



down's syndrome oxford

Newsletter • November 2014

From the chair

I hope you all had a good summer, it was nice to see people at both the **Summer Party and the Unity Club event** which was held at Thomley Hall.



I would like to draw your attention to a few things: first of all, don't forget the **Christmas Party this year will be on a Saturday (not Sunday)**, all the details are on page 2 of the newsletter, but if you are new to DSO it is usually a really fun event and a great way to meet people. All your family are welcome.

Thank you once again to everyone who has helped raise funds for DSO – extended family and friends, organisations and other donations. DSO is for all ages – each year in our budget we set aside amounts of money for different age groups to take advantage of; at the moment the teenage group and adult group are not using all their money, so if you belong to those age groups and have ideas of what you would like to do, please approach me or any of the committee and there is likely to be funding available. It's up to you!

Our **training programme** continues, please keep an eye out for what is planned but hopefully we will run another session on behavioural issues and Makaton signing. If you have a special request or an idea for training, again please approach either me or Elsa Gill.

The more informal drop-in sessions for pre-school age children continue at South Abingdon Children's Centre, and again we hope to arrange other days when professionals come to talk about a specific topic.

Please make sure you are registered on our website to receive emails, as most of these activities are advertised via email to members. You can tick a box so that you only receive information relevant to the age group of your child, but it is the best way to make sure you don't miss out.

Finally – and I mean it this year! – I will definitely be **stepping down as Chairman at the AGM next year**. I love DSO and will still be very involved, but I really do think it is time for someone else to bring their ideas and experience to the charity. Thanks to some fantastic fundraising over the past few years we are in an excellent financial position, so it would be lovely to see some new, or old, people at committee meetings and **to think about how to move DSO forward in the next few years**.

In the meantime, I hope to see you at the Christmas Party on Saturday 6th December.

Katharine Horrocks

Next committee date

Monday 24 November

At the Turnpike Inn, Yarnton, from 7.45pm

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DSO Christmas Party

Saturday 6th December

2.00pm to 5.00pm

*Exeter Hall, Oxford Rd, Kidlington,
OX5 1AB*

Disco & Games by Jeff Lloyd

*Including our regular visit from
Father Christmas*



Please bring:

- **a plate of savoury / sweet food to share**
- **a wrapped LABELLED gift for your child/children**

*Tea & coffee will be available and the bar
will be open to purchase drinks*

Down's Syndrome Oxford is... a charity organised and funded by volunteer parents and supporters to provide information, support and activities for children and adults with Down's Syndrome and their families living in Oxfordshire.

All the funds DSO receives are generated by fundraising efforts by members and the generosity of our supporters. There is no membership fee and most activities are free, although we may ask for a small contribution at some events. Our members include parents, grandparents, friends, teachers, teaching assistants, therapists, medical professionals – anyone with a passion for supporting people with Down's Syndrome.

If you're new to us, or even if you've been part of DSO for a while, you'll find key contact details on the back of this newsletter.

dsos
down's syndrome oxford

Supporting children and adults
with Down's Syndrome and
their families in Oxfordshire



www.dsoxford.org.uk

1,000 miles in one year to support DSO

Inspired by his six-year-old nephew Lucas who has Down's syndrome, Steven Willis is setting himself the challenge of running in races totalling 1,000 miles over the next year to raise thousands of pounds for DSO.

Steven, 31 and from Hastings, East Sussex, began his fundraising feat by running the Oxford Half Marathon in October, and is ending it at the same event in 2015. Steven is doing it because of Lucas Randall, from Cowley, who benefits from the support of DSO. Lucas is also currently undergoing extensive chemotherapy for Acute Myeloid Leukaemia.

Steven says, "Lucas is my motivation: he is such a lovely person despite all of the problems life has thrown at him. He always lights up the room laughing, talking about football and just generally being awesome. I am really excited to just undertake the challenge but hope to stay injury-free and complete the 1,000 miles."

Lucas' mum Shelley Eldridge says her son's diagnosis of leukaemia has changed family life. "As parents our whole world has fallen apart. He has become quite quiet and withdrawn; not the normal funny, happy Lucas. He doesn't really understand what is going on – we have told him he has poorly blood. It is hard seeing him so poorly."

"DSO has been an amazing support for us from the minute we found out Lucas had Down syndrome. I can still remember the day we first met some amazing mums and children, and walking out at the end crying with happiness, thinking everything was going to be OK. I have met some amazing



parents and Lucas has lots of friends, which, thanks to DSO, he can meet and have fun days out with." Shelley adds, "Steven is doing an amazing fundraising challenge for DSO and we are so proud of him."

Steven Willis can be sponsored at www.justgiving.com/steven-willis1. Follow his progress over his fundraising year at <https://www.facebook.com/raceforlucas>

On behalf of everyone at DSO, and especially all Lucas' friends in the Primary Club, we wish him all the very best for the coming rounds of treatment.



Above: Steven with Lucas at the end of the Oxford Half Marathon

Right: Lucas gets visited by two superheroes in hospital!



Charity Zumbathon

Come along and join a Charity Zumbathon in aid of SMA Support UK (Spinal Muscular Atrophy) and Down's Syndrome Support for families in Bucks and Oxfordshire

Saturday 15th November 2014

12:30pm – 3:30pm at Thame Leisure Centre

£15 per ticket available from Sandra (07771

800913) / Rachel (07973 540248). Raffle tickets are also on sale at £1 per ticket.

DSO Lottery update

Join in and win!

If you would like to join then simply set up a monthly payment to the DSO Lottery - account no 2978 6768 and sort code 30 80 45.

It's £5 for one ticket or £10 for two, and send an e-mail to lottery@dsoxford.org.uk We will then allocate your numbers.

Thank you to everyone who is supporting us.

Amanda Foulds & Lucy Sanderson

Recent winners...



June 2014

1st prize - £42.00
2nd prize - £25.20
3rd prize - £16.80

Miss W Parker
Sally Dubock
Will Foulds

July 2014

1st prize - £42.00
2nd prize - £25.20
3rd prize - £16.80

Jo & Stu Crawford
Jon Gill
Ryan Wells

August 2014

1st prize - £42.00
2nd prize - £25.20
3rd prize - £16.80

Andrew Partner
Jo & Stu Crawford
Katharine & Mark Horrocks

September 2014

1st prize - £42.00
2nd prize - £25.20
3rd prize - £16.80

Anne Churchill-Stone
Jo & Stu Crawford
Rachel & Gary Lane

Practical Activities for Developing Speech, Language and Communication Skills in Children with Down's Syndrome 4-11yrs



Thursday
15th Jan 2015
9.30 - 4.30pm

Venue: Oxfordshire Association for the Blind, Bradbury Lodge, Gordon Woodward Way, Oxford OX1 4XL
(5 min walk from Redbridge Park & Ride)

Trainer: Nicola Lathey



Nicola is a hugely experienced Speech and Language Therapist and author of the best selling book, *Small Talk*. Nicola also runs The Owl Centre, based in Oxford.

A training day aimed at Teachers, Teaching Assistants and Parents. Topics include attention and listening, expressive language, speech and oro-motor skills, adapting SLT resources to your child and more...including lots of practical activities to try!

Each participant will receive their own bag of SLT approved resources.

Cost: £25 Limited to 15 places.

To book or for more information please email Elsa Gill

elsagill99@gmail.com



The cost of this training has been heavily subsidised by DSO.

Three Peaks Challenge



In July a team of 5 of us completed the Three Peak Challenge for DSO.

Andy Lawson and I both have a son with Down's Syndrome and have been supported by DSO since their children were born five years ago.

It was a very tough challenge climbing Ben Nevis, Scafell Pike and Snowdon all within 24 hours, but it really was worth it when the final total is around £3,235 of which around £1,625 will be going to DSO.

Another highlight was working together as a team to achieve this and the other members of the team, who without their support would have meant it would not have been possible: Paul Parlett (Driver and cook!), Lee "Massive" Massie (logistics) Richard West (map reader and first aider) and Paul Fennel (experienced climber). Another highlight was the view on top of Scafell Pike at 7am, it was simply stunning!

Money raised from the mountain climb will be split between DSO and two other charities: Respite nursing for Oxfordshire's Sick Youngsters (ROSY), which helps terminally, acutely or chronically ill children and babies in their homes, and Daisy's Dream, which supports children and their families who have been affected by life-threatening illness or bereavement.

Thank you to everyone who supported and sponsored us and thank you to DSO for all their great work!

Paul Gander (dad to Reuben aged 5)

The 'Mud Cows and Bulls' do the Wolf Run

Last year I watched four of my brave work colleagues take part in the Wolf Run challenge and vowed I'd join them if they did it again this year.

I stayed true to my word and when the registration opened I signed up for the 2014 Autumn Wolf Run. This year our group had expanded significantly with 11 of us registering for the challenge. Our team, called 'the mud cows and bulls', once again kindly offered to raise money for DSO.

So, on 6 September we started the 10km wild run and obstacle course. It featured lake swims, mud pits, fallen trees, boggy ground, ditches, hills and dense foliage, with a few obstacles thrown in for good measure. It was like nothing I'd done before, but with such a great supportive team, I was taking on each challenge and loving every minute.

Unfortunately, it all came to an abrupt end for me when I tripped over around the 7km mark and managed to dislocate and break my finger. After a trip to A&E I discovered that the break was a very nasty one and I ended up having surgery to repair it. I now have six screws holding my finger together!

I was devastated and frustrated not to be able to complete the full course, but I'm so glad to have taken part in such a fun and challenging event. And it was even better to find out that we had raised £500 for DSO. Thank you mud cows and bulls!

Lucy Sanderson (mum to Chloe aged 9)



Pre-school Club update



Co-ordinator Helen Kingdon
writes:

The pre-school club went to Peppa Pig World in September. The trip was a very special one, which took place thanks to the additional fundraising efforts of Sarah and Dean Fonge who raised £1,000 specifically to take the preschoolers to Peppa Pig World.

We had a great turnout and were very lucky with the weather indeed! The kids had a great time, and we were especially pleased that Paultons Park offer an "Access Pass" to children with disabilities.

This means that the child and three other people (including an adult!) can jump the queues for each ride once. This made a huge difference to us all on the day as the queues were very long!

We all disappeared off and did our own things round the park, often bumping into each other along the way and enjoying comparing notes.

All the children were shattered by the time we left, but great fun was had by all. Thanks again Sarah and Dean for the fundraising efforts!!

The next pre-school trip is going to be to Crocodiles of the World on Saturday 22nd November. Please be sure to keep an eye out for the email and we hope to see you there!



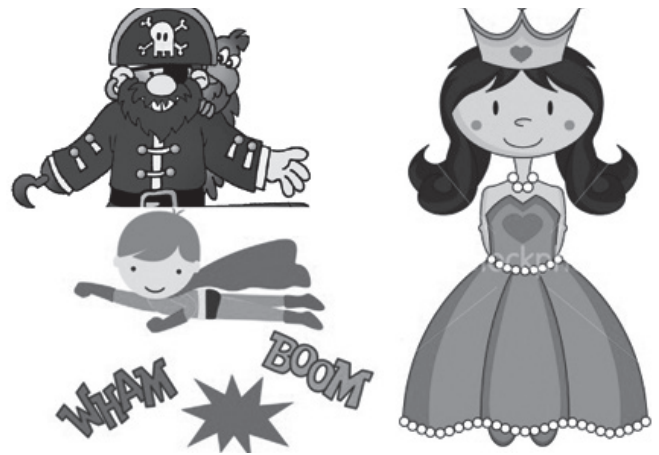
Primary Club update



In July the Primary Club went on a visit to the **Falconry Centre** at Millets Farm. We first had a talk about the different birds habitat, diet, hunting activities.

Throughout the talk some of the braver children got a chance to hold the birds. We then took a walk around the avery's and finished the morning with a flying display.

In October, Spiderman, the Gruffalo and Elsa from Frozen were among the special dressed-up guests at our **Pirate, Princess and Superhero Party** at Dalton Barracks Community Centre near Abingdon. Around 15 primary-aged children, including siblings, enjoyed games, food, dancing and plenty of bubbles.



There were great team games including one involving putting treasure into baskets and another of catching fish in a pond. At the end there was even an additional surprise of being able to use a bouncy castle left over by the army!

It was a really fun afternoon, giving the children the chance to get to know each other better.

10+ Club update



Next event:

An outing to see Shrek the Musical at New Theatre Oxford.



Friday 14th November, evening performance - **30 tickets available at half price: £15 each - great seats in the stalls.** Please contact Jane Pearson to book a ticket: 07490 849900 / 01608 658142 email: janepearsonptl@msn.com

Once tickets are booked, please send your cheques payable to 'Down's Syndrome Oxford' to: Jane Pearson, 3 Old Forge Close, Bledington, Chipping Norton, Oxon OX7 6XW.

Down's Syndrome and Sensory Processing

Why won't my child eat lumpy food?

Why does he lick muddy shoes?

Venue: Sandhills Community Primary School, Terrett Avenue, Sandhills, Nr Headington, Oxford OX3 8FN

Trainers: Leap Children's Therapy

An independent company based in Bucks providing Occupational Therapy services to children and young people.

Should I stop her behaviour or ignore it?

Sat 31 Jan 2015
9.30 - 12.30

My son won't have his haircut! What can I do?

Topics: Understanding what sensory processing is and how it presents in our children.

Practical strategies for dealing with problem behaviours.

Questions & Answers and helpful resources.

Open to all parents and professionals (sorry no crèche)



Cost: Free –however, you must book a place.
To book or for more info please email Elsa Gill elsagill99@gmail.com

Unity Club trip to Thomley Hall

The weather was brilliant for our day out to Thomley Hall and everyone had a great time.

Thomley Hall has been designed for children and adults with special needs in mind so the setting provides a stress-free day out for parents (!!).

In addition to all the activities the centre provides there were visits to the sensory room and also a Mocktail making session for the older kids. Thomley had kindly provided a marquee so we could all sit outside for lunch.

Luckily there was not a raindrop in sight. We were joined by three new children Aaron Terrington (*below*), Henry Crow (*right, middle*) and Theo Serpell (*right, top*).

Thanks for joining us and look forward to seeing you all again soon.



Thomas, Joseph and Katie Stacey enjoying their day out at Thomley!

Our children



Top left - Jon-Paul Lawson on his first day at school

Top right - Chloe Sanderson and Alexander Horrocks have fun dressing up

Bottom - Sam Rees with big sister Lily-Anna and mum Pippa pony trekking on holiday in France.

Our children *CONTINUED*



Top - Joseph Stacey getting creative with play-dough

Bottom left - Thomas Foulds dressed smart for his first communion

Bottom right - Conall Summers surfing on holiday



Top - Jack Gill, Alexander Horrocks and Thomas Foulds bouncing together
Bottom left - Lucy Robinson relaxing amongst the daisies
Bottom right - Hannah Dubock finding treasures during an archeological dig

See and Learn

Down Syndrome Education International's See and Learn programmes offer targeted, evidence-based activities packaged in easy-to-use kits and apps that are designed to support early development for children with Down's Syndrome.

See and Learn programmes are designed to help children with Down's syndrome during the formative early years. Four programmes target language and reading, speech, number skills and memory development. Each programme aims to develop key early skills in small steps with regular practice, providing easy-to-use resources to support a selection of teaching activities.

The See and Learn programmes are developed by Down Syndrome Education International and Down Syndrome Education USA and are informed by the latest research and extensive practical experience. DSE has been at the forefront of educational research improving outcomes for children with Down's Syndrome for over 30 years.

Needs

The early years are a critical period for the development of key skills that provide the foundations for later learning. Children with Down's Syndrome learn more slowly and find it more difficult to learn than many other children and therefore need additional support. Targeted early intervention can help to improve rates of progress and outcomes.

Language and reading

Most children with Down's Syndrome learn to talk later than typically developing children and their spoken language continues to develop more slowly. Language skills are important for learning (thinking, remembering, reasoning) and for social communication. Additional support can help children with Down's Syndrome learn more words more quickly and develop more advanced grammar skills.

Many children with Down's Syndrome can learn to read printed words from 3 years of age or earlier. This can establish key skills ready for learning to read and write in school. Early reading activities can also support the development of spoken language.

Speech

When they start to talk, most children with Down syndrome find it difficult to say words clearly. Many remain difficult to understand throughout childhood and into their adult years. The foundations for speech skills are established in infancy and targeted additional support through the early years can help to improve speech clarity.



Numbers

Many children with Down's Syndrome find learning number concepts particularly difficult. Additional support in the early years can teach a basic understanding of shape, size and colour concepts and of number and counting, providing a solid foundation for later learning in school.

Memory

Most children with Down's Syndrome have relatively poor verbal short-term memory skills but better visual short-term memory skills. This impacts many aspects of learning. Additional support can improve memory function and teach effective memory strategies.

Design

See and Learn offers an evidence-based developmental approach to early learning, drawing on the latest research on how children learn and develop and adapted for the particular characteristics of children with Down's Syndrome.

Designed for children with Down's Syndrome

The design of See and Learn reflects the profile of relative learning strengths and difficulties that is typically observed in children with Down's Syndrome. Information and concepts are represented visually wherever possible to build on the children's relative visual learning strengths. Activities progress gradually and encourage listening, joint attention and concentration. New activities build on previous ones to promote revision and consolidation of learning.

Learning to learn and experiencing success

See and Learn is also designed to teach behaviours that children use to learn - including following directions, responding to questions, imitating, taking turns, initiating, and playing with a partner. See and Learn teaching activities are designed to support success, encourage problem solving, persistence and feelings of competence.

Tracking progress and extending learning opportunities

Each step in each See and Learn programme includes activities (as materials or as apps), clear step-by-step instructions, and record sheets to chart progress.

The guides also include many suggestions for consolidating and extending learning during play and everyday activities at home or at preschool.

See and Learn programmes are designed to be easy for parents to use independently at home or to accompany therapy and other support services.

There are four See and Learn programmes:

- See and Learn Speech - designed to teach young children to hear and produce speech sounds (phonemes), to hear the differences between sounds (discrimination), to develop their speech sound system (phonology), and to produce clear speech
- See and Learn Language and Reading - teaches children to understand and use spoken language from first words to early grammar and simple sentences, and introduces children to reading their first sight words, learning letter-sounds and using phonics for reading

- See and Learn Memory - aims to teach children to be aware of memory from infancy and to develop their visual and verbal short-term and working memory skills

- See and Learn Numbers - designed to teach early math concepts and counting to children with Down's Syndrome.

Editions

See and Learn resources are available as ready-made kits from DSE's online stores. We are also developing new download editions for self-printing and assembly and new app editions compatible with many popular tablet and desktop computers.

see and learn 
visual learning • step by step

www.seeandlearn.org

Special Educational Needs and Disability (SEND) Changes

As a result of the Children and Families Act, SEND changes will be implemented in stages from Sept 2014. The changes will be phased in over the next three years and will be supported legally by a 'New' Code of Practice.

<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

The key points include:

1. Local authorities and health partners to consult with parent carers and young people about decisions that affect their daily lives.
2. A focus on the 'outcomes' that the child or young person is aiming to achieve in their lives via 'person centred planning.' Education, Health and Social Care services will be required to work more closely together to better support the achievement of these outcomes.
3. Statements will be replaced by Education Health and Care Plans (EHCP). These can support children and young people from the age of 0-25. The support of an Independent Supporter will be available to families going through the statutory assessment process.

4. School Action and School Action Plus will be replaced by SEN Support. Guidance booklets on SEN support will be available to view on the Local Offer.

5. A 'Local Offer' will detail what is available in Oxfordshire for children with SEN in educational settings and in the community. This will include how decisions are made and how to complain. The Local Offer can be found at www.oxfordshire.gov.uk - search 'SEND local offer'.

For Help & Advice about the changes, phone Parent Partnership on 01865 810516

Oxfordshire information sites:

www.oxfordshire.gov.uk (Oxfordshire County Council website under SEND)

parentpartnership@oxfordshire.gov.uk (Oxfordshire Parent Partnership)

www.oxfsn.org.uk (Oxford Family Support Network)

National Information Sites:

www.ipsea.org.uk (Independent Panel for Special Educational Advice)

www.specialneedsjungle.com (General advice and chat)

www.preparingforadulthood.org.uk (Information for Post 16s)

www.ncb.org.uk (Early support)

Thank you to 'Oxfordshire Family Support Network', 'Carers Voice Oxfordshire' and 'Parent Partnership Oxfordshire' for this information.

Captain Jack – our story (so far!)

By DSO mum Sarah Stevenson

When Jack was four and a half months I joined our local support group Down's Syndrome Oxford which has been invaluable to me over the last seven years. Most of you will know us as I have been treasurer for the last five years and an active committee member.

I think for any parent, making decisions for your child is always difficult and especially so if you have a child with special needs. At our 20-week scan they told me and Jack's dad Mark that there was **a chance that our baby boy would be born with Down's Syndrome** as his neck measurement was slightly larger than average.

We chatted to the specialist midwife about our options, but for us there were no options. We would have our baby regardless. No amnio and no abortions. It was a short chat with her!

Jack decided to arrive into the world slightly earlier than planned and was almost born on our neighbours' decking as I was adamant I had indigestion! First-time Mum and all that. After a mad dash to the Horton Hospital, Banbury, Jack shot out an hour later after the mention of forceps! After a short cuddle he was whisked off to the Special Care Baby Unit (SCBU).

The consultant told us that they thought he had Down's Syndrome. At the time we didn't cry or get upset; we just knew that we would care for and love our baby no matter what.

Jack was in SCBU for six and a half weeks which was quite hard going but he finally came home only to be admitted again after three and a half months for open heart surgery. We didn't care that he had Down's Syndrome just as long as he survived the operation.

Looking back now I don't know how we coped seeing our baby connected up to all the tubes and wires on the Paediatric Intensive Care Unit but we knew he was in good hands and you just have to get on with it!

We had a few visits to hospital over the next few years mainly for chest infections. He vomited up to seven times a day every day due to the build-up of mucus on his chest and faulty valves at the top of his stomach, and failed to put on weight.

We didn't let this stop us doing anything, travelling to the Seychelles when he was six months old for our honeymoon as well as Lisbon, France and Cornwall! Through all of this Jack was still a contented baby, taking on these challenges as they were thrown at him.

At two years old we went on a holiday to Crete and he suddenly became a different child with regards to his health. **Virtually overnight he stopped being sick and started to put on weight!** He was also a floppy baby and didn't walk unaided until he was four and a half years old.

Mind you that didn't stop him bombing around on his bottom and then later on with his walker. If you see him now it is difficult to believe how poorly he was early on because now he runs very fast and eats loads! He is very sociable, but very stubborn and only wants to do what he wants to do!

When Jack was ready to start school we decided to put him in to our local mainstream school in Bicester since most of the advice we received suggested that children with Down's Syndrome benefit from being around other 'typical' children and could learn by copying them.

During year 1 Jack's behaviour became worse (he had always been a thrower!) often reluctant to line up, go into class, stay on task, to do as he was told by his teacher, or sit on the carpet, so we agreed for him to repeat the year. This didn't help his behaviour and if anything the situation continued to get worse.

This was a very low time for me and as every time I collected him there was negative comments and his whole education was becoming about his behaviour not what he had learnt. **I didn't know what to suggest or do.** I contacted various professionals to try and get some advice but nothing really helped.

The Educational Psychologist involved in school suggested he have his 1:1 sessions as normal but that he went back into reception (joined with nursery) at other times to try and build up his social interactions with the younger kids.

Unfortunately this did not help and Jack would still lie on the floor, refusing to budge only wanting to have an adult's attention. He would also behave like this at home so it just wasn't at school.

Every morning when I tried to get him to eat his breakfast or get changed or go to school he would lie on the floor and refuse to budge! I did go through a couple of very low weeks last October when I was just about to give up **but then Jack came along, gave me a big smile, a huggle (a hug and a cuddle) as we call them and told me he loves me.**

Earlier this year when the headteacher had said they didn't know what to do with Jack in September I knew the problem with his behaviour wasn't going to get better here and that, despite the care of the staff, this mainstream school was not right for him anymore. **So when the Ed Psychologist mentioned perhaps having a look at our local special school we decided to make an appointment.**

I was very upset at the time (February 2014) about this but was impressed by what I saw when we visited. All the questions and concerns I had were answered by the headteacher, and Mark and I both liked the idea of smaller class size and that this would probably benefit Jack. **I think I was so upset about special school because I worry about what will happen to Jack when Mark and I are no longer here and who will help him.**

At special school the staff teach the children about being independent such as cooking, getting dressed, money etc. which are essential skills needed to look after yourself. We also sat in on a lesson in the class that Jack would be joining should we decide to send him there. There were six children, one teacher and three teaching assistants and **I was surprised how calm and quiet the environment was. Each child could be taught at their individual level and with the specific help they needed.**



We decided to get Jack into the special school ASAP as I felt he was not achieving at the mainstream school. He started after Easter with a few mornings accompanied by his TAs from the mainstream school before attending officially after May half term.

He also gets transport to school provided which I wasn't so sure about but as school has been so good at communicating with me I don't feel I am missing out on the after school chats when I would have pick him up. He seems to enjoy travelling on the bus with some of his classmates!

Well, what a surprise in the first full week it was like having a different child. He actually wanted to go to school! He liked his new Teacher (Mr M) and was keen to talk about his new classmates. I haven't had the battles I was having every morning to get him to school. He is more willing to get dressed and wait outside for the bus to arrive.

Obviously, we do still have the odd battle and refusals to move or do anything, but generally he seems happier. **This makes home life much better.** Whether it was that the mainstream school we chose wasn't the right place or the fact that any mainstream school would never have been right we'll never know and **it is very early days at his new school but it seems to be going in the right direction at the moment.**

Please feel free to contact me regarding anything I've written about!

sarah.stevenson68@yahoo.co.uk

Development Groups update

Early Development Groups

EDGs are continuing to provide a much-appreciated service for pre-schoolers with Down's Syndrome. There is a small group that meet in Carterton and then the larger group meets at the South Abingdon Children's Centre.

Sally Dubock has unfortunately decided to 'retire' from the groups after two/three fantastic years, and Colette Lloyd has now been joined by Anne Churchill-Stone.

Anne used to run the groups a few years ago, and her son, who has Down's Syndrome, is now 12. She brings a wealth of experience to the groups and we are delighted that she has accepted the challenge of returning to offer the benefits of her experience to mums of pre-schoolers.

Primary Development Groups

An exciting new development this term has been the introduction of a trial of Primary Development Groups.

This initiative has grown out of a course run by Symbol, in Sussex, where they run speech and language therapy groups for all ages including adults.

These groups are overseen by speech therapists but run by parents or others with experience of DS, who have been trained and are known as co-workers.

We have adapted this model and as such the groups are being overseen by Nicola Lathey (SLT) who attended part of the course at our request. Children have been divided as much as possible by area and ability, although as you can imagine this



is not always easy! We have aimed for no child to have to travel for more than 30 mins to access a group.

The two trial groups are one KS2 one, and one KS1 both in Oxford. These are being run by Colette Lloyd, with a view to her being joined by Anne Churchill-Stone after Christmas, and Marion Simon is taking care of the administration.

On the advice of Symbol we have decided to charge a nominal fee for these groups, which hopefully will help towards their sustainability in the future.

The first sessions have gone well so far, and we are continuing to spread awareness of these groups. We hope that, as weekly sessions, with DS-specific interventions they will encourage language and educational development.

Everyone with primary age children should have been contacted before the summer concerning these groups, if you missed this, or have since changed your mind and would like your child to be added to our list, please let Marion know at secretary@dsoxford.org.uk or on 01608 811781.

Bullseye!

A second annual charity darts event, held at Berinsfield Social Club with the famous Dennis 'The Menace' Priestley attending, raised £650 for DSO.

The fantastic night included a raffle, auction, food and bar and was organised again by Ryan Wells and Darren Bowler from Berinsfield. The event organised raised a total of £1,300 which was split

between DSO and the Kamrans Ward at the John Radcliffe hospital.

Ryan says, "I worked with some people with Down's Syndrome when I left school and was a trainer chef when they did the washing up. Since then I have always supported any charity stuff that involves people with Down' Syndrome.

"When I went to college in London I saw the Chicken Shed Theatre where again I 'bumped into'

Bits and bobs



Our Lady's Abingdon

In May this year Our Lady's Abingdon school contacted DSO as their PTA had chosen our charity to raise money for during their annual sponsored walk. A member of staff at the school has a sister with Down's Syndrome who the children had heard about so they were keen to raise money to help people who have DS.

Katie Lloyd 16 (*pictured above*) went along to the school with her mum, Colette, and gave a short talk to the junior school on the work of DSO and what it was like to have Down Syndrome. The audience were very responsive and Katie also fielded a few questions.

The following week Katie and Conall Summers attended the sponsored walk. There, Conall completed a few circuits of the track and Katie, who decided that looked too much like hard work, (it was a long track!) sold DSO wristbands and bags which were very popular.

A few weeks later, with the children asking after her, Katie was invited back to the school to gratefully collect a cheque of almost £1,500 to help continue the work of DSO, for which we're very grateful.

Impromptu Cake Sale

When Phoebe and Millie (friends of Chloe Sanderson - age 9) did some baking after school one day, they decided to sell their delicious cupcakes to neighbours so that they could raise some money for DSO. All the cakes sold quickly and they **raised £11.30!** Well done girls and a big thank you from DSO.



First Aid training

Recently four parents attended a Red Cross baby and children's First Aid course which was subsidised by DSO. It covered a wide range of illnesses and injuries often suffered by children and included CPR. The course was informative and hopefully gave the parents confidence in dealing with an emergency.

There is an app which can be downloaded which includes useful videos, animations, self-test screen and a hospital finder: redcross.org.uk/babyandchildapp

people with Downs Syndrome who were in the group and they were quality, acting Peter Pan. It touched me big time.

"I'm glad to help DSO: next year could be bigger and better, and we could get some sponsored events in place in the lead-up to it."

Niki and Archie (left), Dennis 'The Menace' Priestley, Jolene and Evie-Mae (right)



Gift Aid declaration

Please tick appropriate response:

☐ I would like DSO to reclaim the tax on all donations I've made since April 2000 and all my future donations until further notice. I understand that I must pay an amount of income tax or capital gains tax at least equal to the tax DSO reclaims on my donation(s).

☐ I am not a UK taxpayer

I enclose my gift of £_____ (cheque/PO payable to Down's Syndrome Oxford)

OR

A regular gift of £_____ per month/quarter/year (delete as applicable)

Commencing on the ____ (day _____ (month) _____ (year)

Name of bank: _____

Address of bank: _____

_____ Postcode: _____

Current Account No: _____ Sort Code: __ - __ - __

Signature: _____ Date: ____/____/____

Bank ref: _____ (completed by DSO)

Bank Instructions: please pay the above amount on the same day of every month/quarter/year (as indicated) thereafter to Lloyds TSB bank (30-94-04) for the account of Down's Syndrome Oxford (a/c 01154094).

Please return this slip to DSO, not your bank, c/o Treasurer DSO, Sarah Hazell, 58 Ashfield Road, Caterton, Oxon. OX18 3QZ.

We will not share your information with any other organisations.

Your Name: _____

Your Address: _____

Postcode: _____

Registered Charity No. 1103850



Fundraising resources

Resources which may be useful if you are organising a fundraising event include:

- Leaflets
- Posters
- Cardboard donation boxes
- Stickers
- Balloons
- T-shirts
- A display board
- Pull up DSO banner
- Charity wristbands

Please contact Marion Simon if you need a supply of leaflets, donation boxes or stickers. (Marion's details are on the back cover.)

DSO emails

Do you receive DSO emails advertising future events and training courses?

If not you can go to the DSO website and register to receive them. If you think you are receiving too many emails about events not relevant, you can also log in and choose which category of email message you want to receive (eg pre-school or professional only.)

Special school days, cake-making and birthday celebrations...

The following money has been given or raised for DSO in the last few months, for which we're extremely grateful.

Donations include:

£15.00	Chalgrove Community Primary School where Owen Lane is a pupil. Year 5 pupils raised money doing a squash and cake sale
£200.00	Suhana belly dancer Hannah Newton from a charity raffle and lucky dip at a belly dance function. (Lloyds bank then matched it donating £203.00!)
£150.00	UK Atomic Energy
£21.30	Phoebe and Millie - making and selling cakes
£1482.00	Our Lady's Abingdon sponsored walk
£460.00	Waitrose, Thame
£211.00	First Steps, Thame – Charlie Sumners pre-school donated from doing a sponsored assault course
£124.95	Berinsfield pre-school doing an odd socks day
£537.89	Oxford Spires scouts from the St George's Day Parade
£236.08	Mr Bennett donated in memory of his wife Joyce
£645.00	Judy Robson's birthday celebrations (Sylvia £30.00; Mr and Mrs Poulsen £70.00; Mr and Mrs Robson £20.00; Judy collected and donated £525.00)
£80.75	1st Upton and Blewbury Guides raised in memory of Freddie Perry
£100.00	David Stafford
£6.47	Yvonne Voyce donated 10% of her Phoenix Cards sales

A huge thanks as well to all those who give regularly by standing order. You can use the form on the previous page to send one-off or regular gifts.

Please remember to fill in a GIFT AID declaration for your donations wherever possible. There is no extra cost to you and the process is simple. It means that DSO receives an extra 28p for every £1 given to us by UK taxpayers.

Contact us

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Primary Club Co-Ordinator

Kelly Stacey primary@dsoxford.org.uk 01235 510222

10+ Club Co-ordinator

Rachel Johnson 10plus@dsoxford.org.uk 01608 677861

18+ Club Co-ordinator (adults group)

Position vacant 18plus@dsoxford.org.uk

Early Development Group Administrator

Netty Lings edgs@dsoxford.org.uk 01993 852391

Early Development Group Leaders

Colette Lloyd (01993 883707) Anne Churchill-Stone (??)

Website: <http://www.dsoxford.org.uk>

General enquiries email address: info@dsoxford.org.uk

Facebook: <https://www.facebook.com/groups/dsoxford>

Twitter: <http://twitter.com/DownsOxford> @DownsOxford

With thanks again to First Move direct marketing in High Wycombe who very generously prints and mails our newsletter free-of-charge.



down's syndrome oxford
Registered charity number: 1103850



The deadline for the March 2015 issue of the newsletter is Monday 2 February. We welcome any text or photos about your child enjoying themselves – not necessarily at a DSO event. Please send material to the editor Andrew Dubock at media@dsoxford.org.uk