OCTOBER 2024

down's syndrome oxford

# NEWSLETTER

## Celebrating 21 years of community, support, progress and inclusion

# From the chair

## Welcome to our year of celebration

**It has been such a pleasure during this year to see our members, families and friends fully participating in our 21st birthday celebrations. The past 21 years have been a time of learning and growth with all the challenges and successes that can bring. We are proud to say that over that time we have supported each other, developed and smiled together. Let's make the next 21 years just as rewarding.**

The year started with the adoption of our 21st birthday logo, designed by the talented Alexander Horrocks. It exemplifies the joyfulness, positivity and enthusiasm our members bring to our charity.

Our timeline on page 4 will show you some of DSO's achievements and events over the last 21 years. There is so much for our families, trustees and volunteers to be proud of.

Throughout this edition you'll also see some shared memories, from the time DSO first came into being to more recent articles and observations.

Among the many activities our members have enjoyed throughout the year, three have really stood out. The 21st Birthday Teddy Bear's Picnic for our youngest members, The DSO Ball for our more grown up young people, and the highly successful Walkathon, which was a huge success for everyone, and raised over £42,000.

I am also pleased to see so many sports, dance, cooking, singing and play activities available to our members of all ages. See page 12 for details and join in!.

Our Tristars Football Team held their third annual Awards Evening in May. Players were delighted with their achievement awards and enjoyed a fun-filled evening with music and dancing. You can see all the merriment on page 14.

In March, we bid a fond farewell to our choir leader Annie, who taught and encouraged our signing singers for five fabulous years. We wish her all the best for the future and are delighted that Amy has stepped up to take over her leadership. Take a look at our colourful team on page 22.

On page 24 you will find an overivew of the 2024 DSO AGM. The trustees reported on the growing demands on DSO and the need to change our structure to ensure our ability to meet those demands and continue to offer our families a rich variety of services and activities into the future. Trustees have proposed to change our structure to a Charitable Incorporated Organisation (CIO) and members voted to proceed with this proposal as well as revising our name to Down's Syndrome Oxfordshire to better reflect the area we support. We will keep you all updated on this transition in coming editions.

## IN THIS EDITION

# Thank you Colette

Colette Lloyd, our EDG Speech and Launguage Therapist for over 10 years, has moved on to new pastures.

I want to extend our gratitude for her incredible 10 years plus of dedication and service. Her commitment has made an impact on so many of our families.

We would also like to thank her for being such a vital part of our DSO famiy. She is always kind and generous and goes the extra mile to ensure our families get the support they need.

We wish her luck in her new job and look forward to working with her in a parental capacity.

# Much has happened in 21 years

2003

DSO becomes a registered Charity and operates out of three Portacabins at the Park Hospital

2007

DSO moves to the Roundabout Centre Barton

The first DSO Walkathon raises over £36,000 to fund DSO services

2018

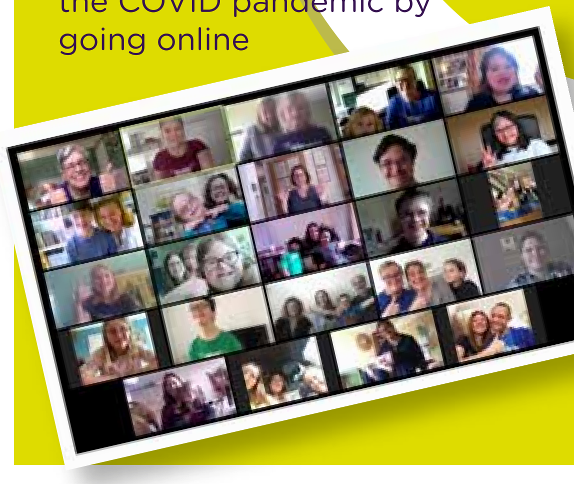
2019

DSO Choir's first public performance

EDG move to West Oxford Community Centre

2020

DSO keeps us united during the COVID pandemic by going online



2021

Our 21 Challenge raises over £52,000 to help fund DSO activities

Tristars Football Club offers players skills, fun and exercise

2021

2008

First Big Step Forward raises funds for DSO

2009

Big Step Forward 2

2012

Move to Caldecott Centre Abingdon

2012

DSO Lottery starts to raise monthly funds for DSO

2015

Elliot's Shed offers members access to equipment, toys and resources

2017

Primary Development Groups help children in a primary school setting

2021

Maths 4 Life programme is initiated offereing access to Maths tailored to our members

2024

The DSO Ball, the Walkathon and other events celebrate our 21st Birthday

2025

DSO change in status to a Charitable Incorporated Organisation to enable greater ability to provide services and raise funds

# Some memories from when it all began

2003 I remember Pat Leprevost who was the speech and language therapist and very supportive, travelling to a London building site with a few of the parents to view a filthy well used portacabins which were still being used. They returned to Oxford and agreed that it was nothing that couldn't be fixed and so they were bought and brought to The Park hospital on articulated lorries.

The Churchill drive is very narrow and there was only a narrow opening in the fencing to the hospital meaning that it was an extremely tight turn for the very skilled lorry drivers. I remember they were all parked up in the Churchill drive while the first driver sweated buckets trying to manoeuvre the lorry through the tight gap……back and forth, back and forth until eventually one of the other drivers suggested using his cab which was slightly shorter as it didn't have a sleeping compartment behind. This was the answer and finally after nearly a day of trying the three buildings were delivered to site where the crane hoisted them into their final position. There was a wonderful drawing done by one of the Park Hospital school children of all of this. We did have it on display in the building but goodness knows what happened to it.

A small group of us parents skilled and unskilled then set about transforming the structure, building a ramp to the doorway, putting in flooring, plumbing in 2 toilets, a kitchen and electricity, namely all that is needed in a new building. A two way mirror was put into the wall between the viewing room and the main playroom where the speech and language groups were to take place, so that parents could watch yet were unseen by their children. Finally we rubbed it all down, painted it all and made curtains and cushions to make it comfortable and user friendly. When it was all finished Helen Lederer, comedian and actor who was a relative of one of our families came and opened the centre.

It was used one day a week for 3 different pre school speech and language groups. These were taken by a speech and language therapist helped by some wonderful volunteers all retired folks who gave their time freely and generously. The children loved them all and it worked very well for many years. The Downs Service led by Dr Jenny Dennis had their offices in an adjacent building and they used the consulting room to see children and families, the dentist came once a month, the eye clinic took place there and of course the building was used in the evenings for parent evenings and activity groups and the Polly Alton toy library also operated from there.

By Libby Chase

# yarnton magic garden

*By Andria Hutchings*

44 of us from the pre school club (from nine families) escaped the rain on Saturday 18th November inside Yarnton Magic Garden's sensory soft play. Fun was had by preschool club children and their siblings while parents, carers and grandparents had a chance to chat. We also all ate lots of cake.

Members were very thankful for our time together. A new family found it a great first event for getting to know our wonderful group and we look forward to seeing them at Stay and Play soon. One grandmother was also so grateful for our event because she lamented there having been no sort of community for support with her autistic son thirty years ago.

# DSO 21st Birthday Ball

As part of DSO's 21st celebration a small team were the master minds of our very first ball.

What an evening that was..... A red-carpet arrival to celebrate with our friends and family which included of course yummy food and music by the award-winning DJ Dan Blaze who made sure the dance floor was filled throughout the night with our favourite songs. I think we can all agree our DSO family know how to party. You all looked so glamorous and that dance floor was never quiet. So many smiles and laughter and a chance to come together to celebrate all that we have achieved in those 21 years and continue to achieve bringing our community together. As with all our events a small team work tirelessly to make magic happen but it comes together with you attending, and it was so lovely to see some new faces joining us, we all really hope to see more of you at future events.

Many thanks must go to our small ball team Lucy, Michelle and Emily and to Worton Hall who looked after us so well from start to finish.

*By Sonia Forrester*


LEGEND

Welcome to

DSO'S 21ST BIRTHDAY BALL!

7pm - Red carpet arrival & photos

7.45pm - Sit down & welcome speech

8pm - Buffet opens
(your table name will be called)

11pm - Carriages

ENJOY YOUR EVENING.

# CLUBS AND ACTIVITIES

Looking for some activities? There are lots of things available every week. Have a look through the list below, there may be some things you would love to do.

## CHOIR

**DSO Singing & Signing Choir**

Sing and sign to popular songs in an inclusive choir. Ages 5+

Every second Saturday term time
2.00 - 4.00pm

Wheatley Park Sixth Form Centre, Holton

Contact Elsa Gill
elsa@dsoxford.org.uk

## EARLY CHILDHOOD

**Stay&Play**

Preschool baby & toddler group for families who have a child with DS.

Wednesdays
9.30am-12.30pm

West Oxford Community Centre, Oxford City

Contact Amanda Foulds
amanda@dsoxford.org.uk

## COOKING

**Cook & Chat**

A social cooking session for people with DS aged 14+

Once a month on Saturday
4.15pm-6.15pm

Thomley Hall, Worminghall

Contact Ellie Walpole
07796 087243

## FOOTBALL

**Tristars Football**

Football sessions for people with DS aged 8+

Wednesday term time
5.00 - 6.00pm

The Dome, Oxford Academy School

Contact Amanda Foulds
amanda@dsoxford.org.uk

## RUGBY

**Witney Wolves**

Tag and Touch rugby for players with SEN aged 8+. Witney Wolves provide a junior and a senior squad.

Sunday
11.00am-12.00noon

Witney Rugby Football Club, Hailey Road, Witney

Contact Matthew Rawlins
MattRawlins82@gmail.com

07584 570107

## DSO DANCE

Weekly dance practice run by Amanda Adler Dance School for dancers with SEN aged 7+.

Monday
5.30pm-6.15pm

Abingdon College

Contact Sally Dubock
sally@dsoxford.org.au

## SWIMMING

### Acquatots SEN beginners class (for children)

Swimming lessons for people
with SEN aged 5-12

Tuesday term time
5.15 - 5.45pm

Managed by Aquatherapy

Hydrotherapy pool, Bardwell School Bicester

Contact Andrea Douglas
aquatherapyuk@gmail.com

### Aquateens/Adult SEN beginners class

Swimming lessons for people
with SEN aged 13+

Friday term time
6.45 - 7.15pm

Managed by Aquatherapy

Hydrotherapy pool, Bardwell School Bicester

Contact Andrea Douglas
aquatherapyuk@gmail.com

### Downs Syndrome Swimming Lessons

Small group lessons for intermediate and advances swimmers with Downs Syndrome aged 8+, Swim England stages 6-9

Friday
6.30 - 8.00pm

Managed by Park Club

17 Croft Drive, Milton Park, Abingdon, OX14 4RP

Contact Sally Dubock or
swimming@parkclub.co.uk

## CRICKET

### Mixed disability cricket sessions suitable for people with DS

Wheatley - Tuesday
Witney - Wednesday
Abingdon - Thursday
Bicester - Fridays

Managed by Lord Taverners

Contact Richard Giles
rgiles@oxoncb.com
07482 577424

## TENNIS

### Downs Syndrome Tennis

Tennis sessions for people with DS and similar disabilities. Ages 5 to adult.

Saturday term time
10.00 - 11.00am

Managed by White Horse Leisure Centre,
Audlett Drive, Abingdon

Contact Sue Auger
sue.auger@gll.org
07776 128723

# Tri-stars 3rd Annual Awards Evening

## Saturday 18th May, 2024

Just a few days before the awards evening we had found out that Oxford United's big game was to be played on the same day as our awards ceremony. A number of the coaches were going to Wembley, however instead of putting a dampener on our plans it added an air of excitement to the preparations.

Whilst setting up for the evening we listened to the football and to the great delight of everyone Oxford United won and were promoted to the Championship League. This gave an added celebration to the evening.

Ben welcomed everyone and we had a fabulous buffet organised by Joy. Garry had recorded his speech, as usual he was enthusiastic and supportive to all the players and coaches. Amy & Amanda gave out an award to all our players highlighting the achievements each of them have made over the past year. Thomas thanked the all the coaches for their dedication and gave each them a gift.

The speeches and presentations were followed by a fun filled evening of music and dancing by Lisa Lashes! The evening ended with an Oxford United tribute singing along to "Sweet Caroline."

A big thank you to the organisers Lucy, Joy, Paula and Lisa. And thanks to Oxford City Rugby Club who welcomed us once again.

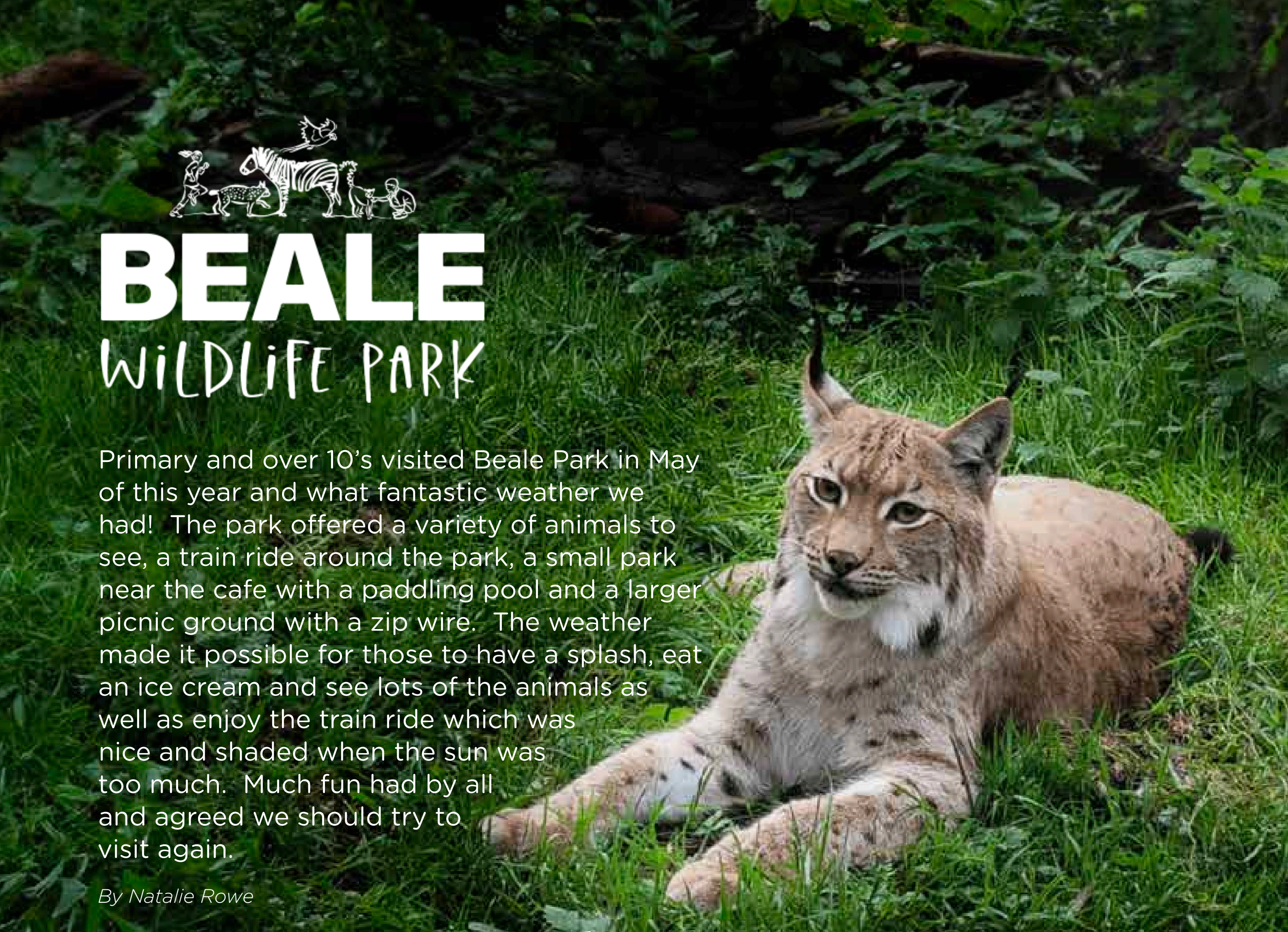
*By Amanda Foulds*


OXFORD UNITED
ACHIEVEMENT
ACHIEVEMENT
ACHIEVEMENT
PERFECT AT PASSING
I'm a demon in defence


ACHIEVEMENT
ACHIEVEMENT
ACHIEVEMENT
ACHIEVEMENT
I'm a demon in defence
PERFECT AT PASSING

“ I got my award for being a great defender. Woohoo! The ball doesn't get past me!”
Ellie H

# BEALE
## WILDLIFE PARK

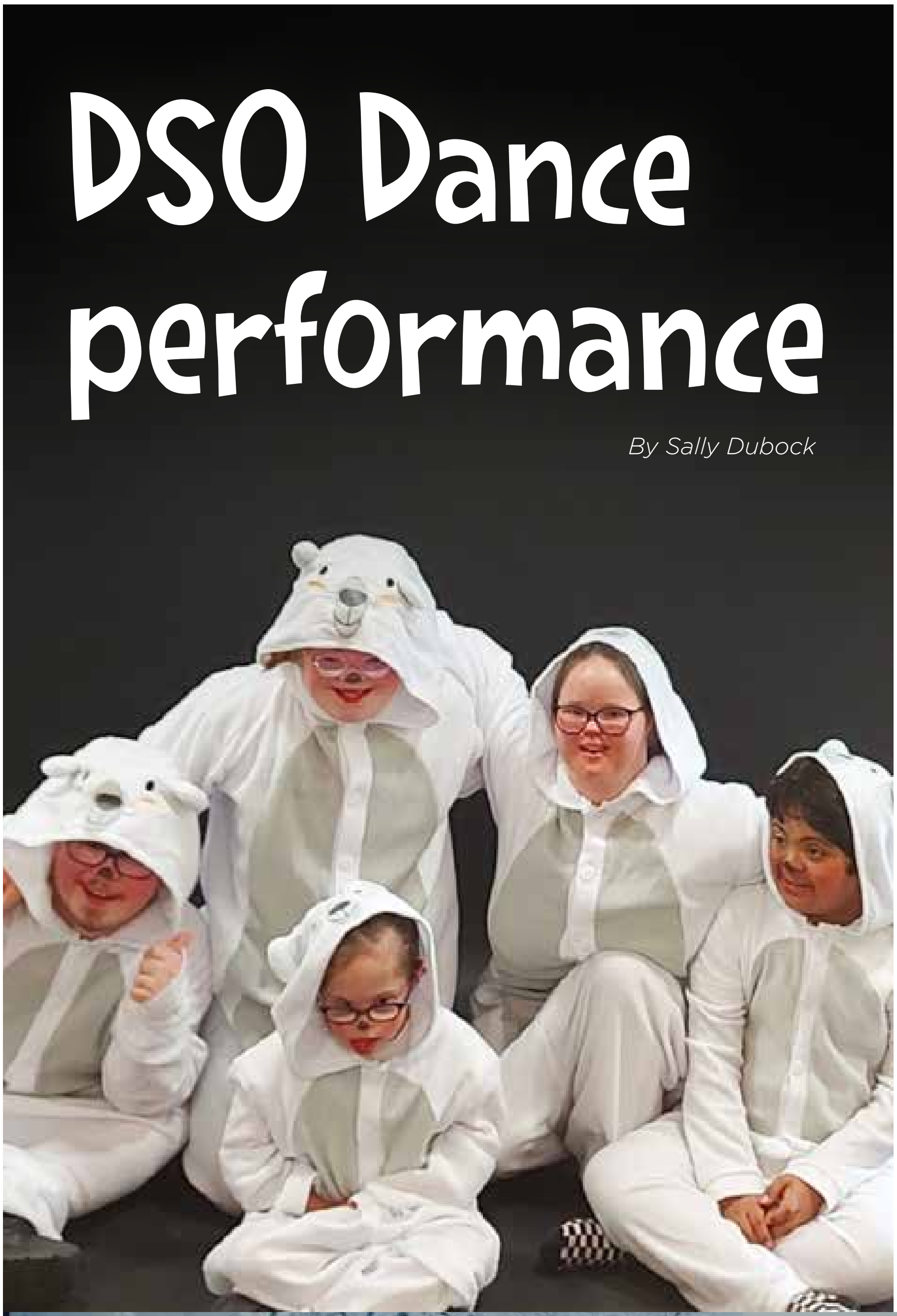


Primary and over 10's visited Beale Park in May of this year and what fantastic weather we had! The park offered a variety of animals to see, a train ride around the park, a small park near the cafe with a paddling pool and a larger picnic ground with a zip wire. The weather made it possible for those to have a splash, eat an ice cream and see lots of the animals as well as enjoy the train ride which was nice and shaded when the sun was too much. Much fun had by all and agreed we should try to visit again.

*By Natalie Rowe*

# DSO Dance performance

*By Sally Dubock*



**It was fantastic to see our DSO dance group taking part in the Amanda Alder Dance Academy show in January.**

Five of our children were polar bears in a show called 'The Key to the Realms' and performed in the show alongside 450 other dancers at Radley College over a special weekend. Thanks so much also to Ailsa Summers for helping the dancers on the stage.

Our group rehearsed each week for several months and performed brilliantly at the show, with deserved applause at the end of their three-minute set.

If anyone is interested in joining the dance group (open from approximately age 7/8 upwards) then please contact me at sallydubock@gmail.com

# ADVENTURE PLAY AT BLENHEIM PALACE

*By Andria Hutchings*

Twenty-nine of us braved the very chilly conditions on the afternoon of Saturday 2nd March to take up Blenheim Palace's very kind offer of free tickets to DSO pre schoolers and their families. Wrapped up warm, we all had lots of fun on the amazing equipment, our littlest ones even making it onto the specially designed toddler zip line. Most of the siblings didn't stop exploring during the three hour session apart from to refuel on fairy cakes, although the grown ups were grateful for the hot drinks from the cafe. As ever, we were grateful for the extra time to spend together as families and build relationships between parents/carers, members with DS and their siblings. Not even some hail and a couple of rain showers prevented us from enjoying our special afternoon out.
A massive thank you again to DSO and Blenheim Palace!

# Pitt Rivers Museum Visit

*By Sonia Forrester*

**We had a brilliant morning back in February half term at Pitt rivers museum, followed by the natural history museum.**

With support from Sarah and Lucy Shaw who has been involved with putting the trail together. I was able to arrange a visit for DSO to go and explore the new trail called Curating for Change (Exploring disability histories at the Pitt Rivers Museum). We had 26 members booked for our visit. The staff were so lovely and nothing was too much trouble with every member included.

I think it's safe to say the touch and feel box was the best followed by the dinosaur hunt. Many thanks to those that came.

# Thank you Annie!

By Elsa Gill

In March, the DSO Choir bid a sad farewell to our wonderful leader, Annie Hawkins.

Annie has relocated to Devon, where she and her son Archie are enjoying a new coastal life! We are thrilled to share that Amy May, who many of you also know as a Tri-stars coach has agreed to step-up to become our new choir leader.

*By Elsa Gill*

# We are 5!

In February, the choir celebrated its 5th Birthday! Choir remains one of DSOs most popular activities and has grown in numbers over the years. Everyone enjoyed a wonderful celebration cake made by choir member Emily Robinson!

# DSO AGM 2024

## CHAIR'S REPORT

### 2023/2024 Highlights

**DSO now supports:**

Over 493 registered members (up from 462 in 2023)

  - 414 (392) Parents, Carers or adults with DS
  - 35 (28) Family and Friends
  - 42 Professionals or Volunteers

**Membership as per group:**

  - 113 registered for pre-school information (+6)
  - 159 registered for primary group information (-3)
  - 143 for 10+ information (-3)
  - 190 registered for 16+ information (+15)
  - Register for individuals with DS and for 21+ information coming soon
- There have been 9 new births since April 2023, 7 of the families have joined DSO
- DSO pilots and data has informed and led to OCC / ICB-BOB (Integrated Care Board Bucks Oxon and Berkshire West) running across Oxfordshire pilots for:
  - Sensory Processing
  - Maths For Life pilot in schools across the county
- Our activity budgets were significantly underspent in 2023
- We are in the process of giving people who are 18+ with Down syndrome the ability to register on the DSO website in their own right.

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### Maths for Life Programme

The Maths For Life Pilot started Feb 2021. 28 students participated in the pilot, with 45 Year 1, and 30 Year 2 students participating since then. The programme has 24 active students in year 3 + 2 schools (Feb 24/25) with Hannah Dubock and Chloe Sanderson achieving Entry Level 1 Maths. DSO data and influence has resulted in OCC running a pilot in 43 schools across the county between Sept 2023 and July 24, supporting over 300 students and covering all Mainstream Schools supporting children with DS. Some SEN schools are also participating and two schools in The Gallery Trust are now on board.

### External relationships and lobbying

- DSO maintains ongoing contact with OCC Children's Services and SEN Department, in regular contact with Deb Smit, Head of SEND. DSO were also the parent carer representative of the appointment interviews for new head of operations for SEND, Nick Field.
- DSO members have experienced more year 6/7 transition issues because of the restricted number of SEN school places. Unfortunately, any transfer placement seems to be a challenge now.
- Relationship with SENSS team and EYSEN special educational needs support service, continues, including early years special teachers' team, which helps support young people coming into education.
- Nasreen Kamal is representing DSO at DSA meetings and will regularly report into our all-members' meetings.
- Oxfordshire Parent Carers Forum (OxPCF): Down's Syndrome community is always represented. OCC interacts formally with the Oxford Parent Carers Forum as point of engagement for all legislative policy changes. Marion Simon and Jos Smith are sharing the load, anyone interested in getting involved is more than welcome.
- Introduction to OCC/ICB – BOB where the health authorities of Oxfordshire, Buckinghamshire and Berkshire West have come together. There is significant disparity in services across these three groups including dental health, access to GPs, etc.
- Rachel Campling has represented DSO via OxPCF on the Sensory Therapy pilot program with OUH.
- Marion is on the OCC Co-production Board, they keep track of all the co-production between the county and parents.
- Jos sits on the OCC Clinical Commissioning Board: which is identifying the therapy services provision e.g., SALT, sensory therapy, physiotherapy.

### DLA support

DLA Support is run by Rowena Pearce. This highly effective, low-cost service, started in September 2018, exemplifies successful virtual support. Rowena uses medical information from letters and family histories to give remote support. This year 16 families were supported including 7 initial applications, and 9 reapplications for DLA. 78 families have been supported to date.

### EHCP and tribunal support

DSO have been working with Barney Angliss since 2021, who was met through the Special Needs Jungle. Barney used to be a teacher, SENCO, and ex local authority, with a lot of legal knowledge. He has been helping families through the tribunal process. DSO will continue to offer to pay him although he hasn't accepted payment so far. 11 families have been supported by this initiative to date.

### Matters arising

- We are still seeking an external trustee, and one internal trustee.
- DSO's budget this year was £63,750. An extra £10,000 was spent to support DSO 21st Birthday activities.

### Secretary's report

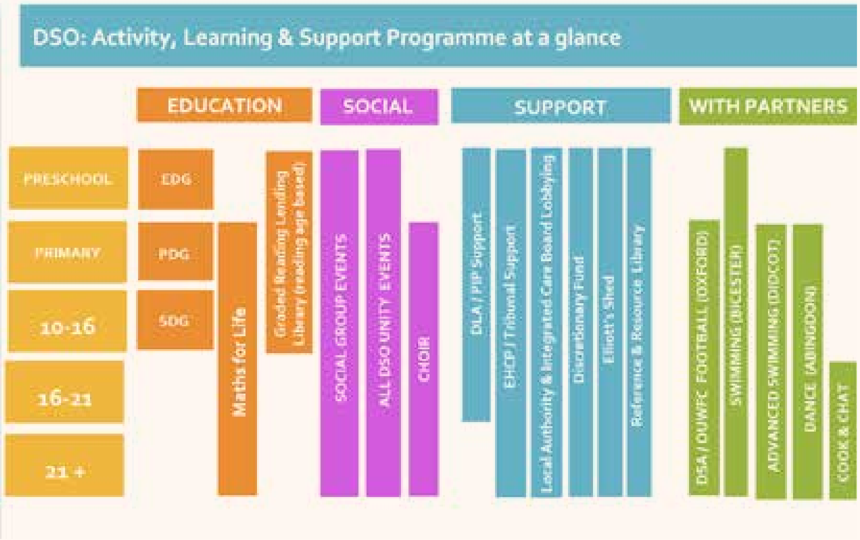
Aiya updated us to let us know all our Charity Commission records have been kept up to date and our regular All Members Meetings are available in our files and shared via email. Risk assessments have been submitted as per DSA requirements.

### Treasurer's report:

- An update on funding and expenditure. How much money was spent this year can be seen in the pie chart in the DSO AGM 2024 presentation.
- We are starting to dip into our reserves.
- Our total expenditure this year has gone down, showing efficiency.

## GROUPS UPDATES

**Stay and Play:** Many new members are joining DSO, but not many coming to Stay and Play. It has been suggested new parents are invited to meet Rowena Pearce, who attends Stay and Play once a month, as an incentive. The hearing support team have attended and would like to attend again. WOCA (West Oxford Community Centre) continues to be a good location.



***DSO continues to provide a rich variety of services and activities to its members, engaging with local authorities and other SEN organisations to offer the broadest access to facilities and opportunities.***

**EDG:** DSO currently runs 4 sessions on a Wednesday morning with 5 children per group. No new children are starting in September. Colette Lloyd, the EDG's speech and language therapist is sadly leaving. A new, highly experienced speech and language therapist will be joining the group. Steph Mills, the new parent contact, has sent out hello again emails to all new parents reminding them about Wednesday EDGs. Social groups on Saturday have been suggested, as some parents can't attend the group on Wednesday.

**PDG:** 23 children are participating this year. Helen Simpson, a specialist advisory teacher who has a holistic approach, now works with DSO. She works very closely with the SENSS team and supports TAs. 1 child has been visited in secondary school this year, with a goal to do more visits next year. There are only 4 children in mainstream secondary school

**Preschool:** Several activities have been run, including Roves Farm, Yarnton Magic Garden, Blenheim Palace and 21st Teddy Bears' Picnic, allowing extended families to get together.

**Primary:** There are 37 members on the WhatsApp group. A few fun activities have taken place during the year, there has been a slightly lower participation from the primary group, looking at possibly working with Sam in the 10+ group for a crossover between the groups.

**10+ Club:** There are 33 members on WhatsApp group. A number of fun outings have been enjoyed, including, John Lawson's Circus with the 16+ group, Snakes and Ladders, Torchlight Night at Millets Farm, Halloween Disco and Thomley Fireworks. With some extra help, more events can be booked.

**16+ Club:** Now led collectively by Amanda Foulds, Elsa Gill, and Katharine Horrocks. Members on WhatsApp group have increased from 51 to 65. A few social activities have een enjoyed including the Halloween Disco, Christmas meal and theatre trip.

**21+ Club:** This new group was created in December 2023, led by Michelle Holt, but opportunity for others to help. There are 28 members in the WhatsApp group including Supported living house representatives.

**DSO Choir:** Choir has 40 regular attendees. Sadly, we said goodbye to Annie Hawkins but are delighted to welcome Amy May as choir leader.

**Tristars Football:** 19 players have signed up and ages range from 10-58 years. The club enjoyed a lovely presentation awards evening in May. Tristars is currently looking for additional coaches.

### Elliot's Shed

A key access box has been installed at the shed to make access easier and more convenient. A wide variety of equipment is available including electric bikes and high chairs.

### TRUSTEES UPDATE

- Demands on DSO are growing requiring more time and commitment from members. A small number of people are handling a significant portion of work, raising concerns over potential burnout.
- Increased reliance on individual or group fundraising efforts has become necessary as seeking large funding sources is time consuming and has low success rate.
- Trustees are personally financially liable which adds risk and responsibility to their role.
- **Finding a permanent solution:** Trustees explored various business and charitable structures. A DSO-wide questionnaire was conducted to identify membership priorities. The recommended option is to become a Charitable Incorporated Organization (CIO), now the preferred standard for many charities.
- **Advantages of CIO and name change:** Eliminates personal financial liability for DSO trustees. Enhances income opportunities and no need to change accountants. Transition can be phased with no set time frame, and further provides an opportunity to change the name to Down's Syndrome Oxfordshire to better reflect the service area.
- **Short-term impacts:** The potential legal costs are estimated at £5000, for which grant funding will be sought if possible. The transition will require some volunteer time from a designated group. There will be a change in the charity number but both organisations can operate in parallel. The timing of the switch is flexible and can be managed at a pace that suits the organisation.
- If the motions to change to a CIO and the name change are approved, a detailed programme of tasks and decisions will be shared with all members. Members will be continuously consulted and involved throughout the process.

**Thank you to all who attended. A full list of future All Member Meetings and the date for DSO AGM 2025 can be found on our website. All welcome.**

# DSO Choir at the Keen olympics

*By Elsa Gill*

On a bright June day, the choir was delighted to perform at the annual KEEN Summer Olympics at New College Sports Ground. KEEN Oxford is a local charity which runs a number of inclusive activities for children and adults with disabilities. (keenoxford.org) Our members had a fantastic time participating in fun games and indulging in strawberries and cream before performing a number of songs. The day concluded with an award ceremony where medals presented to the choir.


CHOIR

# DSO 21st birthday celebrations

# WALKATHON

18 teams made up of over 300 team members took on the 2024 DSO 21Walkathon. Preschoolers joined the event with their very own 21 song danceathon alongside the walkathon and we were very grateful that the sun shone throughout!

Everyone embraced the event with such enthusiasm. Fundraising pages were setup and shared for the run up to the event and we had staggeringly raised £21k before anyone crossed the start line at Midday!

We were entertained throughout the 21 hours with music and 5 live bands, hosted by the amazing team at Radley Stage. Giant bubbles flew in the air and games were played in the centre of the track with Sally.

We were kept refreshed by the wonderful ladies at the Cheeky Tiki Bar and Samuels Strollers delivered a delicious Hog Roast.

Themed laps during the event included Music March, where people dressed up as their favourite music artist or era. There was a superhero lap where people were invited to dress as their personal super hero, Pj's were put on in the evening and we absolutely lit up the site with our light up the night section to finish the themed laps.

*By Sarah Fonge*

The fundraising total continued to grow and we are so pleased, no, ecstatic with the final event total of £42k

Elsa, Andrew and myself would like to thank absolutely everyone that was involved in the 21Walkathon, for believing in the event and for believing in us. We all did it and maybe we will do it again?!?!?!?

# We raised an amazing £42,000

Thank you everyone for your incredible efforts!

The fun continues overleaf

« It was super amazing! I got to listen to the band and see all the funny costumes. I took my turn to do the walking .”

Emily

"I stayed up late and had a good time with my friends. It was fun."

Thomas

# If you go down to the woods tonight

By Andria Hutchings

**43 members of our pre school club (from nine families) were generously hosted by the University of Oxford's Harcourt Arboretum on Saturday 1st June for our 21st birthday party. We were warmly greeted as soon as we arrived by staff who spoke fondly of another mum and son with Down's Syndrome who is now in his thirties.**

We started with a teddy bears' picnic with our packed lunches in the Woodland Barn specially decorated for the occasion. Members with DS were then presented with their own commemorative DSO 21st birthday teddies before the children were shown by Rodger, our knowledgeable guide, how to plant their own sunflower seeds to take home. This activity suggested by the Arboretum couldn't have mirrored better this year's World Down Syndrome Day's theme of 'Growing a Sunflower' to teach children that not all people grow at the same time but they all grow eventually. Older siblings had a great time helping our members with DS get stuck in, as well as chasing each other and the peacocks around the barn.

Rodger then gave us all a guided tour of the Arboretum, which made the event particularly special. His highlight was showing us some now extremely rare common spotted orchids in the meadow. Older siblings had lots of predictable fun with "sticky weed" (or whatever you call it) along the way and we learnt about rhododendrons taking over and the importance of meadows to wild farming, amongst other things. Rodger told us how his son's class whole class learnt Makaton in primary school, which developed organically out of a desire of the children to communicate with their classmate with DS.

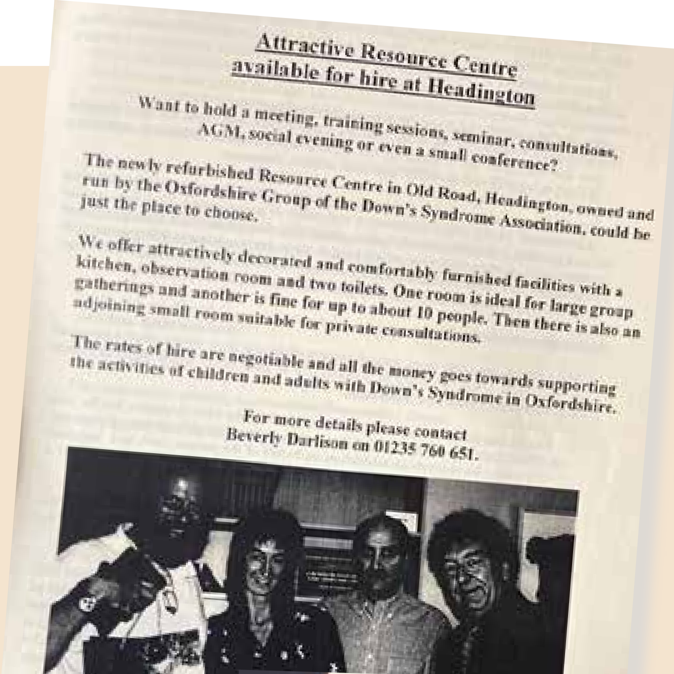



We finished the day with hot drinks (the hot chocolate being very popular on an unusually chilly June's afternoon) supplied by the Arboretum and a very special birthday cake decorated with DSO's winning 21st birthday logo. The cake went down very well with all and, thankfully, the peacocks didn't run off with any of it!

Once again, this was a great event for encouraging friendships between families, particularly siblings, and providing a relaxed and fun environment for parents and grandparents to get to know each other, particularly those who aren't regulars at Stay and Play. One new family hadn't met a baby or toddler with DS in their local area before.

All in all, what a great way to celebrate DSO's 21st birthday! With special thanks to Rodger and his colleagues at Harcourt Arboretum, and Tina Herringshaw-Dodd (pre school club mum) for sourcing and dressing those teddies in DSO 21 T shirts. Over the next few weeks, those special teddies will be making their way to every pre school club member with DS who didn't join us on the day, but feel free to contact andria@dsoxford.org.uk if you haven't received yours yet.

# Memories from the archive



## Attractive Resource Centre available for hire at Headington

Want to hold a meeting, training sessions, seminar, consultations, AGM, social evening or even a small conference?

The newly refurbished Resource Centre in Old Road, Headington, owned and run by the Oxfordshire Group of the Down's Syndrome Association, could be just the place to choose.

We offer attractively decorated and comfortably furnished facilities with a kitchen, observation room and two toilets. One room is ideal for large group gatherings and another is fine for up to about 10 people. Then there is also an adjoining small room suitable for private consultations.

The rates of hire are negotiable and all the money goes towards supporting the activities of children and adults with Down's Syndrome in Oxfordshire.

For more details please contact
Beverly Darlison on 01235 760 651.

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dso
down's syndrome oxford

down & about – the DSO newsletter December 2006

## HAPPY CHRISTMAS and SEASON'S GREETINGS

### Urgent NEWS FLASH

It is truly tragic that DSO is being forced from its home of over 20 years in January next year. The cranes of the developers are already adjacent to the site! Although we have had quite a lot of warning of our eviction, members of the committee have attended a couple of NHS meetings and sadly they are offering ZERO assistance in providing any accommodation that is separate from 'other parent groups'.

PLEASE Don't worry about clinic appointments as the DS service (including Golda Nann) is moving to the new Children's wing of the JR and is also changing – we hope to bring you more detailed information about the service soon.

***Most importantly*** Do you know of anybody or company that could provide us with a new location to call the Down's Syndrome Resource Centre?

We are in-debted to the incredible fundraising and motivation of the committee and NHS service in the 1980's who not only secured the site for the Portakabin's but also bought them (2nd hand) and delivered what we know now as the Down's Syndrome Resource Centre. Also about 5 years ago the committee successfully refurbished the centre providing a bright, clean, warm and happy location for baby and toddler groups, speech and language classes and for the numerous clinic appointments that one has with a young child.

My apologies for the lack of detail but I hope that someone will come forward and write a detailed account of what we had. We believe that there are no other parent support groups in the county that have a home like the resource centre – it's a desperately sad conclusion to what was one of the first dedicated sites and integrated ventures between the DSA and NHS service in the UK.

### Your help please....

On Saturday 13th January we are packing up and clearing out the resource centre – **WE NEED YOU (Mums and Dads)** to help us on the day. We need boxes or crates of all sizes and your physical help to load a van and possibly run an impromptu Garage sale to shift some of the larger items and some cash in the bank for DSO!

Years gone by – Photos of your children on the pinboard in the resource centre

down & about – the DSO newsletter December 2006 Registered Charity No. 1103850

Further use of the photos used in this publication is strictly prohibited

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down's syndrome oxford

## ... is here to help

Down's Syndrome Oxford is a registered charity, run and funded by parents and supporters to provide information, help and activities for children with Down's Syndrome and their families.

Members are children and adults with Down's Syndrome — their parents, carers and supporters of the charity, plus many key professionals. These include physiotherapists, pre-school teacher-counsellors, teaching assistants, health visitors and others working in the community with people with Down's Syndrome.

"We are always looking to expand our contact list and anyone is invited to be a member," said the group's spokesperson Ellie Walpole, whose three-year-old son, Thomas, has Down's Syndrome.

Membership is free and some of the benefits include friendship, family social events and practical assistance with educational and developmental issues.

Parents are sent a regular newsletter and have access to a library and bulletin board and are kept informed about lectures, seminars and workshops that might prove useful. In May last year, the committee organised its own conference in Oxford, which attracted 90 delegates and a number of nationally-recognised expert speakers.

The group, which meets at the Roundabout Centre in Headington, caters for all ages, from birth upwards. There are two parent and toddler groups for pre-school-age children, as well as a youth group for 9-16 year-olds and a swimming club.

"We work closely with all the professionals affiliated to the Oxfordshire NHS Down's Syndrome Service and Local Education Authority, but stand as a separate and independent organisation," said Ellie.

"Oxfordshire is home to some of the most renowned Down's Syndrome specialists in the UK and all of them can be contacted through our committee members."

Anyone who wants more information should either contact DSO directly or ask their health visitor, doctor or the NHS Oxfordshire Down's Syndrome Service to put them in touch.

"All the phone numbers are of families or volunteers, so please do not expect a 24/7 service. But be assured that you will definitely be called back if you leave a message," Ellie added.

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These articles show the many ways DSO has been there to support our families over the last 21 years and some of the challenges it has had to face.

2

# EARLY LEARNING IS THE KEY

Pre-school children and their parents can learn communication skills and have fun at the same time at Down's Syndrome Oxford early development groups.

Activities such as singing and signing for the children are combined with coaching and advice for parents about how they can teach communication skills as part of everyday activities at home.

Parents have an opportunity to meet other families, share ideas and borrow or buy the communication resources that are used in the groups.

Sessions run every Wednesday during term-time at the Roundabout Centre in Headington, and are organised according to age with one for under-twos and the other for two-to-three-year-olds. Each age section is divided into two further groups that meet on alternate weeks. The maximum number of children in each is six.

Any parents who have a child with Down's Syndrome can apply to join and DSO also accepts referrals from professionals working with a child, with the consent of the parents or carers. If a group is full they are invited to join the waiting list, but while on it can observe a session or take part in organised training.

"One of the most important things is to know you are not alone and to meet other families in the same situation as you," said DSO committee member Katharine Horrocks, who attends the early development group with her son Alexander, 19 months.

"When you first learn that your child has Down's Syndrome it can be quite traumatic. It is wonderful to meet people who have been through a similar thing, so you get support from that. But at the same time, Alexander is benefiting from the activities that the group organises."

> "When you first learn that your child has Down's Syndrome it can be quite traumatic. It is wonderful to meet people who have been through a similar thing, so you get support from that."

DSO committee member Katharine Horrocks with her son, Alexander, 19 months

The resourcefulness of our members has been a backbone of the success of DSO.

The dedication and ingenuity of our families has helped provide the facilities and the funds needed to give our young people rewarding and enriched lives, helping them work towards acceptance and inclusion in the broadest possible way in the general community.

Like the highly successful fundraisers that have regularly been organised, and other money making ideas.

**PARK LIFE:** Families step out in aid of Down's

OXFORD MAIL

**FUN TIME:** Michael Hewitt's nanny, Kay von-Son, adjusts his dummy, above. Samuel Toma, four, gets a lift from dad Dorinel Toma, top left. Three-year-old Chloe Sanderson, left, with her sister Annabelle, seven

Pictures: Damian Halliwell

# Peaceful stroll is boost for charity

Emily Allen

**HUNDREDS of people strolled through an Oxford park in the sunshine to raise money for a cause close to their hearts.**

The annual sponsored Big Step Forward walk is Down's Syndrome Oxford's biggest fundraising event.

This year's event took place at Cutteslowe Park, North Oxford, along the Peace Walk route on Sunday.

The charity supports 150 families, providing information and social opportunities.

Among this year's attractions was face painting, a football skills workshops and a barbecue.

Organiser Sarah Stevenson, 41, of Tweed Crescent, Bicester, has a two-year-old son Jack with the condition.

She said: "It's been quite a difficult couple of years for us but we absolutely love Jack and we wouldn't be without him. The charity supports us and it's also a good network to meet local families who have children with Down's Syndrome. If you have problems you can talk to other people about it."

Mrs Stevenson said: "The weather was fantastic. It's just something people can do as a family and to raise money for a charity that is close to their hearts. Everyone started off altogether but there was a few stragglers at the end. There were lots of red faces when the event finished."

Last year's event in South Park, Oxford, raised £12,000 and was attended by 600 people.

eallen@oxfordmail.co.uk

# Then & now

Test your powers of observation! Can you **match the photo** of our gorgeous young people to their baby photo? Have fun. Answers on page 41.

## guess who?

If you would like your young person to appear in the next Then & Now, please send a current photo and a baby photo to newsletter@dsoxford.org.uk


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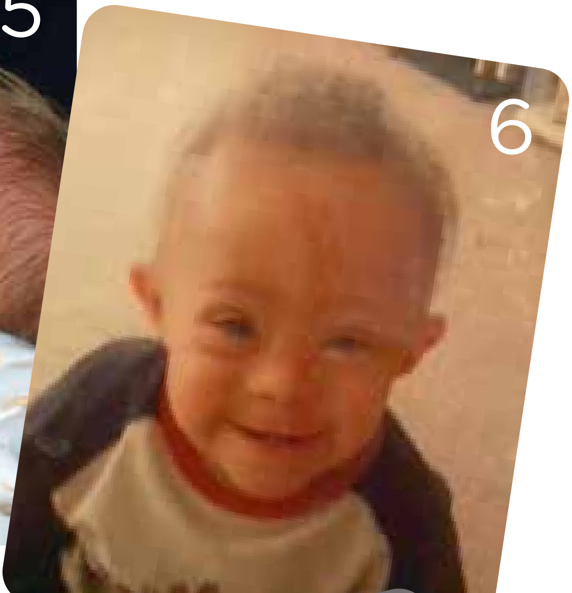
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E


G

# YOUR STORIES

Gabriel has been given a rollator frame from physio and is adjusting to using it! We are, as always, so proud of him managing to take his first couple of steps with the frame. In this picture he is with his great grandad who is 98! Both with their frames.

I (Katelyn Burns) ran the London 10k for DSO in memory of my beautiful friend Samantha.

Samantha had a love for life, music and dancing. She was one of a kind and deeply missed.

ELLIOT'S SHED

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**

Matthew Simmons age 22 has been a DSO member all of his life and they have been a great support to him and the family especially in the early years when they were needed most.

Matthew attended a residential college in Wales called Coleg Elidyr. During his time there he was entered into the Worldskills UK Foundation skills competition and won a place in the final. He was 1 of 8 people chosen from the whole of Wales which was a great achievement.

The final was held in  Manchester last November and everyone had an amazing time. He was there with staff and other students from the college who had also been successful in the other events plus his proud parents of course.

The theme of the competition was street food . Matthew made a vegetable chilli with flat bread and cheese cake. To cut a long story short Matthew won a silver medal which he and the college staff, who had worked very hard to get him there, were very proud.

Matthew has left college now and is living very happily in supported living in Abingdon.

# A huge thank you....

Ben Higgins arranged a fabulous family fun day at the George Hotel in Wallingford to celebrate World Down's Syndrome Day. There was music, dancing, karaoke, dressing up, arts and crafts and raised over £400 for DSO!

Byron Richards raised £800 excluding gift aid for DSO, by participating in a charity boxing match and WON for his sister Poppy in April.

EDG regular Silas was at the school gates in his pyjamas, together with the rest of Kingham Primary School, to raise money for Down's Syndrome Oxford on Friday 24th May.

DSO was the school's chosen charity for Pyjama Day this year after Silas' two eldest siblings presented the charity so persuasively to fellow school councillors, making much of it being our 21st anniversary. The £1 minimum suggested donation from both pupils and teachers in their hoodies and UGG boots raised £225.63 (and 2 euros). Former Stay and Play regular, Barnabas, was at his brother's side in this photo which really captured the spirit of the day.

# ...to everyone

## FUNDRAISING, DONATIONS AND GRANTS

DSO Oxford is extremely grateful to have received the following money from January to June 2024, through fundraising efforts, events, donations and grants.

### FUNDRAISING

Thank you to everyone involved in World Down Syndrome Day fundraising events.
**Our Lady and St Hugh Roman Catholic Church** in Witney held 3 cake sales and raised **£290.**
**St Hugh of Lincoln Nursery** in Witney had an odd sock day and raised **£89.34.**
**Our Lady of Lourdes School** in Witney had an odd sock day and raised **£100**
**Kingham Toddler Group** had an odd sock day and raised **£21**
**Carswell School** had an odd socks day and raised **£61**
**Larkmead School** organised by **Freya Crawford** held an odd socks day and cake sale and Easter egg raffle and raised **£325**
**Aureus School** raised **£245**
**Anna Crow** had cake sale raising **£266.71**
**Absolute Travel and Tours** donated **£250**

A big thank you also goes to:
**Brittany Messer,** who had a car boot sale and raised **£70**
**The Cow Shed, Abingdon,** who collected donations for a sweepstake and raised **£126.87**
**Amy Green,** who completed a 'Couch to 5K' and raised **£200**

### DONATIONS

DSO gives huge thanks for these generous donations:
Thank you to **Henry Hyder-Smith** for your donation of **£200**
Thank you to **Mary Robinson** for your donation of **£200**
Thank you to **Beaverbrooks in Oxford** for their donations of **£1200** for the choir and **£200** for sponsorship of the Walkathon
Thank you to **Christie's** for their donation of **£200**
Thank you to **Judy Robson** who collected donations at her 80th birthday party and raised **£250**
Thank you to **Stanton Ballard** trust for their donation of **£1000**

### JUSTGIVING

The justgiving pages that have been active this year are:
**Byron Richard's** boxing fundraiser - **£800**
**Fin's Fun Run at Blenheim**, mum becca Perkins - **£300**
**Lucas** brownie baking and cake sale at school - **£385**
**Steph Mills** lots of socks - **£430**

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

Answers for the Then & Now Quiz:
1=F Arthur, 2=E Ellie H, 3=C Joseph , 4=G Kayla, 5=B Hannah, 6=A Theo, 7=D Ellie T

# LOTTERY RESULTS

**Message from Andy Fearnside, DSO Lottery organiser.**

March saw the end of the financial year for the lottery, and I am happy to say that we raised **£2478** for DSO all thanks to you!

We would still love some new members so if you know anyone who would like to join, please ask them to email **lottery@dsoxford.org.uk** for more details.

## YOUR CHANCE TO WIN! JOIN THE LOTTERY.

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

To join simply:

1. 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**
3. We'll allocate you a number, email you back to tell you your number, and let you know when you win!

## Congratulations!

**February 2024**
1st Prize - Will Foulds
2nd Prize - Amy Westby
3rd Prize - Marion Simon

**March 2024**
1st Prize - Jo Colehan
2nd Prize - Amber Wing
3rd Prize - Esther Gill

**April 2024**
1st Prize - Mary Robinson
2nd Prize - Sally Dubock
3rd Prize - Jenny Dilnot

**May 2024**
1st Prize - Sally Vinter
2nd Prize - Jo Crawford
3rd Prize - Jenny Dilnot

**June 2024**
1st prize - Ellie Walpole
2nd prize - Marion Simon
3rd prize - Sam Martin

**July 2024**
1st prize - Marion Simon
2nd prize - Kay Haggie
3rd prize - Shaun Goddard

**August 2024**
1st prize - Sally Dubock
2nd prize - Jenny Dilnot
3rd prize - Jos Smith

**September 2024**
1st prize - Jenny Dilnot
2nd prize - Ellie Walpole
3rd prize - Esther Gill

# 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:**

Pre-School Club
**Andria Hutchings**
andria@dsoxford.org.uk

10-15 Club
**Sam Martin-Morrissey**
sam@dsoxford.org.uk

Primary Club
**Natalie Row**
natalie@dsoxford.org.uk

16-21 Club
**Elsa Gill**
elsa@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

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

## GIFT AID DECLARATION

Please tick the 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 at least equal to the tax DSO reclaims on my donation(s).

☐ I am not a UK taxpayer.

## YOUR DETAILS

We will not share your information with any other organisation.

Your name

Your address

Postcode

Please return this form to:

**Down's Syndrome Oxford** (NOT your bank)
**c/o Treasurer, 33 Saffron Crescent,**
**Carterton, OX18 1LD**

# CONTACTS

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chair@dsoxford.org.uk

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**21+ CLUB CO-ORDINATOR**
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**SPEECH & LANGUAGE THERAPIST**
Colette Lloyd
(01993 883707)

**PDG LEADER**
Marion Simon
pdgs@dsoxford.org.uk

**DLA/PIP APPLICATION SUPPORT**
Rowena Pierce
(07512 210851)
SeniorMedicalAdvisor@dsoxford.org.uk

✉ General enquiries email address:
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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 7 February 2025.**

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

down's syndrome oxford

Registered charity number: 1103850