick Watkins for the amazing amount of money raised on the County Ground to Brighton & Hove Albion FC cycle ride.



Check out the website for all the Swindon Cares fundraising dates

Please remember to check the website for forthcoming events and updates.

www.swindondownsgroup.org.uk there are photo's and information, links and phones numbers. If you have anything that you would like added to the website, please contact Jo Messenger

Making It Easier to Assess a Person's Vision: New Tool from SeeAbility

SeeAbility's eye 2 eye Campaign has created a new Functional Vision Assessment tool for supporters of people with learning disabilities. The easy to use tool makes it easier to understand how much a person can see so you can support the person to best effect.

It is free to download from <http://www.lookupinfo.org/index.php?id=1351>.

LIVING WITH MAX by Sandy Lewis

A humorous, yet honest peek into the world of Special Needs, and living with Down's syndrome.

<http://livingwithmax.blogspot.com/>

Down syndrome; a family perspective <http://bit.ly/93FvjN>

Watch 'The Specials' short film for the Webby Awards - its fantastic!!!! <http://bit.ly/cdpFpR>

'Managing Bowel and Bladder Problems in Schools and Early Years Settings - Guidelines for good practice' (2006) by DSA's Continence Adviser, June Rogers, free of charge at:

<http://www.promocon.co.uk/managingbowelandbladderproblems.shtml>

Short Film About 'Shifting Perspectives' 2010 Featuring Some Members Of The London Down 2 Earth Group

<http://vimeo.com/11160659>

Film taken at the 'Changing the Face of Human Rights Exhibition' 2010 <http://vimeo.com/11041494>

Featuring some members of the London Down 2 Earth Group

New Free Online Library Of Easy Read Documents brought to you by 'Pictures Speak Louder'

<http://www.psl.cswebsites.org/default.aspx?page=25182>

'Bruxism in Children with Down Syndrome By Dr. Jonathan Sierk

As a pediatric dentist who works with many children with Down syndrome, I would guess that 25% of parents of all children with Down syndrome ages 3-6 complain of hearing their child grind their teeth

when sleeping, usually when they share a hotel room on a vacation. The baby teeth tend to be very flat compared to the adult teeth and make an easy surface to grind.

The good news is that most kids outgrow this when the permanent teeth start to come in around ages 6-8 or so. Children and adults with Down syndrome do seem to grind their teeth more than others, both while sleeping and when awake. It can be a kind of subconscious, self stimulating behavior. In the baby teeth it really isn't much of a concern, unless the bruxism (tooth grinding) causes pain to either the teeth from grinding close to the nerve of the teeth, or to the muscles that chew from fatigue. These symptoms rarely develop in the primary teeth.

Dentists and parents should be concerned if significant wear develops on the permanent teeth. Unfortunately, most children and young adults with Down syndrome will not tolerate wearing a bite guard at night or the process of making one to prevent the grinding if it continues past early childhood.

If I see significant wear on the permanent teeth of one of my patients I consider placing sealants of white filling material on the biting surfaces of the back teeth so the patient can grind the filling

instead of the teeth. We all wear our teeth down throughout life—you will see 7- and 8-year olds with nice bumps on their new front teeth but usually after a couple years those bumps are gone. It is really

only a concern with significant wear that something should be done. Orthodontic treatment is another possible solution. It just depends on the patient and how their mouth looks.'

Dr. Sierk is a pediatric dentist in Highlands Ranch, Colorado, who treats many children with Down syndrome and focuses on the unique medical concerns of these patients. He is on staff at the Children's

Hospital of Denver where he is an adjunct clinical professor.

Cricket Central - The Times: A damp start

Patrick Kidd Many congratulations to Philip Ring, who attended his first game at Lord's as an MCC member on Sunday. I say his first game but it rained so hard before the match between Middlesex and Essex that play was...

http://timesonline.typepad.com/line_and_length/2010/05/a-damp-start.html