JULY 2023

down's syndrome oxford NEWSLETTER

Recognising our talents

Inclusivity at the forefront

Celebrating our abilities

Guest edited by Chloe and Ellie

Welcome to the July 2023 edition of our DSO newsletter

FROM THE CHAIR

Welcome to our first guest edited issue. Many congratulations to Ellie Holgate and Chloe Sanderson, you have both worked so well together and done an amazing job. If anybody would like to get involved in a future issue of the newsletter, do get in touch with Joy Holgate. Do also take a moment to look at Ellie's AS Level art portfolio on page 30!

It's been another fun filled few months, with many things happening across our social groups. It's hard to believe that the second Tristar Awards evening has already come around. The Tristars continue to go from strength to strength.

DSO Choir had lots of fun with its Disney themed week (Page 17) and a very high standard has been set on the costume front for the next themed day. @DSOChoir also went live on Instagram, so do take a look and share their fantastic reels.

World Downs Syndrome Day saw many of us getting those odd socks out and this year some families also took on some great 21 Challenges (page 7).

On behalf of the Trustees, thank you to everybody who joined our AGM recently. It was great to see so many faces both on screen and in the room. I also wanted to thank Sarah Fonge, who stood down as our Treasurer after 10 years in the role. Thank you for all your hard work Sarah and for continuing to support a smooth transition behind the scenes. Your commitment is very much appreciated by us all.

As we head towards the summer, I look forward to seeing many of you at the Summer Party at Thomley on Saturday 16th July 2023.

Wishing you all an enjoyable summer.

Jos Smith, Chair

IN THIS EDITION

Our Guest Editors

I like being a guest editor because I chose the photos on the cover. Ellie Holgate came to my house to work on the newsletter. We had chocolate cake. We played a game to decide the order of the feature articles.

Chloe Sanderson

It is amazing to be guest editor because it is the best opportunity from Down's syndrome. I helped to chose the cover of Ellie making all the Easter goodies. We wrote a title for our newsletter. I did it together with Chloe.

Ellie Holgate.

CANDLES FOR UKRAINE

Ukrainians of all ages and walks of life have come together to create “trench candles” for soldiers on the front line.

Russian forces have increasingly targeted Ukraine’s infrastructure including power stations and the electricity grid, causing regular blackouts and disrupting heating and water supplies.

The process of making the candles is fairly simple. Cardboard sheets are cut up into lines, then twisted and fitted inside tin cans, the cans are then filled with a mixture of wax and paraffin.

These makeshift candles can be used to warm soldiers up, dry out their dugouts and clothes or even to cook food.

Sofia and Yuliana, our Ukranian members, have been busy making trench candles to send home to help their country’s efforts. It has been our privilege to help them collect the empty cans needed to make these vital goods.

More than ten thousand trench candles have already been delivered to the Armed Forces of Ukraine.

Choir Instagram

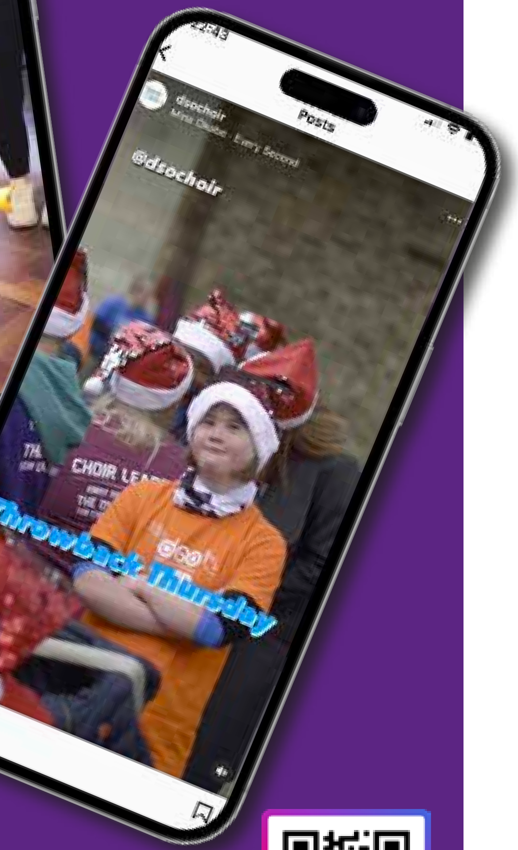
Back in January, the BBC approached our choir and asked us to make an application to perform at the King's Coronation Concert. Sadly, after many phone calls and zooms and lots of questions about Makaton sign language, we weren't what they were looking for and weren't chosen.

During the process, they asked us if we could share video footage with them. We decided to go one step further and created a choir Instagram account, the idea being that not only could the BBC see our fabulously talented youngsters but we could also promote the choir and DSO both locally and far and wide!

We've had a fantastic response since starting the account and have followers from all around the world, the reel we posted on WDSD was viewed over 21,000 times.

If you use Instagram, **come and find us strutting our stuff @dsochoir and please help us to climb the IG algorithm by following and liking our reels.**

By Elsa Gill



FOLLOW US ON

MAKING MUSIC

By Samantha Martin-Morrissey

On Saturday 18th March we had a music session at Abingdon Music Centre. Francis, the director of AMC ran the session with Gillian and 6 families with children ranging in age from 7 to 15. The children and adults had fun listening to music and thinking about how the music made us feel: Happy, angry, excited/silly or sad/tired. We got the chance to play different percussion instruments and some lovely big xylophones. We practised making music that expressed these different emotions and played along to a story that Francis told. We had a lovely musical afternoon.

An Irish Goodbye

Collated by Joy Weideman

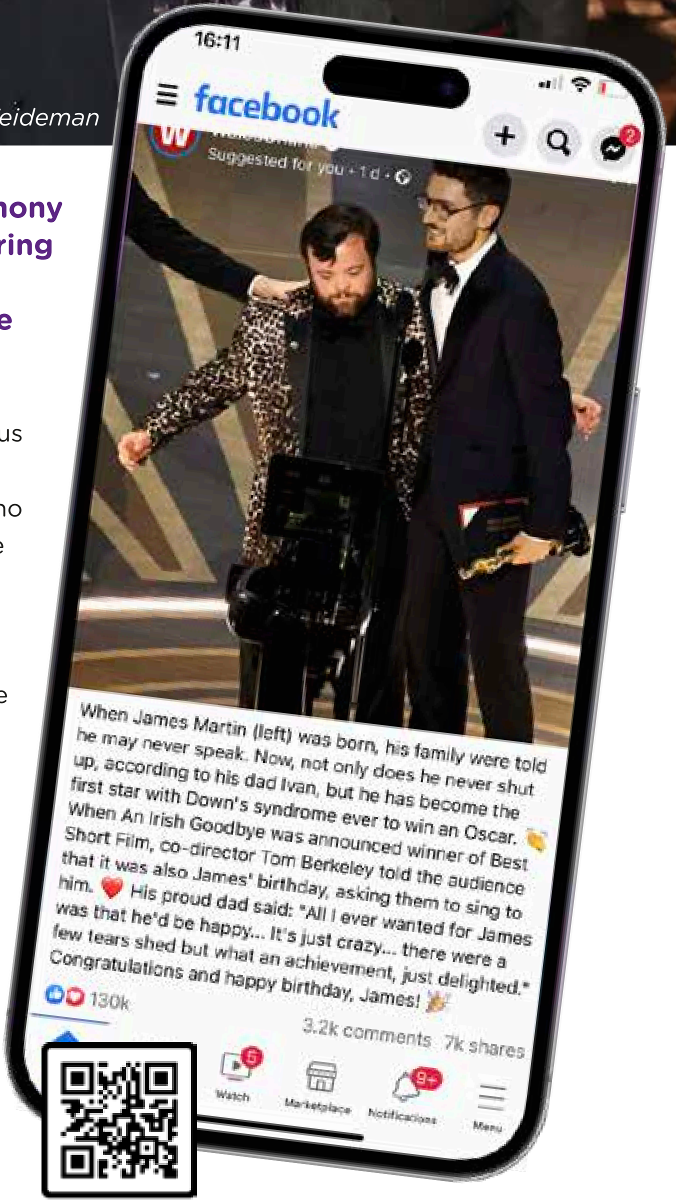
We witnessed a triumph at this year's Oscars ceremony when, for the first time, a live action short film starring an actor with Down's syndrome got the golden gong. The film also won a BAFTA award in the same category this year.

The film's story follows two estranged brothers Turlough (Seamus O'Hara) and Lorcan (James Martin) reunited after the untimely death of their mother. Lorcan, a robust and dedicated farmer who has Down's syndrome, dreams of continuing to work the land he grew up on, but Turlough wants to send him to live with their aunt on the other side of Ireland. When the brothers discover an unfulfilled bucket list belonging to their late mother, Lorcan senses an opportunity: he'll only agree to leave the farm once he and Turlough have themselves completed every single wish on their mother's list...all one-hundred of them.

A touching, gently humorous film, it is a testament to the talent of the whole team and a ground-breaking achievement for James.

James celebrated his 31st birthday on the night of the Oscars ceremony and received a star-studded renditions of Happy Birthday while receiving the award on stage.

Upon returning to a hero's welcome in Belfast, James said: "To win an Oscar and a BAFTA is a dream come true. I work in Starbucks and am an ambassador for MENCAP so to win two awards means something in the disability family. I think that is just amazing."



When James Martin (left) was born, his family were told he may never speak. Now, not only does he never shut up, according to his dad Ivan, but he has become the first star with Down's syndrome ever to win an Oscar. When An Irish Goodbye was announced winner of Best Short Film, co-director Tom Berkeley told the audience that it was also James' birthday, asking them to sing to him. ❤️ His proud dad said: "All I ever wanted for James was that he'd be happy... It's just crazy... there were a few tears shed but what an achievement, just delighted." Congratulations and happy birthday, James!

SCAN ME

to watch an interview with James

WDSD 21 CHALLENGE

World Down Syndrome Day was again the inspiration for some of our enterprising members to raise very welcome funds for DSO, as well as having some fun along the way. Here are some extracts from their Just Giving pages, showcasing what they did.

Rosie has just started taking a few independent steps, we thought in order to celebrate World Down Syndrome Day on 21st March, that we would set Rosie a Challenge21 this year to raise more funds for our local charity, Down's Syndrome Oxford.

Rosie's current Personal best is 7, so we think by end March she might get to 21! (But we don't mind if she doesn't, we go at Rosie's pace).

Down's Syndrome Oxford have been a fantastic support to us since Rosie has been born, and we attend their Early development groups on a Wednesday. We would love to raise some money to give back to the charity and show our support.

Rosie raised £997.00. Thank you Rosie!

It's that time of year where we celebrate World Down Syndrome Day on 21st March - that means IT'S BROWNIE TIME!

Lucas will be baking brownies for anyone who wants them for a donation to DSO - who are a fab local charity that have helped Lucas so much.

Lucas raised £370.00. Thank you Lucas!

Hi I'm Archie, I'm 12, I go to John Mason secondary, I love it, it's going to make me really smart, I have loads of nice, kind and caring friends, I love Liverpool, Firmino is my favourite, Love watching WWE, Dugley boys are the best, KSI is my favourite you tuber and singer, I enjoy playing Roblox & Minecraft whiles FaceTiming my friends, I also like Swimming, and listening to music and going on the treadmill,

I'm wanting to raise some money to celebrate WDSD 2023, on the 21st of March I'm going to go on my treadmill for 21 minutes whiles listening to KSI, to show how proud I am of having my Extra 21 chromosome,

PLEASE HELP ME raise a bit of money for Down's Syndrome Oxford, a local charity that helps children like me in Oxfordshire.

Archie & Amelia raised £360.00. Thank you both!

DSO AGM 2023

Thank you to all who came to our DSO AGM on 26 June. The hybrid in-person and online meeting was very well attended, with those in the room enjoying pre-meeting refreshments and chats afterwards.

Membership

DSO membership has grown in the last year to 462 members – up 8.2% from last year. Of these 392 are parents, carers or adults with DS, 28 are family or friends, and 42 are professionals or volunteers.
During the year DSO has been able to provide support across all our age groups through our learning and support programmes and our social activities.

Maths for Life Programme

Maths for Life has been successfully running for its second year. It currently has 30 active students and is also in 13 schools across the county. Other schools are now beginning to come on board organically, and a pilot will be run in 50 schools in Oxfordshire from September this year. TAs are reporting that the programme is helping empower them through its innovative structure.

External Engagement

The DSO management team continue to have open and active dialogue with the SEN department at OCC, and our team has termly updates with the OCC SENSS team.

During this year DSO has also established a closer relationship with the Oxford Parent Carers Forum. To date we have collaborated on three key areas of mutual interest. These areas are 1. transition from primary to secondary school – which has proved an area of particular concern for some of our members this year,
2. participation in the OUH's consultation process to develop a new Sensory Therapy programme.
3. representation on the OCC/OUH joint Children's Therapy System Board.

DLA Support

DLA support, which we began in 2018, has continued, with Rowena Pearce leading support remotely from Cornwall. She has been able to support 17 families this year with outcomes achieved at the expected level or above. To date, 62 families have been supported by this programme.

Matters Arising

It was noted that we need to find a new Secretary to replace Roberta in her role. We also still need more people to help us with applying for grants and identifying funding sources. Please let us know if you can help with these roles.

This year, due to the disruption in the OCC SEND team, DSO have had to commit more resources than usual to help our members with tactical support, particularly in the area of Year 6/7 transitioning.

Secretary's Report

Our Secretary, Roberta, updated us to let us know all our Charity Commission records have been kept up to date and notes from our regular All Members Meetings are available on request. Roberta is looking for a volunteer to work together with her for a period with the view to take on the role of Secretary in the future. Please contact her if you are interested in helping.

Treasurer's Report

Our new Treasurer, Rachel, gave us an update of funds and expenditure. A percentage breakdown of the monies spent this year can be seen in the pie chart in this article. Our expected expenditure this year is £57K; it was noted that DSO's annual spend is increasing and will require more monies to support its baseline activities.

On behalf of all members, Jos thanked Sarah Fonge (in absentee) and acknowledged her 10 years of selfless service to DSO as Treasurer. We are all extremely grateful for the thoroughness and commitment with which Sarah has executed this role. As Sarah steps down at this AGM and hands the baton to Rachel Campling, Sarah is kindly continuing to provide support during a period of transition.

Trustees Report

Our Trustee representative, Katherine, reported on the outcome of the trustees meetings this year. They have focused on:

- the increasing demands on DSO, with many more activities being implemented, but without sadly a corresponding increase in the numbers of people making these things happen.
- the need to look for larger pots of funding which will require time and lot of work. In the meantime, DSO has to rely on fundraising done by ourselves.
- the importance of minimising burnout of our volunteers. DSO has too much reliance on a small number of people who volunteer their time and expertise.
- the need to make sure structures are in place to secure the ongoing health of DSO without being too reliant on certain individuals.
- discussing options for new operational models for DSO, to ensure it can continue to offer all its activities and services to all its members. The trustees have spoken with other groups across the country to see what we can learn from them and they have created a Strategy Consultation Group. The trustees have also disseminated a questionnaire to all members seeking views on what the priorities are for them. So far, need has been identified for holiday clubs, a venue for families/carers and people with DS, respite care and a swimming club. More news to come once the questionnaire has been analysed in detail.
- interviewing an new external member to join the Trustees.

Group Updates

Stay and Play: is very well attended and over 20 families have used the facility this year. Afternoon online session will no longer being offered post COVID. Monthly visits by our NHS DS nurse continue.

Primary development group: Cherie Williams now runs these sessions and visits the children in their school setting one-to-one. Cherie provides holistic support, having previously worked extensively in SEN. She is helping with SEN and SaLT reports and supports TAs in delivering outcomes for their students. She has seen 22 out of 28 children who are on our books this year. DSO has also started a pilot programme supporting 3 children who are transitioning into secondary school.

Pre-school Clubs: have run a number of activities to bring families and children together based on fun and play. They have also been a great way for extended families to get to know each other.

Primary Club: has been very active with lots of great outings for everyone; an Inflatable party, the Fat Squirrel, the Story Museum and Thomley Hall.

10+ Club: has enjoyed a number of social and educational outings like the Torchlight Maze, Partyman, Laser Kombat and a session Abingdon Music Centre.

16+ Group: has a very active WhatsApp group for its 51 members, who share lots of information vital to this age group, like 16+ benefits, financial assessment for social care, PA/Carer recruitment, college setting experiences, health issues, housing needs and work/training experience. The group has also enjoyed many social activities like the Halloween Disco, a Christmas meal, a Karaoke night, Easter Crafts and an educational visit to Harcourt Arboretum.

DSO Choir: continues to be very popular. 39 people have attended this year with most being regular. Choir has also raised significant funds, with the Christmas performance in Bonn Square raising £2000.

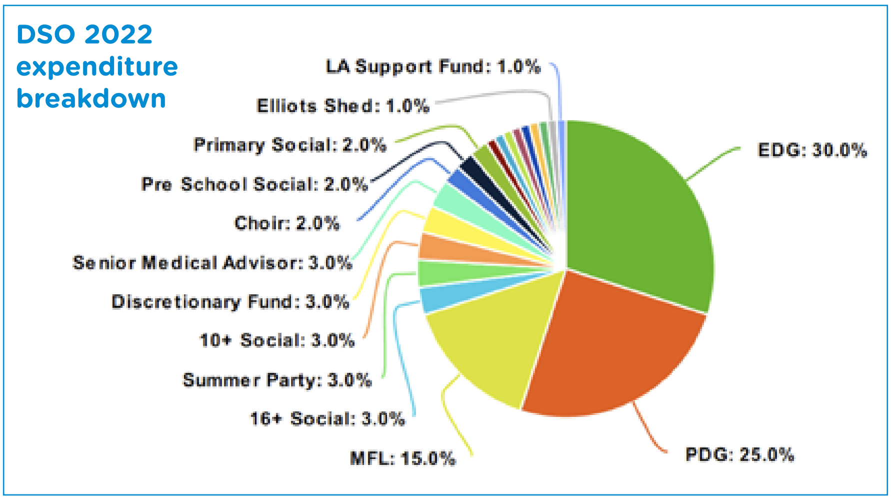
TriStars Football Club: is very well attended, with 21 regular players. The club is now looking for new members and is planning a friendly match against another team. The club had a fabulous presentation awards evening in May, and the players are forming a wonderful camaraderie and great friendships.

Elliot's Shed

Kat, who manages Elliot's Shed and works in social equity, has recently garnered pro-bono work from a company who will help her build an Elliot's Shed library app and website to make it easier for everyone to access what the shed has to offer. Kat has also recently had two electric bikes donated and notes that regular bikes have been very popular lately. Tag-along bikes are available as well as high chairs, toilet training chairs, and a small wheel chair that's handy for long days out. There are toys available as well as step stools for activities like cooking. Do contact Kat with suggestions about what would be most useful for you.

Formal Business

All Trustees were re-elected. Sarah Fonge is standing down as Treasurer and Rachel Campling was elected to replace her. Jos Smith was re-elected as Chair and Roberta Celeste as Secretary.


DSO 2022 expenditure breakdown

This is ME

Collated by Joy Weideman

George Webster, who you might know from his work as a presenter on CBeebies has recently published a book. It's a children's picture book: an autobiography called *This Is Me.*

George reads from his book.. "I have an extra ingredient, a sparkling of magic inside. Some people, they say that I'm special, but that's not what I think … You see, we're made of different ingredients that help us shine like a star.

My glow is what makes me who I am, and yours will make you who you are."

George says. "Everyone has their own talents, uniqueness, strengths and weaknesses. We can all dream big, no matter who we are."

"When I was a kid, there was no one on TV, in films, even in books, with Down's syndrome," George says. "At that time, they thought people like me shouldn't go to mainstream school."

George went to mainstream school: "Loved it, it was really fun." But it wasn't always easy.

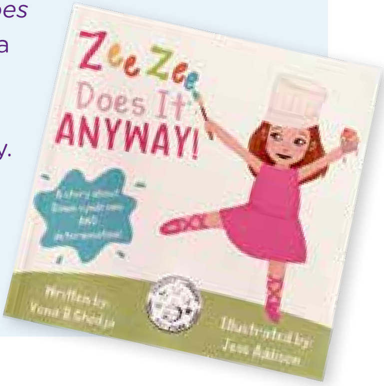
The book is about explaining and celebrating uniqueness, being proud of who we are. "A lot of people are scared, they don't need to be, I want them to understand," says George. And it's about the importance of inclusion and representation.

He talks about "seeing me for me" and not liking it when "people make assumptions about what I can and can't do." e

This Is Me by George Webster, was developed in partnership with Claire Taylor and illustrated by Tim Budgen.

SCAN ME
to watch George dancing on Strictly

This Is Me by George Webster as well as *ZeeZee Does It Anyway* by Dr Vona B Shodja are now available to borrow from the DSO Library.



16+ Club

Karaoke Night

A great time was had at our first karaoke night, everyone joined in and gave encouragement to those that were singing.

We had a mixture of current songs, old choir favourites group songs that had backing dancers and finished off with a good old sing along that of course had to include the parents. It's been the most requested activity to do again so watch this space!

By Sonia Forrester

Tristars Football Awards Evening

By Lucy Sanderson

In May, the Oxford United TriStars football team came together for their second presentation evening, an event to celebrate all the players and coaches who make up this wonderful club. Once again it was a fantastic night full of dancing, friendship and camaraderie.

Over 60 people attended the evening event that started off with a buffet dinner, followed by the awards presentation, and finished with a disco. Head Coach Garry presented each player with a trophy and personalised certificate to celebrate their strengths and achievements. We also thanked all the coaches who do a fantastic job, volunteering each week to support and train the players.

This group of players is really starting to bond and it's lovely to see the players of all ages forming great friendships. They had a brilliant time dancing together, showing off their funky moves, and all joining together to do the Conga!

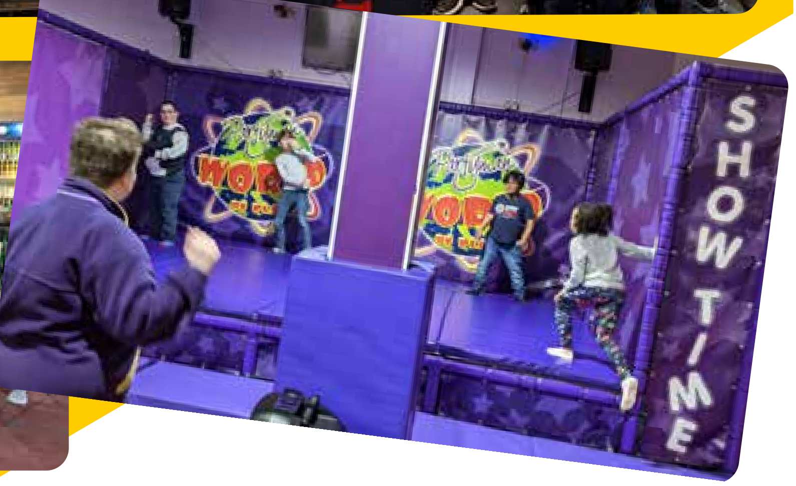
I'm a demon in defence

10+ GROUP

FOCUS ON FUN!

We had a great time at Partyman World of Play and Laser Kombat. At Laser Kombat they left the lights on in the entrance so part of it was dark and part was light so all the young people loved it and some of us parents did too. It was a great workout and I think we all slept really well that night.

By Samantha Martin-Morrissey



SIM-SATIONAL!

Encouraging my brother Sim, who has Down's syndrome and autism, from anything screen-based is no mean feat. However, a recent realisation that he could make a little bit of pocket money while enjoying an activity has led to a new mini business venture.

After attending a recent block-printing course, it occurred to mum that Sim would be capable of creating greetings cards in a similar style. Mum asked Sim to help design some backgrounds for cards. It was wonderful to see Sim so proud of his achievements, and he loved the idea of selling these cards to family and friends. From this Buttercorn Press was born! A strange name you might think, but Sim calls mum Buttercorn. His reason is that he describes mum as a cross between a butterfly and a unicorn.

Now, most evenings our kitchen table becomes Sim and mum's work station. They get busy working on orders and embracing new ideas. Sim's favourite activities are using the hammer and punch tools to set eyelets and trying not to burn mum's fingers with the heat gun! He particularly enjoyed recording his recent interview for the Buttercorn Press Instagram account!

Since the start of May, Sim's cards have been selling in our village stores. They sell around 12 of his cards each week!

To follow him on Instagram scan this QR code.

@BUTTERCORNPRESS

By Micah Lings

Choir Disney Week

In May, Annie suggested a Disney themed choir session to coincide with the release of the new The Little Mermaid film. We already have several Disney songs in our back catalogue, including 'I just can't wait to be King' from The Lion King. Annie also quickly taught us 'Let it go' from Frozen and 'Part of your world' from The Little Mermaid. The Disney theme was very popular and we'll definitely repeat it, although perhaps next time in the Winter when the weather might better suit some of the Disney costumes!

By Elsa Gill

My brother, Tahsin

By Tahmid

Good morning, all. Today is World Down's Syndrome Day, an international celebration of the condition, aiming also at increasing awareness and fundraising for supporting children and young adults with Down's syndrome as well as their families. Today I'll be sharing some thoughts on disability and ideas of success, drawing on personal experiences of my brother, who has Down's syndrome.

The day is selected to be the 21st day of the third month March to reflect chromosome 21's trisomy, or triplication that is the genetic cause of the condition. Occurring naturally, 1 in 1000 babies in the UK are born with the condition. In general, the condition causes varying degrees of physical and intellectual disabilities. My brother, Tahsin, was born in 2012 with Down's syndrome and was assessed to be on the autism spectrum in late in 2020. He's charming, a brilliant drummer, always curious and caring towards others. When he was born, my parents were terrified. They had little to no knowledge of the condition, and few relatives or friends to ask for support after immigrating here, and none with experience with Down's. My brother spent a week in a neonatal intensive care unit and we waited anxiously for reports on his heart condition. He eventually stabilised, his doctors grew confident with his organ function, and my mother could hold her newborn son for the first time.

I'd like to share some of the challenges he faces daily. He has low muscle tone, affecting his ability to communicate, coordinate his limbs and utilise his fine motor skills effectively. He has glue ear, a fluctuating hearing impairment that is lessened by his hearing aids. He's registered as partially blind and has been diagnosed with nystagmus, an involuntary, repetitive jitter of the eyes. His memory isn't always 100% and it takes him a little longer to learn some things. He also struggles to project and think about events in the future.

Intellectual and physical disabilities like the ones Tahsin has, are not insurmountable and it's important to keep things in perspective. Our role as peers of those with Down's is not to cure or try to fix them; but instead accept their differences and provide the social and emotional tools they need to work through the challenges set by the polarising and unforgiving world around us.

Realising this takes time to set in. And the reason it takes time for parents, family, friends of those with Down's is that they are scared and terrified of how the world will treat their loved ones.

> *Our role as peers of those with Down's is not to cure or try to fix them; but instead accept their differences and provide the social and emotional tools they need to work through the challenges set by the polarising and unforgiving world around us.*

For Tahsin, his sensory inputs are chaotic. If he were sat in the front row now, he'd be hearing the traffic outside as loud as my voice, not to mention the echoes of the speakers. He would be trying his hardest to focus on my face, anxious that he can't quite see me behind the lectern, anxious that he can't quite tell how I'm feeling. He'd translate this anxiety and frustration into perhaps making his own noise to organise the sounds in his head, or, because he knows this is an assembly and he should be quiet, he'd pick at the skin on his fingers to distract himself. He would make repetitive movements of his limbs, to get a sense of regularity, something predictable. In other scenarios, where he's frightened and distressed, he finds it difficult to communicate: he can't find the peace to control his voice. Thinking about these challenges, how can one not shout and scream?

I remember watching members of the public stare at my brother misbehaving in a supermarket and my mother desperately attempts to calm him down. And as I grew and I spent more and more time with him independently, I felt those stares and that judgement myself too. My parents outside of the house lived in that shame. That they could not parent their son, and their son's negative behaviour was the proof. People said they needed to be harsher, stricter, but that was the last thing he needed. There was little attempt from people to try and understand.

When he runs up to strangers in the supermarket and gets super close and says hello, that's him wanting to understand how that person is feeling, understand why they're standing alone, looking down at the canned tomatoes with an expressionless face. We can put it together that they're simply shopping and probably doing okay, but for Tahsin he wants to make sure that they are happy, that they are smiling. When he meets new children his age, he'll spend ages looking at their face, trying his hardest to calm the incessant shaking and focus on their facial features, their voice, so when Tahsin sees them again he can say hello and ask them how they are. In conversation, Tahsin will go 'Why's this', 'Why's that' that can get quite repetitive. For him, he's found this magic word that he can attach to anything and continue conversation. He loves talking to people but finds it hard to organise the ideas in his head. These are just a few examples of how Tahsin isn't always naturally compliant. But when his behaviour is met with eye rolls and shaking heads, that judgement? It's only going to make Tahsin, and my parents feel more ashamed, rejected, unworthy. And what's worse is that he's sometimes still too young to be aware of this all. He's only begun communicating his experiences as he builds his conversational skills. When Tahsin struggles, he needs love and kindness to help him through his challenges, not strict, harsh treatment.

Before taking my brother anywhere my parents would worry about how hosts would react, if they would be supportive, if they would be caring and accepting of Tahsin's differences. People saw him as a failure. People still do. People see dependency, see an inability to do things that they can do easily and feel sorry and imagine that it must be miserable all the time for the disabled. They call his condition a curse and shut down his prospects because they don't align with their definition of success. I've been guilty of things like this. When I was younger, I made a Google search. Into a search bar I typed 'How can I fix my brother', 'How can I cure him of his Down's' and hit enter. In that moment I had failed him, I had given up on him. I had failed to believe that he could be happy, that he could have success in his life. I regret that Google search. I was so wrong. We have never stepped in his shoes. We have never experienced what he has experienced and never can from a non-disabled perspective. We don't have a right to project our non-disabled ideas of success.

The idea of success is often one defined by metrics. Your marks in exams, performances on the sports field or how major your part in the school play is. We use these in everyday life to judge and form opinions. And not only in school life. As we leave MCS and go on to be employees and employers, hold shares in companies, where statistics like income, net worth, and numbers define and value our livelihoods, they'll provide more markers of success. And justifiably so: they are easy to measure, easy to compare, easy to put someone down not only without much argument but also without much appreciation of personal context, hardships, and journey. Your effects on the people are hard to measure and describing them is inherently subjective. But the fact we can't quantify them doesn't make them irrelevant. It doesn't invalidate them in our search to define success. I think at a highly selective school, where academic success, numbers are so much at the forefront of decision making that we can grow ignorant of context. We can begin to dangerously think of success as superiority.

For Tahsin, his context is and will always be in part his disability. He may not grow and become a leading academic, a world-class musician, win a Nobel Prize or become an influential politician: he won't be 'successful' in society's definition of the word. But when it comes to making his family, his close friends, and the people around him smile, brightening all our lives with his perseverance, his success is inestimable. Having Tahsin as a brother is the single greatest blessing I have ever and will ever have. He's taught me so much and has made me the person I am today. After 3 and a half years of battling with the council for a place at a school for special needs children, culminating in a court case, they settled a fortnight ago and offered him a place for September. We hope that he'll feel comfortable and more at home there.

I'll end with this. Remember that success is not superiority. Success is something to share. Make your success hard to measure.

Happy World Down's Syndrome Day.

Addressed to the pupils of Magdalen College School, Oxford.

odd socks for WDSD

Many of you joined our friends from all over the world in celebrating World Down's Syndrome Day by wearing odd socks for the day. What fun!

New inclusive Barbie with DS

Barbie has released the first ever doll with Down syndrome, created to allow our children to see themselves in their toys and reflect the world around them. The Barbie doll with Down syndrome is designed to inspire all children to tell more inclusive stories through play.

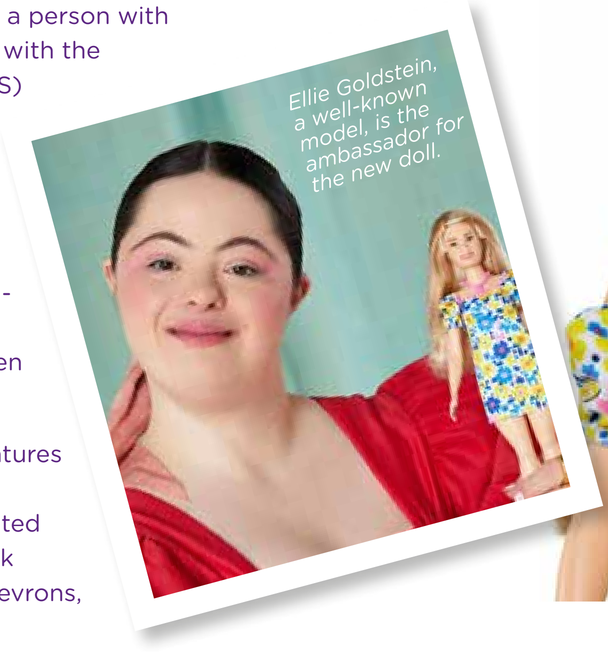
“As the most diverse doll line on the market, Barbie plays an important role in a child’s early experiences, and we are dedicated to doing our part to counter social stigma through play,” said Lisa McKnight, Executive Vice President and Global Head of Barbie & Dolls, Mattel. “Our goal is to enable all children to see themselves in Barbie, while also encouraging children to play with dolls who do not look like themselves.”

To ensure the doll accurately represents a person with Down syndrome, Barbie worked closely with the National Down Syndrome Society (NDSS) in America. NDSS’s guidance and real-world experiences informed the design process from start to finish. Clothed in a floral dress, you can see that this Barbie is shorter in stature, has a rounder face, smaller ears and almond-shaped eyes. The doll’s palms even include a single line, a characteristic often associated with DS.

The doll’s puff-sleeved dress pattern features butterflies and yellow and blue colours, symbols and colours sometimes associated with DS awareness. The doll wears a pink pendant necklace with three upward chevrons, representing the three copies of the 21st chromosome as a symbol that unites the Down syndrome community, meant to represent “the lucky few” who have someone with DS in their life.

“It was an honour working with Barbie on the Barbie doll with Down syndrome,” said Kandi Pickard, NDSS President and CEO. “This means so much for our community, who for the first time, can play with a Barbie doll that looks like them. This Barbie serves as a reminder that we should never underestimate the power of representation. It is a huge step forward for inclusion and a moment that we are celebrating.”

SCAN ME
to watch
the video



Ellie Goldstein, a well-known model, is the ambassador for the new doll.

From little acorns...

By Sonia Forrester

The 16+ group were treated to a VIP visit to Harcourt Arboretum.

We had two super guides who were both knowledgeable and keen to make sure we had a great relaxing time.

We started with a picnic and catch up with our friends followed by a tour and finished with bug collecting near the wild meadow.

The weather and company were fabulous so much so we hope to go back in the summer holidays.

And, who knows, sparking a love of nature may nurture the future environmentalist or gardener in us.

PRE-SCHOOL & PRIMARY GROUPS

FUN AT THOMLEY

Thomley

In April our Primary and Preschool groups enjoyed a fabulous fun-filled day at DSO favourite, Thomley. Thomley is a wonderful place for people of all abilities and boasts a huge outdoor play area, accessible play equipment, a large sand pit, bikes and trikes, play rooms full of toys, a music room, sensory rooms and a soft play area. We look forward to returning for the summer party!

By Emily Higgins

Harley hits the road

By Kay

Harley aged 7 has had an exciting week. On Sunday 4 June he did a 'Smiles' go karting session in Aylesbury in a dual control car.

It was a free session advertised in the Pauline McKinnon monthly newsletter. Harley was excited and scared in equal measure I think! Here are a couple of photos of him; one of him in the car and one high-fiving his little sister Esme (3) beforehand.

Then, on June 5 he featured on the One Show in a piece about adoption. I adopted Harley when he was 9 months old. Scan the QR code to see the show (first item in the episode):

SCAN ME

Cook & Chat

JOIN US

Are you over 14? Have you heard about 'Around the World with Cook + Chat'?

Below is a list of the dates for the rest of this year!

23rd September
4th November
2nd December

Ellie Walpole is looking for a few more participants and a few more 'buddies' too.

Cook + Chat meet at Thomley on the edge of Worminghall. We have exclusive use of the cafe area to have a quick 'Show & Tell' about a country! Then we chat about a recipe, prepare a few simple ingredients and cook together. Most of the time the participants are supported by similarly aged youth (who we call the buddies) so that the parents who remain on site can chat themselves and sometimes get a chance to sample what we have made.

Strictly speaking this is not officially a DSO event as Ellie started this to capture friends from her son T's school in Bucks and to tether in some of his secondary aged friends from Oxfordshire too. Over the years it has morphed and changed format a couple of times as the youth who have been attending have got older and more able and the buddies have gone off to University and jobs!

Please get in touch with Ellie Walpole directly if you would like to try it out. elliewalpole@hotmail.co.uk

16+ GROUP

Easter Crafts

A great time was had at the Easter craft morning. We spent the morning making flower table decorations, Easter cards and Easter cake decorating while we listened to music and chatted to our friends. Who knew we had such an eye for detail!

By Sonia Forrester


STRANGER THINGS

YOUR STORIES

Budding artist **Ellie** has just submitted her portfolio for her AS Level art assessment. She has worked closely with her teachers and been very busy creating this impressive range of paintings, drawings and texts. Her colour judgement and creative interpretation are her strengths. Amazing work, Ellie!

Bill has started Rugby Tots on a Saturday morning. With a bit of encouragement and support from mum he is doing well, joining in with the activities. Hopefully these sessions will help him to develop his ball skills as well as help with coordination, turn taking and listening. It's great fun too!

Sonia has it in the bag!

Sonia Forrester initiated a huge clothes collection for Clear Out May. She collected 457 kg of clothes in 80+ bags and raised £228.50 for DSO.

She collected from DSO choir, TriStars Football and Stay and Play for two weeks before the collection day and also had families dropping off donations direct to her house.

Thank you **Sonia** for your amazing work encouraging all of us to have a Spring clear out and doing invaluable fundraising for DSO at the same time. A big Win Win.

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 high chairs**
- **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**

A huge thank you!

We were thrilled and incredibly grateful when Jemma Hutchings contacted us with this message.

My parents transferred £490.98 to DSO's bank account last night. This is because I was raising money for you on World Down Syndrome Day. I am Silas Hutchings's sister and therefore wanted to raise money for a Down Syndrome charity. I think you are an excellent charity to support because of all the support you give to people with Down Syndrome.

I thought you might like to know how I did so. I wrote to my head teacher asking if I could encourage everyone at my school to wear odd socks and bring in £1, and also hold a bake sale in the school playground on World Down Syndrome Day. He said yes! So yesterday lots and lots of people at school wore odd socks and brought in £1, as well as many separate donations from people who knew me. Odd socks day at my school, Kingham Primary, raised £132.80 and the bake sale and other donations at school totalled around £250. Including church, toddler group and family donations, we raised £490.98 in total. Anyone who wanted to donate but didn't have any cash is going to send you their money electronically.

I appreciate your help and support so much. I have even been to one of Silas's early development groups with Colette (on a teacher strike day) and saw how much he and the other babies enjoyed it – Collette was amazing.

A BIG THANK YOU from everyone at DSO!

FUNDRAISING DONATIONS AND GRANTS

DSO Oxford is extremely grateful to have received the following money from January to June 2023, through fundraising efforts, events, donations and grants.

FUNDRAISING

Thank you to all our 21 Challenge page participants. See details of their inspirational challenges on the 21 Challenge page in this issue.

Rosie's 21 Step Challenge raised **£997.00**

Archie & Amelia's 21 Challenge raised **£360.00**

Lucas's Famous Brownies raised **£370.00**

Jemima Hutchings raised over **£500.00** at her school for WDSD. See details of her amazing efforts above.

DONATIONS

Donation in memory of the late **Patricia Hill** Mother of Charlotte Blois, Grandmother of Ollie Blois **£75.00**

Donation in memory of the late **Stella Beckett** Mother of Craig Beckett, Grandmother of Jamie Beckett **£170.00**

Thank you to the **SSP Foundation** Employee charity nomination through **Shelley Randall** Mother of Lucas Randall. **£500.00**

Thank you to **Caroline Ford** for the sales of WDSD badges **£26.00**

Brittany Messer raised over **£200.00** through her ongoing selling at the Carterton Car Boot Sale.

Thank you to **Stanton Ballard Charitable Trust** for their donation of **£1000.00**

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.

8 July

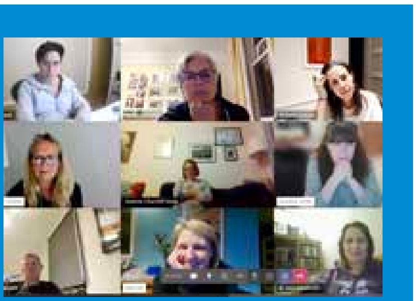
Choir at Thomley

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 on WhatsApp.



17 July

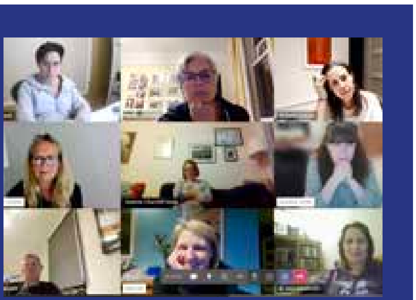
Members Group Meeting

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.

10 Sept

Farmer Gow's Outing

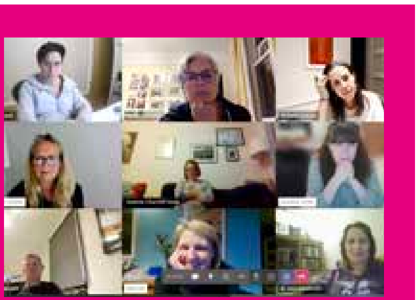
The preschool and primary groups are having a joint visit to Farmer Gow's Activity Farm. Contact Emily Higgins for details.



19 Sept

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.



20 Nov

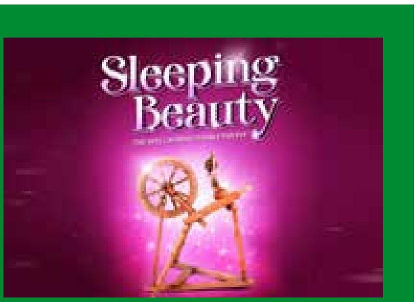
Members Group Meeting

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

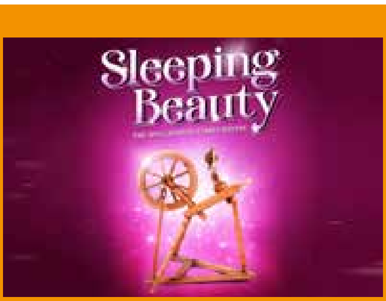
Save the date for our unmissable Xmas Party, 2 -5pm Exeter Hall, Kidlington with entertainment from DJ Aaron Williams.



24 Dec

Panto in Reading

Tickets will be popular for the Sleeping Beauty Panto starring Justin Fletcher. More details later this year.



3 Jan

Relaxed Panto, Reading

A relaxed performance of the Sleeping Beauty Panto starring Justin Fletcher. More details later this year.

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 **£2205** 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!

JANUARY 2023

1st Prize	Jenny Dilnot
2nd Prize	Kat Cornfield
3rd Prize	Emily Robinson

FEBRUARY 2023

1st Prize	Sally Dubock
2nd Prize	Diana McMahon
3rd Prize	Jo Crawford

MARCH 2023

1st Prize	Emily Robinson
2nd Prize	Carolyn Walker
3rd Prize	Marion Simon

APRIL 2023

1st Prize	Nick Smith
2nd Prize	Jo Crawford
3rd Prize	Jo Colehan

MAY 2023

1st Prize	Emily Robinson
2nd Prize	Will Foulds
3rd Prize	Lucy Sanderson

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
Stephanie Mills
steph@dsoxford.org.uk

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

Primary Club
Emily Higgins
emily@dsoxford.org.uk

16+ Club
Anne Churchill-Stone & Sonia Forester
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

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, Manor Farm, Waterperry
Oxfordshire OX33 1LB

CONTACTS

CHAIR
Jos smith
chair@dsoxford.org.uk

SECRETARY
Roberta Celeste
secretary@dsoxford.org.uk

TREASURER
Rachel Campling
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 EDITORS
Lucy Sanderson
Joy Weideman
newsletter@dsoxford.org.uk

MEDIA & COMMUNICATIONS
Andrew Dubbock
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

TRISTARS FOOTBALL CO-ORDINATOR
Amanda Foulds
amanda@dsoxford.org.uk

PRE-SCHOOL CLUB CO-ORDINATOR
Stephanie Mills
preschool@dsoxford.org.uk

PRIMARY CLUB CO-ORDINATOR
Emily Higgins
primary@dsoxford.org.uk

10+ CLUB CO-ORDINATOR
Sam Martin-Morrissey
10plus@dsoxford.org.uk

16+ CLUB CO-ORDINATOR
Anne Churchill-Stone
Sonia Forester
16plus@dsoxford.org.uk

STAY & PLAY AND EARLY DEVELOPMENT CO-ORDINATOR
Amanda Foulds
edgs@dsoxford.org.uk

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:
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 6 October 2023.

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

Registered charity number: 1103850