

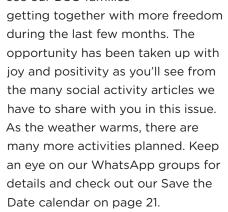
# down's syndrome oxford

# **NEWSLETTER**

FROM THE CHAIR

# THE THEME OF THIS NEWSLETTER IS 'BETTER TOGETHER'.

It has been so good to see our DSO families





### A BIG WELCOME.

We are delighted to welcome many new families to DSO. Meet some of our youngest new members on page 16. Spoiler alert: your heart's going to melt! They'll all be able to join our Early Development Group once they are eighteen months old. And meet our New Parent Group contact, Steph Mills, on page 19.



## WE'RE GREAT SPORTS.

It's great to see so many of you participating in various sporting activities and events. Oxford Tristars Football team enjoyed a training session with Oxford United Manager, Karl Robinson (page 12), DS Active Tennis came second in the Wimbledon Challenge (page 19) and there is a call for new players for the Witney Wolves touch rugby team (page 9). Keep it up everyone!

### **DOWN SYNDROME BILL.**

As many of you may know, the first ever Down Syndrome Bill has been put forward in parliament, with the aim of establishing a national strategy to meet the needs of people with Down's syndrome, especially in the areas of health, education, local services and long-term care. Congratulations to the group leaders in our community who have worked hard to bring this to fruition. Read more in Colette Lloyd's excellent overview on page 2.

### WORLD DOWN SYNDROME DAY.

World Down Syndrome Day is a great opportunity to promote DSO activities, gain greater awareness and advocate for equal opportunity for our members. Our DSO Singing and Signing Choir will be performing in Witney on 20 March to mark the day (see p21 for details). Everyone welcome! And don't forget to promote any activities you are planning on our WhatsApp groups.



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Early in 2021 a group of enthusiastic local and national Down's syndrome group leaders saw an opportunity. Many of them had been campaigning around issues facing people with Down's syndrome, and knew that the services available from birth to old age were a bit of a postcode lottery. So they decided to resurrect the All Party Parliamentary Group for People with Down Syndrome which had lapsed in 2015.

This was designed to give opportunity for the voices of people with Down's syndrome and their family, friends and carers to be heard and addressed in Parliament. Much work speaking to MPs from all parties followed to gather interest and the group officially formed in July 2021. What an achievement!

However, even before the group was officially formed they didn't rest on their laurels. On Thursday 20th May, the ballot for MPs who wished to bring Private Members Bills was held, and Dr Liam Fox MP, was drawn fourth in the ballot. This meant that his Bill would be heard. It was

still pretty unlikely it would get anywhere, but at least the issue would be raised in the Commons. Dr Fox happened to have Annabel Tall in his office, and Annabel has a son with Down's syndrome. The next thing we knew, although much went on behind the scenes, on June 16th 2021 Dr Fox put forward the first ever Down Syndrome Bill. And at the same time the National Down Syndrome Policy Group was established, which included four adults with Down's syndrome, in order to support this work.

The Bill aimed to establish a national strategy to meet the needs of people with Down's syndrome in all areas. Dr Fox said that he wished to destignatise Down's syndrome at the same time as ensuring improvement in services in the areas of health, education, local services, and long term care.

The Bill had its second reading on November 26th 2021, and received unanimous cross-party support! The MPs seemed to have grasped that this was something much needed and were all willing to support it - whatever their party - again, what an achievement!

The Bill has now passed all of its readings and the committee stage in the House of Commons and is awaiting its second reading in the House of Lords on March 18th. In itself the Bill simply says that the Secretary of State must give guidance to relevant authorities on steps it would be appropriate for them to take in order to meet the needs of people with Down's syndrome. It specifically mentions the NHS, social care, housing, education and youth offending. However the real work begins after the Bill becomes an Act, when the details of the guidance in each area will be developed.

There is an amazing amount of work that has gone on to get to this stage, all the members of the NDSPG deserve congratulations for what they have done. Our thanks go especially to Dr Liam Fox, for whether you agree with his politics or not, he chose to take up the mantle and fight for better for our community. There has been some disagreement with the idea of a Bill specifically for DS, however, I believe that if we get the strategies right for a very recognisable group of people with learning disabilities, then that will improve things for the whole learning disability community. Once the knowledge is out there, people won't reserve it exclusively for Down's syndrome, even if that is the group of people that the strategies and initiatives were initially evaluated for.

I can't wait to see this Bill turned into an Act, which by allaccount, and against all odds, it appears that it will be. And then, the guidance, that will help all services to get it right first time for our children, young people and adults with that bit extra!



"We are all very excited that Dr Liam Fox is sponsoring a Bill with the aim of improving the lives of people living with Down's syndrome. I would like to see the Bill becoming law, then I think everyone like me with Down's syndrome will get better healthcare, more access to services and be more included in society. It is possible. It happens for some now, but it shouldn't be a lottery."

Actor, CBBC presenter and Trustee for the NDSPG George Webster



"Everyone needs help now and then. We just need chances in life like anyone else."

BBC's Line of Duty actor Tommy Jessop



# HALLOWEEN PARTY

# 10 +and 16 +groups

In October we held a Halloween party and I think it's safe to say we all had a brilliant time. It was a joint get-together with over 50 attendees from our 10+ and 16+ groups. Everyone that came along made an amazing effort with some truly spooky Halloween costumes. We danced the night away with the lovely DJ Claire who's becoming a regular and provides a really good choice of music. This was followed by way too much Domino's pizza and fizzy drinks. Those wanting a rest from the disco at any point were encouraged to make use of the quieter room where parents also had the chance to relax and catch up with each other over a cuppa knowing we had the main door safe with a door person for security. This gave everyone piece of mind that we wouldn't have any escapees and, of course, it kept out the spooky ghouls and ghosts, vampires and bats that were hanging around outside!

A personal thank you from me to those parents that helped to set up and clear away – you're not just amazing but so quick and efficient. On that note I'd just say don't be shy if you have an idea and want to run an event. All ideas are welcomed and we have a full army of parent helpers ready and willing.

Sonia Forrester

















# SHORT BREAKS

FROM OXFORD COUNTY COUNCIL



If you don't already receive it, be sure to subscribe to the monthly *Short Breaks* newsletter from Oxford County Council.

It contains lots of information about activities and resources for parents and carers in the SEN community, including:

- Play Sessions
- Workshops
- Makaton Training
- Sports Clubs
- Family Events
- Wellbeing Events
- Community Get-togethers
- Support Resources
- Focus Groups
- Outreach Programmes
- Educational Programmes
- Short Courses
- And much more!

Subscription is FREE. To receive *Short Breaks* every month contact Danny at cdsredesign@oxfordshire.gov.uk

# Kassam Stadium VIPs

On Saturday 22nd January the Tri-stars team and their coaches were given VIP treatment when they were invited as guests to the Oxford United v Sheffield Wednesday match at the Kassam Stadium.

We enjoyed refreshments in the members bar before being shown to our seats in the family stand. It was a fantastic match, with end-to-end action, plenty of goals, and a well-deserved win for Oxford. A huge thank you to Oxford United for hosting us and giving our players such an enjoyable experience.









# CHRISTMAS PARTY

We were thrilled to hold the Christmas party in December, and whilst the number of people attending was lower than normal, it was great to be able to get together in person once again. Jeff Allen provided the entertainment with some fun party games, the ever-popular limbo, and a disco. And, as always, we were lucky to have a visit from Father Christmas to finish off the afternoon.

Can you help organize this year's Christmas party? We're looking for a group of people to take on the organization. See page 20 for more information.















# Are you ready? because at witney wolves WE WERE DORN ready!

by Emily Robinson

In September 2021 Lucy Robinson became the newest wolf cub in the Witney Wolves, an SEN tag rugby team offering non-contact rugby to players with a wide range of abilities.

They have both a Junior and a Senior squad and can accept players from 8 years of age and above. The team trains at 11am (so no crack-of-dawn start!) on Sunday mornings alongside the rest of Witney's Mini and Junior teams. The team is run by volunteers and have coaches (club members and parents) helping with individuals to ensure everyone has the level of support they need.

The only experience Lucy had before she joined was some tag rugby at primary school, but she does have a love of throwing and catching balls (especially a rugby shaped one). The training sessions teach them the basic rules of the game through fun and interactive games, and they play a mini game towards the end of each session.

Witney RFC is a large and active club, and the Wolves are just part of the set-up, with total inclusivity. In the same way as the main club teams do, the Wolves get to go on tour and play other SEN teams and get to go along to watch professional level matches.

After a little bit on online training and the necessary DBS checks, Matt and I now help on the coaching team supporting those who need help within the session.

Lucy says "I love going to rugby, it is fun, I like running for try line, and playing cars and caravans. Kate and Gareth are my coaches, and there is another girl called Lucy. I wear my Wolves rugby kit and my rugby boots. Sometimes I have a sausage sandwich afterwards."

If you are interested in joining, please contact Head Coach Kate Nicholls via email on kate.nicholls51@yahoo.co.uk, with some details about yourself or your prospective player, and she will get back to you to discuss current availability and whether they can meet your specific needs on the pitch.









# As the South Oxfordshire wave of NCS, we chose to raise money for Down's Syndrome Oxford (DSO) for our social action project.

We chose to fundraise for DSO as a member of our group is closely related to the charity and is passionate about supporting it. Throughout the week, we did different activities like dressing up for a sponsored walk, campaigning, running a sports day and hosting a quiz. We used a GoFundMe page which enabled people to donate online as well as collecting money in a bucket around Oxford.

On Tuesday 17th of August, we campaigned for our charities of choice through a sponsored dress up walk. We had national heroes such as: the Queen of Hearts, a fearless highwayman, Dr Who disguised as a therapist, a bar maiden, a fairy, a bubbly banana and more. This was to gain more notice from the public through attention-grabbing costumes and by handing out leaflets in the town centre near Westgate. Overall, we felt we achieved a lot since we successfully raised awareness and received donations for our efforts, all in hopes to give aid to families and individuals who may know someone with Down's syndrome.

On Thursday 19th of August, we chose to organise and run a sports day as a method of raising money. We prepared many activities throughout the week such as an egg and spoon race, shoe flinging, raft and other races, as well as a refreshment stand. Our most popular sport was shoe flinging, which consisted of kicking off your shoe as far as possible; this activity became pretty competitive but everyone had a lot of fun. Many families and children were involved and had a great time. Throughout the day we informed people about DSO and managed to spread awareness and raise money while having a good time.

On the evening of the 19th, we hosted a quiz as a part of our fundraising activities. We wanted it to be inclusive of people of all ages so we chose to do a Kahoot. On Monday, we invested time creating our own questions and categories in order to make our quiz unique. The categories included

Disney, history, geography, Harry Potter, TV and music. Overall, it consisted of 59 questions which proved to appeal to everyone. We know this because we had had around 20 people take part whilst also making a contribution by donating to our charity. The top 3 winners all received a Nando's gift card for a free meal.

All in all, throughout the week we managed to raise over £300 for Down's Syndrome Oxford. We are glad we could help this cause and we hope the money raised will help the people within this charity.





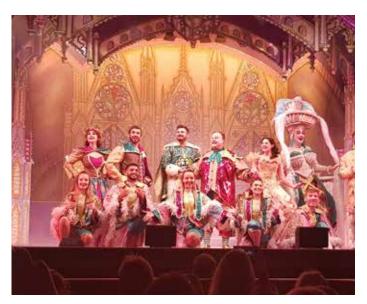
# Christmas PANTOS

We may not be out of the Covid woods yet, but quite a few DSO families made it to one of our three annual panto trips in December 2021.

The Oxfordshire Masons invited us to their private performance of Robin Hood at the Oxford Playhouse and treated our members to goody bags and ice creams. These tickets are provided free of charge to DSO every year and we are very grateful for their continued support.

We also took two groups to the Hexagon in Reading to see Justin Fletcher in Beauty & The Beast alongside the world's best pantomime Dame, Paul Morse. For many of us, it just isn't Christmas until we've seen the ghostbusters skit and a custard pie flinging scene! And it was great to see the return of BALLOON BALLET...

It was joyful to be back in the theatre and face to face with other DSO families. We've already booked seats for next year's show so keep an eye on your emails from September onwards.









# Tri-stars Training

In September. our Tri-stars football team were invited to Oxford United's training ground for a training session with Karl Robinson, Oxford United Manager, and Lauren Haynes, captain of the Oxford United women's team. Karl and Lauren interacted brilliantly with the players, joining in with skills practice before joining in a game. All the players had a great time and thoroughly enjoyed having their photo taken with Karl and Lauren. It was a fantastic experience for them all!

























This week showed power of football

had the privilege of meeting the Oxford United Down's Syndrome team on Wednesday and loved every minute of it.

The team has only been going or a few months, but is being run by some amazing people with the love and support of the parents and families of players of all age groups.

Myself and Lauren Haynes, our women's captain, were invited along and within seconds we were laughing and joking with the players and involved in shooting practice and then a game.

I got kicked a couple of times but I'm pretty sure that was Lauren – if you've seen her play then you'll share my suspicion!

At the end, all of the players came and thanked us but honestly, we should be the ones thanking them because it was a brilliant session, lots of fun, and it once again reminded me of the sheer joy that football can bring.





# THOMLEY HALL ADVENTURE

# preschool & primary groups

In October the preschool and primary groups spent a fantastic day at Thomley Hall, which is a wonderful place for people both with and without disabilities. DSO families had exclusive use and were free to roam the beautiful 9-acre site, utilising the various play areas, play equipment, bikes and trikes, play rooms, sensory rooms, music room and soft play! We also had giant bubbles which was a crowd pleaser! We were joined at this event by 27 children from 14 families.







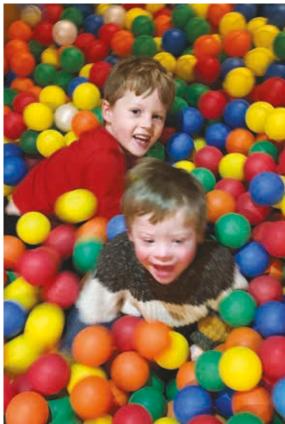












# DSO DANCE

By Hannah Dubock

We have started a DSO dance group on a Monday after school. Miss Lorna is our dance teacher, she is kind. There is a group for younger children and I am in the big children. It is at Abingdon and Witney College. I like dancing, my best bit is leg kicks and leaps. We dance to Dance Monkey and lots of our choir songs we know which is fun. It is really fun, I love Mondays so much. Why don't you come too? You can tell my mum if you want to come. (sallydubock@gmail.com)







# Welcome!

## Welcome to our new families.

This lovely group of little ones are all part of our preschool group. They will be able to join our Wednesday morning Early Development Groups when they are 18 months old.



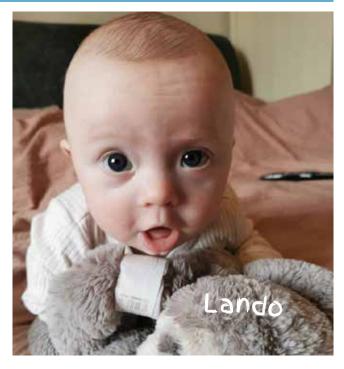


















Every new baby born with Down's syndrome in Oxfordshire (or babes moving into county) will receive a new baby bag from DSO. These include a toy, Introduction to Makaton book and a space blanket, as well as our More than Medical leaflet. Here are a few words from Andria Hutchings, mum to Silas, 6 months old, who moved into Oxfordshire last year shortly after Silas was born.

"It was so good to receive our own copy of More than Medical. There was only one carefully guarded copy in the hospital in Cambridge and it was the only leaflet that didn't depress me because it was so helpful to see children in their families and learn that all children with Down's are different. I really wanted to share it with family and siblings and grandparents did indeed find it very helpful.

The first signs book got Silas' siblings really excited and cheered me up because I could see that we were all in this together.

The toy with handles is exactly the kind of thing Silas' physiotherapist recommended during his first session at home and Silas seems to really enjoy the space blanket. The DSO bag is also really handy."

Emily sharing her feelings after her postnatal diagnosis was also really useful. I could totally identify with those mixed emotions and tears in those first few weeks and her offering to chat either remotely or in person was a comfort since I felt that I'd be able to share with someone who totally understood. Knowing that there was a source of advice out there and accessible was also encouraging. I also loved her pointing out that she couldn't imagine life without her beautiful Bill.

# YOUR STORIES



It was Bill's 4th birthday on 31st

December! He had a party at Sprouts

Play Barn and had a wonderful time.

He loved playing with his friends and
enjoyed being sung happy birthday to.





In the week before Christmas three families – the Foulds, Robinsons and Horrocks – had a wonderful morning at the Royal Albert Hall listening and singing along to Christmas Carols played by the Royal Philharmonic Orchestra. It was part of the Royal Albert Hall's programme of Communities and Outreach relaxed performances (all tickets sold at a much reduced rate), and a real treat to be in a box. The Royal Albert Hall looked beautiful, with strings of fairy lights and a lovely inclusive atmosphere, and the morning definitely got everyone in the Christmas spirit.



Don't forget we have a wide range of equipment, toys and resources available for you to borrow **FREE of charge** from Elliot's shed. Items available include:

- Trip trap/breezi highchairs
- Wooden toys
- Sensory equipment
- Bikes, trikes and scooters
- Eductional resources such as Numicon

If you're interested to find out more about the items available please get in touch with Kat Cornfield at elliotsshed@dsoxford.org.uk











# New faces



We're delighted to welcome Steph Mills who has recently taken on the role of New Parent Contact for DSO.

Steph is married to Simon and mum to Riley and Rosie. Rosie was born in September 2020, and she was diagnosed with Down's Syndrome after birth. Steph quickly joined the New Parent Group and Pre-school

Group and found comfort and reassurance from talking to other parents who had been through the same experience as them.

She's now keen to be this for other new parents. A big thank you to Emily Higgins who has done a great job in this role for the last few years. Emily will continue to be our Pre-school Club Coordinator.



Congratulations to the DS Active tennis team at the White Horse Leisure and Tennis Centre in Abingdon, Oxon who came second in the Wimbledon Challenge in the National LTA Grand Slam tennis challenge.

The team completed the challenge in the latter part of last year but were finally presented with their medals and certificates at the beginning of January.

The competition consisted of the players taking part in a number of different challenges over the course of a month and the scores were then submitted to the LTA. The team with the highest scores in each challenge were the winners.

A massive well done to all those who took part!

Sue Auger,

Tennis Manager. White Horse Leisure and Tennis Centre.

Don't forget, every time you shop on Amazon you can raise funds for DSO at the same time!

smile.amazon.co.uk

amazonsmile

# FUNDRAISING DONATIONS AND GRANTS

DSO Oxford is extremely grateful to have been given the following money from October 2021 to January 2022, through fundraising efforts, donations and grants.

**Nick Pagett** completed the Oxford Half Marathon and raised £1300.00

Donations were made in place of Christmas cards: Stephanie Mills - £20, Jennifer Dilnot - £50.00, Nick Westbury & Co - £300.00 Thanks must also go to Nick for his continued support to DSO with our financial processes and end of year accounts.

DSO was nominated by **Shelley Randall** to her employer to receive a donation from the SSP Foundation. We were sent a cheque for **£500.00** 

**Annabelle Lane** and her team at NCS chose DSO as their charity to support. They undertook a dress up sponsored walk, hosted a sports day and a quiz night. These events brought £204.96 to DSO.

**Dominic & Josie Medcalf** put donations to DSO onto their wedding gift list and raised **£380.00** 

**Monique Drummond** undertook voluntary work for a donation to be given to a chosen charity. DSO received **£205.00**.

Paypal giving, which accumulates donations from various social media platforms and other areas generated £303.89.

Amazon smile brought **£40.95** to DSO this period.

We were also the very appreciative recipients of a donation made from the estate of the late **Mr Michael Culver**. Mr Culver's family chose to make the donation to DSO. We received £7500.00

The DSO Lottery now brings into the charity £183.00 per month.

Many thanks also to the donations we continue to receive via monthly standing orders.

# A VERY SPECIAL DONATION

In December we received a very generous donation of £7500 from Helen Culver on behalf of her brother David Culver (who has Down's syndrome), from the estate of their late father, Michael Culver. We are incredibly grateful to receive this donation and would like to pass on our sincere thanks to Helen and David.

David, now aged 57, and has lived in Abingdon all his live. He lived with his father up until about six years ago and now lives happily in an assisted living house with two other residents.



# Can you help?

We are looking for a small team to take over organisation of the **Xmas Party.** The current group have been running it for 10+ years so it would be great to have some new blood. It would be ideal for a group of four parents to work together. The incumbent group will of course be on hand to share their invaluable advice.

Contact Amanda Foulds at amanda@dsoxford.org.uk if you're interested.

# SAVE THE DATE

0

We've got a lot of exciting events happening over the coming months. Keep an eye out for our emails with more details about each one.



# Sat 19 March Soft Play

Soft play at Snakes & Ladders for the Preschool Club: Saturday 19th March, 2-4pm Audlett Dr, Abingdon OX14 3NJ



# 20 March

# **Choir in Witney**

Come and help us celebrate WDSD at the Woolgate Centre outside Waitrose by the Clock Tower at 11.30am.

# 21 March

## **WDSD**

Are you planning an activity to celebrate WDSD? Share your ideas and plans on the DSO All Members Group WhatsApp.



# 21 March

## **Members Group Meeting**

Join us or our All Member's Meeting. It's a great way to share your ideas. Look out for an email with further details.



# Sat 23 April

## **Camp Mohawk**

Preschool Club Camp Mohawk outing: Saturday 23rd April, Highfield Ln, Crazies Hill, Reading RG10 8PU



# Sun 1 May

## **Thame Music In the Park**

DSO Singing and Signing Choir will be performing on the Dance and Community Stage at 15.30. Come and join us!



# 26 June

## **Summer Party**

Pop the date in your diary. This year we'll be holding our Summer Party at Thomley. More details to follow.



# 27 June

## **Annual AGM**

Everyone is welcome. It's a great opportunity to reflect the work of our charity during the year. Save the date.



# 4 Dec

## **Xmas Party**

Save the date for our unmissable Xmas Party. More details to follow closer to the date.

# LOTTERY RESULTS

A big THANK YOU to all those who take part in our monthly lottery for your continued support.

We have raised **£1773** for DSO so far this financial year.

# Message from Andy Fearnside, DSO Lottery organiser.

Amanda has been managing the lottery since she came up with the idea back in 2012 but needed to step away to concentrate on other roles within DSO.

It's a great way of raising regular funds for DSO, so when she asked me if I'd like to take over, I was more than happy to.

Going forward you won't see much change as Amanda ran a pretty tight ship but I have a few ideas for the future. Watch this space...

We are always looking for new members so please spread the word and email lottery@dsoxford.org.uk for more details.

# Recent prize winners

#### **NOVEMBER 2021**

1st prize - £61.00 Jo & Stu Carwford 2nd prize - £36.60 Jane & Alan Bennett 3rd prize - £24.40 Ella Terblanche

### **DECEMBER 2021**

1st prize - £61.00 Diana McMahon 2nd prize - £36.60 Jos Smith 3rd prize - £24.40 Nigel Orman

#### **JANUARY 2022**

1st prize - £61.00 Mary Robinson 2nd prize - £36.60 Shaun Goddard 3rd prize - £24.40 Jos Smith

# YOUR CHANCE TO WIN! JOIN THE LOTTERY.

Join our lottery! Each ticket is just £5 per month.

To join simply:

- Set up a regular monthly payment to our lottery account Sort code: **30-80-45** Account No.: **29786768**
- 2 Send an email to Andy Fearnside at lottery@dsoxford.org.uk
- We'll allocate you a number, email you back to tell you your number, and let you know when you win!



And don't forget, we have our Social WhatsApp groups, too. If you'd like to be added to a group, please contact the person listed here:

# DSO WhatsApp groups

Have you joined our **DSO Members Group** yet - formerly the DSO Committee Group? We've changed the name and would love more people to join. Open to everyone, it's the place where you can take part in discussions, ask questions, and put forward ideas and suggestions. Our next meeting is on the 21st of March.



Emily Higgins emily@dsoxford.org.uk



Sam Martin-Morrison sam@dsoxford.org.uk



Kelly Stacey kelly@dsoxford.org.uk



Amanda Foulds amanda@dsoxford.org.uk

# **MAKE A DONATION**

Down's Syndrome Oxford relies entirely on its fundraising and generous donations from our friends and supporters to fund the activities we provide for our children. Any contribution you can make will be put to good use and is greatly appreciated.



OR —	
A regular gift of	per month / quarter / year (please circle appropriate)
commencing on	n dd/mm/yyyy
Name of bank	
Bank address	
	Postcode
Account No.	Sort Code
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# CONTACTS

#### CHAIR

Jos smith chair@dsoxford.org.uk

#### **SECRETARY**

Roberta Celeste secretary@dsoxford.org.uk

#### **TREASURER**

Sarah Fonge treasurer@dsoxford.org.uk

#### **NEW PARENT CONTACT**

Steph Mills newparent@dsoxford.org.uk

## TRAINING CO-ORDINATOR/ CHOIR LEAD

Elsa Gill training@dsoxford.org.uk choir@dsoxford.org.uk

### **NEWSLETTER EDITOR**

Lucy Sanderson Joy Weideman newsletter@dsoxford.org.uk

## **MEDIA & COMMUNICATIONS**

Andrew Dubock media@dsoxford.org.uk

#### **MEMBERSHIP & WEBSITE**

Matt Robinson membership@dsoxford.org.uk website@dsoxford.org.uk

## **DSO LOTTERY ORGANISER**

Andy Fearnside lottery@dsoxford.org.uk

### **ELLIOT'S SHED**

Kat Cornfield (07790 889903) elliotsshed@dsoxford.org.uk

#### **FUNDRAISING**

Jos Smith fundraising@dsoxford.org.uk

#### **STAY & PLAY CO-ORDINATOR**

Amanda Foulds play@dsoxford.org.uk

## PRE-SCHOOL CLUB CO-ORDINATOR

Emily Higgins preschool@dsoxford.org.uk

#### PRIMARY CLUB CO-ORDINATOR

Sam Morrisey primary@dsoxford.org.uk

### 10+ CLUB CO-ORDINATOR

Kelly Stacey 10plus@dsoxford.org.uk

#### 16+ CLUB CO-ORDINATOR

Amanda Foulds (temporary) amanda@dsoxford.org.uk

#### **EDG CO-ORDINATOR**

Amanda Foulds edgs@dsoxford.org.uk

## **EDG LEADER**

Colette Lloyd (01993 883707)

#### PDG CO-ORDINATOR

Marion Simon pdgs@dsoxford.org.uk

#### **DLA/PIP APPLICATION SUPPORT**

Rowena Pearce (07512 210851) SeniorMedicalAdvisor@dsoxford.org.uk



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



Website: dsoxford.org.uk



Facebook (closed group): facebook.com/groups/dsoxford



Facebook (public group): facebook.com/
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The deadline for the next edition of the newsletter is:

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