



Newsletter • December 2017

From the Chair

The newsletter may have had a break but our events at DSO certainly haven't! I'm very happy to welcome



back the DSO newsletter filled with reports of lots of activities and events which have happened over the last year or so. Here are a few events featured on the following pages.

Elliot's Shed launched in the summer which means we now have a Shed full of lovely equipment to try before you buy. Many thanks again to Elliot's parents Kat and Seth Cornfield for making these resources possible by raising the funds. Have a look on page 3 if you're interested in what Elliot's Shed has to offer.

Early this year the Oxfordshire **More than Medical booklets** were released, showcasing fourteen DSO families to educate the general public and the medical profession about what life with DS is like in the twenty-first century. The booklets are being distributed around the county. Thanks to Emma Smith for working hard to get this booklet out and distributing it. More on page 10.

Apart from these new developments, other all-time favourites are still happening: our

training sessions for parents and school staff are still going strong. Please continue to keep an eye out for upcoming training sessions in your inbox. We had another great **Summer Party** at Sarah and Dean Fonge's this year complete with pig roast! We had loads of **club activities** as well, much enjoyed by everyone from preschool to 10+.

Not featured in this newsletter but I'm sure we'll hear all about it in the next one, is our Christmas Party which is coming up again on 10 December at Exeter Hall, Kidlington. Hope to see lots of you there!

Enjoy the newsletter and thanks to Lucy Sanderson for kick-starting it again!

Marion Simon, Chair

Next Committee Meeting

Monday 29 January 2018

At the Turnpike Inn, Yarnton

From 7.45pm

New committee members are always welcome. It's a valuable opportunity to meet other parents, find out what's going on, put forward new ideas, and have a say in how the charity is run.



Elliot's Shed

Helen Gaffney writes:

Earlier this year DSO was thrilled to launch Elliot's Shed. Elliot's Shed contains specialist equipment and educational resources for members of Down's Syndrome Oxford to borrow. This provides a good opportunity to 'try before you buy', especially on items that can be expensive to purchase.

This initiative has been made possible by the incredible fundraising of Elliot's parents, Kat



and Seth Cornfield. Elliot sadly passed away in 2015, aged 2, after a long battle with cancer. His parents raised the money to create something for DSO which keeps his memory alive for years to come.

The official launch which took place on 3 June attracted lots of media coverage. It was the headline feature on the *ITV Meridian* news programme and was also covered by the *BBC South Today* news programme and the *Oxford Mail*.



How do I borrow something from Elliot's Shed?

We now have a wide range of items to borrow from Elliot's Shed, many of which are listed on the opposite page.

- ♦ To borrow items from Elliot's Shed individuals must be a DSO member.
- ♦ If you wish to borrow something please email the Elliot's Shed team at elliottshed@dsoxford.org.uk or post a request on the Elliot's Shed Facebook page.
- ♦ Items are loaned out for 3 weeks at a time. If during that time period someone else requests the same item, you will be asked to return the item at the end of the 3-week loan. If it is not requested by another, then you will be given the option to borrow the item for a further 3 weeks.
- ♦ We are asking people sign out the item and leave a deposit of £5 per item when borrowing. On return the £5 will be fully refunded. There are no charges for late returns.

What's in Elliot's Shed?

We currently have the following items available to borrow:

Seating

- Cushi Tush chairs
- Wooden corner seats
- Small seat with straps
- Breezi/Tripp Trapp high chairs
- Trays for Breezi chair
- Toddler seat

Transport items

- Major Maclaren pushchair
- Ergo baby sling

Footwear

- Pedro boots (various sizes)

Toilet equipment

- Toilet step
- Potty chair in sturdy wooden frame

Bikes/trikes/scooters

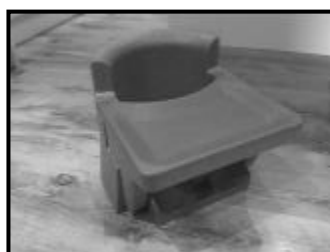
- Bee wheeli bug
- Wooden toddler trike
- Micro scooters
- Scooter with seat
- Large child/young adult trike
- Tomcat Trike
- Weehoo bike trailer
- Small balance bike

Toys

- Large wooden kitchen
- Solid foam building blocks, sensory light cube
- VTech play and learn activity table
- VTech Gro and Go baby walker
- 2 large boxes of assorted toys

Baby equipment

- Fisher Price baby gym
- Tiny Love baby mobile



Coming soon to Elliot's Shed

Bubble tube, fun pod, writing slope, Makaton and Numicon resources, sensory kits, weighted lap pad, rocking balance platform, Ikea egg chair, feeding and drinking equipment.

Keep an eye out for **all new arrivals on the Elliot's Shed Facebook page**. Additionally, you can request a list of equipment by emailing Elliot's Shed.

Update on fundraising

Thame & District Round Table have generously donated £500 to Elliot's Shed to fund new resources.

They have also invited us to join them on a Santa Sleigh run to raise further funds for Elliot's Shed.





Preschool Club



On Saturday 2nd September the Preschool Club had a fun day out at Camp Mohawk, a woodland centre for children and young people with special needs. Unfortunately only a few DSO families were able to attend but the group met up with families from West Berkshire who were also visiting that day, and enjoyed a picnic together.



Preschool Winter Party

The Preschool Club held its winter party at Littlemore Village Hall on Saturday 25th November. 'Hartbeeps' joined the party and ran a 45-minute high energy sensory session which included a great light show. And to top off an enjoyable afternoon, Santa made a surprise visit!



Nik Elliot, Preschool Club Co-ordinator



Primary Club



In May the Primary Club had a trip to the **Winchester Science Centre**, a hands-on, interactive, science and technology centre - and the largest standalone planetarium cinema in the UK!

The children had a great time exploring all the interactive exhibits with the parachutes being a firm favourite. We all watched a fantastic film in the planetarium about the different planets. The day was finished off with an explosive live science show.

Kelly Stacey, *Primary Club Co-ordinator*



**WINCHESTER
SCIENCE CENTRE
AND PLANETARIUM**



Slapstick comedy at its best! In June, the Primary and 10+ Clubs went to see the hilarious **Three Musketeers** at the Cornerstone Theatre in Didcot. It involved just three actors and was full of slapstick, adventure, and chaos that kept us entertained from start to finish. It was brilliantly performed and certainly one of the funniest shows we've seen for a while!



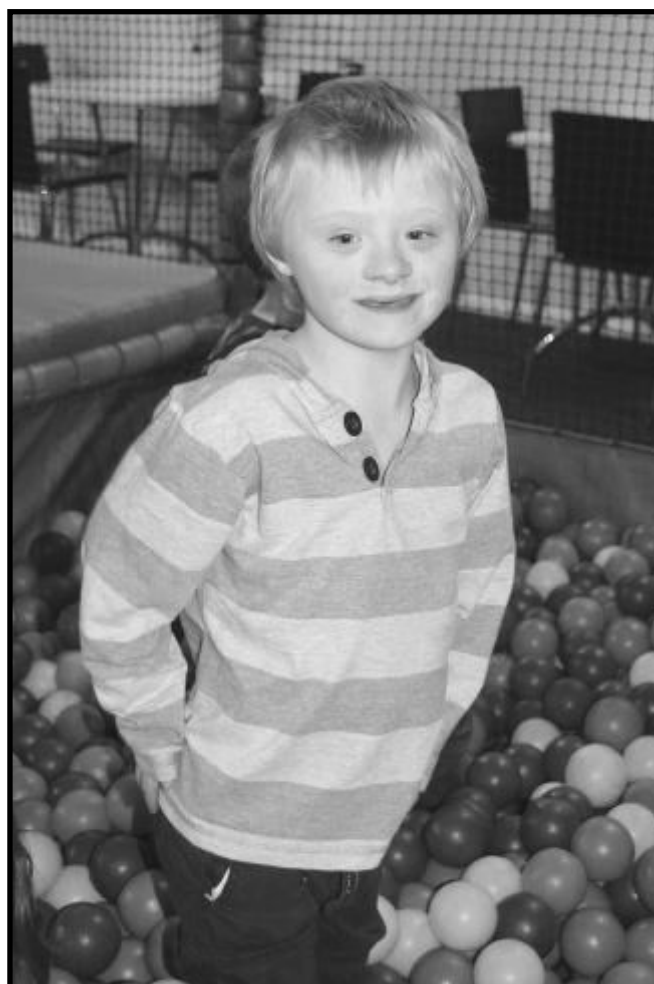
Partyman



The Primary and 10+ Clubs have enjoyed several joint outings to Partyman in Oxford, where we've had exclusive use of the play centre. It's great to have the whole place to ourselves and the children certainly make the most of it exploring the play frames, whizzing down the slides, and getting lost in the ball pits. The staff on duty are always fantastic and constantly entertain the kids. They organize football games, mini discos, and even a frozen sing-along with snow machine. With the kids fully occupied, it's a great opportunity for parents to catch up over a cuppa. As these joint visits have proved to be a great success, I'm sure there will be more to come.

Lucy Sanderson, 10+ Club Co-ordinator







10+ Club



In May the 10+ Club took part in an Anjali dance workshop.

The children seemed to really engage with contemporary style of dance and during the hour-long workshop created a routine which they performed to parents at the end. It was very impressive. The children performed individually, in pairs, and as a whole group, with everyone adding their own flair and individuality.



In November, we were lucky enough to get tickets to see the Mamma Mia musical at the New Theatre, Oxford.

WOW what a show! It was a superb performance, full of brilliant singing and dancing, with plenty of platform boots

and silver sequins. By the end of the show every single member of our group was up off their seat boogying along to *Dancing Queen* and *Waterloo*!

Lucy Sanderson, 10+ Club Co-ordinator



Summer Party



On a hot sunny day in July the DSO community descended in their droves to Waterperry for the annual DSO summer party. A huge thanks once again to the wonderful hospitality of Dean and Sarah Fonge. We were entertained by the brilliant Colonel Custard and his extremely funny magic show, and new this year was the hog roast which seemed to go down very well! We were joined by Rowena Pearce, Specialist Nurse for Complex Needs, and presented her with a vase with individual finger prints of our children to celebrate her retirement and say big thank you for all the work she has done to support our families.



“... more than medical”

Emma Smith writes:

DSO is delighted to have collaborated with Lose the Label to create the Oxfordshire “... more than medical” booklet. We are the second support group in the country to produce this booklet.

The booklet is full of stunning, high-quality photos and tells the stories of local DSO families. It is designed as an information resource for parents, prospective parents, and a tool for professionals beginning from the point of NIPT (non-invasive prenatal testing) discussions and options, through to a postnatal diagnosis. The aim of the booklet is to ensure parents throughout Oxfordshire receive current, complete and balanced information about life with a child or adult with a Down's syndrome diagnosis.

The booklet has been endorsed by the Down's Syndrome Association, and similar versions are being created by other Down's syndrome support groups across the country.



We have printed 2000 booklets and so far we have distributed the booklet to key medical staff at the John Radcliffe hospital in the prenatal, neonatal, screening and foetal medicine units. We plan to make sure that every GP surgery and health visitor has a copy in the coming weeks, so if you are happy to take a copy to your surgery, please get in touch with Emma Smith.

We are open to ideas of how we can use the booklet (for example distributing them to schools to be discussed during PSHE sessions (Personal, Social, and Health Education), so if anyone has an idea or would like to get involved in distributing the booklets please get in touch with Emma Smith.

A huge thank you to all the families involved for telling their stories, to the creators Michelle Clark and Rebekah Docherty, and to photographers Lone Jensen and Andrew Ogilvy. We're really pleased with the finished result and hope that is a useful information source for both prospective and new parents.

*If you'd like to get involved with the distribution of the booklet please get in touch with Emma Smith
secretary@dsoxford.org.uk*

Discretionary Fund

DSO has introduced a new “Discretionary Fund” which will allow a sum of money to be put aside for the specific purpose of helping DSO families in particular need.

How does the fund work?

- ♦ Any member of DSO can apply to the fund, for any amount up to a **maximum of £1500**.
- ♦ The application must be for a specific purpose and should be seen as emergency financial assistance – for example, toys for ill children, one-off donations to families to help with extra emergency equipment, funds to use on a family outing to support a family going through a difficult time, money to help with taxis to visit a sick child in hospital.
- ♦ People can also apply on behalf of a member of DSO, with or without their consent or knowledge.
- ♦ The fund will be administered by three people – the Chair of DSO (currently Marion Simon), a Trustee of DSO (currently Katharine Horrocks), and one other Committee member (currently Colette Lloyd).
- ♦ All applications will be considered, but there is no obligation on the fund administrators to agree to the request.

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.

How do I apply for the fund?



By Email

chair@dsoxford.org.uk



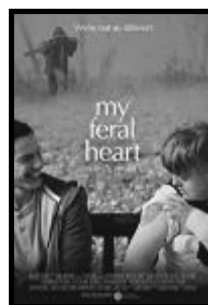
Or by letter

3 Chartwell Drive, Charlbury, OX7 3RH

- ♦ Write an explanation of how much money is needed, what the money will be used for, and any other relevant details.
- ♦ The fund administrators will contact you if they need further information, so please include your contact details.
- ♦ Any request will be considered and you will be notified within four weeks as to the decision.

If you want to read a copy of the full rules, please contact either Marion (chair@dsoxford.org.uk) or Katharine (Katharine.horrocks@mkha.co.uk) and they can forward them to you.

My Feral Heart: now out on DVD



Synopsis: A sudden bereavement throws Luke, a fiercely independent young man with Down syndrome, into a daunting new environment where he finds unexpected support from his feisty streetwise carer and a local heir dealing with his own demons. As friendships bloom and long-buried secrets are revealed, Luke verges dangerously close to disaster.

Available to order through:

<http://bit.ly/DSResearchDVD1>

Training

In October, DSO ran its first training day of this academic year. 'Meeting the needs of pupils with Down's syndrome' was a training day for teachers and TAs who have had very little or no previous training on Downs syndrome.

The training which was delivered by Julie and Lucy of 'Inclusively Down', who are based in Bucks, concentrated on the specific learning profile of pupils with DS and the importance of teaching reading (even before speech). There were many practical tips and examples of resources for schools to use. The day was fully booked and the feedback was excellent!

Following feedback from teachers and TAs we will be running a training day on '**Positive Behaviour**' for school staff in January and we are also currently in talks with Oxford University Press to run a training day on **Numicom** which will hopefully be open to both school staff and parents. Details will be emailed out when confirmed.

Last year our behaviour training sold out in one day, so please urge your child's teachers and TAs to sign up for our email notifications via the DSO website so that they hear about future training as it's announced.

Elsa Gill, *Training Organiser*

Lottery



Recent Winners:

June 2017

1st prize - £39.00	Rachel & Gary Lane
2nd prize - £23.40	Ruth & Nick Smith
3rd prize - £15.60	Diana McMahon

September 2017

1st prize - £40.00	Carolyn Walker
2nd prize - £24.00	Ella Segaran
3rd prize - £16.00	Will Foulds

July 2017

1st prize - £40.00	Pippa Rees
2nd prize - £24.00	Jonathan Gill
3rd prize - £16.00	Anne Churchill Stone

October 2017

1st prize - £40.00	Nigel Orman
2nd prize - £24.00	Rachel & Gary Lane
3rd prize - £16.00	Katharine & Mark Horrocks

August 2017

1st prize - £40.00	Sally Dubock
2nd prize - £24.00	Diana McMahon
3rd prize - £16.00	Sarah Stevenson

November 2017

1st prize - £40.00	Carolyn Walker
2nd prize - £24.00	Katharine & Mark Horrocks
3rd prize - £16.00	Will Foulds

**A BIG THANK YOU TO ALL
THOSE WHO TAKE PART FOR
YOUR CONTINUED SUPPORT.
WE RAISE £120 PER MONTH!**

Joining the DSO monthly lottery

Each ticket is £5 per month. All you need to do is set up a regular monthly payment to our lottery account and we will do the rest. If you would like to join our lottery please contact **Amanda Foulds** lottery@dsoxford.org.uk

Early Development Groups

Sadly, the end of the spring term saw us pack up our things and leave our home at the South Abingdon Children's Centre due to its closure at the end of March.

During the months leading up to this, we had put out feelers to find a suitable alternative venue - not an easy task when trying to consider distance, number of rooms required, availability, etc, but we are pleased to have been welcomed at **Drayton Village Hall** and are adjusting to the new arrangements. We are continuing to look for a venue that may be better suited to our needs. If you know of anywhere in Oxfordshire that has access to 4 rooms and a kitchen and can store some tables, chairs, boxes of toys and a large filing cabinet, please let me know!

Colette, Sally and I lead the seven development groups and are wonderfully supported by Kelly and Mairi (with Jo and Sarah waiting in the wings) who run the **Stay and Play** throughout the morning.

The children have been learning through a range of stories, such as Goldilocks and the Three Bears. This has given rise to understanding 'big' and 'small', as well as lots of nouns for furniture in the house and putting two or three signs/words together to say that 'Goldilocks is eating porridge'. Younger groups have focussed on learning signs for pieces of play equipment at the park and having fun making the initial sounds of these, as well as plenty of picture matching and word matching. It has been a pleasure to help these children develop and encourage them in their learning.

If you have a child of pre-school age and would like to attend the groups, please get in touch to register as there can be a waiting list. We'd love to see you!

edg@dsoxford.org.uk

Netty Lings, *Early Development Group Coordinator*



*Activities for people
with Down's syndrome*

TENNIS



White Horse Leisure and Tennis Centre in partnership with DS Active is running weekly tennis sessions for people with Down's syndrome at the Abingdon Centre.

The sessions run from 11.00am to 12.00pm on Saturday mornings and are open to children aged 5 to adults. The session is split into juniors and adults.

The cost is £2.50 per person.

For more information please contact Sue Auger (Sue.Auger@GLL.org)

Fundraising

A big thank you to all our wonderful fundraisers



Netty Lings (pictured above with Sim) recently turned 40th and had a birthday party to celebrate. Netty very kindly donated the profits made from the bar to DSO. This amounted to a very generous **£90!** Thank you Netty.



In July **Tina Gibb**, cousin of Sarah Fonge, nominated DSO as the charity of the month at her work, Sesame Bankhall Group. They held a 'wear what you like to work' day, and ran a number of additional fundraising activities, including:

- **Trolley Dolly** – Cake sale on the trolley mid-morning
- **Office Survival Kit** – Guess the price of the office survival kit
- **Guess the number of sweets in a jar.**
- **Breakfast** – with the finance staff taking breakfast orders and cooking it

They raised an amazing **£796.52!** Thank you Tina and all the staff at Sesame Bankhall Group.



Helen Gaffney (mum to Fin) recently pounded the streets of Dublin to complete her first marathon. Helen did it to raise money for **Elliot's Shed** and has raised a huge **£836**. What a fantastic achievement Helen, well done!



Donations

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

R H AMAR	£1750.00
Famous for fine foods	

Agata Patel - Cake Sale	£161.45
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Harlequins Rugby Club	£60.00
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Netty Lings Birthday	£90.00
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Jessica Beckett fundraising at Caldecott School	£191.33
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Sesame Bankhall Group via Tina Gibbs	£796.52
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Coventry Building Society	£313.00
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Oxford Gene Technology Charity Committee	£200.00
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Annabelle Lane Tenner challenge	£40.00
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In memoriam donations for the late David Herbert, grandfather of Arthur Fonge	£851.40
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The DSO Lottery continues to bring in funds of £120.00 per month.

Fundraising for Elliot's Shed

Helen Gaffney Dublin Marathon	£836.00
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And a huge thanks as well to all those who give regularly by standing order.

Sarah Fonge, Treasurer

David Herbert

Sadly, Sarah Fonge's father David Herbert passed away on 28 September this year. He was a great supporter of everything we do at DSO and this support – and his musical talent! – will



be missed by us all. The collection at his funeral raised £851.40 for DSO and his wife Bridget has asked for the money to go to DSO social events so that it can be enjoyed by all. Our heartfelt condolences to Bridget, Sarah and family.

Supermarket Fundraising



Asda in Carterton currently have DSO as one of their green token charities, so if you shop in that area please do pop in and support our charity. This set-up runs in most Asda stores, as well as a similar scheme in Waitrose (we had success with the Witney branch about 18 months ago). As we are an Oxfordshire based charity we can put forward DSO in any Oxfordshire branch. If you live near a Waitrose or Asda, do pop in and ask. It's a great way of not only raising money for DSO, but for raising awareness across Oxfordshire.

Our Kids

Celebrating the wonderful achievements of our children



Alexander's award

Alexander Horrocks was delighted to receive a cup for "Sustained Endeavour" at his Year 6 Achievement Assembly at John Hampden Primary School in July. Alexander has been at the school since Reception, and has recently started at Iffley Academy in Oxford.



Amber's prize-winning cupcakes

Amber Davies won third prize in the Cupcake category in her school annual Bake-off competition. (Tasting is done blind, so she won her prize fair and square!) Amber loves baking and she was very proud of her achievement!



Evie learns to swim

Evie Crawford learned to swim over the summer holidays. She attended the DSO swimming lessons at RAF Brize Norton and by the end of the course was swimming unaided. Well done Evie, a fantastic achievement!

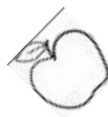
Classmates vote for Arthur

Every week the children in Arthur Fonge's class vote for a 'Child of the Week' and Arthur was delighted to recently receive the accolade. Here are some of the lovely things his class said about him:

1. He's always trying his best.
2. Arthur plays really nice games.
3. He tries with his learning even when it's a bit tricky for him.
4. Arthur is a kind boy.
5. Arthur is good at getting people to join his games.
6. Arthur doesn't give up.
7. Arthur is very friendly.
8. Arthur is a proper gentleman.
9. Arthur is a very nice friend to have.
10. He has amazing ball skills.



Jack Gill looking very smart on his first day at Mabel Pritchard school.



First day at school



Amos Smith, with his sisters Beatrix and Kitty, ready for his first day at Blewbury Primary School.



An excited **Thomas Foulds** on his first day at John Watson Secondary school.



Brotherly love

Adorable twins, **Jack** and **Andrew Campling** with their proud big brother **James**.

Halloween Fun



Vampire **Chloe Sanderson!**



Kya and Kaylah Ford enjoying Halloween.



Harry and Jack Gill all dressed up and ready to go trick or treating with big sister **Millie**.



SAVE THE DATE



DSO's big fundraiser for next year

9 - 10 June 2018

We're having a **21-hour relay walkathon** (representing the 21st chromosome) at Wheatley Rugby Club, with thanks to the Wheatley Playing Field Trust for donating the facilities.

- ⇒ Teams of up to 10 people will have a base camp around the track having at least one member of the team walking over the 21-hour period.
- ⇒ Each team will pledge to raise sponsorship for DSO.
- ⇒ Teams can be made up of multiple families, friends and non-DSO members.
- ⇒ We're hoping to have entertainment to keep everyone going and fundraising opportunities during the event.
- ⇒ We'll be looking for people to make up relay teams and to help out in other ways.

There will be more details in the new year, but if you have any questions do **email Sarah at sarahfonge@hotmail.co.uk**





Do you know about Cerebra?

By Emily Robinson (*Mum to Lucy*)

Although not specifically for children with Down's syndrome, Cerebra is a charity which aims to provide on-going support through research information and direct support to improve the lives of children with neurological conditions.

They offer:

- ♦ information and advice on a number of topics, over the phone or through their website
- ♦ face-to-face support through our network of Regional Officers who can help with form filling and letters, completion of the Disability Living Allowance form, meetings, specific local information and activities
- ♦ a sleep service to give advice and support to families on a wide range of sleep issues
- ♦ a free postal lending library for books and sensory equipment
- ♦ an innovation centre who design bespoke equipment to meet family's needs
- ♦ a monthly e-newsletter full of informative articles and stories
- ♦ workshops and other events across the UK.

We came across Cerebra about 5 years ago when I was looking for a writing slope for Lucy. Lucy wears bi-focal lenses in her glasses and so needs the things she is reading to be at a different angle to when she is writing. Also, due to fine motor issues Lucy used to work on A3 paper at school rather than the A4 size more common. We could not find anything on the market that met these requirements.

I then discovered that Cerebra had a link with Swansea University whereby they develop bespoke equipment where there is none available. They responded very quickly to my query and put me in touch with their chief designer Ross Head and via email and photographs he gained an understanding of what we were after.

A big parcel arrived, with a writing slope perfectly meeting Lucy's needs: A3 size, adjustable angle for reading or writing



and a sliding bar which stopped the paper/books falling off the slope regardless of size. It even had a special secret drawer for pencils and it was pink!

Lucy has used this writing slope at school for most of her primary education (as have other children who have been allowed to borrow it!). The writing slope has gone into mass production and can be purchased from Cerebra – it is now called a Doodle, along with a number of other pieces of equipment which have been designed in response to a specific child's needs.

If you are having problems finding equipment to suit a specific need I would really recommend contacting Cerebra.

They also offer lots of great advice and research findings on their website and through their newsletter – in particular they offer a sleep survey and at home support!

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Elliot's Shed

Helen Gaffney
elliotsshed@dsoxford.org.uk



General enquires email address:

info@dsoxford.org.uk



Website:

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



Registered charity number: 1103850



Facebook:

<http://www.facebook.com/groups/dsoxford>



Twitter:

[@DownsOxford](http://twitter.com/DownsOxford)



With thanks to First Move Direct Marketing in High Wycombe who generously print and mail our newsletter free of charge.

The deadline for the next edition of the newsletter is **Friday 23 March 2018**. We welcome text or photos about your child enjoying themselves—not necessarily a DSO event. Please send materials to the editor Lucy Sanderson at newsletter@dsoxford.org.uk