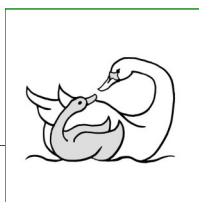


# South Bucks Down's Syndrome Group



In this newsletter you can read news from two members of our ADS (Adults with Down's Syndrome) Group. ADS is proving popular with those who attend and we would like to reach out to other adults with Down's syndrome who may not have heard about the group or know what it does. If you know of someone who might like to come along, please get in touch with Fiona Ellis, whose contact details are on the SBDSG Contacts List which you should receive with this mailing.

We are trying to gather **email addresses** for as many of our members as possible so we can send out information more frequently and speedily. If you think we do not have yours, or if you have a new email address, please send it to me (email address below).

Our new New-Parent Contacts Aisling and Carole, have already been acting in this role unofficially for a while. They can get in touch with parents who have newly-diagnosed babies with Down's syndrome and offer support as appropriate. If you know of someone in this situation who would like to talk to someone from SBDSG please get in touch with Aisling or Carole.

If there is enough support we will organise a  $\frac{1}{2}$ -day **NUMICON** training course for parents and LSAs. Please let me know if you are interested.

Your ideas, suggestions and contributions—for the newsletter or for SBDSG generally—are always welcome. Please pass them on to me, one of the trustees or a group organiser. **Judy Pantridge (Editor)** [judy@pantridge.wanadoo.co.uk](mailto:judy@pantridge.wanadoo.co.uk)

## Chessington Trip

We are planning to repeat this popular family outing on **Sunday 17th May**.

As in previous years, this will be subsidised by SBDSG. Remember to return the enclosed form if you would like to come.

## Report from SPARKLES

It's been a busy year for Sparkles with lots of new faces and huge amounts of money raised. Our Chair Carole Arnold stood down last year and had done such a tremendous job that she was replaced by two people who have split the role. Nick Lockley leads fundraising activities and Sheryl Pope provides parent and speech therapy liaison. We have a fabulous new therapist in Rachel Russell, whose enthusiasm and talent has made a big impact on the children and parents alike.

We have done a lot to raise Sparkles' profile in the past 18 months and consequently the membership and "catchment" has grown, with us welcoming families from across Bucks and many parents contacting us when their children are just a few months old. We are looking to offer half-termly sessions to the under-1s to look at early communication and feeding skills. We also hold coffee mornings and end-of-term activity days to provide time for children and parents to get to know each other better. Our termly parents' meetings are well attended and the commitment shown by parents is what makes Sparkles such a great group to be a part of.

In January Sara Rosenfeld Johnson, a world renowned specialist in her field, delivered training in Wycombe to more than 80 therapists, including many from the local area, on her approach to developing speech and feeding skills. The approach offers a structured and practical way to develop the strength and precision of movement necessary for speech clarity—activities include blowing, sucking through straws and chewing. We were delighted to see so many Parents and Carers at the evening workshop and we are now considering with Rachel how we can best adopt this programme for Sparkles children.

**TVAP**— Major construction work is going on at TVAP at present and future dates for SBDSG meetings have not yet been confirmed. They will be posted the website as soon as possible. Alternatively phone: Peter Jenkins 01628 522455

## New-Parent Contacts:

Aisling Jenkins	Carole Arnold
01628 522455	01494 464064
<a href="mailto:Aislingjenkins@sky.com">Aislingjenkins@sky.com</a>	<a href="mailto:carole@rnold.me.uk">carole@rnold.me.uk</a>

**SBDSG website: [www.sbdsg.org.uk](http://www.sbdsg.org.uk)**

## Activities

We would be interested to hear from anyone with ideas / experiences of successful activities for children and adults with Down's syndrome in the local area. If you have a favourite activity, club, or place you enjoy going to, please let us know. Others may enjoy it too, who have not already discovered it!

### Popstars Dance Classes (and Parties)

Classes held in Tylers Green, Chalfont St Giles and Amersham

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

**Shed at the Park**— an inclusive drama group meeting in Chesham on Tuesdays and Wednesdays [www.shedatthepark.co.uk](http://www.shedatthepark.co.uk)

### Junior Multi Sports Disability Club

7—11 year olds, Fridays 5 -6 pm at the Beacon Centre, Holtspur, Beaconsfield.

**Nicky Rigby writes:** My daughter Lucy, who is 21 years old, returned to live at home after three years at residential college. She started at Burchetts Green College on a "Pathways " course for 3½ days a week and needed to find something to do on Wednesdays. I contacted Starbucks in Marlow to ask if Lucy could do some voluntary work there. They took her on and she started last August clearing tables and stacking the dishwasher. She really enjoys her work. It's very busy and she has to work hard. She has to be an employee, because of Health and Safety regulations, and she earns the minimum wage for her 2½ hours a week. She also brings home a bag of coffee and is allowed

**From Bridget Campbell:** My son, Alexander, started at Foxes Hotel Academy in Minehead in September 2008. He is doing a 3 year course in Hospitality and Catering. He lives in a house with 13 other first year learners and is also learning all the life and independence skills he will need to be able to hold down a job and live independently when he finishes the course. He spent his first term working in housekeeping at the hotel, he will then do a term in the kitchen doing food preparation and a term in the dining room. Here is what he wrote about his first term for the Foxes Times magazine:



My name is Alex Campbell. I come from Bourne End.

I work in housekeeping and it was frightening at first as I did not know what I was doing. I have cleaned the bathrooms, hoovered, swept, mopped the floors and made beds.

The first few weeks were hard. I did not know what I was doing but

I had help from Jackie, Julie, Christine and my friends from the house. I am good at cleaning now. I use the right cloths and chemicals, and work safe so Jackie does not fall over my tray.

I have liked my first term and I am looking forward to going down to the dining room or the kitchen.

**By Alex Campbell**

**Did you know** that you can apply for a concessionary travel card for a child or adult with Down's syndrome? A companion's card is also available for a one-off payment. Both cards allow free travel on buses in Bucks and some further afield. For more information contact WDC : **01494 421232**

## Holiday opportunities — Judy Pantridge

Last Easter an offer came to us through the social services for our daughter, Joanne, to go on a holiday with a charity based in Windsor. We were surprised and rather apprehensive as no-one we knew had had any contact with this group. It was a difficult decision to let her go, to entrust our daughter to strangers, even though we had been assured that all the necessary safety checks were in place. We were encouraged by the application forms. They asked the appropriate questions for us to give the information we thought was needed for a carer to understand Joanne's needs. On the day of departure, when I met the helpers and Joanne's one-to-one carer, I felt much more at ease. They all seemed kind and caring, and sympathetic to the concerns of a worried mother letting her daughter go off with people neither of us knew. Joanne had a great time and returned happy and excited about all that had happened. Each child was given an individual photo book with photos of the various activities on the holiday—very helpful for talking through the holiday memories. It was good to see her so excited and happy to go off independently and we are glad she (and we) had this experience. I have spoken with our link social worker who has sent me a list of organisations which provide holidays or funding for holidays for children with disabilities. If anyone is interested in finding out more about these, please contact me and I will send you more information.