



Down Syndrome Training & Support Service Ltd

Registered Charity Number 1130994. Company registered in England and Wales 6915555

April 2017

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FAMILY SATURDAY SESSION at HAWORTH ROAD METHODIST CHURCH

SATURDAY APRIL 8th, 10am to 12pm

The April session is for families with children aged birth to 11. There will be flower arranging for parents and Easter themed activities for the children including an Easter egg pass the parcel and egg and spoon race. There will also be the regular activities we all love; magic bag, fantastic elastic and parachute. Come along and join in the fun.



RENEWED EFFORTS FOR NEW FUNDING TARGET FOR 2018

We are again setting a target amount of money to raise throughout 2017 to ensure all of our current services are secure for 2018. Our full annual budget is now £130000 and we are delighted to tell you that we already have some funds towards 2018. The outstanding figure was set at £80000 at the beginning of the year and to date we have raised £20000 towards this. This is amazing and means we have the rest of the year to secure £60000.

Next year the World Down Syndrome Congress will take place in Glasgow, 24th to 27th July, (<http://www.wdsc2018.org.uk/>). We plan to take a number of families to the week long event; we will be seeking additional funding to support this.

Please keep on with all of your amazing fundraising efforts. Thank you

£80000
For
2018

£20000

£
£
£

WELCOME TO OUR NEW STAFF

During February and March we interviewed and appointed 3 new members of staff. We are delighted to introduce:



Heidi

Heidi Shepherd, administrator for 16 hours a week. She is working with Claire Powis on finance and bookings. Claire's hours have now reduced from 20 to 10 each week.

Maria Thelwell and Jennifer Senior, our Youth Leader and Youth Pastoral Care Worker, respectively, for the WisH Club. Both Maria and Jennifer bring a wealth of experience to their roles.



Jennifer

Maria worked for Mind The Gap for several years developing a volunteer programme for people with learning disabilities, she has also worked with First Floor, a youth art workshop, and currently works for West Yorkshire Playhouse as the lead on event management including projects such as the Beautiful Octopus Club.

Jennifer studied Youth and Community Development at degree level and has worked in social care supporting young people and adults who need additional care in many different roles since 2008.



Maria

OUR APP

Have you downloaded our app yet? It gives a direct link to our phone, email and website so you can keep up to date with our news. The website always has our newsletter featured on the home page plus links to Facebook, BTdonate and much more. The plan is to have a news update page on our website to keep members informed of events. Having the app will help you access this easily. Follow this link to download. <https://dstssapp.appsme.com> Thank you.



FANCY A PARENTS NIGHT OUT?

On Friday 28th April from 8pm it is 80s night, with band and disco at The Octagon, Bradford Rd, Keighley, BD20 5LY. Tickets £5. Visit www.theoctagonlive.com. Please let us know if you are going.

SPEECH & LANGUAGE SESSIONS AND FEEDING SUPPORT

New trainees

During February we interviewed and appointed three trainee therapists; all currently third year students at Leeds Beckett University. Catherine Winter and Carrie Clements will support Lauren's groups and Jo Gallagher's feeding support group and Jude Simpkins will support Ellie Coleman's groups. It is wonderful that we are able to add to the knowledge and experience of these trainee therapists. All trainees will be with us until the end of the year.

SPEECH GROUP DATES IN APRIL:

LAUREN and ELLIE'S sessions will take place on Sat 29th April. Lauren is also running a session on Wednesday 26th April.

Half hour one to one sessions are available with Lauren or Ellie, booking essential. Cost: £6 per group session, £15 per half hour one to one session.

FEEDING SUPPORT GROUP

This group is now running monthly and is open to any child or young person who is experiencing difficulty feeding/is tube fed. From April the sessions are open to both parents and child so that Jo can observe feeding and offer tips and advice. Jo is supported by a dietician from Bradford Hospitals and one of our trainee therapists. We have also invited an occupational therapist to help with any sensory needs.

The April session is on 24th, 12.30 to 2pm. Please let us know if you and your child are attending.

All sessions are funded by the Henry Smith Charity until 2019.

EARLY DEVELOPMENT GROUPS

All families involved in these groups should have received letters detailing times and dates for this term. Please contact Wendy Rhodes if you have any queries or are unable to attend your session. The sessions are currently funded by Sovereign Health until December 2017.

ALL DATES FOR APRIL ARE LISTED ON OUR APP:

Download using Google Chrome. You need to type (or paste) in the full link as it is not listed in Google Play.

<https://dstssapp.appsme.com/app/dstss/be-seen-be-educated-be-included>

Diamond ladies night & fashion show

Shaheen, Hasanain's mum, was organised an amazing night out at The Royal Taj, 34 Manningham Lane Bradford, BD1 3EA on Saturday 13th May, doors open 5.30, event runs 6pm to 10pm. Ladies £25, children £16, under 5s free. The evening includes a three course halal meal, live makeover on stage, belly dancer, amazing raffle prizes and fantastic stalls. Hasanain will be performing on stage and will love the fame. Dress your best and enjoy a night full of Arabic and Bollywood entertainment. For information, bookings and tickets contact 07523675012.



TRAINING AT THE PAMELA SUNTER CENTRE, BINGLEY

READING LANGUAGE INTERVENTION (RLI) COFFEE MORNINGS



Monthly working coffee mornings have been scheduled to help people who have attended the training course get to grips with some aspects of the programme. The morning in April will cover 'taking a running record' and using it to tweak delivery'. It will run on Thursday 27th April, 9.30 to 11.30am. FREE but please book.

Using visual resources to develop the language and communication skills of children with Down syndrome

Friday 28th April 2017, 9.30 to 3.00pm

The day will cover why the written word is used as a visual tool to develop language skills. Methods to develop clarity of speech, grammar, vocabulary, and lengthen sentence utterance will be discussed and illustrated.

The course will also detail visual timetables, conversation diaries and ideas to develop reading, writing and spelling skills. After lunch there will be a software demonstration of Clicker 6/7 and details on the Reading Language Intervention programme.

COST: Full day £95 per professional (£30 for second person from same school)/£30 per family member. Lunch included in price.

Memory stick of resources available £7

Can I Catch the Bus? Teaching children with Down syndrome and other learning disabilities how to tell the time and use money

Friday 5th May, 9.30 to 3.30pm

9.30 to 12.30 TIME.

This workshop will equip participants with a structured programme of activities and resources to help them teach the passage of time and then how, step by step, to teach a child how to tell the time.

1.30 to 3.30 MONEY

An overview of a programme developed by Wendy Uttley. The programme consists of 120 finely graded activities to help teach a person with Down syndrome or other learning disability to understand and use money. Starting with learning the names for the coins and playing simple shopping games, moving on to learning the value of coins and progressing to working with pounds and pence this programme is suitable to use with a child from approximately 5 years of age.

COST: £95 per professional (£30 for a second member of staff from the same school)/£30 per family member. Lunch included.

Both parts of the course make use of resources available to buy on a memory stick at a cost of £10.

Signing for children with Down syndrome

This training was postponed in March and will now run in June:

Thursday 15th June, 9.30 to 11.30 session 1

Wednesday 21st June, 9.30 to 11.30 session 2

ME, my body, my friends, my life

Sexuality relationships education-(SRE) and Down syndrome

Over two Fridays: 26th May & 9th June 2017, 9.30am to 2.30pm.

All courses are detailed on our [website](#):

Flying our own flag for people with Down Syndrome

EVENTS TO MARK

WORLD DOWN SYNDROME WEEK

On Wednesday 22nd March we held a wonderful open day at the centre. Over 70 people came to visit throughout the day, joining us for refreshments, to buy crafts, gifts and second hand goods in Aladdins cave, to view the many dazzling paintings produced by Les Burrows and the members of the WisH Club and to be entertained by our dance21. A big thank you to the many volunteers who worked so hard to prepare everything; we all really enjoyed the day. We raised £250.70, Bingley Soropomists awarded us with a cheque for £3954.48 and Cllr Joanne Dodds awarded us with a cheque for £1000 from the Lord Mayors Spread a Smile.



EARLY LEARNING BOOKS LINKED TO RLI SCHEME

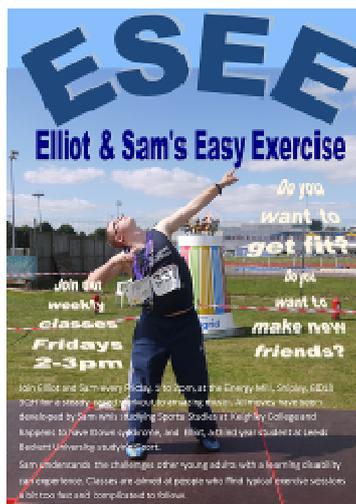
Wendy Uttley launched her first set of 10 books written at level 1 of the Hatcher grading scheme. The books include many of the early vocabulary we introduce in our early development groups, have large clear print and images on a clear white background. Each page has a repetitive sentence as the vocabulary builds and is revisited throughout the set. The books are available in hard copy for £20 plus postage for the set of 10 books or can be downloaded from Dropbox at a cost of £10.



ESEE

ELLIOT AND SAM'S EASY EXERCISE CLASS

Sam Murray and Elliot Scott have put together an exercise routine aimed at adults with learning disabilities who find mainstream fitness classes a challenge. Music and moves have been chosen by Sam who is studying Sport at Keighley College and happens to have Down syndrome, and Elliot Scott a third year student studying sport at Leeds University. The launch of the weekly classes will take place at the Energy Mill, Shipley, BD18 3QH on Friday 28th April 2pm to 3pm.



dance21 •

Every Monday 6 to 7pm at Shipley Lanes. Sessions are for young people with Down syndrome aged 11+.

The young people are encouraged to pay on entry, £3.50; an opportunity to independently handle money and count out 4 coins or pay with a £5 note and request change. Please can you support your young person to achieve this by providing them with a purse/wallet/bag and their own money. Thank you
Funded by David Solomon Charitable Trust, the Cotton Trust and Greggs.

WEEKLY DANCE CLASS AGE 5 TO 11

Classes are on a Saturday, 2.15 to 3.15pm at Bingley Fitness Studio, Unit 2, St. John's House, Clyde Street, Bingley, BD16 4LD with Claire from Footsteps Theatre School.

PAY ON ENTRY In order to help your child develop money skills we would like to encourage parents to let their child pay for themselves as they enter the building. Could parents please provide their child with a wallet/purse/bag with two £1 coins so that they can count out '1', '2' and pay an entrance fee of £2 at the desk. Thank you.

Funded by the David Solomon Trust, the Cotton Trust and Greggs. NO DANCE CLASS 22 APRIL.



WISH CLUB FOR YOUNG PEOPLE WITH DOWN SYNDROME AGED 11+

Our WisH Club aims to run every Friday 6pm to 8pm for young people aged 11 up to 13 years and 6pm to 10pm for teenagers upwards. Young people are welcome to bring along a friend or sibling age 11+ to the club.

We have now appointed two new youth workers, Maria and Jen, see front page, and we have also secured funding for the club until Dec 2017 from Jeans for Genes and Bingley Soroptomists.

A subs system is going to be trialled starting April, where members will pay £2 for the evening. This will help to subsidise activities and help to further develop money skills; which are developing well for some members at tuck shop time.

Keep up to date with what's happening and view photos from the club by becoming a member of the secret WisH Club Facebook group. <https://www.facebook.com/groups/wishclubyouth/>



AUDIOLOGY INFORMATION SESSION

On Wednesday 1st February, we held an informal Audioplogy session at the centre with Rob Gardner, Head of Audiology Services, Bradford and Sue Marsden from the Hearing Impaired Team, Bradford Education. The event was well attended with good feedback:

'The speakers answered most of our questions in relation to Down syndrome. We found the informal chat at the end very good.'

'I am glad we had the chance to get a second opinion on my child's recent audiograms especially as there has been such a big question mark over the need for grommets or hearing aids.'

'Learnt a lot of new things and felt more informed. I actually understand and audiogram properly now !'

Keratoconus and Down syndrome

Raising awareness of the importance of retinoscopy

Research has revealed that optometrists who rely on auto-refractors could be losing vital skills for preserving eye health, in individuals with Down syndrome and other learning disabilities. Keratoconus affects as many as 1 in 10 individuals with Down syndrome, a condition that leads to the loss of their vision when not diagnosed in the early stages. This has been attributed in part to the fact that people who have Down syndrome are less likely to report changes to their eye sight, therefore symptoms go unnoticed by family, friends and carers.

However, a loss of retinoscopy skills in the optometry sector has also been pinpointed as a key area of concern in relation to this condition.

This is supported by optometry experts as well as extensive research from the Down syndrome Vision Research Unit, Cardiff. One of their team, optometrist Stephanie Campbell, wrote a blog highlighting the issues:

Stephanie's blog is available as a downloadable factsheet that you can print out and take to your family's optician.

<https://www.downs-syndrome.org.uk/news/keratoconus-and-downs-syndrome/>

Stephanie's key message:

Ensure that your child/young person has an annual eye examination, with a practitioner that not only understands the communication needs of people with Down syndrome, but also is highly skilled in radioscropy and knows the risk of keratoconus in this group. Ask the following questions:

- Does the optometrist regularly see children and adults with Down syndrome?
- Does the optometrist use retinoscopy with ALL patients, not just those with learning disabilities?
- Is the optometrist familiar with the visual problems of people with Down syndrome?

If the answer is yes to all three, then make the appointment, otherwise go elsewhere. During the appointment ask direct questions about assessing your child / young person for keratoconus. If you do not have confidence in the answers, don't be afraid to walk away.

The views and items on this newsletter are not necessarily those of the Down Syndrome Training & Support Service Ltd. Mention does not necessarily mean recommendation or support.

WEBSITE DETAILING CHARITIES AND TRUSTS THAT CAN HELP FAMILIES WITH FUNDING

<http://www.disability-grants.org/>

Disability Grants is here to help YOU, your family or anyone you're supporting with a disability. Follow the link to search for charities and trusts providing funds towards the cost of disability equipment, holidays, housing, days out; in fact anything above and beyond the normal costs of everyday living.

NEW PUBLICATION FROM LET'S SIGN **OUR SCHOOL SIGNS**



This book is packed full of signs relevant to the school day. We have placed a copy in our library. For details on the publication visit: <http://www.deafbooks.co.uk/>

New online training course - Implementing the Reading and Language Intervention for children with Down syndrome (RLI)

DSE's new online course is designed to support implementation of the Reading and Language Intervention for children with Down syndrome (RLI). Presented and led by Professor Sue Buckley, the course includes 6 modules, each of which includes a video presentation, handouts and an assessment.

For full details follow the link: <https://www.dseinternational.org/en-gb/services/training/courses/>

CHILDRENS SERVICES BLOG

A wealth of research tells us that the first three years of a child's life is vitally important for their health, wellbeing and success in education and later life. The Children's Services Blog looks at this important issue for the Bradford district:

<https://childrensservicesbradford.wordpress.com/2017/01/17/getting-bradford-children-ready-for-school-is-a-key-factor-in-supporting-their-long-term-health-and-attainment/>

DSWestPennine TRAINING DAY FOR FAMILIES AND PROFESSIONAL, PUBERTY AND ADOLESCENCE FOR YOUNG PEOPLE WITH DOWN SYNDROME delivered by the DSA

Saturday 29th April 9am to 1.30pm at Kingfisher Community School, Oldham. For details email: dswestpennine@hotmail.co.uk phone 07842555725.

BILD - British Institute for Learning Disabilities newsletter

<http://technology-trust-news.org/6N7-4SN1C-8DGQ83777C/cr.aspx>

Lots of relevant and interesting articles.

Bradford district Sports Befriender/Mentor Service

Yorkshire Sport Foundation are one of the 44 County Sport's Partnership's and cover South and West Yorkshire. Their aim is to help everyone take part in sport so they can enjoy the significant health and personal development benefits sport can deliver.

They have a free befriender service, which is open to anyone with a disability who is struggling to take part in sport or physical activity. The befriender is a volunteer who provides support to attend a sports club, gym or other physical activity such as a fitness class. So far over 30 disabled people have been offered a volunteer. There is an application form to complete. For more details please contact Andrew Lane by email andrew.lane@yorkshiresport.org or phone 0330 20 20 280 mob: 07964 209 344



Maternity survey

NHS England would like information from women who are pregnant or have had a child in the last two years to help to improve maternity information and care for women.

The survey should take about 15 minutes to complete. Answers will not be shared outside of NHS organisations.

Visit: <https://www.engage.england.nhs.uk/survey/ca5d268c/>

Non-invasive prenatal testing: ethical issues

This report explores ethical issues arising from current and possible future uses of non-invasive prenatal testing (NIPT). It considers views and evidence gathered from a wide range of people and organisations, and from the academic literature. It sets out the potential implications of this technique for prenatal screening and testing for a range of genetic conditions and variations both in the NHS and in the private sector. The full report can be found by following the link: <http://nuffieldbioethics.org/project/non-invasive-prenatal-testing/findings/>

Feeding and Autoimmunity in Down Syndrome Evaluation Study (FADES)

The recruitment period for the FADES Study has been extended to the 1st September 2017. They currently have 51 participants recruited to the study from across the UK and would like more.

The study will investigate early feeding in babies and children with Down syndrome and they are looking for new parents who have a baby under the age of 8 months.

They hope the study will help us understand why children with Down syndrome are more likely to experience problems with their hormones and their gut, help reduce this risk and lead to the development of new treatments to help with feeding. Parents will be asked to complete a questionnaire about their child's feeding and health as a young baby and at 6 and 12 months. This will be followed up yearly until the age of 5 years. The study is based at the University of Bristol and University Hospitals Bristol NHS Foundation Trust but you don't need to go to Bristol to take part.

If you would like to take part in this study, or just want to know more please contact Dr Georgina Williams.

EMAIL: fades-study@bristol.ac.uk

website: www.bristolnutritionbru.org.uk. Click on the 'FADES Study' tab

Easter Family Fun Day at Nell Bank

www.nellbank.com

On Wednesday 12th April, 11am to 3pm, families are invited to a fun day at Nell Bank supported by the Specialist Inclusion Project.

Activities on offer include habitat trail, pond dipping, water play and den building. There will also be sport coaches from FISICAL to run multi sport such as football, cricket, rounder's and tennis.

The day is funded through Short Breaks for families in the Bradford Council area, there will be a nominal fee of £5 a family ticket if you live outside the Bradford area. Please bring a picnic to enjoy with your family as food is not available to purchase on site. Booking is essential. To reserve tickets please contact Nicola Norris
Email: nicola.norris@bradford.gov.uk,
Phone 01943 602032

KEEP UP TO DATE WITH EVENTS

VISIT US ON FACEBOOK OR OUR WEBSITE

PUBLIC FACEBOOK PAGE

<https://www.facebook.com/DownsyndromeTSS/>

For more general and formal information.



CLOSED FACEBOOK GROUP

Our closed Facebook group provides information on day to day activities .

<https://www.facebook.com/groups/DSTSS/>

DOWNLOAD OUR APP

Using Google Chrome. You need to type (or paste) in the full link as it is not listed in Google Play.

<https://dstssapp.appsme.com/app/dstss/be-seen-be-educated-be-included>

CONTACT Wendy Uttley or Wendy Rhodes

The Pamela Sunter Centre,
Down Syndrome Training & Support Service Ltd,
2 Whitley Street, Bingley, Bradford, BD16 4JH
Tel 01274 561308
Mobile 07816 465 845/07512346717
Email: office@downsyndromebradford.co.uk
Web: www.downsupportbradford.btck.co.uk

Knitting and Crochet Group

Friday night get together, 7 to 9pm, to make items for yourself or to sell on future stalls and in Aladdin's Cave. Can't knit or crochet?? We can teach you!!



funding news

We have made an amazing start towards our new 2018 target of £80000 and to date have raised £20000 towards securing our services throughout 2018. A massive thank you to everyone who has donated and to those who are in the process of planning an event:

- Fartown Christian Fellowship, £15
- Wakefield District Health and Community Support Ltd, £5000 which covers the rent for 2017
- Collection tin, Silsden Storm RLFC, £20.39
- Ian Halliday, £150
- Warburtons, £250 towards resources for our early development groups
- Titus Salt School Christmas Fair, £357
- Rose Dunne, raised £217.50 from a sponsored cross trainer event
- Laura Wallace Prints Ltd, £2635 in memory of Sue Feather
- Jennifer Hall, £50 in memory of her brother, David Wray
- Pat Binnington, £50
- Yorkshire Building Society, £500. Staff also volunteered for a day and cleared our car park.
- Bingley Methodist Church, £600
- Mandy Mawer, £20
- Siemens Plc, £25
- Collection Tins, Nina Rani, £91.56
- Julie Kellett, £150 in memory of Leah's grandma
- Collection tins various, £35.31
- Tony Walton, £20
- Liz McLean, collection tins, £16.92
- Barbara Ward, £1400 towards dancing
- UK Gas & Power, £500, via Naseem Akhtar
- Bingley Soroptomists, £3954.48 towards WisHClub
- Lord Mayors, Spread a Smile, £1000



BETTY'S CHARITY EVENT - TIM'S DALES WAY TRAIL ADVENTURE

Ultra Runner and Silly Man Timothy Forster of Bettys Ilkley will be attempting this July to set the Fastest Known Time along the Dales Way National Trail Path (84 miles) in aid of our charity. Tim will be attempting to beat the previously held record of 21 hours and 50 minutes by David Dixon and Andy Jackson. Sponsor him and follow his progress by visiting his Justgiving page <https://www.justgiving.com/crowdfunding/timothy-forster>

£80000
For
2018



WRESTLING FOR DOWN SYNDROME AWARENESS

Richard Szepler has arranged a live wrestling event at the UK Wrestling Training Centre, Alexandra Mills, Batley, WF17 6JA on Saturday 29th April, doors open 6.30pm, first bell 7pm. Tickets: adults £8, children £5 all proceeds will be shared between our charity and UK Wrestling Training Academy.



£20000



JEANS FOR GENES

In February we received £4752 from Genetic Disorders UK towards the running of the WisH Club. Each year, Genetic Disorders UK organises Jeans for Genes Day, when employees and pupils are encouraged to wear their jeans to work or school in exchange for a small donation.

SUPPORTED BY



MY DONATE WITH BT

You can make online donations and create a fundraising page for us by visiting <https://mydonate.bt.com/charities/downsyndrometrainingsupportserviceltd>
You can also donate direct to our bank account by using our new [standing order](#) form. This can also be downloaded from our website.



Richard has also arranged a raffle:
1st prize a HELICOPTER RIDE for two
2nd prize Family ticket for WRESTLEBRATION
Tickets £1 each.
Please contact our centre or Richard on 01924 366066 for tickets.