

NEWSLETTER



Welcome to the February 2023 edition of our DSO newsletter

FROM THE CHAIR

We need YOU!



We really do need you! One of our critical officer roles - Treasurer - will soon become vacant and we have no applicants. Without a Treasurer, ALL DSO activities are at risk.

Our Trustees are at full capacity and unable to step in. This really is a crunch point for DSO because without a Treasurer, suppliers cannot be paid which could result in our activities having to stop.

Can you (or somebody you know) commit one day per week to DSO - even just for one year? Thanks to our outgoing Treasurer, the role is well organised and not onerous, but

requires commitment. It doesn't have to be a full day, as tasks can be spread across the week to fit in with other commitments. Full support will be given.

This is one of two key roles soon to become vacant -Treasurer & Secretary. You can see more about the roles on page X.

On behalf of the Trustees, we are very thankful for all the years of outstanding support from our outgoing Treasurer and Secretary. We would urge volunteers to step forward for these roles, so that DSO can continue to do what it does so well.

In the last few months our members have taken full advantage to celebrate the festive season, with many having loads of fun at the traditional Pantos (see page 26) and at the annual DSO Christmas party, which enjoyed a record attendance this year (see page 14). The DSO Choir performed at Bonn Square, Oxford, to universal acclaim, celebrating the season and also helping to raise significant funds for our other activities.

We report on the submission DSO made to the 'call for evidence' for the Down Syndrome Act and are very grateful for everyone who participated to make this such a comprehensive response (page 5).

All our age-group clubs have been busy with enriching activities for our children and young people. Thank you to our organisers who make these essential outings possible. We appreciate your dedication and hard work.





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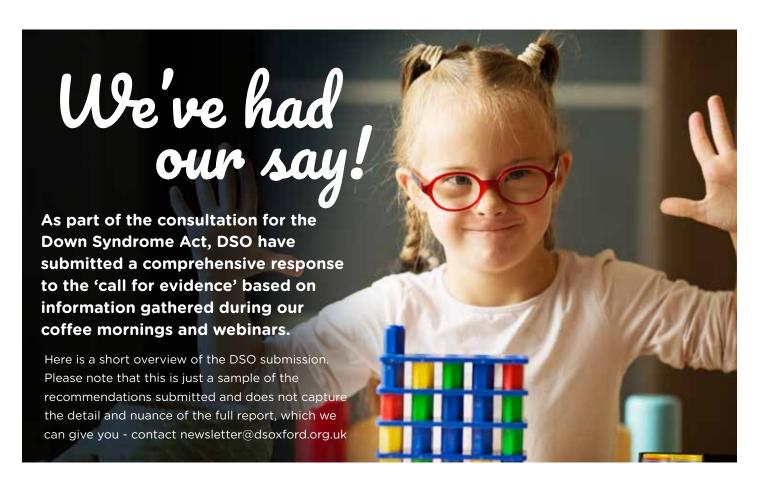
The DSO Choir finished another fabulous year with a festive sing & sign-a-long party. As always, the whole choir would like to thank Annie Hawkins and Amy May who continue to generously volunteer their time to run our wonderful and popular choir.

Elsa Gill









EDUCATION

- Establish a clear education pathway for people with DS in both mainstream and special schools.
- Local Authorities need to fulfil their obligation for properly funded service provision
- Automatically provide early intervention and an EHCP to alleviate the burden on families and charities
- Provide focused training and support for teachers to empower them to confidently help our children reach their potential - with a better long-term focus
- Benchmark education provision against other countries with more equitable DS education success.

HEALTH

- Treatment decisions are too often determined on budget and resource availability rather than long-term need, which can have life-long negative impacts, and represents direct discrimination
- Regular DS specific training should be a mandatory for healthcare professionals - many currently practice based on outdated perceptions
- The current failure to provide effective quality healthcare services due to lack of funding constitutes a dereliction of legal duty to the DS community
- There should be improved baselines in SaLT provision, expanded to support life-long communication needs
- Support groups like DSO shouldn't have to backfill the shortfall in therapies and other services.

EMPLOYMENT

- Government at all levels need to provide better information to employers on how to recruit and retain employees with DS
- Make it easier for small businesses to employ people with DS through tax breaks and grants
- Understand that employment provides more than just an income - better self-esteem, greater integration into the community, lower demands on benefits
- Make 'readiness for work' grants fit for purpose so they can be accessed before getting employment.

SOCIAL CARE AND HOUSING

- Establish a Pathway/process map to help parents/ carers know what to expect and when, regarding entitlement to local and national services
- Establish a "How-to" guide to explain the options regarding housing and adult support
- Create better provisions for small and local organisations to set up supported living facilities
- More social workers are needed, particularly those with specialism in DS, to establish long term relationships and provide advocacy
- Employ someone with DS learning profiles expertise in the LA Social Care team
- Establish a single comprehensive plan for adults with DS that clearly differentiates areas of need
- Establish clarity around care provision for older people with DS after their parents/carers die, recognising their evolving needs.



This is a beautiful tribute that gives great visibility to the Anne de Gaulle Foundation, which has been campaigning for the "creation, management and revival of facilities for intellectually disabled people" since 1945.

"We wished to make a mark, and to be able to put the vision and values of our founders in service of a social project that brings us together, and that reaches far beyond us," explained the foundation's director general Clarisse Ménager.

Thus, for a week, the Parisian airport will help raise awareness for the integration of people with disabilities.

Before this event, the Foundation also raised awareness among Paris Aéroport staff in charge of receiving travellers of the basics of Augmented Alternative Communication (AAC) "to understand better the diversity of communication needs of the people transiting through the airport".

Pre-School and Primary groups









Early Development Groups

The EDGs help the children to develop their communication and social interaction skills through group activities, we also aim to give parents skills and ideas to continue their child's development at home. The activities are engaging and fun which maximise the children's learning ability, helping prepare them for nursery settings and eventually primary school. The EDGs are held in small groups, 45 minutes long and take place during the Stay & Play sessions in a nearby room. There is an emphasis on using Makaton sign language to aid communication. Makaton has been developed by the Makaton Vocabulary Development Project since its first appearance in 1976. Here Elliot, Zoraiz & Ibrahim are working with our Speech & Language Therapist, Collette Lloyd.



Please contact Amanda Foulds by email amanda@dsoxford.org.uk if you would like any more information about the Stay & Play sessions or the Early Development Groups.





The Oxford Children's Hospital has launched a Children's Healthcare Passport. It can be found at this URL:

https://www.ouh.nhs.uk/children/healthcare-passport/

The passport has been developed for any child or young person who has specific needs. The information in the passport will help the staff caring for the child/young person provide appropriate care.

The Healthcare Passport is a parent led document available as an editable pdf. It can be filled out online and saved on your computer.

Once the passport has been completed and saved, it should be emailed to your child's paediatrician or the Learning Disability nursing team if they do not have a paediatrician. It can then be uploaded to your child's Electronic Patient Record (EPR) so that everyone working with them is aware of their needs.

If your child is under 5 years old, it's recommended the passport is updated every 6 months to ensure it stays relevant to their development. If your child is over 5 years old, every 12 months.

The passport is designed to provide key points concisely rather than provide a full history of your child. This will allow healthcare staff to readily read the full passport.

You may find that some sections of the passport are not relevant to your situation - just complete as much or as little of the passport as you need. Once the first passport has been completed, updating it should be easy to do.









DSO CHRISTMAS PARTY

The 2022 DSO Christmas party was attended by approximately 160 members, the largest attendance we have had!

It is one of the events we hold for all the different age groups and is a fantastic chance for all the families to get together. This year Aaron Williams entertained the troops. He was a great success and had everyone up dancing, and at one point a very long conga snaked around the hall. A big thank you to Tom Christy for taking on the red suit this year and giving out the early Christmas presents. We even had an impromptu visit from the one and only Elvis. Everyone enjoyed a delicious tea which all our members contributed towards.

Thanks very much to all the parents and families who help to make this event a great success every year.

Next year's party is booked at Exeter Hall on Sunday 3rd December. Amanda Foulds is stepping down from the planning and Sam Martin-Morrissey will be taking over. Please contact her if you can help this year sam@dsoxford.org.uk

by Amanda Foulds

















A person and a pair of threes

By Maria Betania Silva

On 22nd October last year, my son Ernesto and I flew to Recife in Brazil to launch our book "Uma Pessoa e o par de Três".

The title is in Portuguese because I am Brazilian and I originally wrote the book in my mother tongue. In English, the title loosely translates as "A person and a pair of threes".

This might seem like an enigmatic title but, for parents of a child with Down's syndrome, it is eminently more relatable than for most people.

The 'pair of threes,' of course, relates to the extra chromosome in a pair of 21.

The book is a collection of real stories from Ernesto's life focusing on his unique cognitive skills, seen not through the lens of DS, but looking at him as an individual as he grew from a child to a teenager. Ernesto is now 16, but the stories told in the book cover his life from when he was 8 years old.

The book is about one person, for whom DS is a characteristic, but which does not define him.

Since his earlier childhood I have written about the experiences of his life, trying to follow his way of perceiving and understanding the world around him; how he solved the natural problems of everyday life or even those created by himself.

From this habit of writing down what I observed, I discovered many things that I later thought interesting to reconsider and occasionally discuss regarding his cognitive condition.

One of the things I have come to believe, is that people with DS are not well adjusted to the rational standards that our world typically imposes on them. They are born with another type of logic, a kind of rationality that we - with *our* disability - are not able to have access to.

I hope that one day I can translate my book into English to share with all of you. But more than just the experiences lived by Ernesto and me...I would like to share some issues about the perception of the cognitive aspects of DS. I hope to more deeply explore some of the ideas that cross my mind about this subject. I will go on thinking about this 'work in progress' in my mind.





On your marks!

DSO's Hannah Dubock and Amber Davies were among the competitors at the firstever British Down Syndrome Swimming Championships held in Crawley last November.

More than 130 swimmers from all over the UK, aged between 10 and 50, competed, and Hannah (15) and Amber (12) were racing against several people who were more experienced and were attached to clubs.

Hannah came second in her 50m freestyle race which meant she was awarded a bronze medal in her age category. Both girls loved being a part of the event and making new friends!



YOUR STORIES





Sim goes to training on a Monday evening from 6-7pm at the Witney ATP. People with various disabilities are part of the team. Sim was awarded 'trainer of the week' which he was really pleased about! Well done, Sim.

From Netty Lings



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
- Educational 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

Rachael Bellamy graduated from Foxes Academy in Minehead back in July 2022. After a busy summer settling into her new supported living house in Henley-on-Thames with two of her friends from Foxes, Rachael registered with DSWorkfit. They made enquiries in the local area and introduced her to the manager at The Botanist in Marlow. They have been keen to work with and have training from DSWorkfit and offered her employment. She started at the end of November and took the Christmas rush in her stride. She is enjoying being part of the team, putting the hospitality skills she learnt at Foxes to good use and absolutely loves getting paid at the end of each month!

From Lorna Bellamy













OxFSN has recently published its *Moving Into Adulthood* Handbook. It's designed to be a dip in and out resource that delivers a lot of useful information for family carers and professionals.

This can be a time of uncertainty for many of our families; OxFSN hopes that armed with the right information, support and guidance you'll be able to navigate through this complex stage.

The Handbook has been written primarily for young people aged 14 -25, but there's also lots of information that family carers may find useful for their older family member including information on Benefits, Supported Living, Social Activities etc.

Information will be updated on a regular basis, but if you come across anything that you think would be useful to include, doesn't work or is out of date please do get in contact with OxFSN at info@oxfsn.org.uk

You can find the handbook which is downloadable as chapters on OxFSN's website:

movingintoadulthood.oxfsn.org.uk





WDSD rock your socks

Celebrate World Down's Syndrome Day by Colouring our odd socks! Share your artwork on our Facebook page - facebook.com/downssyndromeoxford





free of charge and always provide a goody bag for the kids, so it's a great

I loved the panto. The best part was getting to sit with T (Thomas W) and getting a high five from Justin!

We also subsidised over 100 tickets for our members to see the fabulous Justin Fletcher in Jack & The Beanstalk at the Reading Hexagon, across two performances. Our families enjoyed the annual soaking from water pistols, the ghostbusters skit and a bra that was meant for three, although we did miss BALLLLOOOON!

We need YOU!

DSO Charity Treasurer

Do you like balancing the books? Are you a details person? Does paying bills on time make you feel happy? If yes, and you have circa 0.5-1 day per week available, you could be our new Treasurer.

You will be responsible for:

- Overseeing the financial affairs of the organisation and ensure they are legal compliance within the accepted accounting practice.
- Ensuring proper records are kept and that effective financial procedures are in place.
- Monitoring and report on the financial health of the organisation.
- Overseeing the production of necessary financial reports/returns, accounts and audits.
- · Managing our bank accounts.

Specific tasks include:

- Liaising with Trustee's members and/or volunteers to ensure the financial viability of the organisation.
- Taking a lead in interpreting financial data to Trustees
- Regularly reporting the financial position at Board of Trustee's meetings (balance sheet, cash flow, fundraising performance etc).
- Overseeing the production of an annual budget and propose its adoption at the last meeting of the previous financial year.
- Ensuring proper records are kept and that effective financial procedures and controls are in place. Liaise with auditors/an independent examiner.
- Paying suppliers, handling expenses and making authorised purchases.

The qualities needed:

 You will work closely with Our Trustees, DSOs Social Group Leads, and DSOs officers (Chair and Secretary), a wonderful collective of volunteers who work together to keep DSO running.

A full handover and support will be given, with the option for the handover to happen over an extended period with our outgoing Treasurer.

DSO Charity Secretary

If you are a bit organised and have 3 to 5h per month to volunteer supporting DSO, the Charity Secretary role is the way to go!

You will be responsible for:

- setting up the DSO All Members Meetings (once every 2 months) and ensuring that they are well administered. This involves setting up the video calls, drafting the agenda and circulating minutes.
- organising and administering the AGM (Annual General Meeting) and supporting the Board of Trustees' meetings when required.
- maintaining the charity records up to date and submitting our Annual returns to the Charity Commission.
- being the custodian of DSO's. documentation, policies and procedures.

You will work alongside our Chair and Treasurer and be part of an amazing group of keen volunteers! Contact Roberta for a chat if you are interested.



A huge thank you!



A huge thank you to the staff at the Oxford branch of Beaverbrooks the Jewellers who recently presented the DSO Choir with a cheque for £1,200. The Beaverbrooks Charitable Trust allocates £200 to each employee to donate to a local charity of their choice. Back in November, they saw the choir performing in Bonn Square and were so impressed that they decided to make us their charity of the year! Isobel presented the cheque to choir members Jack and Amy. We are hugely grateful to manager Anne-Marie and all her team!



FUNDRAISING DONATIONS AND GRANTS

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

FUNDRAISING

The Black Boy, Headington raised funds for DSO during their Friday Coffee Mornings £642.00

Virtue Motors, Mercedes Benz of Beaconsfield held dress down Fridays raising **£529.30** Jim McKenzie, father of Callum put DSO forward.

Lynsey and Maddie ran the Oxford half Marathon for DSO, they raised an amazing **£1035.00** Connection from the Mills family.

DONATIONS

Community Grant received from Stanton Ballard Charitable Trust of £1000.00

DSO received £357.00 from Purple Patch Memory Giving - Donations in memory of Jack Stevenson

Thank you to **John and Frankie Mottram** who donated **£100.00** in memory of Ann Hawkes - grandmother to Thomas Walpole.

We currently and very gratefully receive £160.00 monthly through standing order donations.

SAVE THE DATE

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





21 March

WDSD

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



15 May

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.



13 May

Tristars Football Awards

The 2nd Annual Tristars Football Awards Evening will see all our players and coaches recognised for their achievements.



26 June

Annual AGM

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



8 July

Choir at Thomley

DSO Choir is performing at the Accessival Festival at Thomley. Come along for a great day out 11am - 10pm.



16 July

Summer Party

Pop the date in your diary. This year we'll be holding our Summer Party at Thomley 11am - 3pm. More details to follow.



17 July

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.



3 Dec

Xmas Party

Save the date for our unmissable Xmas Party, 2 -5pm Exeter Hall, Kidlington with entertainment from DJ Aaron Williams.

LOTTERY RESULTS

Message from Andy Fearnside, DSO Lottery organiser.

As always, thank you to everyone for taking part. A total of £1092 has been raised for DSO between July and December, all thanks to you!

If you or anyone else would like to join, please email **lottery@dsoxford.org.uk** for details.

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**
- 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!

Congratulations!

JUNE 2022

1st - £61.00 Katharine Horrocks 2nd - £36.60 Lucy Sanderson 3rd - £24.40 Marion Simon

JULY 2022

1st - £61.00 Anne Churchill 2nd - £36.60 Ella Terblanche 3rd - £24.40 Sally Dubock

AUGUST 2022

1st - £61.00 Marion Simon 2nd - £36.60 Carolyn Walker 3rd - £24.40 Emily Robinson

SEPTEMBER 2022

1st - £61.00 Steph Mills 2nd - £36.60 C Dilnot 3rd - £24.40 Carolyn Walker

OCTOBER 2022

1st - £61.00 Jo Crawford 2nd - £36.60 Carolyn Walker 3rd - £24.40 Marion Simon

NOVEMBER 2022

DECEMBER 2022

1st - £61.00 Mary Robinson 2nd - £36.60 Ella Terblanche 3rd - £24.40 Ella Terblanche



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.

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:



Primary Club

Stephanie Mills steph@dsoxford.org.uk

Emily Higgins
emily@dsoxford.org.uk



Sam Martin-Morrissey sam@dsoxford.org.uk



Anne Churchill-Stone & Sonia Forester anne@dsoxford.org.uk

anne@dsoxford.org.uk sonia@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.



I enclose my gift	of £ (Cheque/PO payable to Down's Syndrome Oxford)
OR —	
A regular gift of	£ per month / quarter / year (please circle appropriate)
commencing on	dd/mm/yyyy
Name of bank	
Bank address	
	Postcode
Account No.	Sort Code
Signature	Date dd/mm/yyyy
Bank Ref:	Completed by DSO
I would like and all my amount of my donation I am not a	UK taxpayer.
	e your information with any other organisation.
Your name	
Your address	
	Postcode
Please return thi	s form to: Down's Syndrome Oxford (NOT your bank) c/o Treasurer, Manor Farm, Waterperry Oxfordshire OX33 1LB

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



Website: dsoxford.org.uk



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



Facebook (public group): facebook.com/
downssyndromeoxford



Twitter: twitter.com/DownsOxford @DownsOxford

SHARE YOUR EXPERIENCES

We welcome text or photos about your child enjoying themselves - not necessarily a DSO event. Please send materials to:

Joy Weideman or Lucy Sanderson newsletter@dsoxford.org.uk

The deadline for the next edition of the newsletter is:

Friday 2 June 2023.



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



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