

journal



DOWN'S
SYNDROME
ASSOCIATION

Editorial Board

Editor – Ian Jones-Healey
Carol Boys
Kate Potter
Gillian Bird
Book Reviews Editor – Stuart Mills

Design and Typography

Clare Grundy

Down's Syndrome Association Journal

Down's Syndrome Association
Langdon Down Centre
2a Langdon Park
Teddington
Middlesex TW11 9PS
Editorial 0333 1212 300
info@downs-syndrome.org.uk
www.downs-syndrome.org.uk

Disclaimer

The Journal is designed to provide a communication forum for members of the DSA through which to facilitate the exchange of information on topics related to living with Down's syndrome. Unless indicated otherwise, the views expressed in The Journal are those of the authors and do not necessarily reflect the official positions or policies of the Editor or the Down's Syndrome Association.

Copyright

© 2021 by the Down's Syndrome Association. All rights reserved and all commercial use of the contents prohibited except as expressly authorised, in writing, by the Association.

Contributing to the Journal

The Down's Syndrome Association publishes The Journal every March and September.

We welcome contributions from our members. If you would like to contribute to a future issue please find details on our website:

www.downs-syndrome.org.uk/our-work/information-services/dsa-journal/

Letter from the Chief Executive



Carol Boys

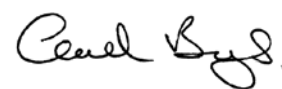
I hope you have managed to enjoy some of the lovely summer sunshine over the last few months. Our fabulous cover image reminds us all of long summer holidays and family fun. The cover stars are three members of the amazing Woodward family, whose fundraising efforts this year are highlighted on page 23.

The delayed World Down Syndrome Congress in Dubai will be taking place in November using online conference technology. This event is a very special opportunity to connect with people who have Down's syndrome and their families and supporters from

around the world. The latest research, best-practice and expertise are also disseminated at the event. Find out more on page 5.

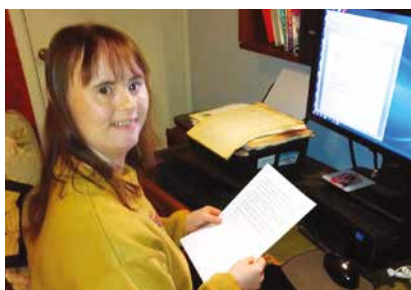
I would like to say a personal thank you to everyone who has supported the DSA through some of the most challenging times – donations of time, enthusiasm, stories, funding, legacies, interviewing skills, insights and experiences. Our members are really important to us and it has been a pleasure to interact directly with some of you at our regular Friday updates. Get all the details of how you can join us on page 3.

Finally, I am delighted to welcome Derrick Evans to the DSA. Derrick, otherwise known as the one and only Mr Motivator has agreed to become one of our Patrons – his passion for making fitness accessible for everyone is hugely inspiring and his regular DSEngage sessions are a joy. You can read more about him on page 6.



Carol Boys, Chief Executive

Letter from Kate Powell



Welcome to the autumn issue of The Journal! We have lots of impressive and amazing stories for you to read. As you can see during the lockdown new interests and hobbies were developed that encouraged creativity in art, music etc.

Personally, on reading each story I was totally inspired by them and I'm sure you will be too.

There must be lots and lots of stories and projects out there ... please share them with us and send them in.

I've had a difficult few months. I have missed all my outside activities due to an infection in my leg. Hopefully it will clear soon.

I hope you enjoy reading The Journal as much as I did.

Stay safe everybody.

Kate

CONTENTS

NEWS

- 3 Keep in touch
- 3 DSAActive sessions
- 4 Our Voice
- 4 Support sessions and groups
- 4 Training
- 4 Tablet give away
- 5 DSEngage
- 5 World Congress goes virtual
- 5 Shifting Perspectives Podcast
- 6 Welcome to our new Patron
- 7 50th Anniversary update

DSA

- 7 In memory of Ellie Walsh

OUR MEMBERS

- 8 Ida's story
- 9 Clara
- 10 Will
- 11 Christopher Jenner
- 12 Three Artists
- 12 Oliver's Eye Operation
- 13 Sam

HEALTH

- 14 Neck instability

RESEARCH

- 16 Supporting research together

FEATURE

- 17 Our Voice: Film and TV

WORKFIT

- 21 Adapting needs
- 21 The Hiring Chain

FUNDRAISING

- 22 Supporting the DSA
- 23 Busy year for Kaefer

On the Cover: Trevor, Darcey and Paighton Woodward, photographed on the beach this summer by mum Steph. Read more about Trevor's amazing fundraising on page 23.

News

Keep in touch with all the latest from the DSA

Although there is nothing quite like the chance to meet face to face, the increased use of tools like Zoom has opened up some amazing opportunities. One way that the DSA has embraced its use is with our weekly, free *Going Forward* update sessions.

Each week you can join the DSA's management team to get an overview of what's been happening within the organisation, what's coming up from DSEngage, DSAActive, WorkFit and our training team, as well as the latest policy and campaigning activity. Hear from members of the Our Voice team and enjoy the pick of some of our best multimedia content. There is also the opportunity to ask questions.



The sessions are held every Friday at 10.30am and normally take about half an hour.

If you're not able to join us, each session is recorded and shared on YouTube afterwards.

Register for your free place now: downs-syndrome.org.uk/DSAUpdate/

DSAActive sessions across the country start up again for the new term



As a new term starts we're hopeful that more DSAActive sessions will be restarting this autumn. You can see what's happening in your local area by going to dsactive.org.uk and clicking on Activities Near You.

We were thrilled to welcome Kate Harris to the DSAActive team over the summer as DSAActive Project Lead. Kate has previously worked within the health sector and has over 20 years' experience working with individuals to overcome barriers to participation in physical activity. She believes that everyone should have the opportunity and knowledge to lead as active and healthy a life as possible.

'I am delighted to be joining the DSA. I am looking forward to further

developing the inclusion of people who have Down's syndrome within physical activities through improved education and opportunities. I believe it is very important that participation in physical activity is an option for everyone, including children, young people and adults who have Down's syndrome. It is essential that the activity is something that is enjoyable and does not have to be sport specific. The activity may be walking, dancing, gardening, dog walking, school PE lessons, team or individual sport, the list is endless! The activity itself does not matter, but the experience of taking part and the benefits that it can have on health and physical/mental wellbeing matter enormously. Then there are the social benefits too. All this whilst hopefully having fun!

I am looking forward to hearing from and working with members who have Down's syndrome and their families/carers to establish what they think about physical activity participation and to work with them and their communities.'

Our Voice

At the Down's Syndrome Association we are lucky enough to have a team of people who have Down's syndrome that work as part of the organisation.

We love co-production and working together is what the group is all about.

Find out about what the group has been up to here:

downs-syndrome.org.uk/news/our-voice-our-stories/our-voice-celebrating-co-production/



Support sessions and groups

Have you checked out our private Facebook groups? They are designed to be a safe space where people can ask us questions, meet new people and discuss topics with those that have similar experiences. We have nine different groups in total, and each group is tailored to a specific age or need.

We have also started a Pregnancy and Baby Support Group. The fortnightly online meetings offer support for parents of babies up to 18 months

of age and expectant parents looking forward to welcoming their new baby. Through these meetings, you will meet our team and be able to ask questions on any topic, including development, communication and benefits.

Other fortnightly support sessions are our Well-being Wednesdays, where parents/carers can unwind and relax in a friendly and non-judgmental group with people who understand, plus our fortnightly sessions on Sharing Positive Support, which offers the opportunity



to share experience around behaviour in children and adults who have Down's syndrome.

Training

Our online training programme continues to provide an array of accessible and affordable sessions for parents and professionals, alongside special events and webinars.

In the summer we were honoured to host a special session with Debbie Austin. Debbie is a family carer. Her daughter, Lucy, has a dual diagnosis of Down's syndrome and autism.

Debbie talked about how she successfully used Positive Behavioural Support (PBS) to understand the communication behind Lucy's behaviours, and as a result has not only seen an increase in Lucy's happiness and quality of life, but a significant decrease in the

behaviours themselves.

Our training covers a huge range of subjects: education and development, speech, language and communication, positive behaviour support, adolescence and puberty, complex needs and autism, employment, support for adults and ageing and dementia.

You can find all the details about our training on our website: downs-syndrome.org.uk/training/

We are also able to arrange bespoke training sessions on request. Contact the team on training@downs-syndrome.org.uk to find out more.

Tablet give away



The DSA was delighted to have given out 30 brand new computer tablets to people who were digitally excluded and did not have access to the internet during the pandemic. It was part of the Digital Lifeline project set up by the Department of Digital, Culture, Media and Sport. We helped to identify people who faced challenges getting online and set them up with the new kit. The project has been a great success and has helped increase digital skills, confidence and of course, enabled people to connect with family, friends and essential services.

DSEngage

Our full weekly programme of popular DSEngage online activities is starting up again from September. We had a little break over August, but now we are raring to go with a whole host of new and exciting classes for you to join online. The weekly programme includes well-loved favourites such as workouts, Mr Motivator, pilates, dance sessions and discos. There will be a sprinkling of new sessions, requested by you, such as karaoke, bingo, craft and drama. Simply sign up each week and join the fun!

Our DSEngage programme was launched in response to the Coronavirus pandemic. It's a weekly online programme of activities for people of all ages that brings everyone together and helps us all to stay busy, active and have fun, from the comfort of your own home. Get all the details: downs-syndrome.org.uk/our-work/services-projects/dsengage/



Shifting Perspectives Podcast

When was the last time you heard someone who has Down's syndrome chatting on a podcast? Possibly never... Well, the Shifting Perspectives Podcast aims to change that.

Series Three hears Christopher talk about his experience of contracting Covid-19, Caitlin talk about how the pandemic has encouraged her and her father to take up running together, Claire talk about her online drama classes and James spill the beans on some very exciting news on the romance front.

We'd love you to listen and leave a review – it makes it easier for others to find the podcast if you do. Search 'Shifting Perspectives Podcast' wherever you get your podcasts from or visit: downs-syndrome.org.uk/the-shifting-perspectives-podcast/

Postponed World Congress goes virtual | 18-20 November 2021

A message from Vanessa Dos Santos, President of Down Syndrome International (DSi), about the congress:

'As President of DSi and on behalf of our board, staff and members, it is an honour and a great pleasure to invite you to the 14th World Down Syndrome Congress Dubai 2021 which will be held virtually. This will be the first time the WDSC has been held in the Middle East and the event promises to inform, inspire and influence everyone who attends for years into the future. It has been really encouraging to see the high level of interest in WDSC 2021

from all over the world, when we were in Glasgow for WDSC 2018 and since then through the DSi membership.

We urge all of you to register to attend, submit your abstracts and tell your friends and colleagues about this unique gathering of the global Down syndrome community. DSi would like to say a big thank you to Dr Manal Jaroor, everyone at Emirates Down Syndrome Association and the WDSC 2021 organising team for all the hard work you are putting in to organising this substantial international event. We know that through your efforts, we



will all participate in a really successful WDSC, which will ultimately improve lives for people who have Down syndrome around the world. We would also like to acknowledge and thank the many partners and sponsors for their support. Thank you to all those concerned. We trust everyone who attends will find WDSC 2021 of great benefit and that you will share your experience with as many people as possible. We look forward to your valuable participation.'

Find out more about how to get involved here: wdsc2021.org.ae

Welcome to our new Patron

We are delighted to announce that 90s television and fitness legend Derrick Evans, AKA Mr Motivator, has joined the DSA as a Patron. Derrick has worked with us for the past six months, offering up his popular Motivational Experience workouts as part of our DSEngage programme on a Wednesday night. He was also put in the spotlight as part of our Our Voice Interviews series. On accepting the position, Derrick said:

'I have always promoted the need for inclusion in every aspect of life and making exercise and all its curative power available and accessible to everyone is important to me. As a Patron of the Down's Syndrome Association, there is a mutual collaboration of mind, body and soul which brings me so much joy, and that feeling of togetherness makes everyone feel so good. Together we achieve more.'



Some of our members have also gone on to join Derrick's 'Motivational Club', ensuring keeping fit always equals having fun. mrmotivatorsclub.com

Our Voice interview with Mr Motivator

Earlier this year, Our Voice members Lyndsay and Isla had the pleasure of interviewing Mr. Motivator MBE. It followed a very energetic workout session with the legend himself. You can watch the full interview here - youtu.be/jf1gbdrHry0 - but we've also extracted some of the highlights below.

Lindsey: Can you introduce yourself and tell us what you do, please?

Mr M: Now I hope you've got all day, Lindsay, because you know, the thing is, I've got so many words in here dying to come out. But anyhow, I'm called Mr Motivator but my actual real name is Derrick Evans. And what I do...I've been doing this for so many years now. I'm really kind of a well-being fitness kind of coach, but I like to think that I'm someone who just, basically, dresses up fitness and health in a kind of sugar coating...so people have a good time while they're enjoying it.

Lyndsay: Did you grow up dreaming of being on TV?

Mr M: When I first came to England in 1962, I was 10 years of age. The only television I had was black and white and the only programme on it was Coronation Street. I had no dreams or aspirations about television. My first job after I left school was in an office. I was working in an office where there was 500 people on one level, and the computer room occupied the basement area of the office. Television didn't really feature at all in my upbringing. It wasn't until about 1983 when I saw the potential to get on to

television...that I thought...you know what? Let me try and see what I could do to break into it. I was watching people doing fitness on television and I didn't like the way they did it. And I noticed that most of them who are on tv, are on for just a little bit and then they would disappear. And I thought I've got to find a way of getting on there and remaining there forever. And I feel like I've been on there forever, Lindsay.

Lyndsay: Tell us about being awarded an MBE...it must have been a very special day.

Mr M: Well...I'll tell you something. When you do something that you love, the reward often is because of the way people react to you. And people have always reacted to me favourably. There's a quote from a poet called Maya Angelou...she said: People may forget what you did. They may forget what you say, but they will never forget how you made them feel. And that's been with me ever since. The joy I get from what I do is incredible That's been my reward. So I jokingly said when the letter came in you've been awarded an MBE and I thought MBE stood for Motivated By Exercise. It was special because it said for service to the health and well-being of the UK and that to me kind of bought home the fact that I've been in the industry for so many years now and what I love doing is being recognised by the nation. And it's great.

Lyndsay: Where did the name Mr Motivator come from?

Mr M: My very first job on television was back in about 1986 and I

happened to get a chance to appear on a programme called This Morning. The programme came out of Liverpool and I had to travel up to Liverpool once a week. They would send me out into the shopping centres and I would go live into the studio, getting people exercising to new music. I remember one morning the lady who presented the programme, Judy Finnigan, said: 'Now let's go over to the man I'm calling 'The Motivator' now and see what he's got for us today'. When I heard that, it resonated with me and I thought I'm not 'the' Motivator...I'm going to call myself 'Mr' Motivator. That's how it started and I immediately registered it and it's been part of my life ever since.

Isla: What is your message to people who have Down's syndrome about keeping fit and healthy?

Mr M: I say this to everyone...it makes you feel good, it helps you cope with stress and it can make you feel that you're different from anyone else...there's a term called 'flawsome'. If you look up flawsome in the dictionary it says it's someone who accepts that they have flaws...I've got a spot here, right...but they still embrace themselves and recognise that they are awesome regardless. We're awesome! The benefits of keeping fit and healthy are really important because just when you're stressed, that's when you put on some great music and dance. Remember this...you obviously get old when you stop being young...and that's why I'm only eight year's old.

50th Anniversary update

We have continued to celebrate our 50th anniversary this year as many, if not all our plans for last year were cancelled.

In July, 50 brave souls jumped out of a plane for us at our charity skydive event. Thank you to all those who braved the skies for us and for families and friends who came along and made the day a really special one.

We have continued to hear the stories of people who have Down's syndrome and are aged over 50 throughout the year. We have shared them online and made sure people's voices and wonderful memories from the past five decades have been cherished.

Our Oral Histories project was halted for a while, but it is now back up and

running. Hear from Alan, Cortina, Miriam, Susan, Anya, Julia and more in their own words.

You may remember we also started a special project with photographer Richard Bailey before the pandemic. It involves showcasing photographs taken by some of the top photographers in the country of people aged over 50.

These amazing photos are now framed and will form part of a showstopping exhibition up at our head offices at the Langdon Down Centre. Watch out for details of our special launch events soon.

Enjoy our 50th Memories and Stories here: downs-syndrome.org.uk/about-dsa/our-history/#MemoriesAndStories



In memory of Ellie Walsh



'Our great friend and colleague Ellie Walsh passed away last year. Ellie was one of the longest serving staff at the DSA. She was always willing to go that extra mile with anyone and help out whenever she could. She loved being part of fundraising events and helped every year at the London Marathon, amongst others.'

It's very difficult to think about the DSA without Ellie; a more conscientious and loyal employee would be very hard to find. Ellie will be greatly missed by her colleagues and also by the many affiliated groups and individual members that she worked with over the years.'

Carol Boys, Chief Executive

Stuart Honeysett, Ellie's son:

When Ellie joined the staff of the Down's Syndrome Association on 30 September 1996 the name on her cheque book was Margaret E Honeysett but she was always called Honey by her friends.

On her first day she decided to use an abbreviation of one of her middle names and her maiden name to avoid confusion with Margaret the receptionist and Pat Honeysett the Office Manager. Most people would not have considered changing their "work" name but for Ellie Walsh, it was just a normal day, shifting herself to help others.

At her secular memorial service, we heard from Sue who is the daughter of Mum's long distance companion of 32 years, Dennis. She shared some stories about who "Honey" was to them and it made me realise just how many different roles she fulfilled and how many

lives she touched. It didn't matter whether she was Ellie, Margaret or Honey; friend, mother, sister or soulmate; Membership Officer, Groups Liaison Secretary, Marathon day volunteer or the first voice on the phone when a new parent rang the DSA Helpline. Whoever she was, whatever she was doing, she always tried to make a difference for others.

Margaret Eleanor Mary Bernadette Honeysett (Ellie Walsh) passed away in the early hours of the 11 December 2020 at the age of 71.

She had recently discovered that she was to face her second fight with cancer having beaten breast cancer nearly 20 years earlier.

Unfortunately, the lung cancer she faced this time joined forces with Covid-19 to finally get the better of her. She will be sorely missed.

Keep calm and play music. Ida's story.

By Liane Beckmann

Music has always played a huge part in my daughter's life. Ida played all sorts of percussion instruments from an early age, at home and at toddler group. Singing, dancing, music and rhymes followed, performing alongside her peers from toddler groups, kindergarten and primary school.

Although there were fewer opportunities for music making and performance during Ida's primary school years, Ida was determined to perform and engage with music whenever she could. On one notable occasion, Ida snuck into a rehearsal and sat next to the pianist; on another, she mingled with a Welsh Choir performing at her school, having crept up on stage through the back door. Whenever I could I booked courses for Ida, including clog dancing and other musical activities organised by Urdd Gobaith Cymru.

At home Ida used our piano, as well as the xylophone, Irish harp, guitars, concertina, percussion instruments, flute and recorders. Ida briefly had piano lessons from a neighbour who is a professional teacher, but I was told that she would never play an instrument properly. It is difficult when you have a child who has Down's syndrome to ask why not? Music is excellent for all people. It speaks straight to the heart.

Ida's journey with the clarinet began when one of her school friends started lessons and Ida surprised us by asking for her own clarinet. A family friend gave Ida her instrument and by 2016 (when she was ten years old) she played her first notes. As well as receiving lessons, Ida learnt from Paul Harris's Clarinet Basics, a great book to start with for individuals and group learning.

Ida got as far as performing a solo rehearsal to raise money for our local Down's syndrome group with the funds used to secure a well-loved Christmas party. As well as taking part in rehearsals for a performance

to play four pieces on her clarinet, she eventually ended up playing the maracas in an orchestra of the Ceredigion Music Service in April 2019.

Mr Geraint Evans, Music Service Manager Director at Ceredigion County Council, said:

'I have taught two pupils who have Down's syndrome and also a number of pupils with different disabilities; music proved to be very enjoyable and beneficial to them. Ceredigion Music Service has always tried to be inclusive and not discriminate against anyone. I shall never forget the huge excitement on Ida's beaming face and her reaction to performing in her first concert with us at the Art Centre. For me that was extraordinary real highlight and what we aim to achieve for all our pupils.'



During her first year of secondary school, Ida was learning tunes from music sheets with numbers for the notes. Ida's father spent much of last year's lockdowns working out the easy clarinet fingering notation that Ida was using... then having a go on the clarinet himself! It is fair to say that things got a little competitive between them to see who would play more pieces for longer. Eventually Ida could play all the pieces she had been given.

Ida's lessons continued virtually during this period and she benefited from being in her school's 'Practise Makes Perfect' group. Although Ida found it challenging not to be in the same room as her clarinet teacher, Viki Wright Harwood, lots of good planning made sure Ida was included. It was lovely and very touching... even just to say hello meant so much to us in those strangest of times.

"I like to play all my favourite songs on my clarinet including Moana, and would like to play Mary Poppins, Frozen, and Beauty and the Beast." - Ida

Through lockdown, Ida worked with a woodwind pipe group where she took part in Ceredigion Music Service's instrument lessons online. She was part of a successful movie night performance on YouTube and performed with the woodwind pupils in concert in secondary school, which made it much more interesting. This helped Ida's independence in playing her clarinet. It was wonderful to see Ida's improvement in practice, dedication and determination. If numbers were missing, we added these to the notes when reading the music and Ida played 'by ear' when she was not feeling confident reading the notation. As a result, she also sometimes improvises by using her own rhythm and tempo, playing some parts she knows faster than those which take more concentration. Luckily my daughter has an infectious enthusiasm for life, and it adds to the fun of playing and performing.

The beauty of music is in its simplicity. It can automatically connect with the brain. That is why I believe music is so powerful and highly useful for all children. Music has helped Ida with movement, her very delayed speech, and improved her muscular strength.

Learning to play an instrument is well known to be good for a person's wellbeing, mental health, as well as teamwork, self-discipline and even mathematical skills. Music is so vital and can reach all people, regardless of any additional needs or disabilities. Making music is one of life's blessings. It is creative and so wonderful. For me, being part of my daughter's musical journey is incredibly special.

Music will encourage so many people. This has certainly proved to be the case with Ida and it has not just been her mum and dad who have noticed how much help music has been during lockdown. I would like to say a huge thank you everyone who has helped Ida on her musical journey!

Ms Viki Harwood (Ceredigion Music Staff) said:

'It is a real joy and privilege to see and hear Ida playing the clarinet, I am grateful that we continued playing during the lockdown. I am very much looking forward to seeing her in school for the first time in more than 21 months. What makes me very happy and gives me hope is to see that Ida has found her way to play the clarinet; what's more, Ida always has a big smile on her face and looks happy when I see her playing. I love to see the concentration on her face! Ida has made so much progress. She plays joyously at an age where others stop playing. People can see that Ida enjoys playing her clarinet and it has proved she can play a music instrument.'



Clara



Hello I am Clara, I am 19 years old and I have got Down's syndrome.

I love dancing because it makes me happy. I go to Tina Phelps Stage School and I do modern, jazz and ballet. Also, I do dancing shows and local festivals. In 2019 I won a cup and was asked to perform my modern solo at the prize giving.

I love swimming because I belong to Runnymede Swimming Club and I compete in different galas. I have got lots of medals for my galas. Also I have got 2 trophies for my swimming. I am doing my workout Zoom class meeting with my friends and my swimming coaches.

I like going to USP College because it makes me happy. I am doing Supported Internship.

In lockdown I am doing my Microsoft Teams with my college friends and my teachers. I love doing my Microsoft Teams so much because I like seeing my college friends and we laughed a lot. In Microsoft Teams I am doing English, Maths and Employability and I just enjoy learning different subjects. Normally I work in Salvation Army charity shop because of lockdown the shop is closed and I miss everyone there.

Love Clara Chamberlain

Will

By Jenny Shepherd



Will is our eldest son. He has Down's syndrome, a profound hearing loss, dyspraxia and relies on lip reading, body language and the use of sign language. I taught him Makaton when he was a small boy in New Zealand and when we came to Britain he had to learn the British signs. He adapted and has added many of his own. He is a skilful and patient communicator and a very intuitive young man with great emotional intelligence. His paintings bear witness to this.

Several years ago when Will was grieving the loss of one of his brothers' (through brain cancer), he was encouraged to start painting as a form of expressing his feelings. Will soon realized through the help of his art teacher, that painting was something that he understood really well. Since then, he has been avidly trying out different mediums and enjoying building on his artistic skills both at home and in his art classes.

During this period of the pandemic, Will has been living full time with us, his parents, and having zoom art classes daily which have given him an enormous incentive to keep up his skills. He has also become extremely interested in following the news of the pandemic and also other key events, such as Black Lives Matter, the American election and events in other countries.

Apart from painting some lovely colourful flowers, vases and landscapes, Will has also created paintings of the virus and some darker canvases





depicting the worrying escalation of the virus. He has also created a visual diary of events almost from the beginning of lockdown, using recycled cardboard and carefully cutting out headlines or photos of his choice to make an extraordinary series of the unfolding of topical incidents. And he can neither read nor write but somehow has managed to make sense out of the week's news through this medium. We are hoping that maybe the local museum may be interested in showing some of them, or that we can somehow create a book with his artwork to mark this extraordinary time as seen through the eyes of Will.



Several people who had seen Will's paintings prior to the pandemic, had been lucky enough to either have one given to them or had already purchased some.

When he first started painting Will had been part of an art fair at the newly opened Turner in Margate and sold one of his paintings, but he had never had his own exhibition. We had planned to have a small exhibition of some of his artwork just before lockdown, but this had to be delayed. However, Will was invited to paint a portrait as there was to be an exhibition at a local well-respected gallery of portraits before the second

lockdown occurred. His was the first painting sold at the exhibition!

It was time for Will to show off his own work! One of Will's brothers decided to set up an Instagram account for him and within a week he had a mass of followers and he has now sold paintings to the States as well as within Britain and Europe. He was also invited to have an exhibition of his paintings in an artist's studio just outside Hastings in June 2021. It was a solo exhibition and Will is so proud.

It has been so exciting to see Will develop in this way and see how his wonderful colour sense can bring such joy. We want to share his success with you all at the DSA and if anyone wants to hear more about Will or see more of his paintings, please do contact him or follow him on his Instagram page [instagram.com/willshepherdart](https://www.instagram.com/willshepherdart). He is giving 20% of the sale of each painting to the Down's Syndrome Association.



Christopher Jenner

By Christopher's mother Sue Jenner

Christopher Jenner, and his parents, have been members of the Down's Syndrome Association since Christopher was born in Oman in 1985. They returned to the UK in 1992 when Christopher was seven years old.

He now lives by himself in a small terraced house and has three wonderful PA's to help him. Christopher works for 10 hours a week at his local East of England Co-op. He goes swimming twice a week, to band once a week, gym once or twice a week and regularly goes to watch his team Colchester United play at his local football ground.

Christopher has been presented with the Chief Scout's 10 Years Service Award in recognition of service to scouting.

He has been in scouting since he became a Beaver, when his parents were based in Qatar. When he was seven he returned to Mersea and was a Beaver and then joined the Sea Scouts.

He has been in The Colchester Gang Show every year and now helps with The Beaver Colony in West Mersea.

He is very proud to have been presented with this award from the Scout Association.



Three Artists

By Jo Messenger and Nicky Parker



Luke has a gravity art piece using pouring acrylic paint.



Zac has a picture using crayons and a heat gun.



Oliver has a picture using a hairdryer and acrylic paint.

Three amazing young men, like many of your members have been shielding through this strange time and to keep minds active they have been learning new skills and creating some fantastic art work.

The boys were all happy being home and having lots of activities and fun - our dilemma as parents - space for all their amazing artwork!

Parents Nicky and Jo love completing challenges and fundraising for charity. This last year they have missed their fundraising events but as they are always up for a new challenge an idea came to mind. Raising funds for a Charity close to their heart and giving

new homes for the wonderful art the boys had produced.

We all know someone affected by cancer and for many people it is very close to home if not very personal. Though Down's syndrome is always at the top of our list, Cancer Research is something that has saved many people including Nicky. This time Nicky and Jo decided to support them. On 2/3 April they launched an online art exhibition.

The artwork was family originals by either the boys or Jo and Nicky as this challenge was for all. The artwork was auctioned in return for a donation on their Cancer Research UK giving page. The artwork was snapped up and over

£1,300 has been raised. Nicky and Jo are so proud of the boys and totally amazed at the generosity of people. The art is now on its way to new homes and the boys are thrilled that so much money has been raised.

No disability should ever stop people doing things and Luke, Zac and Oliver have proved that. This has been a project where their work is totally their own and we are so very proud of them.

Zac said, *'It made me happy because it helps people not get sick. Painting was relaxing, I enjoyed it.'*

Oliver said, *"I like painting and making people smile."*

Oliver's Eye Operation

My name is Oliver. I had an eye operation in May. I have a condition called Keratoconus. This is where my cornea starts to cone and can lead to being blind.

It is very important to get your eyes checked and ask about this as some people who have Down's syndrome can have it.

I was very brave, I had to wear an eyepatch and have drops in my eyes 4 times a day. It is not nice, but it has

saved my eyes. This is the second operation as I had the other eye done in March.

I am very happy now they are done. I want to say thank you to the nurses and doctors that looked after me. They are brilliant.



For further information about Keratoconus see our page about eyes and download the PDF on Adults: Eye Conditions (Health Series) [downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/eyes/](https://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/eyes/)

Sam

By Leslye Pierce

I would like to tell you about my amazing son Sam.

When Clap for Heroes started last year Sam wanted to join in to say thank you to the NHS who looked after my husband who was quite poorly with Covid. He began by dressing in his superheroes onesies and then we began talking about other people helping us through lockdown. Each week we would chat about a certain profession and then find an outfit to show that profession. It really gave Sam something to look forward to as all his usual activities had stopped.

We did stop when everyone else ended clapping but when it restarted Sam yet again wanted to join in. He was brilliant, he has done doctors,

posties, police, farmers, paramedics, shop workers and delivery drivers to name just a few. He was featured in the newspaper a couple of times and was featured on Loose Women. So many people on Facebook would look forward to seeing what he was going to be next.

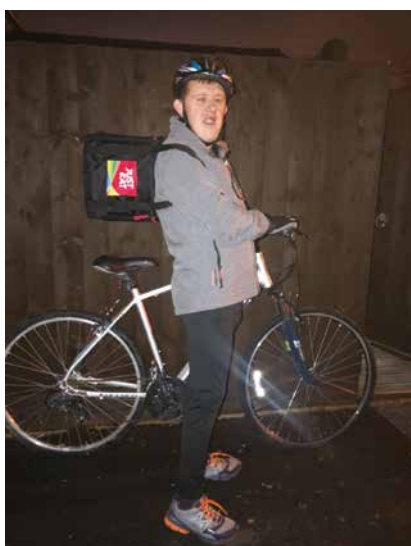
In total Sam had over 50,000 likes and 2,500 positive comments from all over this country and 19 other countries. He was also a finalist in the 'Unsung Hero' category in the Swindon and Wiltshire Health and Social care awards being hosted by Dr Hilary Jones.

We are all so proud of this young man and his promotion of positive Down's syndrome awareness in the wider community.

Sam's favourite outfits were the policeman, the bus driver and the farmer. Sam missed all his sport activity, going to the theatre and most of all seeing his big brothers. One of his brothers lives in Wales and when we told him Wales was closed he was so upset. I used to show him the messages and explain and he loved it. Also people saying thank you to him gives him a huge smile.

Sam is looking forward to hopefully going on holiday, the award night for which he is a fab as an unsung hero and we are just starting a big fundraiser called Sam's 21 challenges.

It will begin on his 30th birthday and run until WDS 2022. Lots of things to really push Sam, all very exciting.



Neck instability

Underlying neck instability is more common in people who have Down's syndrome than in the general population. This causes concern because although significant damage caused by neck instability is rare and most people have mild early warning signs, it can be devastating and result in paralysis and in extreme cases death.

Parents, carers and practitioners should be constantly aware of the warning signs (symptoms) which might indicate that a person who has Down's syndrome is at risk of neck instability.

If parents, carers or people who have Down's syndrome suspect any of the signs or symptoms listed below, (a), (b), the person may have a problem with neck instability and should be seen by a Doctor.

a) Warning symptoms

- Pain anywhere along the neck
- A stiff neck which doesn't get better quickly
- Unusual head posture ('wry neck' or torticollis)
- Alteration in the way a person walks so they may appear unsteady
- Deterioration in a person's ability to manipulate things with his/her hands

b) Poor neck control

Difficulty holding the head up, holding the head at an unusual angle, difficulty nodding or looking up and down and/or difficulty turning the head in certain directions.

Anyone with the above signs could have underlying neck instability and be at increased risk of neck dislocation. Minor impact involving the person with the symptoms may cause spinal damage (e.g. tripping up or a jolt).

Any parent, carer or sports coach with concerns about a person's neck control or any emerging warning signs before, during or after sport sessions, must refer the person for medical assessment.

Neck instability is a highly specialised area of medical practice. The Doctor may refer the person to a specialist centre.

For people who have Down's syndrome who have no symptoms (the majority), there are no reliable tests that can identify those at increased risk of neck instability.

Safe sporting practices, such as appropriate supervision, are essential.

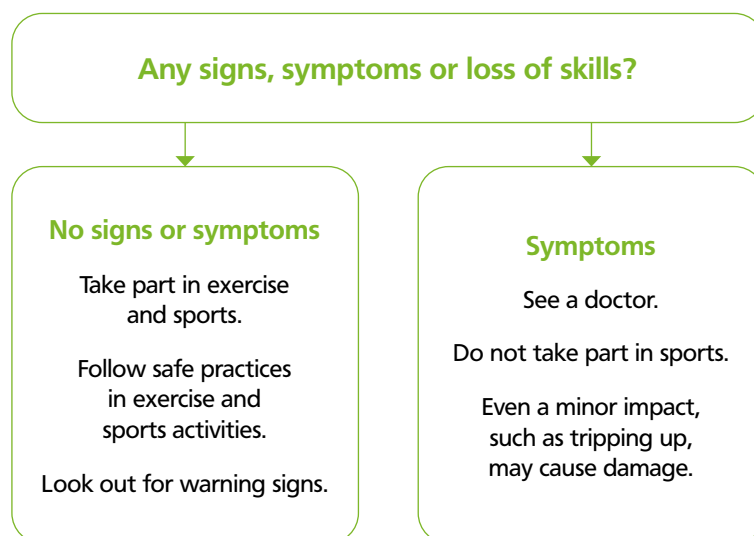
For people who do not have symptoms of neck instability, there should be no additional anxiety about them taking part in non-contact, low impact sporting activities.

Some sports such as trampolining, diving, contact sports and high jump have higher risk for neck injury in all participants (people who do not have Down's syndrome as well as people who do).

Ask the sports provider or National Governing Body of the sport about their safe sporting practices and eligibility criteria.

Based on current information, it is sensible advice for adults who have Down's syndrome to travel in cars with headrests and for children to travel in car seats with neck support.

People who have Down's syndrome who are unconscious are potentially at risk for neck damage. Ambulance personnel and healthcare professionals, including anaesthetists, know how to take special care of the neck in these circumstances.



You can read the full DSA/DSMIG Health Series publication on neck instability on our website: downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/bones-and-muscles/#resources

We have also created an easy guide to neck problems (see opposite).

This can also be accessed on our website: downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/bones-and-muscles/#resources



Knowing about neck problems

Easy Read

A Down's Syndrome Association publication



How we can support research together

We continue to facilitate research which will benefit the lives of people who have Down's syndrome and their families.

In 2019 – 2020 we advised on or supported 27 research projects. We work with researchers by:

- co-producing with people who have Down's syndrome
- advising on the development of projects and project materials
- provide supporting letters for funding bids
- attend partnership meetings and steering committees
- finding participants
- raising awareness of the work of researchers through our website, social media channels, blogs and journal articles.

Any research that we support is carefully considered and reviewed and has to be ethically approved.

Your input is vital

In 2016, Dr Anna Joyce, Research Associate in the Faculty of Health and Life Sciences at Coventry University, wrote the following in an article in issue 134 of The Journal.

'I am eternally grateful to all the families I have met over the years for helping with my research.

'I'm sure I can speak on behalf of all researchers in thanking all the families who come forward to help with research and all the professionals who support us by contacting families and allowing us into their centres.

In short, we need your support; we need your participation and we need to keep doing research so that we can advance the field and improve the world we live in. Without you, our research wouldn't be possible and we wouldn't be where we are today with more people with Down's syndrome being included in society, enabled to achieve and living happier and healthier lives.'



Here are some of the current studies we are supporting – can you help?

Information and support needs survey

Researchers from St George's, University of London, are looking for parents or carers of children who have Down's syndrome to take part in an online European survey study.

The survey will explore parents' and carers' views about the information they have received or accessed about their child's condition and their experiences of support.

In light of the current situation we are all living in, the survey will also explore parents' and carers' views about how the COVID-19 pandemic may have affected their child, their child's medical care, support and family life.

Speech fluency in people who have Down's syndrome

Emily Lowther from Wayne State University, USA is looking at speech traits in people who have Down's syndrome. Her study aims to get a better understanding of the speech traits common in people who have Down's syndrome, and particularly those that affect speech fluency (i.e. flow or ease of talking).

Emily hopes her findings will help us

to develop strategies to address the issues that are making talking difficult and incorporate those approaches with those that support people's overall communication needs.

Evaluating the Quality of Education, Health and Care Plan (EHCP) outcomes for primary school students who have Down's syndrome in England

Camilla Brooks (Department of International Special Needs Education, University of Oslo) is recruiting families of children (ages 5 to 12 years) who attend either a mainstream or special primary school in England only and who have an Education, Health and Care Plan (EHCP).

Camilla will systematically examine the children's most recent EHCP in order to evaluate the quality of their outcomes and provide further evidence of the importance of high-quality outcomes in regard to student success.

Investigating the bilingualism advice given to parents/carers of children with Speech, Language and Communication Needs in bilingual families

Trina Jia Ying Ng is working on her MSc Speech and Language Sciences at University College London.

Her study seeks to understand the advice on bilingualism given by speech and language therapists (SLTs) to parents/carers of children with speech, language and communication needs (SLCN).

Eye care in people who have Down's syndrome: understanding the provision and the impact of COVID-19

Dr Valdeflors (Flors) Vinuela-Navarro works at Aston Optometry School, College of Health and Life Sciences, Aston University – she wants to know about eye care for people who have Down's syndrome.

So, she has made a survey with some questions about looking after your eyes, having your eyes checked, and COVID-19. The survey is for adults who have Down's syndrome (18 years old or above) who live in the UK.

The lived experiences of new mothers accessing feeding support services for infants who have Down's syndrome throughout the COVID-19 pandemic.

Laura Hielscher is a psychology PHD student at the University of Hertfordshire. Laura is looking for mothers of infants who have Down's syndrome (up to 2.5 years of age and who are based in the UK).

Previous research has suggested that infants who have Down's syndrome may experience more challenges with feeding than typically developing infants. As such, mothers of infants who have Down's syndrome may require additional support to successfully feed their baby.

More research is required to examine the challenges that mothers of infants who have Down's syndrome face when feeding their babies and how these can be overcome, and their needs best met.

We frequently advertise opportunities to be involved in research on our social media profiles.

If you would like to find out more about any of the studies mentioned here and/or wish to take part, please go to our website: downs-syndrome.org.uk/our-work/services-projects/research-support/

Our Voice: The representation of people who have Down's syndrome in film and TV

We were contacted by TAPE, a Community Film and Arts program based in North Wales in April.

Part of their spring film festival was the film, 'My Feral Heart', which is about a man called Luke who has Down's syndrome who moves into a care home after his mum dies. It stars the actor, Stephen Brandon.

We were asked to take part in a Q&A session, along with the script writer and producer of the film.

Jane McIlveen, who works in North Wales and Joe Robbie, our representative from Our Voice attended the Q&A.

Joe did an awesome job. He was his normal passionate self, and he gave them lots to think about for their future endeavours.

We knew one of the questions would be 'What do I think about how people who have Down's syndrome are represented in film and TV?' so we put this out to all the Our Voice members.

Their thoughts and comments were shared with TAPE and you can see a selection here.

What do you think about how people who have Down's syndrome are represented in film and TV?

DOWN'S SYNDROME ASSOCIATION



I am extremely proud to know both Sarah Gordy and Tommy Jessop, knowing the tv shows that they have both been involved in as being the most popular tv shows can really show people just how amazing actors and actresses are. This is so important to include more and more people with disabilities in popular tv shows.

I feel that the characters in programmes like EastEnders, Corrie and Call the Midwife with disabilities can bring something quite unique and different into the storylines. I really like to see the transition of these characters throughout the storylines.

Having been involved in performing myself I really can see that there is so much potential out there for so many people with disabilities to be involved in performing in even more tv shows and any form of acting.

Sara



What do you think about how people who have Down's syndrome are represented in film and TV?



I have noticed that more people with Down's Syndrome are being included in TV programmes /films and TV adverts. It is very nice to see. Sometimes it does upset me though, when actors with Down's Syndrome are treated badly/used by people or hurt in the programmes they are in.

James



What do you think about how people who have Down's syndrome are represented in film and TV?

I live independently without carers or personal assistants and I think they should sometimes show people like me. I have a job, I do my own shopping, cooking, washing and cleaning. Please ask them to show people like me because it would give some people with Downs and their parents something to aim for. Please tell the film makers this because people who don't know me, think I can't do things, often because it's what they have seen in plays and things on TV. and it makes my life difficult.

What do you think about how people who have Down's syndrome are represented in film and TV?



Sam thinks that those he has seen are really good actors and he can relate to them. He likes to see them on the TV and films because more people will see them.

Sam



What do you think about how people who have Down's syndrome are represented in film and TV?

I think it is very special and it makes me really proud to see people with Down's syndrome on TV. I like seeing people with Down's syndrome on TV because I know how they are feeling about things. How they are feeling about things and different things they can't have. I like seeing people who are in a relationship and have a boyfriend like me. I think it's amazing to see.

Emma



What do you think about how people who have Down's syndrome are represented in film and TV?



Angus



I think having people with Down's syndrome on TV and film is very encouraging. We are not that different to any other people because we can also reach our dreams to be successful and be who we want be. We are just like anyone else in this world wanting to pursue our own dreams.

Emily



What do you think about how people who have Down's syndrome are represented in film and TV?



I think actors who have Down's syndrome are just like normal people with every day jobs and they are just as good as people without Down's syndrome and can also achieve whatever they set out to do. The more that people see us on the TV the more they will see what we are capable of.

Lindsay



Joe's thoughts on TV and film

What are your views on the way people who have Down's syndrome are portrayed in television and film?

Shia LaBeouf portrayed Down's syndrome in Disney's *Tru Confessions*. So, he does not have Down's syndrome himself...this was back when professional actors pretended to have Down's syndrome and disabilities when they don't. As years went on, he took on a supporting role for an actor who has Down's syndrome in *The Peanut Butter Falcon*. It would be so helpful to have professional actors supportively guide and be in supporting roles beside actors who have Down's syndrome. They could show others, like myself, in and around performing on set, building up that access.

There are certain media platforms I like...*The Show Must Go On*, *Dice Enterprise*, the DSA as well as TV shows from BBC Bitesize, with ideas on education within entertainment.

It would help to grow and develop wider opportunities then the raising awareness of educational entertainment shows like *Tracy Beaker*, the soaps, *Doctor Who* on gaining fairer, equal treatment for people with Down's syndrome and disabilities to have their voices heard and our life experiences shown.

Why did you want to share your views and why are you passionate about this subject?

I wanted to share my views on this ever expanding industry that is the film, TV and performing creative arts and its portrayal of Down's syndrome and disabilities because I am so passionate to do everything I can as a representative for my community to have their equally fair respect in showcasing what they can do, compared to can't, and on this note, I therefore really appreciate to hopefully become a part of this industry myself. It's been a lifelong ambition of mine to be an actor. Any opportunity to show my ability, as nobody likes to be dissed, especially potential actors no matter the difference.



Are there any films that you would recommend?

For a general overview on issues surrounding an equally fairer society, *Descendants* for musically showing a character with Down's syndrome and disability, *Glee* for showing a fantastical outlook on issues surrounding a child

born with different mixed views on society. The live action *Dumbo* and lastly, but not least, for showing an outside point of view group in society, BBC's *Tracy Beaker*.

You can find out more about TAPE here. tapemusicandfilm.co.uk/

WorkFit – adapting to meet the needs of our stakeholder



Aaron is delighted to be back at work in the job he loves at XPO in Manchester after being on furlough.

Over the last 16 months the WorkFit project has adapted to meet the needs of our members and employers faced with the challenges of the global pandemic.

We have moved our delivery online and had great success in engaging with the majority of our stakeholders via these platforms with many telling us that they prefer this way of working. The WorkFit model provides sustainable employment opportunities, although the impact of the pandemic has seen some of our candidates sadly being made redundant.

We now have almost 1,200 candidates at various stages on their WorkFit journey and we are developing opportunities for them with over 500 registered and trained employers.

We are optimistic that we will soon emerge fully from the restrictions in place to keep us all safe and are delighted to say that we have had an increase in the numbers of employers registering with us to offer opportunities. The team are working hard and we have had several new jobs start in May and June following the return of the team from furlough. We've also had significant numbers of candidates returning to work, all of whom have been delighted to do so. Obviously for some sectors, there is still some uncertainty but WorkFit will continue to support everyone to return when it is safe and appropriate to do so.

The launch of The Hiring Chain, in which the DSA was a key participant, has seen the profile of WorkFit increase



Alix was recently recognised with an award from her employer, South West Water, for her valuable contribution in the workplace.

around the world and has brought us into contact with a range of employers who are keen to work with us. We are also building on the strong relationships developed before the pandemic and pleased to report that many of the opportunities that were in development have been re-energised. In short, we are very optimistic about the future of the programme and have incredible support from the employers that we work with, both new and existing.

To see our candidates in their jobs and hear from them and their employers, our YouTube channel can be found at: bit.ly/workfityoutube

WorkFit and The Hiring Chain

"We're all being asked to live differently due to the Covid-19 pandemic, but for many adults who have Down's syndrome, their jobs and independence have been extremely hard won. Therefore, redundancy and long-term furlough has hit people hard. Many adults who have Down's syndrome work in sectors that have been particularly impacted by Covid-19 such as hospitality, catering and retail. Employment rates for people who have learning disabilities are already incredibly low, and we are desperate for them not to fall further. So we're appealing for businesses large or small, to get on board and consider employing someone who has Down's syndrome."

Carol Boys, Chief Executive,
Down's Syndrome Association

Ahead of World Down Syndrome Day on Sunday 21 March, CoorDown, the National Association for people who have Down Syndrome in Italy, launched their global awareness campaign 'The Hiring Chain'. Their message to employers all over the world is that hiring a person who has Down's syndrome not only changes the life of the person concerned, but can trigger a virtuous circle of new opportunities for everyone. The Hiring Chain campaign is working with the Down's Syndrome Association (DSA) here in the UK, to support 'WorkFit', their national employment programme, which has so far developed over 400 employment opportunities for people who have Down's syndrome.

Sting, the award-winning artist, performs the original song 'The Hiring Chain', which is the focus of the campaign video. The video charts



the experiences of people who have Down's syndrome entering the world of employment by a "virtuous" chain of inclusion in the workplace. It shows that the more people who have Down's syndrome are seen at work, the more they are recognised as valuable employees. Challenging low expectations and prejudices, thus creating opportunities for new hires.

The Work and Pensions Committee are currently holding an inquiry into why so many people who have disabilities find it difficult to find jobs. The Down's Syndrome Association continues to feed into this discussion with the aim of supporting the closure of the current disability employment gap.

Supporting the DSA

Support from companies is vital for the work of the Down's Syndrome Association and enables us to help thousands of people who have Down's syndrome, their families and carers.



AXA XL has supported the DSA for a number of years and we greatly appreciate the grant of £15,336 for WorkFit London, giving people who have Down's syndrome opportunities to work. The generous support from AXA XL was further demonstrated with a grant of £12,074 for the charity in January 2021.

The John Laing Charitable Trust also showed their support for WorkFit London with a grant for £20,000 which has been a tremendous boost to the innovative programme. This is the first time the Trust has supported the DSA. Our thanks go to them for their fantastic support.



The DSA has been very fortunate to have the support of Dalmore Capital over the past year as the DSA was selected as one of the three charities they chose to support over 12 months through fundraising and charitable giving from the company. An amazing £19,345 had been donated to the charity and as the partnership has closed our thanks go to the company and its amazing employees who have raised funds.



FOUNDATION

The B&Q Foundation gave a donation of £5,000 enabling the renovation of the Langdon Down Centre's kitchen. This grant has enabled the tired kitchen to be transformed with new units, flooring and lighting, making a great difference to the centre and the groups who use this facility.

EVERSHEDS SUTHERLAND

New support from corporate companies for the charity is very welcome and we were delighted that Evershed Sutherland London donated £5,000 to the DSA.

DIAGEO

Diageo has also joined our corporate supporters and Diageo Mullusk has so far donated £5,218 with other funds to be donated through the other Diageo sites.

Our thanks go to all the companies who have supported the DSA. By joining forces with the charity you are transforming the lives of many people who have Down's syndrome. For more information on how to support the DSA and become a corporate partner contact events@downs-syndrome.org.uk



A busy year for Trevor and his colleagues at KAEFER UK & Ireland

KAEFER UK & Ireland selected the Down's Syndrome Association (DSA) to be their Charity of the Year for 2021-2022. Trevor Woodward, a member of the DSA and KAEFER employee, tells us more...



This year I've taken on quite a few events to fundraise for the DSA.

I started with a #5kfor50. We put together a team of workmates who ran a minimum of 5k for 50 days. Together we raised over £10k. I signed up for the 50 for 50 parachute jump with my wife Steph in July and then, finally, I'm running the London Marathon in October. None of it was really thought through too much, in typical style, but I like a challenge and these have all come together nicely in 2021.

Why the DSA? Well, my daughter Paighton has Down's syndrome. She was born in 2017 and she changed our world for the better. The DSA support not only people with Down's syndrome but their wider network including families, carers and parents.

We know from our family's experience there's a lot to take in and it can be very overwhelming at times. Having somewhere to go to for information, guidance and to connect with the experiences of others is crucial. For me it's not just about fundraising to keep this valuable work going but it's about raising awareness of the importance of equality, inclusion and diversity in wider society.

It's been fantastic also that my company KAEFER decided to support DSA as a charity of the year. We've seen colleagues from around the business get involved in fundraising and spreading positive messages. I've seen a few pairs of #LotsOfSocks worn in the offices on our sites; we've got people signed up for the virtual London Marathon and the parachute jump; and held several events around World Down Syndrome Day.

Collectively we're pushing £25k raised in the first half of the year and we have loads more plans. Our aim is to reach £50k by year end.

Our CEO, Chris, is also leading from the front and just recently raised over £850 himself. The generosity of our employees has been outstanding and, honestly, the charity partnership is bringing some fun and wellbeing back

to the work environment after the tough times we've all had during the pandemic.

At KAEFER we are really committed to try and make a difference longer term and have also engaged with the DSA's WorkFit programme. Our HR team (especially Lynsey and Laura) have been brilliant, organising two work placements so far in our Head Office in Jarrow. Sarah is already working in HR administration and Gary is starting soon in our manufacturing workshop.

So, all in all, lots of great stuff, making a real difference. Personally I'm glad to do my bit and keep fit, but I'm also massively grateful for the whole KAEFER team effort...to everyone who has generously donated time and money. You know who you are – thank you. I'm also grateful for the huge support of Steph and my family who inspire and enable me to do what I do.





Helpline and Information Centre

0333 1212 300

info@downs-syndrome.org.uk

Our Information Officers are available to respond to calls and emails Monday to Friday, 10am-4pm.

Together with our team of specialist advisers, we offer advice about any aspect of living with Down's syndrome including prenatal support, benefits, education, service provision, rights, health, speech, language and communication, complex and adult needs. We also offer individual consultations and assessments.

Our information resources are freely available on our website.

People who have Down's syndrome shape our resources and help to inform our decisions through our inclusive participation activities with DSA Our Voice members. Parents, practitioners and people who have Down's syndrome can also ask us questions on our closed Facebook groups.

We work with affiliated parent support groups in England, Wales and Northern Ireland. Contact us for local support group contact details.

Training

training@downs-syndrome.org.uk

We offer a range of training to support individuals at every stage of their lives. From our Royal College of Midwives accredited Tell It Right® study days to conferences, webinars, workshops and online training about education and development, positive behaviour support, adolescence, support for adults, Down's syndrome and health awareness, ageing and dementia.



Get active

www.dsactive.org.uk

Our DSActive programme aims to provide as many opportunities as possible for people with Down's syndrome to lead active and healthy lives.



Employment

www.dsworkfit.org.uk

Our WorkFit® programme brings together employers and jobseekers who have Down's syndrome, providing tailored support to employers and candidates.



LANGDON DOWN
MUSEUM OF
LEARNING
DISABILITY

www.langdondownmuseum.org.uk
www.facebook.com/LangdonDownMuseum



www.langdondowncentre.org.uk

0333 1212 300

info@downs-syndrome.org.uk
www.downs-syndrome.org.uk

Langdon Down Centre
2a Langdon Park Teddington,
Middlesex TW11 9PS

Office hours are Monday to Friday,
9am-5pm. Emergency numbers
are given outside office hours by
recorded message.

Founder

Rex Brinkworth MBE, BA, Cert Ed, DCP

Patrons

Emma Barton
Paul Bird
Christine Bleakley
Michael Caines MBE
Peter Davison
Dame Judi Dench DBE
Derrick Evans
Perry Fenwick
David Flatman
Shane Geraghty
Sarah Greene
Richard Hibbard
Damon Hill OBE
Georgie Hill
John Humphrys
Kevin Kilbane
Liam Neeson
Craig Phillips
Fiona Phillips
Nicky Piper MBE
Professor O. Conor Ward

Officers

Chair	Georgie Hill
Vice Chair	Sarah Leggat
Treasurer	Darren Warkcup
Chief Executive	Carol Boys

The more members we have, the stronger our voice

To find out more about our services, campaigns, consultations, research and how you can become a member visit
www.downs-syndrome.org.uk



www.ds-int.org