

**PORTSMOUTH
DOWN SYNDROME
ASSOCIATION**

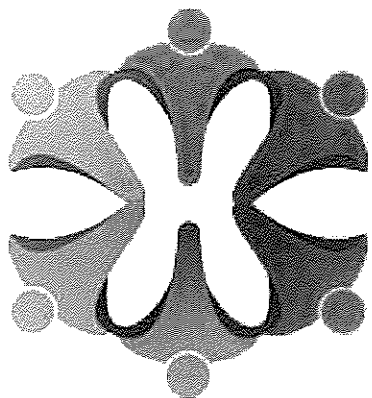
**Unaudited Financial Statements
Year ended 31 March 2024**

James Todd and Co. Limited

Portsmouth Down Syndrome Association

Contents

Trustees' Report and Financial Statements year ended 31 March 2024	1
Independent Examiner's Report to the Trustees on the Unaudited Financial Statements of Portsmouth Down Syndrome Association	30
Statement of Financial Activities for the year ended 31 March 2024	31
Balance Sheet as at 31 March 2024	32
Notes to the financial statements for the year ended 31 March 2024	33 - 36



PORTSMOUTH DOWN SYNDROME ASSOCIATION

Portsmouth Down Syndrome Association Trustees' Report and Financial Statements for the Year Ended 31 March 2024

The Chairperson submits Portsmouth DSA's Annual Report and the Statement of Financial Activities and Balance Sheet for the year ended 31 March 2024 on behalf of the Board of Trustees.

Portsmouth Down Syndrome Association

Also known by the working name Portsmouth DSA

Formerly known as Portsmouth Down Syndrome Support Group and Portsmouth Down Syndrome Association (Footprints)

Registered Charity Number: 1147355

Registered Address: Unit 1, Aspen House, Airport Service Road, Portsmouth, Hants PO3 5RA

Board of Trustees:

Rachael Ross MBE - Chair (Director of Fundraising & Education/Training, School Advisory Service and Training Director, Community Liaison – business, health, education)

Ken Ross – Vice-chair (Development Officer, Fundraising, Community Liaison)

Helen Nelson – Treasurer

Alice Osborne – Charity Secretary

Simon Brock – Trustee

Bank: HSBC, Commercial Road, Portsmouth, PO1 1EP

Independent Examiner: Mrs J D Watts FCCA, ACA
James Todd & Co, 24 Landport Terrace, Portsmouth PO1 2RG

Patrons: We are very honoured to have the support of some wonderful individuals who lend their support to the charity and help us raise awareness:

- Professor Sue Buckley OBE - world leading expert in education and development for children with Down syndrome, and renowned Chief Scientist of Down Syndrome Education International
- Emma Barton (Actor)

Portsmouth Down Syndrome Association

- Scott Heffield (Adventurer and TV Presenter)
- Tim Treloar (Adventurer and TV Presenter)
- Liam Bairstow (Actor)
- Tommy Jessop (Actor)
- Gregory Jones KC and Sheriff in the City of London

Introduction

Portsmouth Down Syndrome Association is an award-winning charity, and we are very proud to have received royal approval and 'Freedom of the City' of Portsmouth for our 'exemplary work'.

Formerly established in May 2009, Portsmouth Down Syndrome Association is committed to improving the lives of individuals across the South of England and beyond. We know our young people can succeed when given the opportunity with the right support, and we believe they deserve the same opportunities and right to be included and experience success as their peers.

Portsmouth DSA provides a range of some of the best specialist services and activities in the UK. Our programme is the most fully comprehensive and progressive service package supporting both the family and the child from the point of diagnosis to young adulthood. Our direct interventions in all areas of development, education and training, assist families and professionals in providing tangible and effective support to improve outcomes. We teach children the skills they need to reach their developmental milestones, succeed at school, and become valued and productive members of their communities. Services are offered free of charge, eliminating financial barriers to ensure broad and equitable access.

Portsmouth DSA works hard to raise awareness, champion inclusion, and celebrate diversity in all areas. Life expectancy has dramatically increased for people with Down syndrome. However, awareness in the community, health and education provision, employment opportunities and regulations have not kept pace with this progress, largely due to lack of representation and interest at governmental levels. As a result, individuals continue to experience inadequate provision and outcomes, discrimination and exclusion on daily basis. We strive to readdress the balance and promote equality for all by equipping individuals & families with the knowledge & skills they need to succeed in all areas and improve outcomes, by raising awareness in all sectors of society & sharing the skills and knowledge required to enable meaningful inclusion. When children with Down syndrome are given opportunities to participate and be fully included, the whole community benefits.

Our activities continue to be very well received by parents and professionals, our services capacity is full, and we continue to operate waiting lists due to high demand. Membership has continued to steadily rise, and with careful planning we have been able to cater for all our new families' needs. We have once again seen an increase in the number of prospective parents with a diagnosis making contact, and also the number of families with a new baby making contact has risen. As a first point of contact new families have been put in touch with our excellent Family Liaison Team who always ensure a warm welcome.

Portsmouth Down Syndrome Association

Governance

Governing Document

Portsmouth Down Syndrome Association is governed by a constitution adopted on 16th November 2011 which has been approved by both HMRC and the Charity Commission.

The Board of Trustees

The Board of Trustees of Portsmouth Down Syndrome Association has overall responsibility for the charity's activities and finance. There are currently five dedicated and experienced trustees working either full time or part time on behalf of the charity, three of whom are parents of a child with Down syndrome.



The **Chair of the Board** and charity co-founder **Rachael Ross MBE**, previously served on the Board of Trustees for Down Syndrome Education International (DSEI) for over five years, as well as on educational boards. Rachael has experience of governance, fundraising, and issues concerning Down syndrome at a local and national level. As a qualified English, Geography and Drama teacher with specialism in 'additional needs', and parent of a child with Down syndrome, she created the national reading scheme 'Up for Reading' for DSEI which was endorsed and supported by over 100 the UK's top publishers and leading authors and helped to raise the profile of Down syndrome across the UK. Her education and awareness articles have also been featured in national and regional education publications such as the Times Educational Supplement.

Rachael is also a Founding Officer for the **National Down Syndrome Policy Group (NDSPG)** working as part of the team which spearheaded the recent Down Syndrome Act 2022, and she drafted the initial Down Syndrome Bill with fellow trustee Ken. The NDSPG acts as Secretariat to the **All-Parliamentary Group on Down Syndrome**. Rachael is BAFTA's first joint Accessibility and Inclusion Patron, and along with fellow trustee Ken, they have been a leading voice in improving authentic representation and access for disabled talent in the film and TV industry.

In recognition of her sustained and outstanding contribution to education and Down syndrome, Rachael was awarded The Points of Light Award in 2015 by the serving Prime Minister, the prestigious Portsmouth Civic Award in 2018 presented by the Lord Mayor of Portsmouth, and she was honoured by the late Queen when she was made an MBE for 'Services to Education and Down Syndrome' in 2019. Rachael was most recently recognised by the late Queen, with a Platinum Champions Award in 2022 and was selected as one of the top 70 exemplary volunteers from across the UK. She was also recognised along with the charity for her 'outstanding' efforts during the pandemic, receiving a 'special recognition' award from the late Queen.

Portsmouth Down Syndrome Association

Rachael oversees the smooth running of the charity and is the **Director of Educational Services**. She is the **Nursery, Schools and Further Education Advisory and Training Service Manager**, co-ordinates the teenage social activity evenings, and is also the

charity's **Director of Fundraising**. She is a Founding Trustee for the National Down Syndrome Policy Group acting as Secretariat to the All-Parliamentary Group on Down Syndrome and has been elected BAFTA's joint first Accessibility and Inclusion Patron.

The charity's Vice-Chairperson **Ken Ross OBE** is the charity's **Development Officer**. He has worked as an entrepreneur predominantly in the real estate, film and charity sectors. He is a Founding Trustee for the National Down Syndrome Policy Group acting as Secretariat to the All-Parliamentary Group on Down Syndrome, and BAFTA's joint first Accessibility and Inclusion Patron. Ken is also the Director and Chair of the Southeast Hants Special Olympic Team. Ken has significant experience in working with national bodies to provide solutions within his areas of expertise with a particular focus on learning disability inclusion within the Arts and real estate sectors, as well as working with various 'think tanks'. Ken has been honoured by HM the Queen, with a Platinum Champions Award and was selected as one of the 70 exemplary volunteers in the UK. He was also recognised along with the charity for his 'outstanding' efforts during the pandemic, receiving a 'special recognition' award from the late Queen. We were delighted when Ken was recognised by the King in the New Year's Honours List 2024, and made an OBE for 'services to Education, Charity and Down Syndrome'.

Helen Nelson is the charity's Treasurer. Helen has been PDSA's bookkeeper for several years and continues to be an enthusiastic volunteer supporting our events and fundraisers. She comes from a senior banking background, bringing her vast knowledge and expertise to the role.

Trustee **Alice Osborne** Alice is a social worker by profession and has worked in the field of disability for over 18 years, becoming a member of the charity six years ago after her son Ted was born. She worked as a volunteer for several years before taking on the role of **Charity and Community Manager**. Last year we were delighted when Alice accepted the voluntary position of Trustee on our board as permitted by our constitution. She continues to be employed by the charity to manage our membership, welcome new families and lead our community liaison team, in particular educating and training health professionals to effectively support new families as permitted by our constitution. The inclusion of Alice to our team marks a significant development in our organisational capacity and outreach. With her expertise and enthusiasm, we have successfully expanded our community network still further, enabling us to engage in a series of new projects and initiatives which will improve (maternity) outcomes for families and individuals.

Trustee **Simon Brock** comes from a senior banking background and brings his expert knowledge of business and finance to the charity.

Most board members carry out various managerial and administrative responsibilities as 'professional volunteers' in addition to their trustee role.

Management and Admin Team

We have a very small but hardworking and dedicated management and admin team, who work

Portsmouth Down Syndrome Association

alongside Rachael, Ken and Alice.

At Portsmouth DSA we fully recognise the positive impact regular social opportunities have on our families. Our talented events officer **Stacey Brooks** was a long-standing volunteer on the events team before stepping up to take over the role of **Events Manager**. Stacey now plans and organises a wealth of exciting social opportunities and events for our members, supported by our charity volunteers, as well as coordinating the junior social activity evenings.

Catherine Crook, co-founder of Portsmouth DSA, has been actively volunteering for the charity since inception. She is also employed for a few hours a week as the charity's **Social Communication Group Manager** ensuring our teenage communication sessions run seamlessly throughout the year.

In September, in desperate need of more admin support for our small team, we welcomed **Hannah Smith** who is employed in the role of Charity Administrator, helping to ensure our centre runs smoothly. Hannah has volunteered for the charity from early childhood and has always supported our Great South Run team, either participating herself or supporting our runners with DS and LD. She has also been an active volunteer at our Special Olympic sessions for many years, winning the **Portsmouth Young Volunteer of the Year Award 2024**. Hannah's positive attitude, creative skills and adaptability have made her an invaluable asset to our team.

The board and management team are actively supported by a strong collective of charity practitioners, the Parent and Community Liaison Team, the Events Team and the Social Media and IT team, as well as additional member volunteers and individuals from the community, all of whom provide valued support for the charity, and some of these have volunteered for many years.

Awards and Acknowledgements

The Queen's Award – the MBE for Charities

Portsmouth DSA is very proud to have royal approval.

It is always wonderful when the charity receives recognition for the hard work and achievements of its governance team, practitioners, volunteers and members.

We were greatly honoured when Portsmouth DSA was awarded the **Queen's Award** for outstanding service in 2021. This award is the equivalent of the MBE for charities; the highest accolade for exemplary service for charities, which is awarded for life. The Deputy Lord-Lieutenant who nominated us, told us we were selected from thousands of organisations, and the national judges were immensely impressed with our 'exceptional' work.

Charity Chairperson Rachael Ross MBE said, *"We are extremely proud that the work of our outstanding team has been recognised by Her Majesty the Queen, and that our charity now has Royal Approval. Our volunteers work very hard, but it's hugely rewarding, and we never fail to be amazed by all the children can achieve. This award is a tribute to the dedication of*

Portsmouth Down Syndrome Association

our brilliant team of trustees, staff and volunteers, our wonderful families, and the local community whose collective efforts and support have helped to make a real and positive difference to the lives of children with Down syndrome."

We were further honoured by **HM the Queen** and the **Royal Voluntary Service** with **The Queen's Covid Special Recognition Award 2021** nominated by the **Lord Lieutenant of Hampshire** for outstanding work for the community during the COVID pandemic.

Portsmouth DSA is proud to have Freedom of the City of Portsmouth

We were delighted to have been granted the prestigious **Freedom of the City of Portsmouth** by the Lord Mayor this year, for our '*phenomenal support for the community and to recognise dedication, self-sacrifice, skill and hard work by those who supported the community during the COVID pandemic*'.

Additional Awards and Acknowledgments

We were very proud to win the **Shaping Portsmouth Education Award 2020** for our 'outstanding contribution to the field of education in the region'. We were thrilled to win the Persimmon Homes **Best Educational UK Charity Award in 2019**, beating over 3,500 national & local charities to the accolade and securing a substantial grant of £100,000 towards our new centre.

Trustee Rachael, and former trustee Lucy have previously been awarded the **Points of Light Award** by former PM, David Cameron, in recognition of outstanding charity work. Rachael was also awarded the prestigious **Portsmouth Civic Award for Services to Education and Down Syndrome** in 2018, presented by the Lord Mayor of Portsmouth. In 2019 the charity's work was further spotlighted when Chairperson Rachael was made an **MBE by the Queen for services to education and the field of Down syndrome**. In 2024, Trustee Ken was made an **OBE for services to charity, education and down syndrome**.

Three of our members received national recognition for their 'outstanding' and 'exemplary' work in their communities. In June 2023 Rachael and Ken were recognized as two of 70 **Platinum Jubilee Champions** with medals presented by King Charles and Queen Camilla. We were also delighted that Charity Manager Alice was selected from thousands to be a **Coronation Champion** in 2023 by Queen Camilla.

Charity ambassador Max received the **Portsmouth Inspirational Men 'Inspiring Young Man Award'** in 2022.

Our administrator Hannah was awarded **Young Volunteer of the Year 2024**, for her sustained contribution in the charity sector.

Three of our volunteers, Katherine Bull, Jenny Beard and Siva Ramaraj received **Inspiring Portsmouth Volunteer** certificates from Portsmouth City Council.

Portsmouth Down Syndrome Association

Portsmouth DSA was finalist runner up in the **National Diversity Awards** in 2023.

These awards reflect the hard-working community at Portsmouth DSA. They have helped to increase awareness about Down syndrome and have also raised the profile of the charity which has in turn had a positive impact on fundraising and donations, and improved community relations.

Objects

The charity's objects are set out in the charity's governing document:

- To offer support and social activities for families
- To preserve and protect the health and welfare of children with Down syndrome
- To advance the education of the medical profession and the public when appropriate about childhood disability

Our Long-awaited Charity Relocation

After extensive delays caused by the COVID pandemic, and subsequent delayed refurbishment works, we were delighted to finally relocate to our wonderful new centre last year. This modern facility not only meets our charity's growing needs but also enhances our capability to expand our services, for the first time enabling us to employ an onsite administrator, further streamlining our operations. Our new centre features expansive office space, a large kitchen, dual therapy rooms enabling simultaneous sessions, an interactive sensory room, a spacious teen room, and a generous family room where we have hosted a highly successful party celebrating the King's Coronation. The centre is already proving invaluable, and we eagerly anticipate its official opening later this year.

Activities

Portsmouth Down Syndrome Association remains committed to improving the lives of children with Down syndrome and their families by providing invaluable support and friendship, as well as essential services and training. We continue to directly support families, schools, education professionals and health professionals in Hampshire, and the surrounding counties of Dorset, West Sussex and Wiltshire. We continue to receive further requests for support and information from across the UK and internationally, from individuals, support groups, health and education professionals and a variety of organisations.

In the current economic climate, many families experience difficulties accessing specialist services, and we have continued to see a steady rise in families contacting our charity, particularly those living further afield as there are no Down syndrome support services in their areas. There has also been a notable rise in education professionals and particularly health and social care professionals making contact to ask for advice and support. It is reassuring to see a rise in new support groups setting up, along with established groups expanding their range of specialist service, and we continue to signpost families to their closest support group if they have one and to relevant support services. Many of these alternative groups have used the Portsmouth DSA services model and have asked for advice from our trustees and practitioners, and some have attended our sessions and training for guidance.

Portsmouth Down Syndrome Association

We are proud to be able to share our skills, experience and knowledge in such a positive way, and we actively encourage all support groups to do the same.

We continue to support families seeking asylum in the UK, and our volunteers have risen to the challenge, going above and beyond to ensure that individuals were warmly welcomed and continue to have the necessary resources and support they need, or that virtual advice is given to the relevant professionals.

Our social activities include coffee and information mornings, social events, information sessions and our very popular seasonal parties.

We also provide a wide range of specialist health, social and educational services to families and related organisations across Portsmouth, Hampshire, surrounding counties and beyond. These activities usually include our New Family Support Service, Baby Support Groups, Early Development Groups, Learn and Play, Makaton Signing for adults, Makaton Singing, Communication Groups, Social Communication Groups, our Teenage Buddy Initiative and an extensive Education Advisory Service for schools, nurseries and further education colleges. These services are progressive and comprehensive, starting from the point of diagnosis which increasingly can be prenatally, and provide support for the child and their family throughout their time in education.

Accompanying the services are specialist training packages which are often bespoke to meet the specific needs of our young people, parents and related professionals. This year we have been delighted to receive invitations to train a wide variety of professionals including teaching and support staff, doctors, maternity nurses and midwives, social workers, healthcare students, GPs and optometrists as well as parents and school students.

Comprehensive Specialist Support from the Point of Diagnosis Through to Adulthood

Specialist Services

Portsmouth DSA provides the best and most extensive programme of free specialist social and educational support in the UK, delivered by leading experts in Down syndrome. It is a comprehensive and progressive package that starts from the point of diagnosis, and continues throughout childhood and beyond, offering support in all areas of social and educational need for young people, their families and related professionals.

Pre-natal and Post-natal Support

We have found that developments in ante-natal screening have led to an increase in pre-natal diagnoses, leading to an increase in the number of families and professionals contacting us at this time. Our Parent and Community Liaison Team offers support and information from the point of diagnosis for families and professionals.

Down Syndrome Specific Maternity Pathways

After many years of dedicated advocacy, we were thrilled when 2 regional hospitals contacted us asking for our support in creating their inaugural Down syndrome specific maternity

Portsmouth Down Syndrome Association

pathways. We are delighted that one of these pathways has now been approved and implemented, and the charity featured in the hospital's PR and media with a message of thanks for our support. We are optimistic that these specialised pathways will raise awareness in the medical community, combat measurably poorer maternity outcomes and higher rates of stillbirth for babies with Down syndrome, improve services for families, enhance quality of care and help ensure clear and consistent support for families, with better life outcomes. We continue to work in positive partnership with hospitals.

Parent and Community Liaison Initiative



We are very proud of the links **Alice Osborne** and our community team have nurtured with hospitals, and health professionals, and Portsmouth DSA is very much the 'go to' organisation when advice is needed about Down syndrome specific interventions.

Our Community Liaison Initiative includes a comprehensive support system for new parents from the point of diagnosis. Professionals supporting the family make a referral to Portsmouth DSA with the family's permission. Our team make contact with new families in hospital, at home and/or at our centre to answer any questions and offer advice and support. The

team also regularly works with midwives, nurses, paediatricians, GPs, social workers, portage workers and other relevant health professionals to ensure they have the information and training they need to effectively support families and colleagues.

Our **Parent Welcome Pack** is distributed to maternity units and hospitals in the region and continues to be very well received by new families. A world leading toy manufacturer are also impressed with our support pack and continue to support the initiative by donating a soft toy for each new family for inclusion.

Supporting literature is distributed to health professionals including our '**Delivering a Diagnosis of Down Syndrome**' and '**Positive Language**' advising how best to deliver a positive diagnosis and what language is best to use when considering Down syndrome.

Our programme offers bespoke training to health professionals including our '**Down Syndrome Today**' training and to date our team has had the pleasure of delivering training to thousands of midwives, paediatricians, GPs, maternity nurses, health visitors, social workers and other related professionals, always with 100% positive feedback.

The initiative continues to be a big success especially as families are now automatically sign-posted/referred to us by professionals. We continue to receive excellent feedback from parents and health professionals about our initiative.

"After your amazing talk, I took the learning points back to my practice and we've

Portsmouth Down Syndrome Association

updated our annual reviews for patients with Down syndrome. Already patients and relatives have given great feedback and we have picked up hypoparathyroidism in the first week in a new patient to our practice who had never had a review with his previous GP, so a massive thank you". (GP, Hampshire)

"Portsmouth DSA have helped us immensely over the last year since we had our prenatal diagnosis. The support provided by their visits, alongside meeting families were without doubt the main reason we were able make the decision to continue with the pregnancy." (PDSA Parent 2023)

"If you're worried about getting a diagnosis you won't look back once you join Portsmouth Down syndrome Association. It's such an amazing place that does so much. They have really helped me to feel normal and understand it's ok to have the bad days as we've all been there. It's a family I never knew I needed." (PDSA Parent, 2024)

"PDSA provides wonderful personal and practical advice to children and their families, right from the point of diagnosis. As a group of paediatricians, we have also benefited from some fantastic teaching provided by the charity. Forging a closer link between medical staff and the PDSA will undoubtedly enhance the experience for young people with Downs syndrome." James Hammond, Paediatric Registrar, Wessex

"PDSA guidelines are a great resource to help the neonatal team support the families in those wonderful and challenging first few days of life. 35 neonatal nursery nurses from the Thames Valley and Wessex Neonatal Network had the privilege of listening to PDSA representatives in a recent conference run by the Neonatal unit in Portsmouth. This session touched us all and had a very positive influence in the way we think about children with Down syndrome." Susi Hill, Practice Educator, Neonatal Intensive Care Unit QAH

Creating and Supporting Unique Community Initiatives

Special eye clinic partnership



We were very proud to have been instrumental in the establishment of **England's first Down syndrome specialist eye clinic at Portsmouth University**, offering highly specialist services for children and adults with Down syndrome. Our team collaborated to provide comprehensive training for staff and devised a differentiated programme enhancing the accessibility and effectiveness of eyecare services for individuals with Down syndrome. The clinic was in high demand, with families travelling from counties across the south of England to access these services.

Portsmouth Down Syndrome Association

Unfortunately, the clinic was a victim of the COVID pandemic as it failed to secure continued funding as funds were diverted, and families were devastated when the clinic closed its doors in 2023. However, we are delighted to support the relocation of many of the staff and specialist equipment to a nearby local opticians Percy Harrison's offering the same specialist care, and we continue our positive partnership with them.

Baby Support Groups

Parents receive support from the point of diagnosis, and this support follows on seamlessly after birth.



Portsmouth DSA **Baby Support Groups** are delivered by our expert practitioners and offer a comprehensive support system, for parents and infants up to 18 months old. These sessions provide crucial guidance on the healthcare services and routine check-ups that parents should expect, outline the benefits available to them, and offer assistance with the completion of application forms. Furthermore, parents receive tailored advice on various aspects of child development and are introduced to effective activities that can be practiced at home to foster their child's growth and development.

Crucially, parents are introduced to other families, and are encouraged to form their own network of support. Many of our families have lasting friendships that have spanned 16 years or more.

Learn and Play Sensory Sessions

Our **Learn and Play Sensory Sessions** are for pre-school families and are designed to introduce stimulating play and learning environments with an emphasis on sensory play to activate the child's senses in a fun and relaxed setting. These sessions are delivered by **Alice Osborne** and supported by volunteers, meaning that our staff are free to chat with parents, offer advice and answer any questions they might have. Alice also coordinates the pre-school activities and services including our **Makaton Signing Classes** for adults and our **Makaton Sing and Sign** sessions for pre-school children.

New Sensory Room

Our new interactive sensory room was completed this year. This innovative space is dedicated to supporting early brain cognitive development and sensory exploration. Featuring a range of stimulating experiences—from soft lighting and soothing sounds to tactile activities and vibrant visuals—our sensory room offers a safe and engaging environment for infants to explore, grow and have fun.

Each element of the room is tailored to nurture the developmental needs of young children, helping to boost motor skills, enhance sensory perception, and promote emotional well-being. Our sensory room provides an ideal setting for infants to reach important early

Portsmouth Down Syndrome Association



milestones while also offering parents a unique opportunity to engage in meaningful play with their infants in a safe space.

Early Development Groups

Early intervention sessions have proved to be invaluable for our pre-school children, teaching them a wide range of skills to enable them to achieve their early developmental milestones, and help prepare them for school. The groups provide regular structured activities which cover areas such as speech and language, reading, cognitive development, early number work, social skills and fine and gross motor skill development. These sessions are provided monthly for the children who are under 24 months, and then increase to fortnightly. Parents and their associated professionals are

also invited to attend termly twilight training sessions covering a range of relevant topics, which this year have included 'early numeracy skills', 'encouraging positive social skills and managing behaviour' and 'fine play and motor skills'. As well as parents, we encourage associated professionals to attend.

Specialist resources are utilised such as the **See and Learn Reading and Speech and Language materials**, and **Numicon** equipment. Parents are encouraged to continue activities with their children at home to increase effectiveness. The sessions not only benefit the children who take part, but also parents can experience new methods and resources which will support their child's development. Groups consist of only two to four children to enable maximum learning to take place.

Thank you to **National Lottery Community Fund**, the **Zurich Community Trust**, the **Percy Bilton Charity**, **Garfield Weston Foundation**, the **Hants and Isle of Wight Community Fund**, **Hall and Woodhouse** and the **Wickens Family Foundation** who provided donations to help fund our pre-school learning or for furniture and equipment.

Communication Groups

There is a national shortage of specialist Speech and Language Therapists and after struggling once again to replace our therapist who left us due to family bereavement, we decided to take steps to train our own co-worker to deliver our **Communication Groups** with support from Symbol UK and Portsmouth DSA practitioners. We welcomed Elena Ryabinova to the team who now delivers these weekend monthly groups for school age children aged 4 – 11.

These Communication Groups, coordinated by Alice, are the next educational phase building on the foundation skills developed in our Early Development Groups. Groups consist of three or four children with a focus on interaction and communication skills, with targets and activities set to practise at home throughout the month. Interventional strategies are used to support all areas of development, and aim to improve speaking and listening, language, reading and social skills.

Social Communication Groups

Children move on from the Communication Groups to our teenage **Social Communication**

Portsmouth Down Syndrome Association



Groups once they reach secondary school age. The format for these groups for our senior members (aged 11 upwards) has evolved to consider their changing needs as they get older and have been extremely successful. These groups are larger, and more informal with a maximum of 10 individuals. Parents are not present, and the young people take on more responsibility for their session; they set up the room and decide which topics they would like to discuss, they use iPads & iPhones, but the sessions continue to develop their speech, language, conversation and social skills in a safe environment.

These monthly sessions are coordinated by **Catherine Crook**, and led by our co-workers **Tracy Leason** and **Danni Frances**. Tracy has an abundance of experience delivering SALT programmes and has worked with children with DS and SEND in an educational setting. Co-worker Danni who works alongside Tracy, has experience of working with young people with a learning disability and Down syndrome and is currently working as a part-time teaching assistant at Redwood Park Academy school whilst studying for a BA in Education, Special Needs and Disability at Chichester University. Both Danni and Tracy are well liked by the teenagers. Our Communication Groups and Social Communication Groups are overseen by **Leela Baksi (Symbol UK)** specialist Speech and Language Therapist. The young people enjoy attending and the sessions and they continue to be popular with our members, offering invaluable social opportunities.

Our Unique Buddy Initiative – Special Partnership with King Edward VI School

We have developed strong links with many schools in the region including **King Edward VI School (KES)** who have been active supporters of our charity over past years, and who often participate in our Down Syndrome awareness celebrations each year.

We know that our young people often don't access the same social opportunities as their peers and are at real risk of social isolation. We have been delighted to continue our exciting **Buddy Partnership** which is now in its sixth year with some older students from King Edward VI School who join us for our Teenage Social Communication Group outings with the aim of developing friendships and social skills.

The partnership has been hugely successful, and the students and our teenagers have embraced the opportunity to engage with massive benefits to all taking part.

Outings have included swimming, ski-slope donutting, and our ever-popular barn dance.

The buddy initiative is overseen by **Rachael Ross** (senior) and **Stacey Brooks** (junior group).

Portsmouth Down Syndrome Association



It has been wonderful to watch the friendships developing throughout the year.

The academic year's partnership ended in a successful summer camp at the end of August at King Edward VI School, where pupils and our teenagers took part in fun activities, and outings including trips to the zoo and a theme park.

We were delighted last year to establish our **Junior Age Buddy Initiative** with KES enabling us to be able to offer this same exciting buddying experience to our junior age group. Activities are focused on the school

site, and include sports, games and dancing. This new initiative has proved very popular and provides vital socializing opportunities for our juniors.

"It is a real pleasure and privilege for King Edward VI School to be partner in a long-standing relationship with Portsmouth Down Syndrome Association. Through numerous activities and social events, PDSA members and KES students form deep and meaningful bonds, and in doing so help one another to grow and learn. It would be very easy to assume that the benefits of this scheme are targeted solely at nurturing the young people from PDSA, but the truth is that the learning gained by KES students is equally profound. This is one of our longest and most cherished partnerships." **Neal Parker, Head, King Edward VI School**

We would like to thank everyone at KES for working with us in partnership enabling us to provide such an exciting and unique opportunity for our teenagers.

"I love going to Marwell Zoo and Paultons Park. I love making friends with Nadia and the others and doing things without mum and dad. I feel safe. I love spending time with my mates from PDSA & KES, we do really cool stuff and have fun." PDSA Teenager

"PDSA means I get to enjoy fun activities monthly with new friends, and I love seeing the enjoyment that every single person gets out of it. It was a wonderful experience I learned so much and made so many great friendships and happy memories - I can't wait for next summer!" KES Student

Thank you to **Portsmouth City Council Inclusion Grants, Mencap and John Lewis** for their contributions this year towards our communication groups, and thank you to Jody and **Percussion Play**, who generously continue to sponsor our Teenage Buddy Initiative.

Flagship School, College and Nursery Education Specialist Advisory Service

Portsmouth Down Syndrome Association worked hard to create and develop our leading **School, College and Nursery Advisory Service**, Directed by **Rachael Ross MBE**, it is now in its fifteenth year and we believe it is the best and most comprehensive example of its kind in the UK.

Portsmouth Down Syndrome Association

Our programme supports the successful inclusion of our members across more than 100 educational establishments across the south. We are proud to have now supported some of our older members consistently throughout their education from nursery all the way through to further education. We have seen the advantages of this sustained intervention are manifold, including early identification and intervention for emerging issues, smoother transitions between educational stages, a higher rate of successful mainstream inclusion, and enhanced social and academic outcomes overall.

We receive enquiries from non-member schools and schools in neighbouring counties as awareness about the service spreads. The service is in high demand, and we operate waiting lists.

This bespoke support service is a comprehensive package covering all aspects of education, assessment, development and inclusion, individualised to meet the needs of the student and school. The student is visited in the school setting once a term, and school staff and parents receive advice in all areas of development including successful differentiation and teaching strategies, individual assessment and target setting. An annual report is provided to support the student's educational needs in their Annual Review.



The package includes remote support for parents and staff throughout the year, as well as bespoke training and a trouble-shooting service to address any issues which might arise over the year.

This is our most expensive service, and as more of our members reach senior school age, service provision in this area is expected to grow rapidly which will impact on the charity's costs.

Whilst many primary schools have previously benefited from our support and have had experience of teaching a child with DS, this still remains a largely unfamiliar area for the majority of senior schools.

Careful consideration has been given to this, and the service has been adapted accordingly. The

Senior Schools Advisory Package includes transition support, one full day visit a term, with additional twilight training or feedback after the visit, and each new school also receives an additional training session at the start of the term, or just prior to this.

Several termly training sessions are also included in the outreach programme on a variety of relevant topics delivered by our expert practitioners or experts in the field of Down syndrome. This year, as well as our annual DS overview and learning profile training, we have featured topics including 'maths for life', 'behaviour and supporting friendships', 'scaffolding independent learning skills' and 'supporting speech and language across the curriculum' and we have equipped schools with useful resources, films and toolkits to facilitate inclusion.

All training is relevant and based on up-to-date and evidence-based research, and we are

Portsmouth Down Syndrome Association

very pleased to note that our training evaluation sheets continue to be 100% positive.

Last year, we made the decision to review our training model, and fully open our training to a much wider audience. We were delighted when representatives from Hampshire County Council and Portsmouth City Council joined us for a variety of sessions. We have been delighted to have previously been joined by the SEND County Inspector, who attended our inclusion training. She was very impressed with the session and has since been actively recommending our services to schools.

Our chairperson and director of education Rachael was once again invited to contribute to the **Hampshire Inspection and Advisory Service SEND Publication** which was circulated to all schools in the county. Our guidance has also been featured in the national **Times Educational Supplement** with a circulation of 59,000 as well as online coverage.

Having our work showcased in this way is a great opportunity for us to raise the profile of DS and the charity, and to spread our important message direct to schools and teaching staff who do not automatically receive the training they need to successfully include our children.

Feedback has continued to show that our Nursery Advisory Service and Nursery Twilight Training Service remains very popular with our pre-school parents and related professionals. Although the training takes place outside of working hours in the evening, the courses are always full. Again, feedback has been 100% positive.

The School, College and Nursery Service has provided an excellent PR opportunity for the charity and has helped us develop and maintain strong links with the school communities with many of these schools holding fundraising or awareness days on our behalf particularly during Down Syndrome Awareness Week in March. We have been able to offer schools a variety of resources for their awareness celebrations, including new PowerPoint assemblies for junior and secondary age groups.

This year the charity partnered with some of our schools to produce **Down syndrome specific case studies** at the request of the **Department for Education**, with the intention of including them in the forthcoming **Down Syndrome Act Guidance**.

The charity has previously invested time into exploring alternative accreditations and exam courses which are more suitable for our young people, some of these had not been accessed previously and will offer more choice and opportunities, in particular the **WJEC examinations** board portfolio of alternative qualifications known as the Entry Pathways.

The attraction of these qualifications for schools and pupils is that its prescribed content is more flexible allowing schools to more easily include a pupil in a GCSE class, and schools can more easily dual enter pupils for examinations. We have produced advice literature for parents and professionals about all the options available, and an explanatory training session for schools (and parents). Our practitioners have allocated extra time to work with the relevant schools, to explain more about the options available and to help them plan. Our schools have been keen to explore these alternative pathways and they have embraced our training and guidance. These alternative options have revolutionised exam possibilities for our teenagers and can also be of benefit to other pupils in the school community, and as our eldest cohort of pupils reach exam age, they are leaving school with GCSEs and more meaningful qualifications.

Portsmouth Down Syndrome Association

We were very grateful to receive a donations from the **King Charles III Charitable Fund**, **PKCF** and **Tesco Groundworks** towards our school service, and thank them for their support.

Our Education Practitioners

Our services are all delivered by experienced and highly qualified experts in the field of Down syndrome. **Kate Milford** is our in-house education manager. Kate has more than twenty years' experience teaching in mainstream secondary schools, most recently as Assistant Headteacher and SENCo with responsibility for inclusion. In this role she has gained a wealth of experience, delivering training on a range of special educational needs and supporting teachers to differentiate their curricula. Kate has first-hand knowledge and experience of strategies which can be implemented to allow students with Down Syndrome to flourish both socially and academically, whilst also developing independent skills in preparation for adulthood. Kate has been an asset to the team.

Allison Powell has a background in secondary education, and further trained as a specialist advisory teacher with Down Syndrome Education International. Allison co-delivers our Junior and Senior School Advisory Service and training, and is a recognised authority on the education of children with DS, formerly working with Ups and Downs, Southwest. Allison has worked to develop a training programme and supporting literature to advise schools and parents on alternative accreditations and exam pathways which best enable our young people to gain a wide range of recognised qualifications at school and our senior school pupils are reaping the rewards of this and are studying for and gaining meaningful qualifications enabling greater options at further education level.

Becky Baxter (LETS Go!, formerly Down Syndrome Education International) has over 21 years' experience of working with children with Down syndrome. She is also a qualified speech and language therapist, specialising in Down syndrome, and is the Chair of the Clinical Excellence Network for Down Syndrome. Becky co-delivers our Early Development Groups, Nursery and Infant School Advisory Service along with practitioners **Sarah Holton, Sam Wood, Tracy Nye and Kate Dale**. Becky and her team have been working with Portsmouth DSA since 2009.

Our Head Patron, **Professor Sue Buckley OBE**, is one of the foremost global experts in education and development for children with Down syndrome, and for well over 46 years, her pioneering work has been enabling children with DS to reach their full potential. Sue is always ready to offer her friendship and expert advice to the group.

We are fortunate and very excited to continue to work with some of the top educationalists and DS experts in the UK, and the world.

Safeguarding

We take the issue of safeguarding our children very seriously. Trustees and service providers have been approved by the Disclosure and Barring Service (DBS) which has replaced the Criminal Records Bureau disclosure (CRB checks). Using the DBS update service, these records are checked regularly for any changes by our elected Safeguarding Officer who has

Portsmouth Down Syndrome Association

attended safeguarding training and shared relevant information with charity staff and volunteers. Key charity staff and volunteers have also attended safeguarding and first aid training. We have a Safeguarding Policy with all relevant supporting documents and all trustees and relevant staff, practitioners and volunteers are familiar with this document and are aware of procedure should there be any concerns.

Social Events and Parties

Many children with a learning disability do not have the same access to social opportunities as their peers, and families can feel socially isolated. We encourage our families to develop their own network of support, and our social events and parties remain of key importance to provide families providing opportunities to come together, have fun make friends and share experiences.

Events over the past financial year have included our Titchfield Railway Day and Picnic generously hosted by the **Fareham and District Society of Model Engineers**; our very popular Easter party where children characters and received chocolate eggs donated by **Asda, Sainsburys and Tesco** and soft toys donated by **TY Toys** who have supported our event for many years; a spooky Halloween party supported by the **Royal Navy**; and a very successful outdoor activity evening at Fairthorne Manor where children are given the opportunity to take part in activities such as kayaking, archery and climbing. All our events are extremely popular and well attended. Our Christmas Party in December was another big success. The **Events Team** once again excelled themselves with this event, making an amazing Santa's Grotto and hosting a fantastic party for the children.

Thank you to **Little Life** for very generously sponsoring our Christmas party this year, to the representatives from the **Zurich Challenge** team who very generously supported our Christmas party with volunteer hours and toy donations, **One Stop** who once again made a donation towards our celebrations, and **Asda** who regularly support our coffee mornings.

Portsmouth DSA knows how to throw a good party, and the biggest thanks must go to our amazing volunteers led by our events manager **Stacey Brooks**, who every year go above and beyond to ensure our members have access to these amazing social opportunities.

VOLUNTEERS

We encourage a community spirit within our membership, and a good percentage of our members volunteer either on a regular or ad hoc basis. We estimated that over 600 volunteers formed part of our cheer teams or supported our event over the **Great South Run** weekend in addition to our 250 runners. The outstanding **Rapid Relief Team** of volunteers once again generously donated time on the day, along with refreshments and food for all our supporters. Our families and the Events Team regularly volunteer to support collections and other charity activities.

We are fortunate that we have a strong core of volunteers who support regularly, but it would be good to see some new faces supporting our activities. All members and members of the community are very welcome to join any of our support teams, or volunteer on an ad hoc basis.

We have regular volunteers who help run our coffee mornings for parents and members of the community, and also an events team of volunteers who help plan and organise our many social

Portsmouth Down Syndrome Association

and fundraising events. These teams included members from the wider community, as well as parents. Their support has been invaluable, and this has allowed us to timetable extra awareness events and fundraisers with our charity partners this year. Our charity is largely operated by volunteers, and we are very grateful to everyone for their support.

In 2021 we were honoured by the Queen who awarded the charity the Queen's Award for Voluntary Service; the highest accolade any charity can receive, and the equivalent to an MBE. This award is part of the UK honours system and awarded in recognition of 'sustained excellence and outstanding contribution to the community'.

It is credit to our inspirational leadership team, all of whom are full or part-time volunteers themselves, and our wonderful army of volunteer supporters. We were also delighted to receive an additional **Special COVID Recognition** honour for our work during the COVID pandemic. Each volunteer was proud to receive an individual **Queen's Award certificate** and a **Special Covid Recognition Certificate**, and this number included some of our teenagers with Down syndrome and their older siblings.

Fundraising, Awareness and Community Support

With the support of our volunteers and Events Team, we have organised several fundraising events over the past academic year, including the **Great South Run** in October. The run takes place annually in Portsmouth, and we continue to take advantage of its location to make it one of our largest annual fundraisers. Participant numbers have not yet recovered to pre-COVID levels, but we had a large team of entrants in all runs and remain the best represented regional charity to take part. This was a great PR opportunity to spread awareness about the charity to the wider community, and we received some very positive feedback from the organisers and members of the public. It was wonderful to see our green army of charity vests, and some of our runners were featured on the local news and radio.

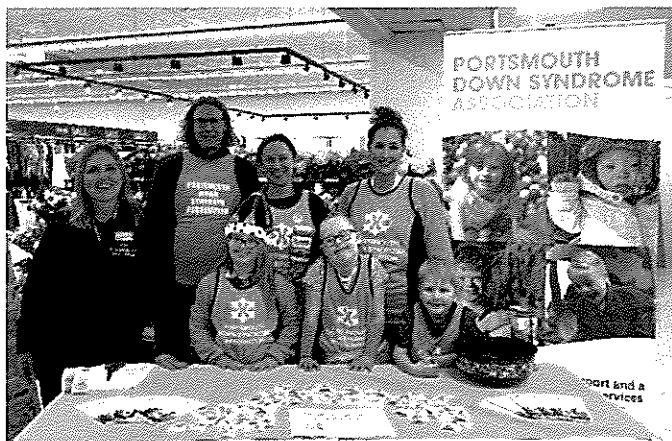
In particular, we were thrilled with the number of under 18s who turned out on the Saturday to support us, including many of our children, as well as athletes from the **SE Hants Special Olympic Team** who joined us for the 5k for the fourth year running. We also had a huge team of volunteers as usual who encouraged runners at various cheer points around the course..

We were very grateful to the **Rapid Relief Team** who provided free hot food and refreshments to hundreds of children, families, runners and supporters on Saturday, and to the **Great South Run organisers** who once again donated a free marquee for our families on Saturday.

Our annual **Down Syndrome Awareness Week** celebrations were held in March accompanied by our social media awareness campaign which was generously sponsored by local solicitors **Warner Goodman** for the thirteenth consecutive year, which meant that we were able to reach a much wider audience. As usual our celebrations were well supported with schools, hospitals, businesses and individuals holding awareness assemblies, events or fundraisers, and our **'Rock Your Socks'** awareness campaign was widely supported.

Other key fundraisers included our annual **HMS Warrior 1860 Black-tie Dinner and Auction** in November and our **T21 Sponsored Walk in October**.

Portsmouth Down Syndrome Association



We have worked hard over the years to nurture strong links with our community, and support from the business community has continued to be good, although we are still feeling the impact of COVID and the cost-of-living crisis on donations, and many businesses, including supermarkets, have withdrawn their usual charity community schemes which have been of benefit to us in previous years.

We have enjoyed charity partnerships with **The Royal Sussex Lodge** who have been excellent partners raising funds for the charity, as well as continuing our long-term partnership with **Warner Goodman Solicitors**, who generously sponsored our Down Syndrome Week Awareness celebrations for the 13th consecutive year, as well as actively supporting our fundraising events. **Percussion Play** continue to be generous sponsors of our Teenage Social Outings. We are delighted to more recently partner again with the **Man V Fat Havant** team, and look forward to working with them again this year.

Community and business donations have also included donations from **Portchester Pétanque** and **Hayling Legends** who have once again generously held fundraisers in aid of our charity, the **Wickens Family Foundation**, **TK Maxx**, **Joseph Smith SMS Developments**, **Emsworth Loves Local**, **Southsea Tennis Club** who organized a 24 hours tennis-a-thon, and **Evelyn Partners**.

Local businesses have continued to offer the charity their expertise and support pro bono for which we are very grateful, including our web designers **Design Image** who provide invaluable support in all areas, Jon and the team at **Progression Signage** who have donated free signage and PR materials to us for many years, the **Taylor family** who donate a window cleaning service, and the **Free Kicks Foundation** who offer our members exciting football club mascot experiences, and the **Disabled Sailors Association** for providing incredible sailing opportunities.

Our parents and families remain supportive. Many took part in the Great South Run or encouraged friends and colleagues to do so. Some also held fundraising events on behalf of the charity, have taken part in sponsored challenges to raise funds or approached their employers to support us including parent **Max Oxlade** who completed an intrepid skydive from 15,000 ft.

A big thank you to all our donors, fundraisers and volunteers for your valued support.

Improving Representation in the Media

The charity actively promotes inclusion and equality, and we believe that it is essential for individuals with Down syndrome and learning disabilities to be offered equal opportunities to

Portsmouth Down Syndrome Association

be fairly represented & included in the media world. We have continued our work with **BAFTA** on their diversity board to advise about inclusion in the TV and film industry. We were proud to have co-commissioned a review into inclusion policy, culminating in **inclusion and diversity guidelines** which were disseminated throughout the industry, leading to visibly improved opportunities and better representation for people with DS and other disabled talent.

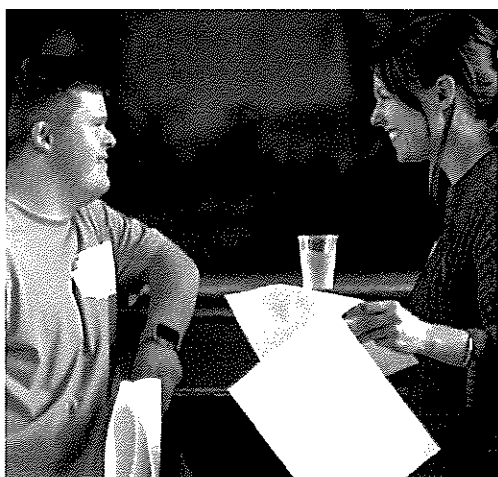
Over the past two years we worked with our contacts to ensure the refurbished **BAFTA** building was fully accessible for all. The report promotes a more inclusive media community, with increased opportunities for individuals with LD; an exciting prospect, and we are proud to have encouraged and contributed to this.

Already as a direct result of our work and recommendations, the first actor with Down syndrome, **Tommy Jessop**, was invited onto the BAFTA elevate programme, and is the first voting member of BAFTA and also the first to present an award at the BAFTAs. We were delighted when Tommy was selected for the programme, and his first meeting was with none other than Martin Scorsese! We look forward to seeing much more of Tommy on our screens. Last year, we were delighted to see TV Presenter **George Webster** win his well-deserved BAFTA – the first actor with Down syndrome to receive the award.

Our successful partnership with the producers of the multi-award-winning film, **My Feral Heart** created a wonderful opportunity to raise awareness, especially when our leading actor Steven Brandon (who some of you would have met at our special charity screening a few years ago) beat fellow nominees including Michael Fassbender, Eddie Redmayne, Ewan McGregor and Daniel Radcliffe amongst others, to win Best Actor in the **National Film Awards**.

Following on from this, we have joined forces with **SweetDoh Productions** to produce a short film, **Innocence**, which offers leading roles to actors with Down syndrome and LD and is currently being submitted to film festivals. To date the film has won **The London Lift Off Film Festival Award**, and awards at the **International Lift Off Film Awards**, along with the **Don Quixote Award at the Krakow Film Festival**. As a result, we are currently producing a featurelength script for the film, which we hope will be turned into a feature length film, providing further opportunities for individuals with DS to have leading roles in film.

Stage 21 Acting Masterclass



Stage 21, a distinguished national acting masterclass, was established by our partners at **Sweetdoh Productions** in collaboration with **Portsmouth DSA** and funded by the **Arts Council**. Over the past three years, this initiative has provided valuable training and experience, with recent workshops conducted in Manchester, London and at Portsmouth's prestigious **Kings Theatre**—which generously donated its facilities for three days. Specifically designed for young adults with Down syndrome, Stage 21 offers a unique opportunity to train with seasoned professionals from the acting industry. We are pleased that two of our program's alumni have earned BAFTA awards for their work.

Portsmouth Down Syndrome Association

PR

Successful PR is important as it not only helps parents to know where they can find support and raises awareness about Down syndrome and the charity, but also plays a key role in fundraising. We continue to work hard to raise the profile of the charity in the local area. We have established good communications with parents, schools and local organisations and continue to build a strong network of support.

We have had several articles printed in the local news and local free papers about our events and services, and our Vice-chair Ken and Chair Rachael have also taken part in numerous local and national radio and TV interviews over the year, along with some of our staff and members.

We also think that it is important to share our knowledge and expertise with others, and we were delighted when we were approached by the County Inspector for Inclusion after meeting with us at our centre and attending our training sessions, and invited to contribute once again to **Hampshire County Council's HIAS SEND Publication** which is circulated to all schools and education professionals in the county. Rachael's article 'Key Strategies for Successful Inclusion' was circulated to all schools in the county which was sure to have raised the profile of the charity. Another of Rachael's articles promoting successful inclusion was featured in the **Times Educational Publication**, with a huge national audience of educational professionals.

The charity **Facebook** page (18.7 followers), **Twitter** page (2,697 followers), **Instagram** (1,552 followers) and our new **LinkedIn** pages (503 followers) have continued to help improve communication with our members, and also acted as a medium where businesses, members of the community and our supporter's families can find out more about what we do.

We enjoyed our first '**viral**' post on Facebook this academic year, which featured member Alfie as the Portsmouth Football Club Mascot courtesy of the Free Kicks Foundation, which gained an extraordinary 28K likes and nearly 500 shares.

The Members' only Facebook Page is regularly utilized where members can share news and photos in a closed setting. It is wonderful to see families sharing news about their child's achievements for our 'Proud Parent Moment (PPM)' on 21st of each month.

We actively encourage our members to support our social media pages, as it is vitally important to our fundraising efforts that we have a strong and recognizable presence in the local community.

Our interactive website, designed by graphic website designers **Design Image Limited**, has continued to be popular with both families and the community, and lists all our dates for events as well as showcasing our latest news.

We think it is very important to liaise regularly to highlight issues surrounding DS with those in positions of authority, our local councillors and MPs. These issues have included service provision, screening and abuse, and we were cautiously pleased to see that our hard work lobbying the Secretary of State for Transport was previously rewarded with a review and update of the eligibility criteria for the Blue Badge for individuals with DS.

Local councillors receive a regular newsletter updating them with the work of the charity, and raising any issues our members are experiencing like access to SALT or Blue Badge eligibility.

Portsmouth Down Syndrome Association

Some of these individuals take part in our Down Syndrome Awareness Week celebrations, and you might even see a few rocking their socks with us, or joining our Great South Run team.

We have regularly attended think tanks and also visited the Houses of Parliament and 10 Downing Street where we have had the opportunity to discuss with MPs, Ministers, civil servants and policy makers the work we do and its importance.

There are still great advancements to be made in this area to help our children access the support they need to thrive and to access the opportunities they deserve. We would encourage all our members to have an active voice, stay in regular contact with their MPs and service providers and support our awareness campaigns.

Driving Change at a National (and International) Level!

The National Down Syndrome Policy Group

In 2021, we were delighted to join forces with other key charity leaders to establish the **Down Syndrome Policy Group**. Our charity's chair and vice-chair, Ken and Rachael, are two of the 15 founding officers who work towards supporting people with Down syndrome to have a say in the formation of policy in matters that impact their lives. The group is supported by leading national organisations such as Mencap, as well as over 125 Down Syndrome organisations. We believe it is very important that people with Down syndrome are at the heart of any policies about people with Down syndrome. The NDSPG includes officers, ambassadors, patrons and advocates with Down syndrome, and we are very proud that a number of our teenagers have played an active role.

The Down Syndrome Act 2022

The first undertaking of the **National Down Syndrome Policy Group** (NDSPG) was to lobby for a **Down Syndrome Act** to improve opportunities, services and outcomes for people with Down syndrome. They were delighted when Dr Liam Fox MP sponsored the Down Syndrome Bill. Rachael and Ken played a key role writing the initial draft of the Down Syndrome Bill, and working closely with Liam, ministers, civil servants and ambassadors with Down syndrome at Parliament. After a huge campaign which was well supported by PDSA members and the wider community, including rallies outside Parliament, the Bill finally completed its journey to become a historic **Down Syndrome Act**, and England is the first country in the world to have passed such legislation.

It was thought that a Down Syndrome Act was an impossible feat, but we are very proud to have championed this, and it demonstrates what can be achieved when our community joinstogether with one voice. We now continue to work with the NDSPG, parliament and our community to help influence the creation of the **Down Syndrome Act Guidance**, the first draft guidelines being expected later this year in the areas of:

Portsmouth Down Syndrome Association



- Community and wellbeing
- Education
- Employment
- Healthcare and Research
- Maternity Care

We previously organised 3 large-scale guidance consultation meetings for people with Down syndrome and their families in Westminster and Leeds for which parliamentary civil servants join us to hear views on education, healthcare, social care

and employment. Again, it was wonderful that teenagers from Portsmouth DSA and our patron **Tommy Jessop** was able to join us.

To further complement our celebrations, we organised a meeting at **10 Downing Street**, where ambassadors with Down syndrome met with **Maria Caulfield the Under Secretary of State for the Department of Health and Social Care** to highlight the daily issues they face and to discuss the creation of the Down Syndrome Act Guidance. It was a very successful meeting, and a great opportunity for our ambassadors who were a credit to our community. The meetings also paved the way for further discussions.



Downing Street Hosts Portsmouth DSA and the NDSPG

Members of **Portsmouth Down Syndrome Association** experienced a memorable pre-election highlight with an invitation to visit No.10 Downing Street. In a special gathering, ten young representatives from the charity were warmly welcomed by Mrs. Murty, the wife of the former Prime Minister Rishi Sunak.

Mrs Murty accompanied the group on an exclusive tour of Downing Street, followed by lunch.

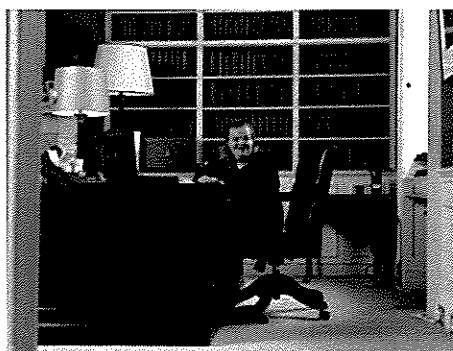
Portsmouth Down Syndrome Association



Charity Ambassador Max Ross said, "Mrs Murty was very kind and put us all at ease. She told us to call her 'Ash' and she shared personal stories about herself, including her favourite colour is pink, and that she and her daughters love Taylor Swift's music. Then she asked us to tell her all about ourselves."

Ken and Rachael with the **National Down Syndrome Policy Group** also helped organise a large reception the previous day at Downing Street for over 150 individuals with Down syndrome from across the UK to celebrate the enactment of the Down Syndrome Act 2022 and to raise awareness about the condition. Guests included actor **Tommy Jessop** (Line of Duty) and CBBC Presenter **George Webster**. It is thought to have been the largest gathering of people with Down syndrome in the building's history.

Three individuals with Down syndrome, including Portsmouth DSA Ambassador **Max** were interviewed by **Downing Street Press** and took part in an iconic photo shoot to mark this landmark occasion. The articles were then prominently featured on both the former **Prime Minister Rishi Sunak** and **Mrs Murty's** social media pages.



Portsmouth Down Syndrome Association

Reflecting on the week's events Rachael said, "We were honoured to be invited to No10 once again. We were able to speak with ministers and key policy makers about the daily challenges people with Down syndrome and their families face. The week was a huge success, and we certainly achieved our aim to raise awareness about Down syndrome at the highest national level."

ICB Symposium

The **Down Syndrome Act 2022** established a unique position within the Integrated Care Board (ICB), specifically dedicated to Down syndrome. This role is intended to provide more tailored and efficient healthcare services for individuals with Down syndrome, enhancing coordination in addressing their specific needs. The focused approach aims to improve the quality of care, health outcomes, and the responsiveness of support services to better meet individual requirements.

Rachael and Ken with the National Down Syndrome Policy Group, organised a national ICB symposium for Down Syndrome leads, hosted in the **Department of Health and Social Care**, London to examine the new role, highlight existing good practice and encourage networking. Amongst others, we were delighted to feature Portsmouth DSA's patron **professor Sue Buckley**, and welcomed speeches from **Minister Maria Caulfield** and the **Secretary of State, Victoria Atkins**.

Over half of England's ICBs were represented, and we received excellent feedback from delegates with multiple requests for a follow-up symposium.

School Census Success!

Portsmouth DSA has lobbied over past years for the inclusion of Down syndrome as a separate category in the **annual school census** alongside other conditions such as autism and hearing impairment. Working with the National Down Syndrome Policy Group, and supported by the majority of DS organisations, we garnered the support of Education Secretary Gillian Keegan, and Ken and Rachael presented the case to the Star Chamber for approval. We were delighted when they consented to our request, and from January 2025, Down syndrome will be included in the school census, meaning that for the very first time, the number of pupils with Down syndrome in schools and the location of these pupils will be known. We will no longer need to estimate these figures.

Amongst other benefits, this could enable local authorities to plan and evaluate for more targeted specialist provision, facilitate the effective dissemination of Down syndrome specific education guidelines, interventions, and resources, and help predict and inform future staff and training needs regionally and nationally. It will help identify trends. We will be able to seamlessly monitor the transition to and from mainstream or special settings, compare mainstream inclusion figures in different regions, and identify regions that rely too heavily on an 'automatic' special school pathway. Figures can be used to support research, tribunals and to argue for more specialist support and training. It will most certainly lead to increased accountability.

Meaningful data is fundamentally important and has the great potential to improve experiences and outcomes, but as with all information, its true value lies in its effective utilization. **As a community, we all now have a collective responsibility to ensure this new data is used to our advantage.**

Portsmouth Down Syndrome Association

The All-Party Parliamentary Group on Down Syndrome

The **National Down Syndrome Policy Group** serves as secretariat for the **All-Party Parliamentary Group on Down Syndrome (APPGDS)** and played a pivotal role in its re-establishment after a hiatus of twelve years. Chaired by the **Right Honorable Sir Liam Fox**, the APPGDS aims to campaign for changes to government policy to improve the lives of people with Down syndrome, and it aims to raise awareness of issues affecting people with Down syndrome and the prospects for improving life outcomes.

The support from Sir Liam Fox and the APPGDS has been crucial in facilitating the formulation, adoption, and execution of relevant policies. We were delighted when APPGDS members unanimously supported the Down Syndrome Bill on its journey through parliament to enactment. Their sustained support has also been essential in maintaining the progress of the Down Syndrome Guidance and bolstering our successful proposal to include Down syndrome as a distinct category in the national annual school census.

Finances

The annual accounts are compiled by James Todd & Co.

Trustees are committed to raising the total estimated funds required to fund services for a year in advance, and these funds will now be built upon in preparation for the forthcoming year. We are extremely grateful to Leonard Gold for their continued support. We are also grateful to Helen Nelson our charity bookkeeper, who meticulously maintains the charity's books.

There has been a rise in membership and members accessing services over the past year. It has become more evident that members living further afield are much less active and engaged as distance is an issue. The level of engagement of general members has still not recovered to pre-COVID rates.

We have membership criteria in place, and as a charity managed largely by volunteers, our families are regularly reminded that in line with our criteria there is an expectation that families are active and support the charity in any way they are able. Very few members leave and there continues to be a high demand for our services. This, combined with a marked increase in running costs and resources, means that going forwards, numbers and associated costs are almost certain to increase steadily and are unlikely to decline.

Trustees remain mindful that **fundraising is a key issue** especially considering the cost-of-living crisis, as **the future of the charity is wholly dependent on successful fundraising by its members**. There have been steep increases in areas of operational costs, and our contracted practitioners have been forced to increase their fees by 20%. We are aware that more of our children are now reaching senior school age, and these are the costliest of our services. We also need to consider the increased operational costs of our new centre.

We support families from the point of diagnosis, and our children from birth through to the end of school and further education, and we estimate that the cost for very basic services (baby support group, early development group, communication group and nursery/school advisory service) is approximately £26,000 upwards per child (not including assessments, reports, training for parents and related professionals, trouble-shooting service, training for

Portsmouth Down Syndrome Association

practitioners and staff, bespoke training for schools, SRE training, resources, social events, drama so the real cost is probably £30,000+). We have 132 families (over 500 members), and our aim is to support them from the point of diagnosis and throughout childhood.

We also provide support and advice for non-member families, schools and organisations in the community, and the wider community. We therefore need to continue to ensure there are sufficient funds to meet this objective by increasing our reserves on an annual basis if possible, with a minimum of one year's running costs in reserve at any one time.

The Year Ahead

Fundraising remains a crucial concern to enable the continuation of our work. **We invite the entire Portsmouth DSA community to support these vital efforts**, ensuring our charity's ongoing success.

After facing delays due to COVID-19 and subsequent backlogs, we are excited to announce the **official opening of our charity centre will take place in November**. Over the next year, one goal is to secure funding to **complete the furnishing of the centre**, including updating older furniture and seating, but funding service provision will take priority so this may be a more long-term objective.

We have a very small staff team. Ideally, **we need at least two new staff members** to better manage the increased administrative duties and support the expanding services for schools. However, this is once again contingent upon the availability of funds.

Over the forthcoming year, we are committed to maintaining and strengthening our collaborations with families, local communities, organisations, and government agencies. We remain dedicated to providing a broad spectrum of specialist services and to enhancing opportunities and national policies with the aim of positively impacting and transforming the lives of people with Down syndrome, helping them develop the crucial skills needed to become integral and valued members of their communities.

We look forward to implementing two new exciting initiatives in the Autumn term. We are delighted to be establishing **Music Man Project Portsmouth** which will offer music tuition and performance opportunities which are not always accessible to people with a learning disability.

We also hope to introduce our **'Friends of Portsmouth Down Syndrome Association'** initiative which we hope will attract much needed support for the charity in the form of volunteers and charity partnerships.

I would like to extend my heartfelt thanks to the Portsmouth DSA Board of Trustees, our dedicated volunteers, families, and supporters. Only with your invaluable support will our charity continue to thrive.

Portsmouth Down Syndrome Association

This report was approved by the Board of Trustees

Signed by order of the Board of Trustees 2/10/24



Rachael Ross MBE

Chair, Portsmouth Down Syndrome Association's Board of Trustees

Portsmouth Down Syndrome Association

Independent Examiner's Report to the Trustees on the Unaudited Financial Statements of Portsmouth Down Syndrome Association

I report on the accounts for the year ended 31 March 2024 set out on pages twenty five to thirty.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year (under Section 144(2) of the Charities Act 2011 (the 2011 Act)) and that an independent examination is required.

It is my responsibility to:

- examine the accounts under Section 145 of the 2011 Act
- to follow the procedures laid down in the General Directions given by the Charity Commission (under Section 145(5)(b) of the 2011 Act); and
- to state whether particular matters have come to my attention.

Basis of the independent examiner's report

My examination was carried out in accordance with the General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statements below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that, in any material respect, the requirements

- to keep accounting records in accordance with Section 130 of the 2011 Act; and
- to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the 2011 Act

have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Mrs J Watts FCCA, ACA
James Todd and Co.
24 Landport Terrace
Portsmouth
Hampshire
PO1 2RG

Date: 31 October 2024

Portsmouth Down Syndrome Association

Statement of Financial Activities for the year ended 31 March 2024

	<u>Notes</u>	<u>2024</u> <u>Unrestricted</u>	<u>2024</u> <u>Restricted</u>	<u>Total</u> <u>2024</u>	<u>Total</u> <u>2023</u>
Incoming Resources					
Donations and grants	3	218,407	30,987	249,394	196,007
Investment Income		2,070	-	2,070	1,279
Total Income		220,477	30,987	251,464	197,286
Resources Expended					
Raising Funds	4	7,553	-	7,553	8,435
Charitable Activities	5	209,142	10,378	219,520	166,360
Support Costs	6	165,423	3,177	168,600	105,335
Total Expenditure		382,118	13,555	395,673	280,130
Net Income / (Expenditure)		(161,641)	17,432	(144,209)	(82,844)
Net movement in funds					
		(161,641)	17,432	(144,209)	(82,844)
Reconciliation of funds					
Total funds brought forward		545,472	-	545,472	628,316
Total funds carried forward		383,831	17,432	401,263	545,472

Portsmouth Down Syndrome Association

Balance Sheet as at 31 March 2024

	<u>Notes</u>	<u>Total 2024</u>	<u>Total 2023</u>
Fixed assets	13	221,271	307,666
Current assets			
Debtors	10	19,142	48,232
Cash at bank and in hand		161,666	191,492
		<hr/>	<hr/>
Total current assets		180,808	239,724
Creditors			
Amounts falling due within one year	11	(816)	(1,918)
		<hr/>	<hr/>
Net current assets		<u>401,263</u>	<u>545,472</u>
 Funds of the charity			
Unrestricted funds		383,831	545,472
Restricted funds		17,432	-
		<hr/>	<hr/>
		<u>401,263</u>	<u>545,472</u>

Approved by the trustees on 2/10/24

and signed on behalf of all trustees



Mrs R Ross - TRUSTEE



Mrs H Nelson – TRUSTEE

Portsmouth Down Syndrome Association

Notes to the financial statements for the year ended 31 March 2024

1. ACCOUNTING POLICIES

Basis of preparation of accounts

The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) issued on 16 July 2014 and with the Charities Act 2011.

The charity constitutes a public benefit entity as defined by FRS102.

Donations

Donations and sponsorships are recognised in the accounts when the charity becomes entitled to the resources and the monetary value can be measured with sufficient reliability.

Government grants

Grant income received under the Government's Coronavirus Job Retention Scheme is recognised in the Statement of Financial Activities as income in the period to which the underlying furloughed staff costs relate.

Expenditure

Resources expended are recognised where it is more than likely than not that there is a legal or constructive obligation committing the charity to pay out resources and the amounts of the obligation can be measured with reasonable certainty.

Management and administration costs

Only those costs specifically identified as for the administration and management of the charity are included in the accounts as such costs.

Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Leasehold improvements	over the term of the existing lease, which ceases in October 2026.
Fixtures and Fittings	straight line over 5 years.

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset and is credited or charged to profit or loss.

2. EXPENDITURE IN FURTHERANCE OF THE OBJECTS OF THE CHARITY

All expenses paid in furtherance of the objects of the charity are donations.

3. DONATIONS AND OTHER INCOME

	<u>2024</u>	<u>2023</u>
Donations and other income	217,156	154,791
Grants	<u>32,238</u>	<u>41,216</u>
	<u>249,394</u>	<u>196,007</u>

Portsmouth Down Syndrome Association

4. RAISING FUNDS

	<u>2024</u>	<u>2023</u>
Great South Run	<u>7,553</u>	<u>8,435</u>
	<u>7,553</u>	<u>8,435</u>

5. CHARITABLE ACTIVITIES

	<u>2024</u>	<u>2023</u>
School Services	74,455	94,423
Communication Groups	7,558	8,113
Early Development Groups	14,260	9,747
Staff Costs	81,022	28,490
Social Events & Entertainment	26,262	19,373
General Expenses	9,434	2,226
Nursery Outreach Service	<u>6,529</u>	<u>3,988</u>
	<u>219,520</u>	<u>166,360</u>

6. SUPPORT COSTS

	<u>2024</u>	<u>2023</u>
Accountancy	828	815
Bookkeeping	415	411
Cleaning	1,003	-
Insurance	1,664	897
Bank charges	118	111
IT Costs	2,164	704
Service charges	33,654	40,923
Rates	4,254	-
Postage	287	304
Stationery & Printing	679	363
General	-	-
Venue Hire	1,914	2,478
Training	18,970	20,983
Legal costs	780	2,580
Repairs & Renewals	15,040	6,646
Telephone	435	915
Depreciation	<u>86,395</u>	<u>27,205</u>
	<u>168,600</u>	<u>105,335</u>

8. TRUSTEES REMUNERATION

There were no trustees' remuneration or benefits for the year ended 31 March 2024 nor for the year ended 31 March 2023.

Portsmouth Down Syndrome Association

9. STAFF COSTS

	<u>2024</u>	<u>2023</u>
Wages and Salaries	96,435	54,469
Social Security Costs	2,756	-
Pension Costs	1,861	957
	<hr/>	<hr/>
Total wages Costs	<u>101,052</u>	<u>55,426</u>

No employee earned £60,000 pa or more.

The average number of employees during the year was 6, this consists of two full-time employees and four part-time employees.

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>2024</u>	<u>2023</u>
Trade debtors	300	-
Prepayments	18,842	48,232
	<hr/>	<hr/>
	<u>19,142</u>	<u>48,232</u>

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>2024</u>	<u>2023</u>
Accruals	816	1,918
	<hr/>	<hr/>
	<u>816</u>	<u>1,918</u>

12. ACCOUNTANCY FEE ANALYSIS

	<u>2024</u>	<u>2023</u>
Accountancy	270	270
Independent Examination	558	545
	<hr/>	<hr/>
	<u>828</u>	<u>815</u>

13. TANGIBLE ASSETS

	Leasehold Improvements	Fixtures & Fittings	TOTAL
Cost			
Cost brought forward	318,282	16,589	334,871
Additions	-	-	-
Disposals	-	-	-
	<hr/>	<hr/>	<hr/>
Cost carried forward	318,282	16,589	334,871
Depreciation			
Depreciation brought forward	26,855	350	27,205
Depreciation charge	83,074	3,321	86,395
	<hr/>	<hr/>	<hr/>
Depreciation carried forward	109,929	3,671	113,600
	<hr/>	<hr/>	<hr/>
Net book value brought forward	291,427	16,239	307,666
Net book value carried forward	<u>208,353</u>	<u>12,918</u>	<u>221,271</u>

Portsmouth Down Syndrome Association

14. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	<u>2024</u> <u>Unrestricted</u>	<u>2024</u> <u>Restricted</u>	<u>Total</u> <u>2024</u>	<u>Total</u> <u>2023</u>
Fixed Assets	221,271	-	221,271	307,666
Current Assets	180,808	-	180,808	239,724
Current Liabilities	(816)	-	(816)	(1,918)
	<u>401,263</u>	<u>-</u>	<u>401,263</u>	<u>545,472</u>

MOVEMENT IN FUNDS	<u>At 1.4.23</u>	<u>Incoming</u>	<u>Resources</u>	<u>At 31.3.24</u>
Unrestricted Funds				
General Fund	545,472	220,477	(382,118)	383,831
Restricted Funds				
Miscellaneous Funds	-	30,987	(13,555)	17,432
	<u>545,472</u>	<u>251,464</u>	<u>(396,823)</u>	<u>401,263</u>

24. OPERATING LEASE COMMITMENTS

	2024	2023
Within one year	13,750	27,500
Between two and five years	-	13,750
In over five years	-	-
	<u>13,750</u>	<u>41,250</u>