

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,

As the evenings draw in and the trees gain glorious colours, your trustees are busy planning future events. May we specially welcome new parents who have contacted us and look forward to meeting you. The annual Christmas Party is arranged for Sunday 7 December at the usual spacious hall in Epsom. Children up to about age 15 enjoy this fun event. Families meet, giving a great opportunity for brothers and sisters to meet others with Down's syndrome in a warm and cheerful atmosphere. There will be musical activities led by DJ Stephanie, modelled balloons to take home, Christmassy crafts, tea and Father Christmas. Please book in good time, the programme is enclosed or downloadable on our website. Only £7 per family is required beforehand with your names.

Our next Family Day, fixed for Saturday 9 May, will include activities and drama for children as well as for members seeking helpful information. Please keep the date and plan to bring the family for an informative and social occasion. We are seeking a suitable venue which will be announced on our website when confirmed.

Shirley Quemby, Editor

TRUSTEES INVITE HELPERS

dsOK trustees enjoy organising events in support of our members, whether your child is new, growing up or considering leaving home. However, we are all family people and feel short of help. This is limiting the activities we are able to offer. We have ourselves benefitted from active organisers over the years, leading to improving confidence and independence of our sons and daughters. We regret not being able to arrange discos and bowling for our members' families and Education Days to increase the knowledge in schools of the learning profile of pupils with Down's syndrome. We particularly feel the need for a Social Secretary (or two to work together) please. Have a chat with a trustee if you would consider this contribution to dsOK.

BOOK BY A SISTER

As a member of Down's Syndrome Scotland, dsOK receives *Full potential*, its twice yearly magazine. The current edition tells of a book written in Cornwall by a 9 year old sister which will help other children who become siblings of a baby with Down's syndrome. *I Love You Natty: A sibling's uplifting introduction to Down's Syndrome* by Mia and Hayley Goleniowska from Downs Side Up blog, publisher: Downs Side Up, price £5.99 plus p&p (Amazon paperback). The review tells of a variety of contents including notes and poems written by Mia, discovered by Mum, Hayley, around the house and includes Mia's drawings and family photographs. Hayley writes: "This is exactly the kind of book I searched for when Natty was born to read with Mia at bedtime. I believe it will have a positive impact on new parents as well." Two extracts quoted from the book: "Mummy and daddy explained that Natalia has an extra chromosome in every building block of her body, which I think looks like a jelly bean. It is just a part of who she is, like we both have brown eyes." And: "We all need extra help sometimes..."



NEW BRISTOL STUDY

Feeding and autoimmunity in children with Down's syndrome is the title of a study described in the magazine of Down's Syndrome Scotland and initiated at the University of Bristol. Babies with Down's syndrome aged up to 8 months are invited to take part for which the majority of the study will take place at home. The babies will be followed until they are 5 years old to try to identify factors that could increase the risk of conditions where the body reacts against its own cells. Most babies and children will not develop autoimmune conditions but this work could enable the risk to be lowered. Visit for more information www.bristolnutritionbru.org.uk or tel. 0117 342 1756 or email: fades-study@bristol.ac.uk

MARVELLOUS

This film, on BBC2 on 25 September, dramatised in a most delightful way the life of 68 year old Neil Baldwin, a man with learning difficulties who had decided to be happy. His likeable personality and persistence led him into circus work, football support with Stoke City, full acceptance at the local University and friends who included Royals, politicians and an Archbishop. Mainly acted by Toby Jones, from time to time during the film, we meet the real Neil, of interest to all of us whose lives include people with learning difficulties. The author, Peter Bowker, is a former teacher of young people with special needs.

DSA E-NEWSLETTER

As the DSA Journal is only published twice yearly it is pleasing to note that a more frequent e-newsletter is now also available. A note on the DSA website announces the October edition has just been sent. Any member who has not received their copy is invited to contact info@downs-syndrome.org.uk with your up-to-date email address.

THE DSA HEALTH BOOK

DSA has sent copies of this book to adult members with Down's syndrome enabling recipients to be prepared when visiting a medical professional. Personal information should be filled in by the member, with help if they wish, and their GP. This preparation will be helpful when the adult with Down's syndrome sets up their annual health check but could be useful if the member visits a medical professional whether unexpectedly or for a regular appointment. Replacement pages are available from the DSA website. A website www.dshealth.org is given to guide GPs whose experience of a patient with Down's syndrome could be limited. DSA specially asks for comments from owners of the *Health Book*, their parent or carer and from GPs. Send approval and suggestions to info@downs-syndrome.org.uk when you have read, and possibly used, the *Health Book*.

LEAVING HOME

Deciding where to live can be a stressful situation for families, and it can be difficult to know where to start. The DSA has created a new series of resources on supported living for families, from the early stages of thinking about where to live to dealing with life in your own home. Download the series from www.downs-syndrome.org.uk and search on 'Adulthood'. In addition, visit www.learningdisabilities.org.uk for a downloadable booklet, *Leaving Home Moving On*.

SUPPORTED LIVING AND QUALITY OF CARERS

Many of our parent members have been putting in a huge contribution towards the independence of their son or daughter with Down's syndrome. At some time, that support and care must be handed to someone else. The move from the family home tests the results of all that teaching and encouragement to be independent but the young adult continues to be, to varying degrees, naive and vulnerable. How much time and supervision will family members have to continue to provide, to augment the care available, to ensure the young person is still stretched and stimulated in the new setting? Will there be intelligent conversation? Paid carers are often on restricted hours and could be concerned mainly with the physical care of their client.

THE CARE ACT

Sutton Mencap recently held a meeting for its members at which Sutton's Executive Head of Services for Adults and Safeguarding explained plans for the forthcoming Care Act. Many changes will come into force next April (2015) with more during the following April. Consultation has been thorough and it appears there is general agreement that the Act will work. By Googling 'Care Act', your editor found a helpful summary by *The Guardian*, a report by Surrey County Council and of course the Government explanations, the latter being in Easy Read.

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
29 March 2015 please**

ADVOCACY FOR ALL

This remarkably active organisation supports speaking up groups for people with learning difficulties mainly in Kent and South London boroughs. There are colourful newsletters illustrating activities enjoyed by members which include visiting libraries, museums, or simply learning how to travel to London in a group to see some sights. Members discuss and agree their plans. There have been visits to schools, hospitals and a fire station. Members are keen to share their needs and experiences with professionals including explaining the need for leaflets to be in Easy Read form. Tel. 020 8300 9666. For the Kent Office tel. 01233 668 518 and the Sutton office 020 8669 0500. www.advocacyforall.org.uk

PEOPLE FIRST

This national charity is run by and for people with learning difficulties to encourage members to speak up for themselves. It is a self-advocacy organisation which supports local groups in London boroughs and across the country. Its national office is now at 336 Brixton Road, London, SW9 7AA, tel. 020 8874 1377 or visit its website www.peoplefirstltd.com

SIMPLE SIGHT SAVERS

A Consultant Ophthalmic Surgeon recently gave a talk on this subject. Many of us will know that our son or daughter with Down's syndrome has poorer sight than we would wish. The speaker advised regular sight testing and care with food for saving sight. Eye friendly nutrients are found in many fruit and vegetables. Fatty acids derived from fish, nuts and oils can help to protect sight. Vitamins B and E can help to protect against cataracts and eating just one portion of fish each week can reduce the risk of developing age-related macular degeneration. Being overweight is a threat and aerobic exercise can help to increase oxygen supplies to the optic nerve and lower any pressure that builds up in the eye. Wearing sun glasses is strongly advised when the UV index rises above three. Finally, giving our eyes a break from staring at a computer screen by looking away every 20 minutes and focusing on something 20 ft away for 20 seconds is recommended.

COLLIS CURVE TOOTHBRUSH

Thanks to a member, this was first described in our July 2010 dsOK newsletter. Another member has recently reported that this is the only way their child's teeth could be cleaned. Although the Collis Curve toothbrush resembles a normal toothbrush, the bristles 'cuddle' the teeth. Complicated brushing techniques are not required, the brush is easily accommodated in a small mouth, is well adapted for brushing someone else's teeth and for special needs and disability care. Different sizes and designs are colour coded by their tops. Visit www.colliscurve.co.uk email info@colliscurve.co.uk or tel. 01934 862415.

THE LATE ANN HUTCHINSON

The saddest news is that Ann had a fall in August and died. The family lived in Ashtead until moving to Somerset. Ann was a capable, quiet and well liked parent member of the DSA South West Thames Branch, forerunner of dsOK. Ann served on the Branch committee, becoming Treasurer 1991 - 1995. Before and after her move from Surrey, Ann served on the DSA National Executive Committee. Simon and Ann set up in 1992 a Parents in Partnership group in Epsom, held monthly with a programme of speakers. Over the years, the family has given generously of their time to raise funds for the DSA, including Rachel's Brownies for the DSA Silver Jubilee. dsOK trustees have sent their sincerest condolences to the family.

AUSTRALIAN SEB

A friend has directed your editor to an article about an Australian lady whose son, Seb, was born with Down's syndrome, is now six and a delight to her and all he meets. Caroline White writes on the BBC Ouch blog following the sad story of the Thai twins, one of whom was taken to Australia and the one with Down's syndrome apparently left behind. Caroline likes to think that Seb changes outdated attitudes wherever he goes, a view echoed by many dsOK members (most of the time!).

<http://www.bbc.co.uk/news/blogs-ouch-28755786>

The same article continues with a photograph of Rosa Monckton and her daughter, Domenica Lawson who has Down's syndrome. Domenica, 19, now has a job in a local pub in Brighton. Rosa writes: "It wasn't until Domenica started at City College Brighton and Hove on a catering course and began living away from home for three days a week that I realised how capable she was."

SURREY PARENTS' PAGES

An A4 publication produced by Surrey Family Information Service contains much information which could help parents of children 0 - 19 (to 25 if a child has special educational needs). The Spring 2014 edition gives many ideas on encouraging a child to enjoy reading - and how parents can find more books for a wider choice. The Down's Syndrome Association strongly recommends that children with Down's syndrome are taught to read even as early as age 3. It has been found over many years that reading brings on talking. Do continue with signing - signing and reading can work together - but flash cards and simple colourful books could gradually have a rewarding effect on your child's communication ability. Many questions can be answered at local libraries, or, for Surrey enquiries, visit: www.surreycc.gov.uk/fis

SURREY MUMS ON LINE

A flier in a Surrey Library suggests Mums might enjoy this opportunity for conversation to share news, events, advice and offers. surreymumsonline@yahoo.co.uk Tel. Michelle 07900 600 237 or Natalie 0777 5913 971.

PSDS

"This well-established charity, Providing Support for Children with Down Syndrome, is dedicated to helping children with Down syndrome reach their full, wonderful potential". Based in east Surrey, it runs activities related to the teaching of youngsters with Down's syndrome and fun for their families. Visit their website www.psds.info or email: enquiries@psds.info The following telephone numbers are listed on their website: 07921 268240, 07976 734611, 07940 432053, 07721 411329.

RISING STARS, SUTTON

The Contact a Family *Play & Leisure Guide* reports that this Baby and Toddler Group, which works in partnership with Bliss, meets on Thursdays 9.30 - 11 am in term time at the Sutton Christian Centre, 25 Tate Road, Sutton SM1 2SY and welcomes children with disabilities and their pre-school siblings. Parents/carers can relax, chat, have a coffee and share experiences (highs and lows) and childcare tips. Tel. 020 8642 8117 or email: bliss.sutton@gmail.com Contact is advised before visiting this group.

NETWORK INTERVENTIONS

This local yet worldwide organisation offers solutions to many of the behaviour problems experienced by parents of young children. Their newsletters often include practical ideas. Improving communication abilities may assist with the concerns experienced. Chat on the phone or by email is

invited. NETWORK Interventions' newsletter is available by email. The opportunity to drop-in in the Ebbisham Centre, Derby Square, Epsom KT19 8AG is now available on Monday mornings. Parents are asked to make contact beforehand. Visit: <http://networkinterventions.com> or tel. 03333 440201.

UNWELCOME BEHAVIOUR AT SCHOOL

The DSA's guidance to teachers, published when inclusion was just beginning, explained that unwelcome behaviour can result from expecting too much of the young pupil. If a child, during class, begins diverting attention from the work by moving away, dropping a pencil etc. this is often an indication that the pupil feels the work is too difficult for him or her. Similarly, some with Down's syndrome find concentrating on the same subject for - in their view - a long time, will also lead to this type of diversion. Teachers who understand this anxiety are prepared with a new activity such as a reward for work achieved so far e.g. a short spell on the trampoline or their bicycle, or starting a different - perhaps more active - work topic. Praise (and reward) continues to be important for the student with Down's syndrome for far longer than might be assumed.

MEETING STRANGERS

Children are often taught Not to Talk to Strangers. For our child who learns more slowly and is usually difficult to 'unteach' this can lead to sullenness, shyness and even not knowing who to ask when directions are needed. All potential friends begin as strangers including children and teachers at playgroup and school, medics, neighbours, shop assistants and parents' friends. Children generally adapt instructions as they grow older but, for the child who continues to take instructions literally, even into their teens, teaching 'Not to Go with a Stranger' is advised. It is often the lady serving in a shop who is the most reliable person to ask for directions. Teaching to shake hands will help to lessen a child's enthusiasm to hug and kiss!

NUMICON NEWSLETTER

Experience shows that children - and adults - with Down's syndrome learn best through their eyes. The Numicon method is visual. Numicon send out newsletters. Visit their website at <https://global.oup.com/education/content/primary/series/numicon/?region=uk> for latest developments and advice on curriculum changes.

Their June newsletter suggested a fun Numicon football activity. The class can explore sorting and rounding with the number of goals scored, and work out the fractions, decimals and percentages of supporters from each team in the stadium. For Key Stages 1 and 2 and, with extension ideas for every task, you can stretch those who need an extra challenge.

TOILET TRAINING

Down's Syndrome Scotland's magazine, *Full potential*, has a two page article full of thoughtful advice for parents looking to start toilet training. Preparation includes Keep a record, Visual prompts (such as the Makaton sign for toilet), Clothing (easy pull up and down with spares handy), Seating (balance and comfort are crucial), Timing (consistency and a rigid routine including with the nursery or other carer), Rewards (plenty of praise and a 'high five' is suggested, and books to aid relaxation). If problems arise e.g. perhaps an over active bladder, contact your local continence nurse. The website www.eric.org.uk (helpline 0845 370 8008) is recommended or ask DSS for a copy (recent magazines are not on their website): 158/160 Balgreen Road, Edinburgh EH11 3AU tel. 0131 313 4225 www.dsscotland.org.uk and say you are a dsOK member

MAKING DECISIONS

Life is full and busy but a vital skill we have to give to our child is the ability to make decisions. We can do this during the ordinary activities of the day by giving opportunities to choose food, clothes, toys, games, the route along the pavement, goods in the shop. As we impart responsibility, we cannot expect perfection for some months or even years, but perfection is not always necessary. Each achievement, however small, increases confidence. It is better that our young person makes mistakes while we are there to advise them than that they go out into the world unpractised at making decisions at all. A vital aspect of this skill is the ability to say "No" to going with a stranger, or of course accepting food from one.

SURREY SPORTING OPPORTUNITIES

Lawrie Baker has notified us of opportunities for disabled people in Surrey including Shooting, Football, Cricket and Inclusive Sports. Contact lawrie.baker@surreycc.gov.uk

RICHMOND ACTIVITIES

The Holly Lodge Centre organised free activity sessions during the summer holidays, all specifically for children with special needs. Possibly there will be something similar during future school holidays. The contact is: Anna King, Centre Manager, The Holly Lodge Centre, Holly Lodge, Richmond Park, Richmond, TW10 5HS, tel. 020 8940 8730 aking@thehollylodgecentre.org.uk

THAMES EXPLORER TRUSTEES

Information about the activities offered by this organisation have appeared in recent dsOK newsletters. Apparently their programme continues during shorter days. Contact Lorraine Conterio, Trust Manager, Thames Explorer Trust, The Pier House, Corney Reach Way, Chiswick, London W4 2UG tel. 020 8742 0057 or email: lorraine@thames-explorer.org.uk or visit www.thames-explorer.org.uk The Trust encourages understanding and enjoyment of our great River Thames by young people (and their parents) of all abilities.

SPORT IN SUSSEX

Gemma Finlay of Active Sussex has offered to circulate to your editor their new Disability and Inclusive Sport e-news. Gemma is NGB Development Manager (Inclusion). Visit <http://www.activesussex.org/newsletter/> to read her information. Cricket for all ages and Boccia are mentioned in her summary. To contact Gemma email gfinlay@activesussex.org Gemma has agreed to inform trainers, coaches and sports leaders of our publication, *COACHING*, which may be downloaded from the dsOK website. This guides any leaders who have a child or adult with Down's syndrome in their group of pupils.

HORSHAM AREA FUN DAYS

An edition of the *District Post* tells of Short Breaks Family Fun Days which give children and teenagers with disabilities and their families opportunities to try out a range of stimulating and exciting new activities. For information email: marketing@impulseleisure.co.uk or tel. Southwick Reception on 01273 238111. Pre-booking is advised.

HORSHAM AREA SPRINGBOARD

Another report in the *District Post* tells that the Springboard Project has Springboard Houses where families may bring their children and enjoy play facilities during the week. Attractive indoor and outdoor spaces are described. tel. 01403 218888 www.springboardproject.com email: info@springboardproject.com

ANNUAL PICNIC

On Sunday 22 June, after lunch in the picnic field, dsOK families joined in the Charity Day of the Malden and District Society of Model Engineers Ltd., Thames Ditton. Free rides on the two miniature railways were much enjoyed as well as the welcome tea and cake in the refreshment hut.

BEING ACTIVE

As in the general population not everyone with Down's syndrome is interested in being active. There could be further discouragement simply because even finding and entering a leisure centre, understanding the procedure necessary to swim in the pool, and leaving afterwards could be more of a challenge for a young person with learning difficulties. A family member or willing buddy could make a difference. In some areas there are groups of young people willing to become buddies. A local Volunteer Bureau could be worth consulting.

dsOK MEMBERSHIP

From time to time it is appropriate to thank members for the generous efforts which have contributed to our funds. dsOK are pleased to be able to offer free membership to DSA members but, to retain it, please remember to renew your DSA membership. It is tempting to sit back and enjoy the fruits of the fundraisers in the past but fundraising by dsOK members and their friends is always welcome. dsOK can claim Gift Aid which will increase your donation by 25%. Our funds enable us to provide a wide variety of information to families, individuals and professionals, all in support of increasing the potential skills and independence of people with Down's syndrome of all ages.

DATES FOR YOUR DIARIES

Sunday 7 December Christmas Party
2015

Saturday 9 May Family Day

Sunday 28 June Capital to Coast sponsored cycle ride

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

CHAIRMAN/SECRETARY

Mrs. Karen Edmonds (Son 1994) 020 8330 1597
61 Ruskin Drive, Worcester Park, KT4 8LJ

VICE CHAIRMAN/MEMBERSHIP SECRETARY

Mrs. Bambina Gonsalves (Son 1996) 020 8640 7248

NEWSLETTER EDITOR/MINUTES SECRETARY

Mrs. Shirley Quemby (Son 1971) 020 8642 3720
43 Devon Road, Cheam, Sutton, SM2 7PE

WEBMASTER

Mr. Ajit Mané (Daughter 1981) 020 8979 7485
66 Wensleydale Road, Hampton, TW12 2LX

Mrs. Kathy Maillet (Son 1994) 020 8669 8942
9 St. James Road, Carshalton, SM5 2DT

Mrs. Helen Pattison (Son 2001) 01372 842911
15 Links Green Way, Cobham, KT11 2QH

TREASURER

Mr. Bart Gomes

DOWN'S SYNDROME ASSOCIATION

The Langdon Down Centre, 2a Langdon Park,
Teddington, TW11 9PS 0333 1212 300 (fax 020 8614 5127)

e-mail info@downs-syndrome.org.uk

website www.downs-syndrome.org.uk