

# ***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](http://www.downsyndromeOK.org.uk)

**news**  
**Number 39**

**Dear Members and Friends,**

Your team of trustees has enjoyed working together to set up a variety of activities which, as parents and volunteers, we all believed would be of benefit to you and your families. We are a friendly and supportive bunch. Our planning meetings, over a number of years, have brought many opportunities to share tips and experiences for the benefit of all of our families as well as leading to offering information and fun for all of you. For reasons unclear to us, attendances at dsOK events have become very low. It has especially disappointed us that no parent of a baby has for some years joined our team - perhaps this has hampered our efforts to attract your support. Do you want downsyndrome OK to continue? Three of your long-serving dsOK trustees, Karen, Bambina and Shirley are now stepping down, leaving dsOK in the capable hands of Ajit, Kathy and Helen. These three feel deeply that dsOK is still of real value to present and future folks born with Down's syndrome and of course their families as well as the professionals involved with them. dsOK fills a gap between the national office of DSA and smaller local parent groups. You are invited to consider seriously how you can help this smaller team to continue to ensure dsOK continues to support and serve you. Your skills and enthusiasm will be warmly welcomed.

**Shirley Quemby, Editor**

## **DISCO IN JANUARY**

A welcome return for our ever popular teens and twenties discos. We have booked Nork parish church hall, Banstead, SM7 1LG for Saturday 28th January 7.30 - 10.30. This is a social event for teens and young adults aged 16 - 29, a fun social evening with Starlite Sounds. Enclosed is an invitation for members with sons and daughters, siblings and friends of this age range. For additional copies, download from the dsOK website or photocopies will be accepted. The cost will be £7 per person to include drinks and light refreshments available during the evening. If your young person/people need personal care or support a responsible adult must stay on the premises. dsOK looks forward to receiving your booking form, indicating the number who will be attending, and enclosing your cheque. Your name(s) will be on a list at the door marked paid.

## **MIKAEL UNDRUM**

Continuing our tradition that a person with Down's syndrome tells our Family Day meetings about his life, we were impressed with the wide range and abilities of Mikael Undrom. An NVQ in catering gives him regular work. In addition he is a Special Olympian, a golfer, a skier, plays with Fulham Football Club, does long jump and running. Truly an inspiration. Well done Mikael!

## **WORLD WITHOUT DOWN'S SYNDROME**

Our readers have surely been saddened by the negative attitudes that have arisen during the years since screening has been available for pregnant mothers. For most of us, most of the time, the experience of being a parent of a child or adult with Down's syndrome has been a joy as well as a challenge. The positive publicity earned by actress, Sally Phillips in the press and on BBC2 about her 12 year old son has brought out many supporters of the fun and benefits of having a family member with Down's syndrome. Being diagnosed at birth, early stimulation can begin when changing the first nappy - enabling parents to feel positive straight away. We need to share our knowledge and experience with as many people, especially in the medical world, as we can.

## **dsOK TRUSTEES**

The trustees who are retiring are not fed up with working together, nor with dsOK - other family needs are the cause. We thank them all and Bart, our treasurer, for their years of support and wish them well.

## **PROPOSED NEW DRAMA GROUP**

Trustee, Kathy Maillet, would like to start a drama group for teens to adults in Woodmansterne, Surrey. The aim is for one evening a week term time, probably between 5 - 6 pm. Please email or call Kathy (see reverse of newsletter) if you would be interested in your young person attending and specify which day of the week would suit. A successful similar activity for younger children was run by Kathy in Carshalton for some years from 2003.

## **THE MATHS FACTOR - FUN AND PROGRESS**

We have received a warm commendation for this system, created in 2010 by Carol Vorderman, which has been found to motivate a pupil with Down's syndrome to enjoy maths and want to do a little every day. The Maths Factor not only leads the pupil to learn skills by encouraging small steps but describes how to progress from Reception to their present level, filling in gaps in their understanding as they progress. Visit: [www.themathsfactor.com](http://www.themathsfactor.com) and take the tour. Make the start with your child or young person when they will not be tired, perhaps during school holidays, so that the joy and habit of a little progress every day is gained. Use PC or iPad. Rewards are ideal for your youngster and also provide variety - check out The Tower of Achievements.

The Maths Factor offers a month's trial for £1 for which members must quote the unique code **TMF-1M1-DSOC** which expires on 9th February 2017. If you need any help contact [support@themathsfactor.com](mailto:support@themathsfactor.com)

**DR. JANET CARR OBE**

## DR. JANET CARR OBE

We recently learnt that dsOK member, Dr. Janet Carr OBE, had moved from Surrey to be near to family. Dr. Carr has always been a valued supporter of our Branch especially in the early days when she came to give talks to our members on behaviour modification. In 1964, before the foundation in 1970 of the - now - Down's Syndrome Association, Dr. Carr set up a cohort of babies with Down's syndrome and followed them for 50 years.. According to Google she is organising the publication of her remarkable longitudinal study. We wish her contentment in her new area.

## ROSA MONCKTON'S DAUGHTER

Following Sally Phillips' publications, Rosa Monckton reported on her daughter, Domenica's, progress. With no satisfactory openings after Domenica, now 21 and niece of Nigella Lawson, completed her catering course at Brighton College, Rosa set up 'Team Domenica' a charity with a café open to the public which gives training to 21 people with learning disabilities. See the Daily Telegraph of 13 October 2016.

## WE'RE ALL EQUAL CAMPAIGN

Dr. Elizabeth Corcoran, is a member of the Down's Syndrome Medical Interest Group and she and Lord Shinkwin are leading a group of people with disabilities, their families and supporters in the campaign "Don't screen us out". Underexpectation of the potential of those with Down's syndrome leads to misunderstanding and serious errors of judgement. Visit <http://allequal.org.uk/> for more information.

## DOWN SYNDROME EDUCATION INTERNATIONAL

Known to many members as DownsEd, DSEI is a mine of information in relation to how babies, children and adults learn and are best helped to reach their maximum potential. DSEI's knowledge and advice follows many years of thorough research and experience, sharing this guidance with countless individuals with Down's syndrome and their families. DSEI now offers an online course to support teachers, teaching assistants and therapists, advisory teachers and psychologists working with young people with Down's syndrome aged from 4 to 16 years whether in a mainstream or special education setting. In the few weeks since it was launched, participants in over 30 countries have been attracted to the course, "Effective Education for Children with Down Syndrome in School". The course is also suitable for parents seeking the latest research and best practice guidance on education for their child. Contact: email [news@dseinternational.org](mailto:news@dseinternational.org) or visit <https://www.dseinternational.org> or tel. 0300 330 0735.

## SEND INFORMATION DAY GUILDFORD

dsOK have been invited to participate in a Support4Send and Parent Voice information day at Yately School, GU46 6NW on Saturday 25 March 2017. Advice and information will be offered to parents and carers of children and young people with special needs up to age 25. Readers, possibly from other groups who would like more information, should contact <http://www3.hants.gov.uk/childrens-services/specialneeds/support4send> or tel. 01962 845870.

## KEYRING HOUSING

When seeking accommodation for your son or daughter with Down's syndrome, consider checking KeyRing. Residents (their Members) live in their own homes and support each other by sharing their skills and talents. A volunteer in each locality is like a good neighbour who helps out if difficulties arise and helps Members make links in the community. Visit [www.keyring.org](http://www.keyring.org) The London and South East office is in Dalston (Tel. 020 3119 0960) and the Sutton KeyRing Living Support Network is at St. Helier and District Community Association, Hill House, Bishopsford Road, Sutton, SM4 6BL.

## dsOK PICNIC 19 JUNE 2016

We were again invited by the Malden & District Society of Model Engineers Ltd. to enjoy their model trains at Claygate Lane, Thames Ditton, on their annual open afternoon for groups with disabilities. downsyndrome OK was well represented by the families of four trustees and at least six other members. Interestingly, our offspring with Down's syndrome were aged from in their 30s to very young. It is always a treat to catch up with members known for many years. On this special afternoon, the fun of riding the trains is free, thanks to the generosity of the Society. Excellent refreshments too!

## TRAVEL SUPPORT CARD

Transport for London offer this card which enables the holder to ask for help from a uniformed member of the staff on the service you are using whether bus, train, tram or other forms of public transport in Greater London. Its message is "Please can you help me?" to which may be added your name, a contact number or indeed a note to help the staff member .e.g. please speak slowly/please show me on a map. The card may be printed off <http://content.tfl.gov.uk/travel-support-card-printable.pdf> A new card is obtainable on line at [tfl.gov.uk/accessguides](http://tfl.gov.uk/accessguides) or tel. 0343 222 1234. To arrange specific assistance contact [tfl.gov.uk/accessguides](http://tfl.gov.uk/accessguides) in advance.

## VITAMIN THERAPIES

Rex Brinkworth MBE, founder of the DSA in 1970 and parent of a baby daughter with Down's syndrome, recommended vitamins as his studies over 30 years told him vitamins and minerals were poorly absorbed by the intestines of children with Down's syndrome. Many early members followed his advice. In 1995 a parent (from the USA), Peter Elliott, saw the need for research into Rex's recommendations and set up the Down Syndrome Research Foundation as a separate charity to work with the Down's Syndrome Association where possible. Peter addressed our Branch in 1996. For more information visit [www.dsrf-uk.org](http://www.dsrf-uk.org)

## WE'LL PAINT THE OCTOPUS RED

A book recommended by a parent which she describes as beautifully illustrated and attractive to a brother or sister of a child born with Down's syndrome. It could also help the child themselves to develop identity awareness. The author is Stuve-Bodeen and the book is available from Amazon. Being American, the word diaper would have to be substituted.

## KINGSTON VOLUNTARY ACTION

A wealth of information is available from this organisation to assist local voluntary bodies and individuals involved in the voluntary sector. Contact [info@kva.org.uk](mailto:info@kva.org.uk) for their newsletter.

## MY FERAL HEART

Look out for this film whose hero has Down's syndrome. Visit [www.myferalheart.co.uk](http://www.myferalheart.co.uk)

## BED MAKING

There can be a risk to straining the back when a young person is learning to make a bed. This can be lessened if the bed maker is taught to rest forearm or elbow on thigh or knee especially when the mattress has to be lifted. The person with Down's syndrome might not think of this risk.

## BRITISH STAMMERING ASSOCIATION

Possibly as rare a disability as Down's syndrome but, as with DSA, there is much helpful information available from the BSA. Seeking help and advice is equally as valuable and should not be delayed. Contact: The British Stammering Association, 15 Old Ford Rd, London E2 9PJ. Tel. 020 8983 1003 or visit [www.stammering.org](http://www.stammering.org) There is also a helpline.

## dsOK EDUCATION DAY 8 OCTOBER 2016

Problems including venue changes challenged us during the 15 months taken to organise this important event for your children's education staff and of course for parents. The date was given to you 18 months in advance. Two expert speakers, known to dsOK, were booked months beforehand, a spare copy of the booking form was sent to every dsOK member in August for you to pass to your child's teacher or Learning Support Assistant, yet only 11 people had booked by the closing date. Trustees extended the date and emailed schools and education authorities and the number doubled. dsOK have subsidised ten of these informative days, this one planned for 70 delegates plus helpers, and St. Philomena's School in Carshalton gave a pleasant space for displays of literature and positive ideas for encouraging pupils to achieve their potential. Evaluation forms by delegates praised highly the detailed information shared by our speakers. dsOK are grateful for the time given by speakers, helpers, trustees and the professionals who gave up their Saturday to ensure the youngsters in their classes would benefit from this event.

### EDUCATION DAY SPEAKER

Both speakers flowed with invaluable information to help the parents and professionals who joined us on Saturday 8 October. Cecilie Mackinnon told of a Handiwriter which helps a child to hold a pencil properly and which she has found preferable to the triangular grip which can slide onto a pencil. It grips around the hand below the thumb but is not at present illustrated on Cecilie's comprehensive website: [www.downsability.co.uk](http://www.downsability.co.uk)

### CRAYON ROCKS

Recommended by a parent, these were on display at the annual Special Educational Needs exhibition in Islington in October. They look like pebbles (approximately egg shaped) and have bright (safe) colours. They encourage the child to use the tripod (pincer) grip as they cannot be used for crayoning if held in the fist! There could be a choking hazard if put in the mouth. We are assured children love these crayons. <http://crayonrocks.com/gallery.html>

### EASY READ TIME TEACHER

Visit [www.Easyreadtimeteacher.com](http://www.Easyreadtimeteacher.com) for information publicised at the Special Educational Needs Exhibition illustrating clocks which, with colour markings, may help to teach telling the time. This was found by a parent member and was displayed at our dsOK Education Day on 8 October. Smaller clock faces have watch straps - brightly coloured!

### FAMILY IN USA AND DAD'S BLOG

This was noted in a BBC News App in August telling of an American family in which the fifth of their six children has Down's syndrome. The whole family is enjoying Wil, written up by Dad in a blog which is worth reading: [thatdadblogger.com](http://thatdadblogger.com) (*In the past there has been concern that a younger child in the family could be allowed to become the family clown. Nowadays, let us hope Wil's behaviour is directed without dampening his sense of fun. - Ed*)

### SIGNING FOR EARLY COMMUNICATION

Parents have been advised for many years to teach their baby with Down's syndrome to use signing to help to improve their learning and to reduce the frustrations of being unable to speak clearly. Makaton is based on British Sign Language, created for children. Amazon now offer DVDs of Makaton-signed songs by Singing Hands. Topics lead to a broad understanding of animals, numbers, colours, alphabet, emotions and places to visit. As speech develops, parents will find that their child gradually drops the signing. Cost per DVD is about £13. Visit [www.amazon.co.uk/Signing-Singing-Hands](http://www.amazon.co.uk/Signing-Singing-Hands) or [www.singinghands.co.uk](http://www.singinghands.co.uk)

## DOWN'S HEART GROUP

This well established national group, invaluable to all families whose child with Down's syndrome was born with a heart defect, holds its annual meetings around the country at venues attractive to young families. A newsletter is published. Visit its website [www.dhg.org.uk](http://www.dhg.org.uk) or tel. 0300 102 1644.

### WEARING GLASSES

The discovery by a little boy or girl they need to wear glasses can be quite frightening. As with any foreseen change for a child with Down's syndrome, careful preparation will usually help to overcome fear. Your local optician could have books with cheerful illustrations and stories about young patients. Or try your children's library. Consider asking a mother of a child wearing glasses in your shopping centre where she found kindly service for her youngster. Be sure to read advice from Dr. Maggie Woodhouse, experienced adviser to the DSA for more than 20 years, which is published on the DSA and dsOK websites.

### SPECTACLE FRAMES

In dsOK news 38 we reported research at DSA and have now received details of a website which followed this study which appears promising for families where their youngster has to wear glasses. Alicia Thompson, experienced dispensing optician, uses medical imaging cameras to capture a 180 degree facial image in less than 2 milliseconds. Fun was added to the measuring sessions by watching images rotate and turn upside down! The website suggests a group of parents could invite Alicia and her equipment, which is portable, to a suitable room to guide on their children's needs. Email her on [thompaj3@aston.ac.uk](mailto:thompaj3@aston.ac.uk) [www.downs-syndrome.org.uk/news/making-it-possible-for-children-with-downs-syndrome-to-have-accessible-and-properly-fitted-glasses/](http://www.downs-syndrome.org.uk/news/making-it-possible-for-children-with-downs-syndrome-to-have-accessible-and-properly-fitted-glasses/)

### LOCAL PARENT GROUPS

For local parent groups (affiliated to the DSA), visit the Down's Syndrome Association website. Member families of local groups across the country benefit immeasurably from contact with other families who have a member with Down's syndrome and recommend to parents, especially new parents, that you make contact with a group near to you. Sharing information - successes and problems - can help everyone involved whether it is about speech and language, toilet training, schools, behaviour or work and adult considerations. Yes, there can be information from the internet but a screen can never provide the benefits of personal contact. The DSA also offers valuable courses on how babies, children and adults with Down's syndrome learn and grow in confidence and ability.

### GET ON DOWN'S

It is good to know that Lu Cooper's group for parents of youngsters with Down's syndrome, as well as families with a pre-natal diagnosis, is running well. It meets for coffee (and cake!) at Cedar Lodge, 3 Metcalfe Avenue, Carshalton SM5 4AW on Wednesday mornings during term time. Contact [getondowns@btinternet.com](mailto:getondowns@btinternet.com) for times. There are also evening social events for the adults whose children enjoy playing at Get On Down's.

### SALT IN WINDSOR

Clare McIntosh runs a charity which provides SALT (Speech and Language Therapy) to pre-schoolers with Down's syndrome in Windsor. She asks anyone interested in joining to contact her on [Claremcintosh.uk@gmail.com](mailto:Claremcintosh.uk@gmail.com) The website is [www.chattertots.im](http://www.chattertots.im)

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

## THE SCIENCE OF BABIES

A special request to expectant Mums, please, to contribute to a TV production planned for the spring. The programme will celebrate the powerful, emotional and astounding story of the first year of life which will also help to raise awareness of Down's syndrome. If your baby is due in February to April, please email producer victoria.harris@nutopia.com for a friendly informal chat.

## ACHIEVING SUCCESSFUL INCLUSION

The Down Syndrome Development Trust in Sussex is offering training workshops, the next on 28 February, towards identifying the tools and knowledge needed to achieve successful inclusion within a mainstream setting. These will help participants to gain greater awareness of some of the physical and cognitive considerations which can hamper learning and how inclusion affects social experiences within school. Differentiating the curriculum is included. Contact hello@downsyndromedevelopment.org.uk or tel. Managing Director (and parent), Sen Smallwood on 07897 373839 for more information.

## INCLUSIVELY DOWN

This independent Specialist Teaching service for children and young people with Down's syndrome is based in Buckinghamshire and offers training, consultancy and support to schools, settings, families and professionals nationally to equip them to meet the individual needs of pupils with Down's syndrome. dsOK is asked to notify the details of this service to families and schools in our area. Visit www.inclusivelydown.co.uk or contact julie or lucy @inclusivelydown.co.uk Tel. 07785 994071 or 07950 000712.

## FOOTBALL IN SUSSEX

Albion in the Community run regular disability football sessions across Sussex for youngsters aged 5 upwards. Tel. 01273 668590 or email: disability@albioninthecommunity.org.uk to find out more. We understand they ran a Down's syndrome football match on 10 August 2016.

## SURREY SPORTING OPPORTUNITIES

Lawrie Baker at Surrey has kept us posted on various activities. Contact him at lawrie.baker@surreycc.gov.uk for an update.

## SPINNING SON

Ever been fascinated by watching clothes spinning in a washing machine? On today's news a boy with Down's syndrome featured. Having climbed inside, the family dog barked to draw attention to the child's predicament and he was rescued with a few bruises and wounds. So much extra teaching about care and danger need to be explained to our youngsters, visually and patiently, as they grow up.

## DATES FOR YOUR DIARIES

2017

**Sunday 8 January** Meeting of Trustees  
**Saturday 28 January** Disco, Nork

## THE HALOW PROJECT

From a small beginning in Surrey ten years ago, in an effort to enable five young adults with learning disabilities to achieve some independence, this Project has grown to include social and work type activities for nearly 200 young people with learning difficulties. Initials of the first five form the word, HALOW. Founder parents are Damon and Georgie Hill whose son was born with Down's syndrome. There is now a busy office in Quarry Street, Guildford, with a team of staff. The Parent2parent tel. is 01483 447960 and the website www.halowproject.org.uk

## THAMES EXPLORER TRUST

The Thames Explorer Trust, founded in 1988, supplies dsOK with its programmes which give the chance to everyone to get to know our great London river and have fun on a variety of its activities. Children and young people of all abilities are more than welcome (with parents of course). Experienced leaders accompany all exploration whether for wildlife, archeology, indoor visits, boat trips or outdoor 'mudlarking'. Events take place year round. Group activities may also be arranged. Watch the Trust's website at school holiday times www.thames-explorer.org.uk or email lorraine@thames-explorer.org.uk or telephone 020 8742 0057. Booking is essential and say you are members of downsyndrome OK

## EDITOR'S FAREWELL

When our son's condition was diagnosed more than 40 years ago, it is unbelievable how information which we needed was delivered to us so quickly, from a variety of sources. For this reason, your editor has collected and shared information of help to parents and professionals, including giving talks and writing newsletters, ever since. However, this will be my last newsletter. After 43 rewarding, encouraging years on the Branch and dsOK committees, I am now retiring in order to concentrate on finding suitable accommodation for our independent and able son who should not still be at home with his (ancient) parents.

### 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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