

Newsletter • March 2015

From the chair

As usual, there is a lot of activity to report on, and you will see much of it further in the newsletter, but it was lovely to see so many people at **our Christmas Party in December and the Disco in January.**



At both these events we had members there ranging in age **from small babies to grandparents**. We would love to organise more events suitable either for all ages, or a slightly older age group, so if you have any ideas please let the committee know.

At the moment there is quite a bit organised by DSO members for babies, toddlers and school age children, but we feel the **older age groups** may be missing out. The funds are available, so feel free to submit any ideas!

As I said in the last newsletter, I am standing down as Chair, and sadly our Treasurer, Sarah Hazell, will also be standing down at the AGM. **We are now on the lookout for two people to take on these roles**, so if you would like to know more about what is involved, please contact either me or Sarah for more information. Our contact details are on the back of this newsletter.

DSO can only carry on if people come forward to volunteer, in any capacity, so if you would like to help out **please come to one of our committee meetings**. I know that every family has demanding lives/jobs/other commitments but **we really need you!** **DSO's training programme** for parents and professionals, organised by Elsa Gill, continues to be very successful and well received, with places booked up well in advance. There may be a slight pause during spring and summer, but rest assured they will continue in the autumn, in time for the new academic year.

Hopefully, we will see you at one of committee meetings or the AGM in June.

Katharine Horrocks

Next committee date

Monday 19 May At the Turnpike Inn, Yarnton, from 7.45pm

AGM date Monday 22 June

Venue TBC

DSO football tournament

Sunday 10 May at Milton United FC

As well the football there will be a raffle, tombola and cake stall, so we are looking for **donations for prizes and help on the day itself.** Last year's event was a huge success; help us have the same impact this year!

Look out for more details nearer the time by email and on Facebook and contact <u>niki.archer@yahoo.co.uk</u> for more information.

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DSO Disco

"On Saturday 24 January we held a disco at Exeter Hall in Kidlington for DSO members and their families and friends.

It was a great night, with well over 100 people coming along to enjoy an evening of music, dancing, and karaoke. There was even an opportunity for people to show off their flexibility and suppleness with a spot of limbo dancing. With the exception of a short break for the buffet, the dance floor was occupied all night. From toddlers to teenagers to adults, everyone had a boogie and I witnessed some pretty impressive dance moves!"

Lucy Sanderson











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.



Singing Hands

On 28th February the Pre-school and Primary clubs had a session with Suzanne and Tracy from Singing Hands. Singing hands present stories and nursery rhymes using Makaton signing. Nearly 100 people attended the event and everyone had a lovely time joining in with the songs. Then over a cup of tea and biscuit there was chance for a chat and play with families who hadn't seen each other for a while.For those of you who have watched their DVDs repeatedly you will be pleased to know there should be two new ones out in time for Christmas.





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 <u>lottery@dsoxford.org.uk</u> We will then allocate your numbers. Thank you to everyone who supporting us. *Amanda Foulds & Lucy Sanderson*

Recent winners...

October 2014

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

November 2014

1st prize - £43.00 2nd prize - £25.20 3rd prize - £17.20 Andrew Partner Emily & Matt Robinson Jo & Stu Crawford

Jo Colehan

Emily & Matt Robinson Andrew Partner

December 2014

1st prize - £43.00 2nd prize - £25.20 3rd prize - £17.20

January 2015 1st prize - £42.00

1st prize - £42.00 2nd prize - £25.00 3rd prize - £17.00

February 2015

1st prize - £42.00 2nd prize - £25.00 3rd prize - £17.00 Sarah Stevenson Nigel Orman Jo Colehan

Ryan Wells Netty Lings Katharine & Mark Horrocks

Miss W Parker Jon Gill Sarah Stevenson

Training update

Elsa Gill writes: We've had a busy few months of training sessions, including 'Behaviour' delivered by Gillian Bird of DSA and 'Sensory Processing' delivered by LEAP in Bucks.

Speech Therapist, Nicola Lathey ran a training day "Practical activities for developing speech, language and communication skills in children with Down's Syndrome 4-11yrs" in January which proved so popular that we ran a second in February. As the title suggests the training was very practical and participants left with a folder of ready-made resources which they could start using instantly at school or at home.

Nicola's informal but knowledgeable style was very popular. She screened film clips, showing her using the resources with children as a clear guide of how they could be used. The day ended with each participant having a 1:1 session with Nicola so she could talk through personalising the resources for each individual child.



The feedback from the training was very positive. "A fantastic course", "Picked up some great, practical ideas to work on. It was great to hear other's experiences and things that worked."

We will be running this course again in the next academic year and after the feedback we received, Nicola is also designing a similar course for preschool children which we will also run this autumn.

Down's Syndrome: 'Communication For Life' Developing communication skills for real life communication challenges of the teenage years and young adulthood.

For families and professionals supporting children and young people with Down's syndrome, 9yrs to young adulthood.

Looking at communication issues in the context of adolescence, a time of transition from childhood to adulthood. Exploring ideas and strategies that can support communication around key issues.

If puberty is on the way, or has already arrived, this course will help map out future directions and priorities, as well as discussing practical solutions for everyday challenges.

Date:9.30am-4.30pm, Sat 25 April 2015Venue:Didcot Civic Hall, Britwell Road, Didcot
0X11 7JNCost:£20Trainer:Leela Baksi, Symbol UK



To book please contact Elsa elsagill99@gmail.com

Check for last minute places!

Evening Talk: Fiona Silley, co-author of 'Reading and Language Intervention for Children with Down Syndrome'

DSO has a very exciting and one-off opportunity for a talk by Fiona Silley (nee Duff), co-author of the DSE International 'Reading and Language Intervention for Children with Down Syndrome '(RLI).

RLI is a highly individualised, daily intervention designed to meet the needs of students with Down's syndrome. It is suitable for children across a wide ability range and the content is adapted for each child.

Date: Venue:

Cost:

 7-9.30pm, Thursday 26th March 2015
Mary Town Room, West Oxford Community Association, Botley Road, Oxford OX2 0BT Free, open to both parents and professionals

This talk is free to attend, however, places are limited, therefore, you must book a place. Email: elsagill99@gmail.com





TAs and Teachers joining the DSO database – Parents we need your help!

Feedback from the teaching staff attending our recent training sessions has been extremely positive, however, it is clear that apart from a handful of clued up TAs, very few teachers or TAs know that DSO has a mailing list or that anyone can sign up to receive emails about forthcoming training days.

We have a full programme of training planned for this autumn which we know teachers and TAs will be interested in hearing about. Therefore, we need as many Sencos, teachers and TAs as possible to join our email mailing list so that they can hear about the training as it is announced. Sometimes, training sessions are so popular they book up very quickly with parents, before news can filter through to teaching staff via parents handing over flyers at the school door.

It is unlikely that a new TA working with your child in September will know about DSO or our training programme. We will be mailing schools, however, the best way to ensure that your child's TAs know about our on-going training programme is to tell them yourself and to urge them to join our mailing list.

To make this as easy as possible we have produced a flyer which you can cut out or photocopy and hand over at school. It is very easy for anyone to sign up or unsubscribe via our website. **See page 6** >>



Dear Senco, Teacher or TA,

Down's Syndrome Oxford (DSO) 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.

As a parents group we are very keen to support those who work with our children. We are proud of the range of training we run for both parents and professionals, however, we are aware from feedback that many teaching staff simply don't know about the training we run. Recent topics have included behaviour, sensory processing and practical speech activities.

We want to build up our database of school staff, ready for the autumn term, so you can hear about training as it's announced. Signing up is free and very easy.

We are also keen to hear if you have any suggestions for future training or if you would simply like more information. Contact Elsa **elsagill99@gmail.com**

How do I sign up to hear about training?

- 1. Go to the DSO website **www.dsoxford.org.uk**
- 2. Click on the '**Connect'** icon on the homepage.
- 3. Complete the form. Choose to receive emails (by clicking 'professional' you won't receive emails about social events) or you can also choose to receive our quarterly newsletter. We will never pass your details to a third party.

Sporty Fundraising Feats



Well done to Theo Champion, 8 years old, who recently raised £30 for DSO by undertaking two hours of sponsored sport. Theo and his big sister Evie are friends with DSO member, Jack Gill.



Thank you to Jo Sumner and Helen Gaffney and her girls who did a 5K 'Run or Dye' in Oxfordshire last October and raised £200 for DSO.



Almost £700 was given to DSO out of nearly £3,000 raised by a massive Zumbathon in the Thame area. Around 100 people joined the Zumbathon last November. The event was not only supported by local people, but also businesses such as Waitrose and Co-Op and Nakd.

Update: 1,000 miles in 1 year

I've been on the run since October now and have now covered 370 miles from the 1,000 I've set myself and raised £1,500 out of the £5,000 I am trying to raise.

To put into context how big a challenge this is for me, in the two years I had been running before this I had covered a total of just under 500 miles, so I now have to double that in half the time! I have run in about 15 races, one of which was my first marathon, with numbers two and three to follow in the next few weeks.

What keeps me going? Well, my nephew and DSO member Lucas plays a big part in it. When I'm out running and I start to tire I just think about what he and his mum and dad are going through.

I also have a very good bunch of friends up and down the country that pitch in and keep me company when they can. And the people from my running club, Hastings Runners and a group of them that are known known as Ten-mile Tuesday. The guys from DSO have been great, and just in general the running community as a whole are very supportive when I explain what I am doing. I'm proud of my medals so far - see photo below.

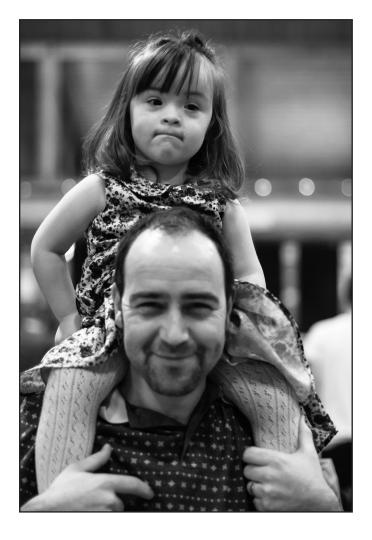
I am enjoying every mile no matter how hard it is and I am just happy that I can help raise awareness and funds for a great charity that does so much good and offers so much help to families in need.

Steven Willis

Sponsor Steven at <u>www.justgiving.com/</u> <u>steven-willis1</u> Follow his progress over his fundraising year at <u>https://www.facebook.</u> <u>com/raceforlucas</u>



Christmas Party!

















Update on Jack's new school

Sarah Stevenson writes:

I've had a fair bit of response from the article I wrote last time about sending Jack to Bardwell Community School in Bicester so I thought I'd just do a quick update on how he is getting on.

I think overall Mark and I agree that Jack has made progress over the last 3 (nearly 4!) terms he has been there. His reading, writing and speech have all improved as has his singing (eek!). I was really impressed on a recent visit to school for the Bardwell Bake Off with his handwriting and he was very keen to show me his work (whilst eating oat cookies made by his class). His confidence and social skills have improved. He is in a class of 8 with 1 teacher and 4 teaching assistants.

In the last term before Christmas he was invited to represent Bardwell at the Singing for Children Concert in St Edbergs Church. This is where schools in and around Bicester are asked to perform in the local church to raise money for charities that help children.

The church was packed and I was nervous but as you can see he is having a lovely time. He stayed on the stage as they had practiced and carried out his dance to the Grand Old Duke of York. It was a very proud Mummy moment as he hasn't wanted to do this previously.



Jack was asked to be Elvis in the school Nativity. Elvis Presley? Yes, it was Christmas through the Ages! I purchased a delightful synthetic Elvis costume from a well-known internet company and as he performed with his class in front of parents and staff. He is a real little mover!

As you know with most of our kids it's not all plain sailing and Jack's behaviour, especially during transitions is still very challenging, but overall he has made progress and we think he is really enjoying school.

Please contact me if you would like to on sarah.stevenson68@yahoo.co.uk / 07833 546359

Development groups leadership course

Have you ever thought about expanding your skills and possibly one day working with children with Down's Syndrome?

We are looking to expand our team at DSO of people with the capability and interest in running Early or Primary Development Groups.

There is a course coming up which aims to facilitate people to setup and run such groups. It is $\pounds400$ for three days, spread over four months, and we may be able to help with the cost of attending.

If you, or someone you know, may be interested in attending such a course, please ring Colette Lloyd or Katharine Horrocks for a discussion around your interest, previous experience etc. There is no guarantee of a job with us at the end of the course, however we, as a charity, feel that it would be useful to have more people trained in this area, in case future needs arise, and for the disseminating of information. Hence the willingness to possibly part-fund the course.

In the first instance, please contact one of us as soon as possible for an initial discussion: Colette Lloyd 01993 883707 (Friday daytime or evenings best, but before 9pm!) Katharine Horrocks 01844 261424

Development Groups update

We have welcomed four new families to the **Early Development Groups** this term and they have enjoyed their initial sessions with Colette.

Both Anne and Colette have been working hard with their groups so far this year and the children are making good progress with their signing and understanding. Parents are gaining lots of ideas for activities that they can be doing at home to consolidate and extend their child's comprehension and language development, too.

There will be the opportunity for more children to join EDGs, which run every Wednesday morning in term time at South Abingdon Children's Centre, in September.

The groups are for children from the age of 12-15 months through to school age and focus primarily on Speech and Language development.

There is no charge for attending the groups and siblings can be looked after during the sessions if needed. Please register with Netty Lings at edgs@dsoxford.org.uk or on 01993 852391 as early as possible to ensure your child gets a place at the earliest opportunity.

If you are not sure if you have already registered (we know how overwhelming it can be at the start and you may think you have registered simply by joining DSO's mailing list or expressing an interest to Rowena Pearce) so please do not hesitate to get in touch and check if your child's name is on the list!

We look forward to hearing from you and meeting you soon.



EDGs: all too much for Jamie Beckett!

Three **Primary Development groups** are being run this term, two by Colette Lloyd, one in Bicester and one in Witney, and one by Anne Churchill-Stone in Abingdon.

These are run as an extension of the Early Development Groups. They provide a way of both sharing information with and between teaching assistants, as well as offering an opportunity for extra practice of targeted activities that all children with Down's Syndrome benefit from at varying levels. Some of the activities that we do are continued speech work, vocabulary extension, utterance lengthening and auditory memory.

These appear to be being well received both by the children and by their TAs and the schools have made us very welcome and are appreciative of the extra input that the children and staff are having.

Currently we plan to finish these groups, at Easter, when all children whose parents were interested will have received a block of sessions. We will then evaluate the experience through questionnaires and decide if it is a worthwhile way of spending DSO money.

If you are interested in future groups and have a child of primary school age please contact Marion Simon at <u>secretary@dsoxford.org.uk</u> or on 01608 811781.

On the buses

Have you ever wondered what happens to all of our unclaimed bus passenger change?

Each year Oxford Bus Company donates all unclaimed passenger change to worthy local causes. In February, staff voted on which charities should receive a portion of this money and DSO was one of the most popular choices. Hannah and Jessica Dubock collected £500 for DSO.



Bits and bobs

Congratulations to Otto Baxter who won best actor in the disability awards at the Cannes Film Festival 2014.

This was for his role in 'Ups and Downs'. The film was nominated for the Van d'Or awards 2013 and Otto went to the ceremony. It was also shortlisted for Bafta Triforce Film Festival 2014.



And congratulations as well to 16 yearold Katie Lloyd has just passed her Maths and English IGSCEs. Katie has three other GSCEs to do and is also taking a BTEC and her NVQ Level 1 in catering.



Here's Lucy Robinson in her new Erin's World glasses – frames designed specifically for children with Down's Syndrome and small noses!

Mum Emily writes, "They are great, she is actually looking through the whole of the lens rather than over the top and there is no slippage down her nose. We can also see all of her gorgeous eyes. A small change that makes a massive difference!" Emily bought them from Vision Express in Bicester who were hugely supportive.

A big thank you to the Environment and Economy department at Oxfordshire County Council, who raised £250 for DSO by putting on their pantomime, Lackwise to Kenneford, loosely based on Aladdin.

Writer and director Kevin Broughton says, "For some years we put on a pantomime, which we fund ourselves, but we hadn't done so for a few years because of the changes taking place here. Now that things are more settled we decided to reinstate it. It's a very cheap affair, full of in-jokes but it's a bit of fun in the run up to Christmas. "One of the cast is the aunt of DSO member Lucas Randall. She had mentioned that Lucas had leukaemia and diabetes, but that he had been getting support from DSO – so we thought it would be good to help by sending anything we raised to you.

"As well as the play there were nibbles on sale to raise a bit of money. We all had a great time rehearsing and performing it."



Down's Heart Group Conference and Family Weekend: 16th and 17th May, Combe House Hotel, Holford, Somerset

There will be talks in the morning, lunch and afternoon workshops. The conference costs $\pounds 25$ with extra costs for crèche and activity workshop.

There is a social supper on the Friday evening and a dinner and disco on Saturday night. All are welcome – you can choose just to come to the conference, or the dinner and disco – just let us know which bits you are interested in.

Contact <u>info@dhg.org.uk</u> or call 0844 288 4800 for booking and more details. Last booking dates: 30th April for accommodation and crèche/activity workshops; 7th May for conference.

Oh yes it is! Alexander Horrocks (9) and his brother Robert (6) were thrilled to have a special meeting with Dame Jolena Jollychops at a performance of "Beauty and the Beast" in Oxford.

Alexander and Robert also took part in a production of "Puss in Boots" at Thame Players Theatre in January, and Alexander had the role of Carson the Butler. Here they are with Dame Abbey.





Chloe Sanderson (9) who attends Langford Village Primary School, a mainstream school in Bicester, has been chosen to be part of the school ballroom dance team.

On Saturday 21 March, the same date as World Down's Syndrome Day, Chloe and her 15 team mates will take part in Junior Strictly Oxford. The mixed team of 8 girls and 8 boys will be dancing the tango and jive and competing against other Oxfordshire Schools.

Chloe has passion for dancing so is thrilled to be part of the team and to be given the opportunity to perform in front of an audience and judges.

Congratulations to Sandy Alton and the team at the Down's Syndrome and Complex Needs Service who were recently inspected by Sue Edwards, Head of SENSS and her team.

SENSS covers a range of SEN services across the county including Services for Autism, Hearing, Vision, Physical disabilities, Sensory, Language & Communication Services.

The inspection results were very positive about the DS/CN service – "a small team with a big punch and with hands-on pro active strategies".



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 £ OR | (cheque/PO payable to Down's Syndrome Oxford) | | |
|-------------------------------------|---|-------------|--------|
| 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, <u>not</u> 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

Balancing and bouncing

DSO mum Emily Robinson writes,

My daughter Lucy (8) started mainstream gymnastics classes in September. I was initially nervous about whether this is something she would be able to do, but also something she should be doing given some of the physical limitations that can be associated with Down's Syndrome.

As usual, she has proven us wrong! She is a very physical child who loves climbing and jumping but she is tiny for an 8 year old (just over 1 metre!). She absolutely adores her gymnastic class. There are about 40 children in the class (gulp), Jane Brook's Woodstock Gymnastics Club held at The Marlborough School, and she is probably the oldest by far but physically one of the smallest.

The children are divided up by both size (so the equipment is suitably adjusted) and capability. They use lots of different pieces of equipment; a huge trampoline, an inflatable runway which they jump, skip or roly-poly along, balance beams and asymmetric bars, springboards as well as the mat.

I felt more comfortable with this gymnastics class compared with others as one of the instructors is Sam Pattern (who used to be one of our EDG childcare helpers) and so was happy that someone who understood Down's Syndrome would be there. Lucy also has a teenage helper if she needs extra support (no extra charge!).

By the end of her first term she had achieved her Level 8 badge, which she wears with huge pride on her club sweatshirt and she is bounding towards her Level 7! I wish we had started this sooner, as usual it was my anxiety that stopped me and as usual she has proved me completely wrong!



Challenges, quizzes and book sales

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

Donations include:

| Donacions | |
|-----------|--|
| £117.00 | Lucy Sanderson and the Wolf Run Challenge |
| £27.68 | Jasper Furniss for growing and selling flowers |
| £695 | Sandra Brooks for a charity |
| | Zumbathon |
| £45.00 | Morna Whitlock from the sale of her book |
| £40.00 | Christine Bentoff |
| £10.85 | Emily Robinson and her mother in |
| | law's collection box |
| £21.67 | Department of Oncology |
| £305.00 | Oxford Brookes university |
| £100.00 | From a family in Italy whos son is at |
| | Oxford Brookes. |
| £215.00 | Annette Driver for a Christmas Quiz |
| £3500.00 | Critchley's charitable trust |
| £650.00 | Darts match – Hissey |
| £10.00 | Julie Brett and her Ice bucket |
| | challenge |
| £618.88 | Dean Kelly's and Elsevier |
| £12.22 | Yvonne Voyce donated 10% of her Phoenix Cards sales |
| £250.00 | Oxfordshire County Council |
| | |

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.

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.)

Contact us

| Chair Katharine Horrocks | chair@dsoxford.org.uk | 01844 261424 | | |
|---|--|--------------|--|--|
| Secretary & Fundraising Marion Simon | Opportunities secretary@dsoxford.org.uk fundraising@dsoxford.org.uk | 01608 811781 | | |
| Treasurer Sarah Hazell | treasurer@dsoxford.org.uk | 01993 840771 | | |
| Assistant Treasurer Emily Robinson | info@dsoxford.org.uk | 01869 347194 | | |
| Training Elsa Gill | elsagill99@gmail.com | 01865 741216 | | |
| DSO Lottery Organisers Amanda Foulds/ Lucy Sanderson | lottery@dsoxford.org.uk | 01865 875832 | | |
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| Primary Club Co-Ordinat Kelly Stacey | or primary@dsoxford.org.uk | 01235 510222 | | |
| 10+ Club Co-ordinator Rachel Johnson | 10plus@dsoxford.org.uk | 01608 677861 | | |
| 18+ Club Co-ordinator (a Position vacant | adults group) 18plus@dsoxford.org.uk | | | |
| Early Development Group Netty Lings | p Administrator edgs@dsoxford.org.uk | 01993 852391 | | |
| Early Development Group Leaders Colette Lloyd (01993 883707) Anne Churchill-Stone (01235 533011) | | | | |
| 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 @DownsOxford | | | | |

With thanks again to First Move direct marketing in High Wycombe who very generously prints and mails our newsletter free-of-charge. ne oxford number: 1103850



The deadline for the July 2015 issue of the newsletter is Monday 1 June. 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