

Twenty One & Co—Autumn 2009 Newsletter

News from 21 & Co



Our **coffee mornings** at Norbiton Children's Centre and the Croft Centre are going well with quite a few families coming along to each one, which is very good news, and clearly something that members want. Upcoming dates this year:

Norbiton: 6 November and 4 December

Croft Centre: 20 November



Monday afternoon communication and siblings groups:

This year we have had quite a changeover of staff with Jenn joining Elaine to run the children's groups in September, then Elaine having time off for her hip operation and Mila joining us to take over from Elaine. Both Jenn and Mila moved onto new jobs in May,



Elaine returned to run the younger children's groups, Claire joined us to run 2 drama groups for our older children and Louisa took over from her in September. Did you keep up with that!

Our siblings group continues to be popular. We are very sad to say that Vanessa, who started with us 5 years ago, has moved on. We will miss her hugely and can't express our thanks for what she has done for us enough. But we welcome Morgan, who has taken over running the sibs group.

This term we are running 2 social communication groups for our younger children and 2 drama groups for our older children. The trial drama sessions in the second half of last term were a great success.

We've welcomed Louisa (drama group leader), Louise (drama group support) and Jo (children's group support) this term as well as a few children to both drama and children's groups. The children are already settling in well to their groups.



Pre-School Groups: these groups are run by Tatty Bowman and in great demand. Each September Tatty takes on more children and runs more groups! Children can start from 1 year. Please contact Tatty if you would like to know more. This term Tatty has 16 children in 4 groups!

New developments: We are looking at starting a **Saturday club** for our older children, from about 8 years old. More information to follow but we are currently looking for a venue, considering activities and looking at staffing needs. Quite a lot to be thinking about and we are not there yet but look out for news.

Alison Roberts, our Treasurer, moved to Abu Dhabi with her family in August. It goes without saying that she is stepping down as Treasurer. I don't know where to begin to thank Alison for everything she has brought to 21&Co, from being a founder member to taking on the Treasurer and fundraising roles. We will miss her as a friend and colleague and the children will be missed by all the friends they have made at 21&Co.

Trustees: As Alison has stepped down as Treasurer we needed a new one and I would like to welcome Mark Bowman as our new Treasurer. There was no gentle introduction for Mark and he had to get straight down to work!

I would also like to welcome 4 new trustees—Alison Press, Emma Morgan, Julia Darbyshire and Claire Griffiths. We are really excited to have them on board and they are already getting involved.



Spring Ball

**Put the date in your diary
Saturday 6 March 2010
At the Landmark Arts Centre**

More information to follow but do start telling friends
and family

We will need great Auction lots and loads of raffle
prizes so please start thinking about who you can ask
and what you can contribute!

Don't forget that this is our major fundraising event

WE NEED YOUR SUPPORT

News and Information from the DSA



Family Fund Extra

The Family Fund supports children with severe disabilities and serious illnesses living at home, where the parents/carers are on a low-income. The Fund works to provide the things a family need most – a washing machine, bedding, and clothing or perhaps a few days away – they aim to make a real difference to their lives.

In 2007/08 Family Fund helped 48,000 low-income families to the value of £28.2 million. The Fund provided this support in the form of grants, helping children and young people across a whole range of disabilities including learning difficulties, physical disabilities and mental health problems.

Family Fund Extra is the Fund's way of finding new ways to support and make a difference to all families that care for a disabled child or young person.

You can find out more—how you might be able to benefit and how you can help at the Family Fund Extra website: <http://www.familyfundextra.org.uk/Home.aspx>

SIBS—for brothers and sisters of disabled children and adults

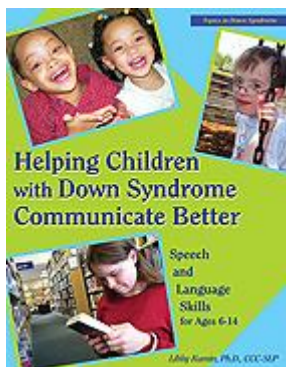
Sibs is the UK charity for people who grow up with a disabled brother or sister. They support siblings who are growing up with or who have grown up with a brother or sister with any disability, long term chronic illness, or life limiting condition.

There are pages for young siblings, adult siblings and tips for parents about how to support their children: <http://www.sibs.org.uk/>

Tell it Right campaign

This is the DSA's campaign for better, accurate, up-to-date information for parents who have a pre or post natally diagnosed condition such as Down syndrome. With earlier and non-invasive testing becoming available it is important that the right information and support is available at the time of testing. Sign up to the campaign here:

<http://petitions.number10.gov.uk/TellItRight/>



Mini Workshop with Libby Kumin

You can find Libby Kumin's latest book here as well as some activities to practice language and speech skills that you can use at home and throughout the day:

<http://www.woodbinehouse.com/>

[HomelsAtTheHeartOfCommunication.asp](http://www.woodbinehouse.com/HomelsAtTheHeartOfCommunication.asp)



DS-ASD

The second meeting of the DS-ASD (now styled ASD-DS) group took place at the Langdon Down Centre on 27 September. Parents with children also diagnosed as being on the autistic spectrum came from all over the country, so lots of parents and lots of children! Many thanks to Susannah and Stuart for organising this bi-annual meeting.

The DSA is now including a page in each Journal devoted to ASD-DS and there is a page on the website. You can also join a mailing list to receive Stuart's information and be in contact with other parents of children with DS also on the autistic spectrum.

Website: <http://www.downs-syndrome.org.uk/information/my-child/ds-asd.html>

Email list: <http://listserv.down-syndrome.net/SCRIPTS/WA-DOWNS.EXE?A0=DS-AUTISM-UK>

Guidelines for SLTs and the Tribunal Process

These have just been published by the Royal College of Speech and Language Therapists. It is a long document but if you are in dispute or likely to be in dispute over SLT you might find it useful reading and worth drawing the attention of your local NHS SLT department and LEA to it.

Quotes:

"Speech and Language Therapists have a duty of care for any child they are writing advice for. Advice should be written with the needs of the child in mind, not the available resources."

"Any models of intervention, facilities and resources recommended should relate to the speech language and communication needs of the child and not to the speech and language therapy resources available."

(paras 3.2.1 and 3.3.1)

http://www.rcslt.org/news/send_best_practice

2010 Conferences and Courses

The Down's Syndrome Association has just published its Learning Opportunities Programme for 2010 and this year we are pleased to be offering 25 conferences and courses throughout the year, in Birmingham, Bristol, Cardiff, Leeds, Teddington and Manchester.

If you would like a copy of the full programme please contact Lesley Alabaf at the DSA on 0845 230 0372 or email lesley.alabaf@downs-syndrome.org.uk. Alternatively their website www.downs-syndrome.org.uk has full details of the programme for 2010, and includes details of the special discounts available in 2010.

The conferences and courses in the first 6 months of next year at Teddington are:-

- 3 day Co-worker Training Course - 25th Feb, 25th March and 22nd April
- Including Pupils with Down's Syndrome In Mainstream Primary School—Thursday, 10th June

DownsEd Shop is online

The DownsEd shop is online—you can buy resources, Christmas cards all online. The See and Learn series can be bought as ready made packs but don't forget that you can download the materials from the website for free to make your own resources. Find out more here: <http://shop.downsed.com/epages/DownsEd.sf>

Waitrose Twickenham collection for 21&Co

The Twickenham branch of Waitrose has 21&Co as one of the three charities they are supporting this month.

Every time you shop at this branch you will be given a token that you can put in one of the charity boxes by the tills.

Each month Waitrose choose three charities and allocate £1000 in total. At the end of the month they divide up the £1000 according to the number of tokens in each box.

So, if you shop at Waitrose or could shop there please go to the Twickenham branch—and ask everyone you know to go there too—and donate their tokens to 21&Co—if you're lucky you'll be able to sneak more than one token!

We have Rachel Derrick to thank for nominating us .

For Something Special Fans



Justin Fletcher is appearing in Cinderella at the Capitol Theatre, Horsham from 10 December to 3 January. He will be playing Buttons.

You can find out more at the theatre's panto website: <http://www.horshampanto.com/>

Clothes for Sturdy Children

I know that many of us have children who are on the small side for their age but quite a few of us have children who are rather more sturdily built or who perhaps aren't particularly larger than average but have a big tummy. If you are struggling to find clothes for a larger child then you might find these resources helpful:

www.sturdykids.co.uk: website recommended by a parent on the UK Down syndrome email list. Not a lot on it at the moment—mostly school uniform—but they have plans to extend their range. They have a measuring guide and do shorter leg lengths in bigger waists.



Next: www.next.co.uk. The Next catalogue has a few items for boys and girls that they do in their 'plus' size. On the website you have to display each item to see the sizing options to see if they do it in plus sizing or not which is a bit annoying! But at least they do have some fashionable clothes in a more generous fit. For school uniform they have a lot of different styles and I noticed that they have a slightly smock shaped pinafore which looks as if it would be a good fit for rounder tummies. I have never seen the larger fit clothes in store.

BHS: www.bhs.co.uk: Still doing their 'generous fit' school uniform. They already have school uniform items on sale so if you need anything look now! I can personally recommend this range. I got summer dresses for Sophie 2 years ago and her winter uniform last year and it is all age appropriate and a good fit. I actually didn't believe it would be so much bigger so when I ordered her summer dresses the first time I still ordered one size too big and they were huge!

Boden: www.boden.co.uk: This is another personal favourite. They have a comprehensive garment size guide for all their children's clothes so you can compare waists, hips, leg length, rise and so on to figure out what will fit best. I find their boys' 'baggies' and 'sailing trousers' really roomy—they easily accommodate a nappy.



Let me know if you have any recommendations well fitting clothes for larger children or for smaller children that are also what children want to wear. I know that getting school uniform for a very small child can be difficult so please pass on any recommendations.

Stick on Tattoos !

This could be of interest to any parent but particularly if you have a runner or escape artist: stick on tattoos that have a contact number in case a child gets lost: It is an American site—cost \$20 for 24 tattoos : <http://kidsafeink.com/>. If anyone tries them out let us know how it works for you.

Articles and Information

Stuart Mills, Information Officer at the DSA, has recently sent out links to a load of articles on topics that are of interest to us parents. He posts to emails lists set up by the DSA and to the UK Down syndrome email list so you can receive his information directly if you subscribe. This is a great resource—Stuart's information comes from a wide range of sources, including other DS organisations, which would be hugely time consuming to look for, even if you knew what was out there to look for! Many of these articles are written by or with parents so they are not theoretical.

Creating successful mealtimes/Moving ahead with food: matching oral motor skills and food textures: Joan Medlan Guthrie, 2007

http://www.ohsu.edu/cdrc/oscsn/documents/Creating_Successful_Mealtimes.pdf

Throwing—suggestions for managing throwing behaviour: Down Syndrome Victoria:

<http://www.dsav.asn.au/Sharon/Throwing.pdf>

Practical Approaches to Behaviours that Drive You Crazy: Disability Solutions:

<http://www.disabilitysolutions.org/newsletters/files/four/4-1.pdf>

Magic and sparkles: a creative approach to modifying children's behaviour - Mandy Wood and Gillian Bird (Psychologists at the Down Syndrome Educational Trust, Portsmouth, UK):

<http://www.down-syndrome.org/practice/321/practice-321.pdf>

Strategies for Children who Wander: DSA Queensland:

<http://snipurl.com/shm6y>

Dealing with Death: DSA New Zealand:

<http://www.nzdsa.org.nz/assets/dealingwithdeath.pdf>

Surviving a Trip to the Hairdresser: DSA New Zealand:

<http://www.nzdsa.org.nz/assets/hairdresser.pdf>

Toilet Training: by Donna Heerensperger, RN BScN, Clinical Resource Nurse: Canadian DS Society:

http://www.cdss.ca/images/pdf/parent_information/toilet_training.pdf

Stop Running by Building Skills: Carol Johnson, Information Manager, CDSS:

http://www.cdss.ca/images/pdf/parent_information/stop_running_by_building_skills.pdf

Stubborn Behaviour, A Different View: Carol Johnson, Information Manager, CDSS:

http://www.cdss.ca/images/pdf/parent_information/stubborn_behavior.pdf

"The Groove" - Need for sameness, repetition and order in people with DS

<http://www.advocatehealth.com/luth/documents/downsyndrome/groove.pdf>



Win a 5 day ski break!
12 November to 16 November
Competition closes 25 October (be quick!)

Skiing for All is celebrating the New 2009/10 Ski Season in style by giving away a fantastic 5-day ski break in Zell am See, Austria. The Competition is open to anyone with a Cognitive Disability, including complete Skiing Beginners

The winner will receive:

- **4 nights in a luxury self-catering apartment** sleeping up to four people, right in the heart of Zell am See
- **2 days of one-to-one skiing sessions** (Friday and Saturday 10.00 – 15.00) with [Anna](#), a British Psychologist and an Austrian-qualified Ski Instructor, at the Kaprun Glacier (covered with real snow all year round)
- **Skipass**
- **All skiing equipment hire**
- **Free return transfers**
- **And more!**

See the Skiing 4 All website: <http://www.skiing4all.com/Promotions.html> for more information and the competition entry form.

Details were sent out by Stuart at the DSA

And finally

We welcome contributions from our members. Please let me know about articles, shops, services, etc that you have found helpful.

If you have anything to sell or give away it can be included in the newsletter or regular emails.

You can email me—sue@ifnotnow.co.uk—or phone 07817 537213 (please leave a message or text if I don't answer).