

# Swindon Down's Syndrome Group



## Chairs Chat

Happy New Year! I hope you all had a wonderful Christmas break. Lots and lots has happened since the last newsletter. October saw a visit to the Stratton Fire Station. Our thanks to Mark Evans for making us feel so welcome. A great morning playing with water, trying on kit and exploring the engines and station before squash and biccies. November became a worrying month as we realised that we still needed to raise over £12,000 for the Speech and Language Therapy Groups for the year 2012/13. Moderate panic set in but with all of you responding to our endless emails to vote for us in the NATWEST Community Force grant we gained £6,000. Thank you. Oliver, Stephen, Luke, Zachary plus mums and Terry all did the Swindon Fun Run and raised lots more with G4S matching Terry's £500. And to Andy Messenger who did the Half Marathon and raised a great deal. Thank you. Belinda Chandler raised money also by running 2 craft workshops. The first a wreath making workshop at Steam and we are really grateful for Steam's support in giving us the venue free and offering discounts on entry to the museum for the whole family. The second was a family Christmas Crafts morning. Both were fab and I love all my makes. Thank you. Several families made an extra effort to sell Christmas cards and with a collection at Tesco and an amazing jumble sale we are almost there. We have another grant that is making some very promising noises. Now to get started on raising funds for 2013/14. We don't want to get into this pickle again! We are trying to raise funds by making it fun for all and raising money along the way. Our first is on the 14<sup>th</sup> April - Charity Dinner Dance. We know times are tough so we are just having a 3 course dinner with disco and raffle and keeping the costs as low as possible. Come and join us!

Nicky

### Resource packs

Has your child just started at a new pre-school/school? Did you remember to collect the resource pack from their previous placement? These resource packs are very expensive but we believe they are worth their weight in gold to the pre-school/school. We need the pack back at the end of their time there so that all re-usable parts can benefit another child as they have benefited yours.

Please collect back what you can and return to

Nicky.



### **Jumble sales**

Saturday 11th February

St. Barnabas Church Hall, Gorse Hill, Swindon

Jumble, help, cakes or just come along on the day. Help needed to set up from 8am and to clear away from 12 noon. Please bring jumble to the hall on the morning of the sale

before 9.30am

### Facebook page

We are now on Facebook - <http://www.facebook.com/pages/Swindon-Downs-Syndrome-Group/198521990184135?sk=wall> – Check it out.

Swimming

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.

Please contact John Stow for further details: [John.Stow@ntlworld.com](mailto:John.Stow@ntlworld.com)

01793 337710

Les Slinn Gym sessions

New dates for Les Slinn's gym sessions. There is a cost of £2.50 per child/young adult, siblings are welcome, but if the class is large then the children with Down's will get priority. There will be only one time slot for each session.

The gym sessions were fantastic last time and Les has done a lot for the group, so please take this opportunity to come along.

**18th Feb, 3rd March, 7th April**

If you need to get directions please check out his website [www.lspersonaltraining.com](http://www.lspersonaltraining.com) this will give you the map and postcode. Please contact Jo to let her know if you intend going.



Thank you too the following....

Tesco bag pack £550

M&S bag pack £612. 82

Jumble Sale £532.12

Val Taylor £186.00

Marlborough Golf Course £500

DS Active

Wednesday's at 5pm at the Haydon Centre, Swindon. Term time only £3.00 per session payable at the start of each term. Contact Jo for more details.

Rubber Chicken Inc.

New course to include animation workshops. The animation will be included in the final performance at the Arts Centre on 8<sup>th</sup> June. Open to all between the ages of 10 - 17 whether they have Down's syndrome or a sibling with Down's syndrome. Contact Nicky for details.



### 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](mailto:n-parker5@sky.com) - 01793 640234



### PGL Day Liddington

On Tuesday 10th April 2012 we have planned an Adventure Activity day at PGL Liddington. For Ages 8 years and over and is open to immediate family only, for the daytime activities. If any of your family is unable to attend the activities during the day, for any reason, they are very welcome to join us for the evening barbecue. The day will start at 9am with breakfast. We will then split into our chosen groups and have two activities then lunch, two more activities and finally a family BBQ. The group has been fortunate enough to be awarded a grant by the Gannett Foundation to cover the cost of the day but we will be asking for a **fully refundable deposit** of £5.00 per person. The cheque should be made payable to the Swindon Down's Syndrome Group. **The cheque will not be cashed unless you fail to turn up on the day.** If a place is booked and not taken up then we will cash the cheque as we will be charged for all the places booked. If you book and then find someone in your party is not able to come then please contact me as soon as possible. If the place can be re-allocated then you will not be liable for the payment. If it is too late to re-allocate the place then you will still have to pay. **All cheques will be returned for you to destroy on the day if all your party turns up.**

#### A list

Zip Wire

Low Level Ropes

Aeroball

Giant Swing

#### B list

Sensory Trail

Archery

Zip Wire

Tunnel Trail

There are only 50 places for the activity day which will be on a first come basis. Please note that should two siblings choose different groups a helper/parent must be available for each of them.

Please contact Jo or Nicky or Mandy Hancock [amanda.hancock@virgin.net](mailto:amanda.hancock@virgin.net) as soon as possible for details.

When you shop online please consider shopping through: [www.http://www.easyfundraising.org.uk/causes/swindondowns](http://www.easyfundraising.org.uk/causes/swindondowns) and raise money for the Group. It won't cost you a penny as retailers make the donation as a thank you for shopping with them. Go to the website and then click on the retailer you want to use. When you make a purchase the retailer will give a donation to the Group. It is that simple!! Even if you don't want to use it for shopping you can still raise money for free by registering to do surveys or simply searching the net.

## SWINDON DOWN'S SYNDROME GROUP'S DINNER DANCE

Due to the huge success of our Charity Ball last year, many have said two years is just too long to get together socially. So next year, we are going to hold a Charity Dinner and Dance instead of a formal Charity Ball. We are still planning on making a small amount of money for our Speech and Language Therapy groups. However, there will be no auction, but we are planning on holding a small raffle.

The Dinner Dance will be held on Saturday 14th April 2012 at the Marriott Hotel in Swindon. The evening will consist of a fixed 3-course meal, including coffee and mints, a disco and a raffle.

**This event is open to all those over the age of 18.**

Tickets prices are £30.00 each and need to be bought and paid for by 31st January 2011 at the very latest.

We have also reserved 30 double rooms at the Marriott for this event. Price including breakfast is £72.00. If you are interested in booking a room, email me on [kkimwest@gmail.com](mailto:kkimwest@gmail.com) and I will give you a code to use.

If you wish to attend this spectacular event (please bring friends and grow our family), and have the chance to dress up for the evening (smart casual), then please contact Kim as soon as possible to book your tickets.



**THANK YOU**

Thank you to Cliff Puffett who arranged for £1,000 from the closure of the Computer Suite at the County Ground to be donated to our Speech and Language Therapy Group.

### Thank you Father Christmas

Thank you to Father Christmas for giving up his time in his busy schedule and making lots of children and young people very happy. The Christmas party was a great success and we all had lots of fun. Thank you to Mark Atree for dropping in and visiting past and future Salamander participants and talking to nervous parents about the course.



**THANK YOU**

to G4S

£500 matching money  
raised by Terry Parker  
from the Swindon Fun  
Run

### Coffee Afternoons

Croft Children's Centre, Old Town,  
Swindon, SN3 1RA.  
Coffee afternoons are on the first  
Thursday of each month at  
12.30pm - 2.30pm.



### **We have the most fantastic news!!!!**

Because of your support the Swindon Down's Syndrome Group have been awarded £6,000 by NATWEST Community Force.

The money will help fund the Speech and Language Therapy Groups next year. It is a fantastic amount of money and we are really grateful to NATWEST Community Force for supporting our families in this way and to all of you for voting for us and persuading so many others to do so too!!

Thank You

In memory of Kathleen Parker,  
Eileen Joyce and Tom McEnroe -  
we extend our sympathy to their  
families

## **Item's from Head Office you may find very useful**

Looking after someone: a guide to carers' rights and benefits 2011/12 The new edition of Carers UK Guide 'Looking after Someone' is now available to download free at

[http://www.carersuk.org/professionals/order-publications/item/971-looking-after-someone-a-guide-to-carers-rights-and-benefits-uk9024?dm\\_i=74C,MT1N,R8OPT,1UH3Z,1](http://www.carersuk.org/professionals/order-publications/item/971-looking-after-someone-a-guide-to-carers-rights-and-benefits-uk9024?dm_i=74C,MT1N,R8OPT,1UH3Z,1) or try <http://snipurl.com/215lzf>

This guide sets out carers' rights and how carers can get financial and practical help as well as help with combining work and caring.

### **FAQ's on Personal Independence Payment (PIP)**

Following feedback from the DSA and other organisations the Department of Work and Pensions (DWP) have developed some Frequently Asked Questions around the new Personal Independence Payment which is due to replace DLA for adults between 16 and 64 in 2013. These will help answer some of the concerns you might have.

<http://www.downs-syndrome.org.uk/news-and-media/dsa-news/854-faqs-on-personal-independence-payment-pip.html>

Netbuddy have updated their iPad Info Pack <http://www.netbuddy.org.uk/info-packs/apps-ipad/>

**Problems with your benefits? Our benefits advisers can help. Call DSA's Helpline 0208 614 5100**

If you need advice about behavior and/or medical conditions in Down's syndrome our advisers are here to help. DSA Call 020 8614 5100

**One Year Down This Path - A Fathers Perspective On Down Syndrome**

<http://www.youtube.com/watch?v=-jZoPggEfVQ&feature=share>

Do you have an education question? Call the DSA Education Adviser - Tue & Wed on 0208 614 5100

## **How to get the most out of your GP – new Contact a Family video**

[http://www.youtube.com/watch?v=IO\\_1PTQW8EU&feature=channel\\_video\\_title](http://www.youtube.com/watch?v=IO_1PTQW8EU&feature=channel_video_title)

Having a good GP can be invaluable. They should take into account a parent's concerns and ideas to enable joint decisions to be made about a child's healthcare. However a recent survey by Contact a Family showed that three quarters of families questioned felt their GP had no involvement in their child's condition.

Ella Baines, a GP and mother of a child with complex needs, has worked with Contact a Family to produce a video offering some useful advice about how to get the most out of your doctor.

Also, read Ella's top ten tips:

<http://www.cafamily.org.uk/index.php?module=newsmodule&action=view&id=709&src=@random4864ff40710ee>

or try <http://tinyurl.com/6375u2z>

## **My Rights, Your Responsibility – new info pack for parents**

**My Rights, Your Responsibility** is a new information pack for parents of disabled children. The new resource from Council for Disabled Children (CDC) gives information on your child's rights to access activities, community facilities and other services.

[http://www.ncb.org.uk/cdc/wider\\_projects/my\\_rights\\_your\\_responsibility.aspx](http://www.ncb.org.uk/cdc/wider_projects/my_rights_your_responsibility.aspx)

A Letter to New and Expectant Parents of a Baby with Down syndrome

<http://bellaverita.wordpress.com/2011/10/07/a-letter-to-new-and-expectant-parents-of-a-baby-with-down-syndrome/>

or try <http://snipurl.com/21cmy2>

## **'iPad Technology Helps Down Syndrome Student Communicate'**

<http://www.newschannel5.com/story/15875502/ipad-technology-helps-downs-syndrome-student-communicate>

## **Family Fund - Tip Off**

Just had a tip off from a colleague that the Family Fund are now targeting under 2s, 15 to 17 year olds and Grandparents. The fund still welcomes applications from all but the above groups will receive special consideration

<http://www.familyfund.org.uk/>

## **If you are on a low income, check with your energy supplier now for possible rebate!**

<http://www.cafamily.org.uk/index.php?module=newsmodule&action=view&id=717&src=@random48650298f19ce>

Hospital Communication Book - free resource to help people with a learning disability to communicate when they go to hospital

<http://t.co/upd9Q5cG>

**Working Together: Easy steps to improving how people with a learning disability are supported when in hospital** - Guidance for Hospitals, Families and Paid Support Staff

<http://www.hft.org.uk/Resources/Home%20Farm%20Trust/Family%20Carer%20Support/Documents/WorkingTogether.pdf>

My Kind Of A Future - A workbook to help young people with learning disabilities prepare for the future

<http://www.learningdisabilities.org.uk/publications/my-kind-of-a-future/>

Updated Free Resource From FPLD - Personal Planning Book. This book is to help people with learning disabilities to create a detailed personal plan. <http://www.learningdisabilities.org.uk/publications/personal-planning-book/> Takes a while to download.

Meeting the emotional needs of young people with learning disabilities - free resource

<http://www.learningdisabilities.org.uk/publications/meeting-emotional-needs-ypld>

**You are Not Alone - Caring for a son/daughter with a learning disability & emotional difficulties** - free resource from the

**Foundation For People With Learning Disabilities** <http://www.learningdisabilities.org.uk/publications/you-are-not-alone/>

New Blog - Downs Side Up - Thoughts, experiences, tips and information for those involved in raising and educating a child with Down's Syndrome. <http://www.downssideup.com/>

**A toolkit to help people employ their own personal assistants**

ARC has written a short guide (attached) to employing a new PA in the form of a toolkit, funded by Skills for Care. There is lots of advice, from sample adverts through to sample letters of appointment, contracts and even Health & Safety policy. It also talks about supervision and developing/training your new PA.

<http://panet.org.uk/wp-content/uploads/2011/08/3-personal-assistants-toolkit-WEB-v2.pdf>