

downsyndrome OK

Help for people with Down's Syndrome, parents, carers
and professionals in southeastern England

Affiliated to the Down's Syndrome Association

www.downsyndromeOK.org.uk

news
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Dear Members and Friends,

Plans for our promised **EDUCATION DAY** are now in hand. Please note the date and encourage the teachers of your children and young people to keep the day free. We all appreciate that they give up a Saturday for this informative event but those who attend assure us they not only find our speakers helpful for their pupils with Down's syndrome but also for encouraging others in their schools and colleges. We are inviting speakers who specialise in the topics which have been requested by both professionals and parents.

Our annual **CHRISTMAS PARTY** for our younger families is again on the first Sunday in December but has moved! A different URC Centre - **COBHAM**. The invitation is enclosed and we ask you please to book early to help our volunteer team.
Shirley Quemby, Editor

DSA TRANSITION WORKSHOP

DSA advise there will be a one day workshop on Transition to Adult Life at national office, The Langdon Down Centre, 10 am - 3 pm (including lunch) on **Thursday 12 November**. dsOK members who have attended one of these have found it helpful. Parents and carers, especially in Greater London and adjacent areas, whose youngster is approaching or into their teens, are particularly invited. Full details are on the DSA website (Transition Workshop) or telephone Lesley Black for more information.

dsOK CHRISTMAS PARTY

Same entertainer - super Stephanie - but a different venue - where you came in May for our Family Day. The programme is enclosed so please hold the date - **Sunday 6 December** - and book in good time for this annual fun activity for our younger families. The cost is the same and please remember the gifts 'from' Father Christmas for your children!

FAMILY DAY MAY 2016

Be sure to note **Saturday 14 May** in your diaries as our next Family Day is being arranged for that day. A helpful talk and family fun for all ages are being planned.

dsOK NEXT EDUCATION DAY

Note **Saturday 8 October 2016** and spread the word, please. Several parent members have already offered to be on hand to help nearer the time and trustees would be pleased to hear from more. The Trinity Centre in Wallington will welcome us for the day. Public transport is handy and there is parking on site.

DONATIONS TO dsOK

Since arranging for VirginMoney to process donations to dsOK which are given through our website, several generous gifts have been made to us. VirginMoney make sure Gift Aid is collected on our behalf. dsOK Trustees wish to express our gratitude for the funds which have been raised and given so that dsOK may continue to work towards creating and developing the conditions which will enable all with Down's syndrome in our area to attain their full potential. Meetings which help families to learn more about Down's syndrome are subsidised by dsOK which means our funds can run low without the continuing vital support of donations. Thank you to all kind donors.

AWARD TO CLAUDE FOR SPORTS

Claude Gonsalves has reached Level 2 in Badminton and has also won a Jack Petchey Award for taking part in multi-sports. This Award gives him a certificate, a gold medal and a badge. Congratulations, Claude!

PICNIC FUN



"On Sunday 21st June the Malden & District Society of Model Engineers Ltd. at Thames Ditton once again opened its gates to welcome various special needs groups, including dsOK and 21&Co. My wife and I were delighted to come again, after we enjoyed the day a couple of years ago. Having interviewed two satisfied customers, this correspondent can inform our readers that the best bit was 'going in the tunnels' (Mikey, 6 and Lucy, 3, for once in agreement with one another) and that they are already looking forward to next year.

"In addition to the trains, it was good to catch up with other families like ours and compare notes on the triumphs and challenges of our children. For those of you who didn't manage to make it, even if you aren't keen on the trains, there is a frantic amount of waving goes on and the excellent refreshments are worth the trip alone - I would recommend a visit next year. Thanks again to the Malden Society."

Reported by John Seymour

MY PERSPECTIVE PHOTOGRAPHS

Printed in the DSA *Journal* and on their website, we could all enjoy the talent of the people with Down's syndrome from across the world who sent in their prints for this competition. Congratulations to those of our dsOK members who are winners and runners up. Caroline Lawless, mother of finalist, Hugh, wrote to dsOK: "Hugh's photo was given the title *Alliance* and showed a number of hands together including his own in an image of friendship. At the time, Hugh was a 6th form pupil at Cricket Green School, Mitcham, and his photography teacher explained this is the image Hugh wanted to take. The DSA have asked to use it in their literature."

ANOTHER PHOTOGRAPHER

On a BBC News App in June, wildlife photographer, Oliver Hellowell, was quoted as explaining that he "sees the world differently due to having Down's syndrome".

DSA MEMBERSHIP

Free membership of dsOK is open to all DSA members but DSA membership has to be maintained for dsOK *news* to continue to reach you. Most are posted but, if you wish to receive yours by email, send your name and membership number or postcode to info@downsyndromeOK.org.uk with the subject 'Newsletter'. If you move house or change your email address - we need to know, please!

EMPLOYING A PERSONAL ASSISTANT

For readers considering guiding their son or daughter to use their direct payment towards employing a Personal Assistant a toolkit is available from DSA at Teddington. Entitled *Employing personal assistants*, it weighs about 2 lb/900g and comprises six clear booklets covering the benefits, recruitment, managing and training of the employee plus "Sorting out problems". Templates suggest wording for all aspects of the necessary paperwork. The publisher is Skills for Care, West Gate, 6 Grace Street, Leeds, LS1 2RP Tel. 01132 451 716 email: info@skillsforcare.org.uk

SURREY INDEPENDENT CARE

A member reports Surrey has a care agency to help adults who wish to employ a Personal Assistant using direct payments. Clients outside Surrey are accepted. Not only is the client able to appoint the Personal Assistant of their choice but additional activities are arranged enabling clients to meet and socialise. Our member has found the PAs are quite young, act as a buddy, and are drivers who have been well trained. The cost is £17.80/hour. Contact County Care Independent Living tel. 01483 224 183.

WILLS & TRUSTS

Families which include a member who has a disability are advised to seek experienced help when writing their Will. Royal Mencap offers free 'Planning for the Future' talks from time to time which indicate the problems and pitfalls of which parents should be aware. dsOK have previously had speakers on Wills and different types of trust, the last talk being reported in dsOK *news* No. 31. Our adviser on that occasion reminded us also of the importance of Lasting Powers of Attorney. Where no family members are willing or able to act as trustees, Mencap has a trust company which can do this work. For more information contact Julie Schwarz on 020 7696 6932 or go to www.mencap.org.uk/mencaptrustcompany

A YOUNG ENTREPRENEUR

On a BBC News App in July, a friend heard about a young entrepreneur with Down's syndrome who runs her own fashion business. Well done to her!

DSA PARENT GROUPS

Many of these began as Branches but some years ago all were asked to become companies and charities in their own right and affiliate to the DSA. Branch committee members and charity trustees in different parts of the country have met for sharing experience from time to time but with little continuity. Earlier this year, Nicola Enoch, mother of a ten year old, invited representatives from all over the country to help to set up a forum/consortium of parent support groups: Down's Syndrome Parents Support Groups Network (DSPSGN). Nicola envisaged sharing information, resources and best practice to create a central hub and hopefully stop reinventing wheels! dsOK were in full support but were not free to attend in Leamington Spa on 11 June. However, Lu Cooper, founder of Carshalton's Get on Down's group, reports for dsOK on her day at the new forum, summarised below (*fuller report from dsOK Editor - thank you, Lu*).

The meeting was attended by about 50 delegates from 20 support groups around the country and organised into two main events: sharing best practice and workshops. Sharing best practice covered midwifery training, early development and social groups, twilight hours initiative and literacy. The workshops included early years, school years, adulthood, training and research, PR and Advocacy, governance, speech and language and resources. Talks on a fabulous computer based learning tool and on Cerebra's 1000 family study rounded off 'a great day'. Another meeting will be planned for the new year.

FAMILY DAY MAY 2015

The families and friends who came to the URC church centre in Cobham - a new venue for dsOK - had a great time with dance, drama, lunch and party games. Although we did not have formal speakers this year, much information was shared during the day whether the family member with Down's syndrome was very new, of school age or a working adult. Special thanks to Hannah Sampson, who has Down's syndrome, a professional dancer with the Stopgap Dance Company, who told us about her life and the countries she has visited with Stopgap.

VISUAL SEX EDUCATION

A teacher of deaf pupils has described to us a DVD *The Primary Guide*. Videos are available in standard format and as a subtitled version. Carefully timed pauses are featured and large clear subtitles make this resource suitable for pupils with a range of communication difficulties. The DVDs are accessible and user-friendly, with easy to use menu choices, ideal for teaching children and young people with learning disabilities. This could be a useful resource for a group or school. Each DVD may be previewed online at www.lifesupportproductions.co.uk Contact Wilf Parsons, Life Support Productions, PO Box 2127m London NW1 6RZ or tel. 020 7723 7520.

DOWNSSIDE UP

This website includes useful ideas for parents looking to teach and increase the abilities and confidence of a youngster with Down's syndrome. In the Adults section there are photographs of Hannah Sampson who danced for us in May and Kate Powell, editor of the DSA magazine *Down to Earth*. Visit www.downssideup.com or follow the link from the Twincess website (see next page).

The views expressed in articles in this newsletter are not necessarily those of the company. No responsibility can be accepted for services described.

**Contributions for the next issue to the Editor by Sunday
13 March 2016 please**

FIVE TO THRIVE

Surrey Family Information Service have published four fascinating pages of an article which shows "The things you do every day that help your toddler's growing brain". It leads with "The toddler brain is amazing ..." followed by "baby brains are getting built, toddler brains are getting organised". Brain cells form in response to experience. Baby was born with very few connections yet in the first year the brain doubles in size with billions of brain cells connected. To adapt this fascinating information to stimulating our baby with Down's syndrome, we need more emphasis on all the experiences and great patience because results will usually take longer. The five simple things recommended to feed the brain of our baby/toddler are: Talk, Play, Relax, Cuddle and Respond, each with a paragraph explaining reasons. Parents may email SUBSCRIBE to parentspages@surreycc.gov.uk to receive free Parents' Pages.

TWINCESS WEBSITE

This delightful title refers to identical twins, Abigail and Isabel, each born with Down's syndrome in June 2011 and who are now starting school. Their parents in Chorley, Lancashire, have set up a website: www.twiness.co.uk which includes not only much encouraging reporting for other families on the sisters' progress but also advice on the family's efforts to publicise and explain Down's syndrome and increase funding for this work. A page of interesting links is rewarding to check out, too.

PORTAGE SUPPORT

Portage was brought into this country some years ago. Portage workers are peripatetic and visit the homes where there is a pre-school child with special needs. They are trained to observe the level of achievements of the baby then suggest to parents what they can teach next with ideas on how. However, there could be a waiting list - as there is in Sutton. Do not be discouraged. Take an interest in the progress of any baby or child who is around the age of yours. This will help you to see what needs to be taught next. When that child becomes more advanced than yours, find another baby to observe. This is more positive than seeing more able babies progressing faster than yours and feeling envious. Most babies with Down's syndrome will develop skills in much the same order as do other children - extra patience is needed to help yours to get there! Be sure to keep all your teaching visual and fun, breaking each stage into very very small steps. It often helps to teach the last step first. Download from the dsOK website: *A booklet for Nursery and Reception staff* for ideas which also includes notes relating to health.

STARTING SCHOOL

The Downs Side Up website (www.downssideup.com) illustrates an amazing variety of simple but vital needs and ideas for the family whose child is about to start school. DSA is there plus DownsEd (now Down Syndrome Education, tel. 03003 300735 email: hello@dseenterprises.org) and others. There is also guidance for teaching teenagers.

PAEDIATRICIAN REQUEST

A paediatrician at St. Helier hospital, Carshalton, has asked that leaflets be made available for new parents of a baby with Down's syndrome. dsOK trustees are working with Lu Cooper, founder of Get on Down's, to supply suitable information. Would any parents like to tell your Editor what you wished you had been given at the time of diagnosis?

ONE STEP AT A TIME, SUTTON

This active playgroup was formed as a charity in 2014 and creates a safe haven in the garden for children with special needs to relax and play together. Outings and fundraising events are also arranged. Visit www.onestepatime.me.uk or tel. 07480 662 460 for more information.

BOOK BY A SISTER

Following the reference to the book *I Love you Natty* in dsOK news No. 35, Mia and Natty's Mum, Hayley Goleniowska, have created a blog entitled *Downs Side Up* and published a set of conversation cards providing invaluable information for parents whose baby has been diagnosed as having Down's syndrome.

Visit www.downssideup.com and www.amazon.co.uk/Talking-About-Downs-Syndrome-Conversations-for-help-and-guidance-for-the-whole-family.

NUMICON NEWS

The Numicon method of teaching mathematics visually has been found by many of our members to combat any unwillingness to study numbers. Keep up to date by joining Oxford Owl. To receive regular updates and a taster of the Numicon teaching, planning and assessment resources available, register at www.oxfordowl.co.uk/numicon Find here School Improvement Pathways including Problem Solving in Mathematics and Mathematics Reasoning.

NETWORK INTERVENTIONS

As always, the newsletter from this organisation contains sensible advice for parents facing behaviour problems. A cause might be due to gaps in a child's social development and a blog is offered for more information. If a child is not happy with being expected to do homework having been in school all day, Network Interventions can suggest ways round this! They remind us of their free coffee mornings on a Monday at their Epsom Clinic. For details tel. 03333 440201 or email: info@networkinterventions.com

CROYDON CARERS' IDEAS

An email newsletter is available from Croydon Carers which lists a variety of activities especially useful during school holidays. Not all are restricted to residents of Croydon. The Centre's main service is to provide advice and information around education, health and social care to parents/carers of children and young people (and young people aged 16 - 25 directly) with special educational needs and disabilities. Carers Support Centre, 24 George Street, Croydon CR0 1PB. Contact jennyjones@carersinfo.org.uk or tel. 020 8649 9339.

KIDS CROYDON

This organisation also offers help on SENDIAS (Special Educational Needs and Disability Information Advice and Support). Contact KIDS, Suite 35, Challenge House, 616 Mitcham Road, Croydon CR0 1AA, tel. 020 8684 2878 or email croydon@kids.org.uk

MY BABY WANTS TO WALK

We are tempted to help our little person to put their weight on their legs by holding their hands, maybe with two people or walking behind. Our child with Down's syndrome needs to experience learning to balance. For this, their hands need to be below shoulder height or even lower - a bit hard on the adult's back but important!

WORDS OF SONGS ON YOUTUBE

A member reports there are words of songs on YouTube. Singing often helps with cheering up and singing certainly encourages fluency for someone learning to talk. A child might learn and repeat the last line of a nursery rhyme first.

HELP WITH LITERATURE

Helping our youngsters to keep up with understanding the basics of stories and history all strengthens their confidence. Parent members find comprehension is improved by reading Horrible Histories, Rapid Response, graphic novels of all Shakespeare's 'violent' plays and cartoons. Fun and enjoyment of reading increase!

DANCESYNDROME

From the Twincess website, visit www.dancesyndrome.co.uk to learn about award winning leaders of dance, some with Down's syndrome. They state they are "dancer led, disability inspired". For more information email: info@dancesyndrome.co.uk

DANCE FOR PEOPLE WITH DOWN'S SYNDROME

Angelina Alessandre MBE created classes in London for children with Down's syndrome more than 25 years ago based on experiences in Hungary (Peto Institute) and England. Dr. Ron Heavey MBE was the pioneer who gave her specialist training. Ballet-like exercises are used to achieve good posture and these lead to graceful movement and the ability to learn choreographed dances to a variety of inspiring music. The dancers enjoy opportunities for personal expression and sharing with others. Benefits of this approach are co-ordination, co-operation, concentration, communication and a gain in confidence. Saturday classes for ages 12 - 35 are full but Angelina offers a two day training and follow-up to anyone (with interest and a little flair) wishing to set up classes themselves. To find out more, visit www.asneeds.co.uk or email info@asneeds.co.uk or tel. Angelina on 020 7585 2431 for an appointment or email Elisabeth on elisalucia@talktalk.net.

THE LARONDINA DANCE COMPANY

This group sprang out of Angelina's classes 12 years ago and meets in Battersea on Thursdays. Their mature dancers have displayed their talent on many stages in this country and abroad. Elisabeth Blackwell, their Communications Officer, writes: The two oldest are now 45 and lack neither in fitness nor speed. Visits to a Saturday or Thursday class may be arranged on request.

FREEWHEELERS THEATRE COMPANY

This remarkable group of people of various ages is far more than a theatre company. It is a multi-media company, founded in 1989, which brings disabled and non-disabled artists together to create innovative work in drama, dance, film and music, challenging perceptions. Visit www.freewheelers theatre.co.uk for their forthcoming programme with plans for November, December and beyond. There are both major productions and regular weekly activities. On Monday evenings there are Youth Theatre sessions at The Bridge Centre in Leatherhead and, on Fridays, Dance and Media Workshops in Cobham. Actors with Down's syndrome gave excellent performances in *A Twist of Oliver* mentioned in our last dsOK news. For information on Freewheelers, including other Dance and Music groups, email info@freewheelers theatre.co.uk or tel. 07599 077044.

THAMES EXPLORER TRUST

Information about activities along the River Thames reach your editor around school holiday times but it is not always possible to send these attractive details out to members. If your family would like to explore London's great river with experienced leaders do keep an eye on their website. Children and young people of all abilities are more than welcome (with parents of course). Wildlife, archaeology and fun feature in their plans. Visit www.thames-explorer.org.uk or tel. 020 8742 0057. Back numbers of dsOK news will show you the type of activities, and times in the year, when opportunities arise. Mention you are downsyndrome OK members.

DISABILITY SPORTS COACH CLUBS

All the details in dsOK news No. 36 in Sutton reopened in September at 11 - 12.30 on Saturdays at the David Weir Leisure Centre SM5 1SL. Activities are for children and adults with disabilities aged over 11 and newcomers will be especially welcome. Visit www.disabilitysportscoach.co.uk/clubs or tel. 020 7021 0973 or turn up with your £2.50 fee. These clubs may be found all over London.

CAPITAL TO COAST SUNDAY 3 JULY 2016

During the autumn, we hear of keen fundraisers thinking of signing up for the annual Brighton Ride. For a less crowded, pleasanter ride, well organised and with a choice of distances, we should direct these friends to Capital to Coast as The Down's Syndrome Association is a beneficiary. To register to ride or help, visit www.capitalto coast.org.uk or tel. 020 8420 6944 or email info@capitalto coast.org.uk and say you are a member of downsyndrome OK.

FUN ON WHEELS

Sutton Ramp Events - offering spaces for BMX, skate boarding and even scootering - is now called Urban Youth Action. We understand groups meet in several of Sutton's parks. Teaching is offered and refreshments are for sale at sessions. Visit www.urbandyouthaction.co.uk (where you will find lots of people in front of a large photo of St. Helier hospital) or tel. 020 8770 0944. An indoor venue is being sought and volunteers 14 - 18 and over 18 will be welcomed, too.

BLACKPOOL HOTEL INVITATION

dsOK has been contacted by the Bond Hotel in Blackpool. We understand groups of people with disabilities are welcome and offered a wide variety of activities with plenty of support and help. Groups of eight or more, not families, may be funded by Blitz. www.bondhotel.co.uk

DATES FOR YOUR DIARIES

Sunday 8 November	meeting of trustees
Thursday 12 November	DSA Transition Workshop
Sunday 6 December	Christmas Party, Cobham
2016	
Sunday 10 January	meeting of trustees
Sunday 13 March	meeting of trustees
Saturday 14 May	Family Day
Sunday 3 July	Capital to Coast cycle rides
Saturday 8 October	Education Day

TRUSTEES

All trustees are available to DSA and dsOK members seeking help or support. E-mails can be sent to <firstname>7@downsyndromeOK.org.uk (note the extra 7)
Website www.downsyndromeOK.org.uk

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