

PORTSMOUTH DOWN SYNDROME ASSOCIATION

England & Wales · Charity number 1147355

Details

Other names	PORTSMOUTH DOWN SYNDROME ASSOCIATION(FOOTPRINTS), PORTSMOUTH DOWN SYNDROME SUPPORT GROUP (FOOTPRINTS), FOOTPRINTS, PORTSMOUTH DOWN SYNDROME ASSOCIATION, PORTSMOUTH DSA
Status	Registered
Legal form	Other
Registered	2012-05-21
Register	View on the Charity Commission register

Contact

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Activities

Objects: (1)TO OFFER SUPPORT AND SOCIAL ACTIVITIES FOR PARENTS AND CARERS OF CHILDRENWITH DOWN SYNDROME OR ADDITIONAL NEEDS, LIVING IN THE GEOGRAPHICAL AREA OF PORTSMOUTH OR SURROUNDING AREAS. (2)PRESERVE AND PROTECT THE HEALTH AND WELFARE OF CHILDREN WITH DOWN SYNDROME OR ADDITIONAL NEEDS AND THEIR FAMILIES WITHIN THE GEOGRAPHICAL AREA OF PORTSMOUTH OR SURROUNDING AREAS. (3)ADVANCE THE EDUCATION OF THE MEDICAL PROFESSION AND GENERAL PUBLIC WHEN POSSIBLE ON THE SUBJECT OF CHILDHOOD DISABILITY AND ITS IMPLICATIONS FOR THE FAMILY.

Activities: Portsmouth Down Syndrome Association provides support, advice and educational services for children and their families in South Hampshire. We offer an extensive range of services including early development sessions for preschool children, communication therapy, parent and professional training days

and a school outreach service. We also hold social events, drama groups and seasonal parties.

Classification

- **How:** Provides Human Resources, Provides Buildings/facilities/open Space, Provides Services, Provides Advocacy/advice/information
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities

Geography

- **Area of benefit:** LOCAL
- Hampshire
- Portsmouth City

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£315,228	£407,136	-	-
2024-03-31	£251,464	£395,673	-	-
2023-03-31	£197,286	£280,130	-	-
2022-03-31	£208,270	£193,986	-	-
2021-03-31	£130,709	£120,089	-	-

Trustees

Name	Role	Appointed
Rachael Ross MBE	Chair	2012-05-18
Alice Osborne		2023-09-07
Dr Spencer Pitfield OBE		2025-03-01
Gregory Jones KC		2025-03-01
Ken Ross OBE		2015-01-09
SIMON CHRISTOPHER BROCK		2013-07-09

PORTSMOUTH DOWN SYNDROME ASSOCIATION

England & Wales - Charity number 1147355

Accounts



**PORTSMOUTH
DOWN SYNDROME
ASSOCIATION**

Unaudited Financial Statements Year ended 31 March 2025

James Todd and Co Limited

Portsmouth Down Syndrome Association

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PORTSMOUTH DOWN SYNDROME ASSOCIATION

Portsmouth Down Syndrome Association Trustees' Report and Financial Statements for the Year Ended 31 March 2025

The Chairperson submits Portsmouth DSA's Annual Report and the Statement of Financial Activities and Balance Sheet for the year ended 31 March 2025 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 and CEO (Director of Fundraising & Education/Training, School Advisory Service and Training Director, Post 11 Services Manager, Community Liaison – Business, Health, Education, Music Man Project, Portsmouth, National Down Syndrome Policy Group, All-Party Parliamentary Group, and Parliamentary Liaison)

Ken Ross OBE – Vice-chair and Treasurer (Development Officer, Fundraising, Community Liaison, National Down Syndrome Policy Group, All-Party Parliamentary Group, and Parliamentary Liaison)

Alice Osborne – Charity Secretary (Charity Centre Manager, Pre-school and Primary Services Manager, Manager for Community Health, Training, Family Liaison Team& Membership)

Simon Brock – Trustee

Gregory Jones KC – Trustee

Spencer Pitfield OBE – Trustee

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

Independent Examiner: Mrs J D Watts FCCA, ACA
James Todd & Co, Furzehall Farm, 110 Wickham Road, Fareham,
Hampshire, PO16 7JH

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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)
- Scott Heffield (Adventurer and TV Presenter)
- Tim Treloar (Adventurer and TV Presenter)
- Liam Bairstow (Actor)
- Tommy Jessop (Actor and Advocate)

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

Introduction

Portsmouth Down Syndrome Association is an **award-winning charity**, and we are very proud to have been awarded **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

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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 for the school service in particular. Membership has continued to steadily rise, but 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. 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.

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 finances. There are currently six dedicated and experienced trustees on the Board, three of whom have a child with Down syndrome. These members carry out various managerial and administrative responsibilities as full and part-time 'professional volunteers' in addition to their Trustee roles.

Helen Nelson, the previous Charity Treasurer and book-keeper retired earlier in the year and was replaced by **Ken Ross as Treasurer, and Tracy Dukes our new book-keeper**. We would like to whole-heartily thank Helen for her years of dedication and exemplary service.



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 education boards. Rachael has experience of governance, fundraising, and issues concerning Down syndrome at a local and national level. As a qualified English, Media, Geography, Sport 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.

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Rachael is a Founding Officer and Trustee of the **National Down Syndrome Policy Group** (NDSPG), where she played a key role, with fellow trustee Ken, drafting the Down Syndrome Bill, which led to the landmark **Down Syndrome Act 2022**. The NDSPG also serves as Secretariat to the **All-Party Parliamentary Group on Down Syndrome**, and both Ken and Rachael are the group's **parliamentary liaisons**.

Rachael is also BAFTA's first joint **Accessibility and Inclusion Patron**, a position she shares with Ken. Together, they have been instrumental in advancing authentic representation and access for disabled talent in the film and television industry.

In recognition of her outstanding and sustained contributions to education and advocacy for people with Down syndrome, Rachael has received numerous honours. These include the **Points of Light Award** (2015) from the Prime Minister, the **Portsmouth Civic Award** (2018) presented by the Lord Mayor of Portsmouth, and an **MBE** in 2019 from the late Queen for *Services to Education and Down Syndrome*. In 2022, she was honoured during the Queen's Platinum Jubilee year with a **Platinum Champions Award**, and was recognised as one of **70 exemplary charity leaders** for her exceptional efforts during the pandemic, receiving a **Special Recognition** award from Her Majesty, Queen Elizabeth.

Within Portsmouth DSA, Rachael plays a 'hands on' central role in day-to-day operations as **CEO**, and her professional volunteer responsibilities include being the **Director of Educational Services** and **Director of Fundraising**. She manages the **Nursery, Schools and Further Education Advisory and Training Service**, coordinates **teenage social activity evenings**, and oversees the overall strategic direction and smooth running of the charity.

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 charity leaders 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'**.

Trustee Alice Osborne is a qualified social worker with over 18 years of experience in the field of disability holding a master's degree in the Applied Psychology of Intellectual Disability. She became a member of Portsmouth DSA eight years ago following the birth of her son, Ted. After several years as an active volunteer, Alice took on the part-time paid role of **Charity Centre Manager**, while continuing to generously contribute many additional hours on a voluntary basis.

We were delighted to welcome Alice to the **Board of Trustees** last year in a voluntary capacity, as permitted by our charity constitution. Her appointment has strengthened the connection between staff and trustees, providing valuable insight, continuity, and a direct link

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to day-to-day operations. Alice's professional expertise and unwavering commitment continue to enhance the strategic direction and effectiveness of the charity.

In her ongoing staff role, Alice manages our **membership services**, welcomes new families, and leads our **community liaison team**, with a particular focus on educating and training health professionals and volunteers across the UK. Alice's work plays a vital role in improving how professionals support new families from the point of diagnosis and with her knowledge, passion, and leadership, we have been able to grow our community network and launch a series of new initiatives aimed at **improving maternity outcomes** for families and individuals with Down syndrome.

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

We were delighted to appoint two new highly experienced Trustees in March:

Trustee Greg Jones KC is a **former patron** of Portsmouth DSA until becoming a Trustee, and a long-time supporter of the charity. His roles include being a **well-respected Alderman and Sheriff of the City of London**, as well as serving as the **Chancellor of the Diocese of Manchester**.

Trustee Spencer Pitfield OBE supports strategic leadership and management, with **expertise spanning politics, education, SMEs and the environmental sector**. He was a **councillor and magistrate** for 16 years, and former **CEO of Paces Charity**, Sheffield. Spencer was awarded an **OBE by Prince William in 2016 for 'Political Service'**.

We warmly welcome both Greg and Spencer to the team and look forward to working with them and benefitting from their vast experience and expertise.

Management and Admin Team

We have a very small but hardworking and dedicated management and admin team, who work 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 part-time **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 five hours a week as the charity's **Social Communication Group Manager** ensuring our teenage communication sessions run seamlessly throughout the year.

Hannah Smith 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

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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 dedicated group of charity **practitioners**, along with the **Parent and Community Liaison Team**, **Events Team**, and **Social Media and IT Team**. In addition, we benefit from the ongoing support of member volunteers and individuals from the wider community, many of whom have generously given their time and expertise for several years. Each of these contributors plays a vital role in the charity's success, and their commitment and service are deeply valued.

Awards and Acknowledgements

The Queen's Award – the MBE for Charities

Portsmouth DSA is very proud to have Royal Approval and freedom of the City of Portsmouth 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 said 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 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.

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 incredibly proud to receive the **Shaping Portsmouth Education Award** in 2020, recognising our *outstanding contribution to education in the region*. The previous year, we were thrilled to win the **Persimmon Homes Best Educational UK Charity Award**, standing out among more than 3,500 national and local charities and securing a £100,000 grant to support our new centre. In 2023, we were honoured to be named the runner-up in the prestigious **National Diversity Awards**.

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Chair, Rachael, and former Trustee Lucy Field have previously been awarded the **Points of Light Award** by No.10 Downing Street and 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 advocacy**.

Three of our members received national recognition for their 'outstanding' and 'exemplary' work in their communities. In June 2023 Rachael and Ken were recognised as two of 70 UK **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, and was appointed as a **Queen's Baton Bearer** in the baton relay to herald the Commonwealth Games 2022.

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

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

These awards are a testament to the dedication and hard work of the Portsmouth DSA community, shining a light on the efforts of our volunteers. While no one volunteers in pursuit of recognition, it is incredibly meaningful when their contributions are acknowledged and celebrated.

Beyond individual recognition, these awards have played an important role in raising awareness about Down syndrome and have significantly enhanced the charity's public profile. This increased visibility has had a positive impact on fundraising, community engagement, and support for our ongoing work.

Official Charity Opening by HRH Prince Edward, Duke of Edinburgh

After extensive delays caused by the COVID pandemic, and subsequent delayed refurbishment works, we were delighted to finally relocate to our wonderful new centre in 2023. 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 teenage room, and a generous family space where we have hosted a highly successful party celebrating the King's Coronation, as well as our coffee mornings and community meetings.

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We were thrilled last year when the His Royal Highness Prince Edward the Duke of Edinburgh visited our centre to officially open our new centre with other prestigious guests including the Lord Mayor of Portsmouth and the Lord Lieutenant. The Duke enjoyed a tour of our building and chatting with our young people, families and supporters. The Duke said,



“Thank you so much for inviting me here today. I know that Portsmouth Down Syndrome Association has been at the leading edge for a long time, and I’m delighted to hear about all your new projects and initiatives. It’s been lovely to meet you all and to get a glimpse of the brilliant work you are all doing here.”

HRH Prince Edward, Duke of Edinburgh

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 are finding it increasingly difficult to access specialist services, with more cuts looming on the horizon. As a result, our charity has seen a steady rise in enquiries, particularly from families living further afield where there may be less access to specialist services and support. We’ve also seen a notable increase in contact from education professionals, as well as health and social care professionals, seeking advice and support.

Over the past few years, it has been reassuring to see a rise in the number of new support groups and the expansion of services offered by established ones. Unlike other organisations, we do not operate within set boundaries and have never turned a family away. However, we recognise that distance can present real challenges to engagement. To help address this, we continue to signpost families to their nearest support group, where available, so they can make informed choices, and we also signpost them towards other relevant 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. 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.

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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, Makaton Learn and Play, Makaton Signing for adults, 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, Integrated Care Boards, social workers, healthcare students and GPs as well as parents and school students.

We continue to **support families seeking asylum in the UK** and families from all backgrounds, 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.

Ukrainian Partnership

We were proud to be the first and only organisation to reach out to frontline **Down syndrome groups in Ukraine** and offer practical, hands-on support and friendship at the outbreak of the war in those areas most impacted. Since then, we have continued to nurture our valued partnerships with several Down syndrome organisations across Ukraine including Poltava, Kharkiv, Zhytomyr, Kyiv, Zaporizhzhia, and Vinnytsia. This ongoing collaboration has been made possible through the support of our humanitarian aid partners **Vans Without Borders**, who play a vital role in facilitating and strengthening these vital connections.

Comprehensive Specialist Support from the Point of Diagnosis Through to Adulthood

Specialist Services

Portsmouth DSA provides the best and most extensive programme of specialist social and educational support in the UK available at no charge, 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.

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Down Syndrome Specific Maternity Pathways

After many years of dedicated advocacy, Portsmouth DSA's training programme has played a pivotal role in establishing a collaboration with Portsmouth University Hospital, one of the UK's largest acute hospital trusts, serving over half a million patients annually. Working closely with their Midwifery Screening, Fetal Medicine, Infant Feeding, Neonatal, Paediatric and Community Teams, Portsmouth DSA has co developed the region's first Down Syndrome Specific Maternity Pathway. After positive feedback, another hospital has approached Portsmouth DSA to collaborate on a similar initiative. These tailored pathways are designed to improve the parental experience, enhance clinical outcomes, reduce birth-related mortality, and provide all involved with clear, unbiased, and up-to-date guidance.

You can read more about our work here in our maternity casestudy to be **featured in the Down Syndrome Act Guidance** : [Portsmouth-DSA-New-Parent-Maternity-Pathway-Casestudy-.pdf](#)

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 now make an automatic 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, health visitors, 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.

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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 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

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Baby Support Groups

Parents receive support from the point of diagnosis, and this support follows 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. We are delighted to continue our collaboration with experienced Makaton teacher, Ros Keeble, and **Makaton** continues to play an important role in the sessions including singing and signing. When time allows, we also offer Makaton Signing classes for parents and professionals.

New Sensory Room

Our new interactive sensory room was completed last 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 milestones while also offering parents a unique opportunity to engage in meaningful play with their infants in a safe space.

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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 including **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 three or four children to enable maximum learning to take place. Our pre-school services are coordinated by Charity Manager **Alice Osborne**.

Thank you to the **Boshier-Hinton Foundation** and **Moneybarn** who provided donations to help fund our pre-school learning this year.

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, last year 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 delivers these weekend monthly groups for school age children aged 4 – 11.

These Communication Groups, 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.

Thank you to **the Hants and Isle of Wight Community Fund (HIWCF)** who provided an inclusion grant to help support our sessions.

Portsmouth Down Syndrome Association



Social Communication Groups

Children progress from Communication Groups to our teenage **Social Communication 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 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 have been 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.

Portsmouth Down Syndrome Association

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



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 to invite KES along to our centre opening this year where our teenagers showcased our wonderful buddy initiative to **HRH the Duke of Edinburgh**.

"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**

"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**

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

Thank you to Jody and **Percussion Play**, who generously continue to sponsor our Teenage Buddy Initiative and to the **Boshier-Hinton Foundation** for their grant to help support our SCGs and buddy initiative

Flagship School, College and Nursery Education Specialist Advisory Service

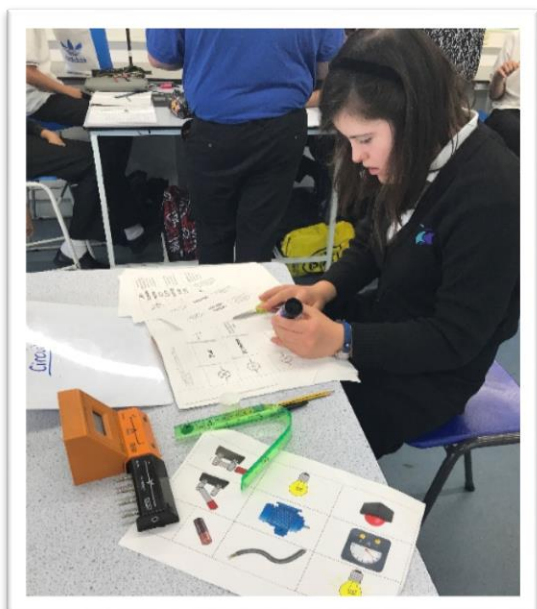
Portsmouth Down Syndrome Association worked hard to create and develop our leading **School, College and Nursery Advisory Service**, Directed by **Rachael Ross MBE**, it is now in its sixteenth year, and we believe it is the best and most comprehensive example of its kind in the UK.

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 and beyond. 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 School 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 across all age groups including pre-school. Training is 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 ‘**Support with School Transition**’, ‘**Differentiating the Curriculum**’, ‘**Supporting Social Inclusion**’, ‘**Scaffolding Friendships**’, ‘**RSE and Digital Safety**’ and we have equipped schools with useful resources, films and toolkits to facilitate inclusion.

Portsmouth Down Syndrome Association

All training is relevant and based on up-to-date and evidence-based research, and we are very pleased to note that our training evaluation sheets continue to be 100% positive, with over 99% of replies rating our training as 'excellent'.

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 has contributed 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.

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

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**.

You can view our case studies here: [Case Studies - Portsmouth Down Syndrome Association](#)

We were very grateful to receive donations towards our school service from the **Landsec Futures Community Grant**, **The Mercers' Company** and **The Syder Foundation**, and a substantial grant from the **Bailey Thomas Charitable Foundation**. We thank them for their valued 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 Programme, and is a recognised authority on the education of children with Down syndrome, 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 22 years' experience 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.

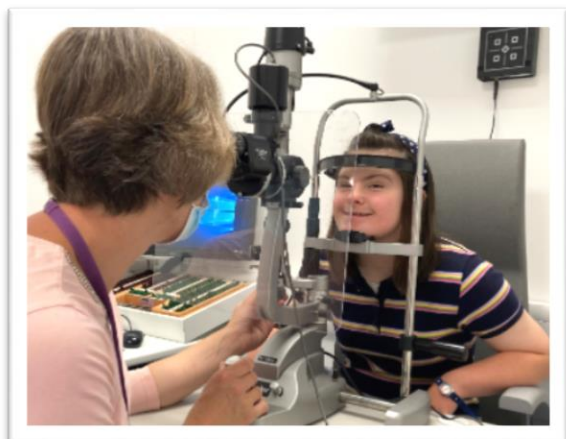
Our Head Patron, **Professor Sue Buckley OBE**, is one of the foremost global experts in education and development for children with Down syndrome, and for well over 47 years, her pioneering work has been enabling children with DS to reach their full potential. Sue is always ready to offer her friendship 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.

Portsmouth Down Syndrome Association

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. 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.

Unfortunately, the clinic was a victim of the post-COVID slump as the clinic failed to secure continued funding from the university as funds were diverted. Families were devastated when the clinic closed its doors, but we were delighted to support the relocation of many of the staff and specialist equipment to a nearby local opticians **Percy Harrisons** offering the same specialist care, and we continue our positive partnership with them.

Music Man Project Portsmouth

In September, we were thrilled to have partnered with the national **Music Man Project UK** to launch **Music Man Project Portsmouth**, our regional branch of this inspiring initiative.

Open to anyone aged 11 and up with Down syndrome or a learning disability, the weekly sessions held at our charity centre, provide accessible music experiences and inclusive performance opportunities for all abilities.

Blending the core Music Man Project programme with some of our own creative touches, each session features music, movement, signing, and percussion. The sessions are delivered by practitioner **Emma Bannister Palmer** who brings a wealth of experience and enthusiasm as a music teacher and musician, managed by **Rachael Ross**, and supported by our fantastic **volunteers**.

The journey builds toward a televised performance at the **Royal Albert Hall**, bringing together regional groups from across the country, currently planned for **April 2026** (date to be confirmed).

"Great session this evening. We truly enjoyed it. Lately, my son has been more withdrawn, less verbal, and struggling with increased anxiety. The MMPP sessions have been incredible - like therapy for him. We're hopeful they'll help guide him back from wherever he's retreated, and we'll see our beautiful, happy boy shine through again."
Parent 2025

Thank you to the **Music Man Project** and the **Axis Foundation** for their generous grants to support the Music Man Project Portsmouth.

Portsmouth Down Syndrome Association

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 younger children.

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.

Thank you to **Jazz Apple** for their donation towards our events, and the **Zurich Challenge Team** for their donations towards our Fairthorne Activity Evening and social events, and to their volunteer team for regularly donating time to support our coffee mornings and weeding our front car park.

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 over 300 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 who are parents and members of the community, and everyone is 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 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**' and is awarded for life.

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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.

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 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.

Fundraising, Awareness and Community Support

The Great South Run

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 over 300 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.

Sadly, the Great South 10-mile run was cancelled due to bad weather, but we were overwhelmed by the huge number of runners who undertook their own independent 10-mile run so that the charity did not lose their sponsorship, including the intrepid North Harbour team who completed the challenge in the wind and rain, supported by their families. As a result we were delighted that the total sponsorship raised was not impacted, and one of our best totals in recent years.

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

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Down Syndrome Awareness Week Celebrations

Our annual Down Syndrome Awareness Week took place in March, supported once again by our dedicated social media awareness campaign. We are especially grateful to local solicitors **Warner Goodman**, who generously sponsored the campaign for the fourteenth consecutive year. Their continued support enabled us to reach a significantly wider audience.

As in previous years, the celebrations were warmly embraced by the community. Schools, hospitals, businesses, and individuals participated by hosting awareness assemblies, special events, and fundraising activities. Our popular '**Rock Your Socks**' campaign received widespread support across the region.

Highlights of the week included a visit from the ever-popular **Singing Hands** and the **Lord Mayor of Portsmouth**, and our annual rock gig at the **Spinnaker Tower**, featuring the band **Uncovered**, who kindly donate their time and talent to the charity.

Inaugural Portsmouth DSA Community Awards

The theme of this year's Down Syndrome Awareness Week celebrations was 'Improve Our Support Systems', and while we acknowledge there is much work to be done, we also wanted to take the opportunity to celebrate examples of good practice and thank those professionals in our community who embrace our partnership and go above and beyond.

Generously hosted by the **Lord Mayor of Portsmouth** at **Portsmouth Guildhall**, the evening celebrated the exceptional contributions of community professionals, partner schools, and our dedicated volunteers, including some of our remarkable teenagers. Awards were presented by prominent members of the community, alongside our teenage volunteers, who played an outstanding role throughout the event. We would like to offer our congratulations to all this year's award winners. The evening was a resounding success and served to further strengthen our connection with both the local community and our members.

Thank you to the **Warner Goodman LLP** for generously sponsoring our awards evening, and further congratulations for being the deserving recipient of our '**Outstanding Charity Partnership**' award.

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

Community Partners and Supporters

We have worked hard over the years to nurture strong links with our community, and support from the business community has continued to be strong, 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.

A big thank you to our fabulous charity partners for 2024-25, including **The Royal Sussex Lodge**, **Warner Goodman Solicitors**, **Percussion Play**, **Man V Fat Havant**, **Zurich**, **David Lloyd**, **Pure Offices**, **Lui Gong**, **NHS Business Support**, and **Glowsure Insurance**, who have all gone above and beyond to provide friendship and support. Thank you to **Vans Without Borders** and to various **Down Syndrome Organisations** in Ukraine for our continued valued partnership.

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Thank you to **Portchester Pétanque** and **Hayling Legends** who have once again generously held fundraisers in aid of our charity, **Cllr Chris Atwell** for his ongoing support, and to **Next**, **The Royal Navy**, **Sporting Bears**, **Grubb and Goove**, **B&Q**, **Dominus Dei Lodge**, the **Asda Foundation**, **Jazz Apple** and **TK Maxx** for their donations.



A big thank you to **Garfield Weston** for their generous grant towards core costs.

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 PR materials to us for many years and did a fabulous job with our new centre signage, 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.

Thank you to our local supermarkets, including **Asda Havant**, **Asda Waterlooville**, **Tesco North Harbour**, **Havant and Fareham**, and to **Gunwharf Quays**, **Whitely and Victorious Festival** for their ongoing support, and **UK Garrison** and **Hampshire Cosplay** for bringing an added level of excitement to our collections.

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.

Thank you to our **Brighton and London Marathan** Runners, **Jamie**, **Joey**, **Josh** and **Marc**, and to **Stoneham AFC U14** and **Portsmouth RFC Vets**, for helping to raise awareness by adding our charity logo to their kits.

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

Portsmouth Down Syndrome Association

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

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.

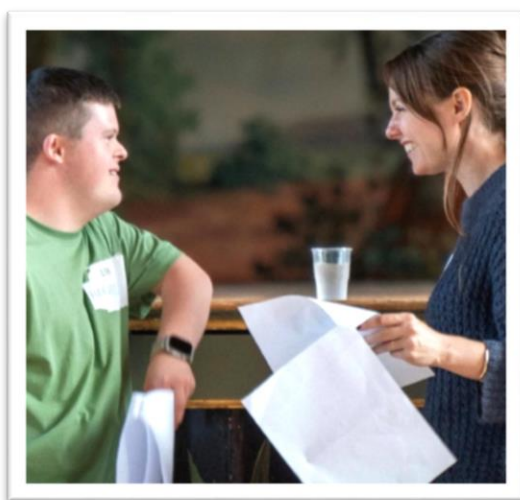
Over recent years we worked with our contacts to ensure the refurbished **BAFTA** building was fully accessible for all. The report promotes a more inclusive media community, with increased opportunities for individuals with LD; an exciting prospect, and we are proud to have encouraged and contributed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

Hot on his heels, 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

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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 programme's alumni have earned BAFTA awards for their work.

Public Relations and Publicity

Public Relations & Raising Awareness

Effective PR is vital, not only to raise awareness of Down syndrome and our charity's work and drive essential fundraising, but also to help families access support. We continue to work hard to raise awareness in the local area and also on a national platform through our work with the **National Down Syndrome Policy Group**.

We've built strong relationships with parents, schools, and local organisations, creating an ever-expanding network of support. Our events and services have been featured in local papers, and our trustees, staff, and families have participated in a range of local and national media interviews. We're grateful to all who help share our message.

We have been proud to contribute to Hampshire County Council's **HIAS SEND Publication**. Rachael's article, '**Key Strategies for Successful Inclusion**', was circulated to all schools in the county, and another piece was published in **The Times Educational Supplement**, reaching a national audience.

Our social media platforms: Facebook (18.5K followers), Twitter (2.6K), Instagram (1.7K), and LinkedIn (576), continue to grow, helping us engage with families and supporters. We enjoyed our first '**viral**' post on Facebook last 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.

Our private Members' Facebook Group remains a valued space for families to share updates and celebrate achievements on our monthly '**Proud Parent Moment**' day. A strong social media presence is essential to our community engagement and fundraising success, and we encourage all members to support and share our pages for their overall benefit.

Our website, developed by **Design Image Ltd**, remains a key information hub for families and the public. We plan a much-needed refresh in the year ahead.

Policy & Advocacy

We remain committed to highlighting key issues impacting people with Down syndrome and their families on issues such as education, healthcare, service access, new legislation, and more, through regular contact with councillors, MPs, and other stakeholders and through lobbying parliament when appropriate.

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Such lobbying has previously influenced change at a national level, including the updating of Blue Badge eligibility criteria and the inclusion of Down syndrome in the annual school census for the first time this year following approval of our report by the Star Chamber. Local councillors receive regular updates and many actively support our events, even joining us for Awareness Week or the Great South Run.

We've represented the community at think tanks, in Parliament, and at 10 Downing Street, sharing the importance of our work directly with MPs, ministers, and civil servants. There is still much to do to secure fair access to services and opportunities, and **we encourage all families to stay engaged, speak up, and support our awareness campaigns. Working together, our voice is amplified and we achieve better outcomes for our community.**

Driving Change at a National (and International) Level

The National Down Syndrome Policy Group (NDSPG)

In 2021, we were delighted to join forces with other key charity leaders to establish the **National Down Syndrome Policy Group**. Our Charity Chair and Vice-Chair, Ken and Rachael, are two of the 15 founding officers including officers with Down syndrome, who work towards supporting people with Down syndrome to have a say in the formation of policy in matters that impact their lives. As Trustees for the NDSPG, Rachael and Ken have the collective responsibility for parliamentary and All-Party Parliamentary Group (APPGDS) liaison, and the NDSPG provide the official secretariat to the APPGDS.

The group has been 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, and a strong group of over 120 adults with Down syndrome are members of the **National Down Syndrome Advisory Group** who meet regularly and feed into our work.

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 by drafting the Down Syndrome Bill, and working closely with Liam, ministers, civil servants and ambassadors with Down syndrome at Parliament to ensure its successful passage through 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 works

Portsmouth Down Syndrome Association

as one. 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 after significant delay in the areas of:



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

When the Call for Evidence was launched, we organised three large-scale consultation events in **Westminster** and **Leeds** for individuals with Down syndrome and their families, as well as virtual meetings for group leaders and professionals. These in-person sessions were attended by parliamentary civil servants who listened to views on education, healthcare, social care, and employment. We were especially proud to have **teenagers from Portsmouth DSA** and our **patron, Tommy Jessop**, join us to represent the community.



To further support the development of the Down Syndrome Act Guidance, we previously arranged a **special round table at 10 Downing Street**. There, our ambassadors with Down syndrome met with the Under Secretary of State for Health and Social Care to share their lived experiences and discuss the challenges they face daily. It was a highly successful and empowering meeting, and our ambassadors were an absolute credit to our community. These important conversations have since opened the door for ongoing dialogue and progress.

Portsmouth Down Syndrome Association

While there is still work to be done, the significance of the Down Syndrome Act and



accompanying Guidance cannot be overstated. The initiative has attracted international attention. The former **U.S. Ambassador** hosted a celebratory reception for our organisation at **Winfield House** and requested regular updates. Additionally, Trustees Ken and Rachael were deeply honoured to receive an invitation from the **Ethiopian Ambassador** to collaborate on developing similar legislation aimed at improving outcomes for people with Down syndrome, **not just in Ethiopia, but across the whole of the 54 African nations.**

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.

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.

Portsmouth Down Syndrome Association

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**.



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.

Previously 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 the former **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 which we hope will take place in the near future.

Portsmouth Down Syndrome Association

School Census Success!

Portsmouth DSA has actively 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 the Education Secretary, 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 in the future, 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.

Update: Following our communication with the Department for Education identifying serious inaccuracies in the Down syndrome data collected during the January 2025 School Census, the Department has decided to withdraw this data for the current year.

They acknowledged the concerns we raised, noting that there have been teething issues with this year's data collection. As a result, the data does not meet their usual high standards of accuracy and reliability.

The Department explained that with the introduction of any new data items, a period of adjustment is often needed before submissions stabilise and reach the expected levels of consistency. They have assured us that steps will be taken over the summer to improve the process and outcomes, and they welcomed our continued input.

We have expressed our appreciation for their transparency and collaboration, and we all hope that next year's data collection will reflect greater accuracy and reliability.

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.**

The All-Party Parliamentary Group on Down Syndrome (APPGDS)

The **National Down Syndrome Policy Group (NDSPG)** serves as the secretariat for the **All-Party Parliamentary Group on Down Syndrome** and played a pivotal role in its re-establishment after a 12-year hiatus.

Portsmouth Down Syndrome Association

Portsmouth DSA Chair and Vice-Chair, Rachael and Ken, represent NDSPG within the Parliamentary space and the APPGDS, playing a vital role in its activities and advocacy.

Now co-chaired by **Damian Hinds MP** and **Andrew Cooper MP**, the APPGDS works to influence government policy with the aim of improving the lives of people with Down syndrome. It also seeks to raise awareness of the challenges faced by people with Down syndrome and highlight opportunities for enhancing life outcomes.

The group's support has been instrumental in shaping, advancing, and implementing relevant policies. We were particularly pleased when APPGDS members unanimously supported the Down Syndrome Bill throughout its parliamentary journey to enactment. Their continued backing has also been crucial in progressing the Down Syndrome Guidance and in strengthening our successful campaign to include Down syndrome as a distinct category in the national annual school census.

We are very grateful to Portsmouth DSA and NDSPG members for supporting our work, lobbying their MPs and keeping their MPs updated with our progress.

Finances

Our annual accounts are prepared by **James Todd & Co.** (formerly Leonard Gold Accountants). We extend our thanks to them for their continued support, and to our new bookkeeper, **Tracy Dukes**, for her invaluable work.

The trustees remain committed to securing the estimated funding required to operate services at least six months in advance. We are now building on these reserves in preparation for the year ahead.

Over the past year, we have seen a continued rise in both membership and service usage. However, it remains increasingly clear that families living further afield are less active and engaged due to geographic distance. Overall engagement levels among general members have yet to return to pre-COVID levels.

As a charity with a very small staff team and largely managed by volunteers, we remind families that our membership criteria promote collective member responsibility with an expectation of active participation and support wherever possible. Without this vital involvement and support, we cannot guarantee the continuation of future services for all.

Membership remains strong with very few families leaving, and demand for our services continues to grow. Coupled with a significant rise in operational costs and demand on resources, we anticipate that both numbers and associated expenses will continue to increase steadily.

Trustees are fully aware of the significant financial pressures brought about by the ongoing cost-of-living crisis. **The long-term sustainability of the charity depends entirely on continued and successful fundraising, which remains a top priority, as well as member support.**

Portsmouth Down Syndrome Association

In response to rising costs, some of our contracted practitioners have been compelled to increase their fees by 20% to include VAT, with a further increase in fees this year, and we are facing substantial increases in operational expenses.

At the same time, securing grant funding has become increasingly challenging, as many funders are reverting to stricter eligibility criteria and focusing on more specialised or niche areas. This shift further underscores the importance of diversifying our income streams and strengthening our fundraising efforts to ensure the charity's continued viability.

We support families from the point of diagnosis through to the end of schooling and further education. The estimated cost of delivering only our core services, including baby support groups, early development and communication groups, and our nursery/school advisory service, is around **£26,000 basic per child**, and this does not include additional assessments, reports, parental and professional training, a troubleshooting helpline, bespoke school training (including SRE), resources, social events and activities.

With **132 families** and **over 500 individual members**, our mission is to support every child and family from the earliest stages and throughout childhood. Additionally, we continue to provide support and guidance to non-member families, local schools, organisations, and the broader community.

To meet these growing demands and responsibilities, it is vital that we continue to strengthen our financial reserves. Our goal is to once again build and maintain a minimum pre-Covid reserve equivalent to one year's running costs (up from 6 months) to further safeguard the future of our services and ensure long-term sustainability.

The Year Ahead

Fundraising remains a critical priority to ensure the continuation and development of our work. **We warmly invite the entire Portsmouth DSA community to actively support these essential efforts**, helping to secure the charity's future and ensuring that all members can continue to access the services and activities they have come to rely on.

We are now well settled into our new centre. Signage is in place, and many of the key rooms have been furnished. Looking ahead, **our focus will be on completing the furnishing** of the remaining rooms and, where possible, **replacing some of the older furniture** and chairs, many of which were inherited from our previous centre and are now tired.

Our team is very small. Ideally, we need to **recruit at least two to three additional staff members** to manage growing administrative demands, to help with fundraising and to support the expansion of our services, particularly in schools. However, this will only be feasible if funding becomes available.

In the coming year, we remain committed to deepening our partnerships with families, local communities, organisations, and government bodies. Our goal is to continue delivering a wide range of specialist services while also influencing national policy to improve opportunities and life outcomes for people with Down syndrome. We aim to equip them with

Portsmouth Down Syndrome Association

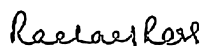
the skills they need to become valued and active members of their communities, while providing support and friendship along the journey.

A key area we hope to develop is **dedicated support and opportunities for our growing number of post-18 members**. Unfortunately, due to limited staffing and resources, it has been impossible to set time aside for this to date, but it remains a clear priority for the future, as we work toward a more inclusive and lifelong support model.

Finally, I would like to express my sincere thanks to the Portsmouth DSA Board of Trustees, our dedicated volunteers, the families we serve, and our generous supporters. It is only through your continued commitment that our charity can grow, thrive, and make a lasting difference.

This report was approved by the Board of Trustees 03 / 09 / 2025

Signed by order of the Board of Trustees



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 2025 set out on pages thirty five to forty.

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.
Furzehall Farm
110 Wickham Road
Fareham
Hampshire
PO16 7JH

Date: 03 / 09 / 2025

Portsmouth Down Syndrome Association

Statement of Financial Activities for the year ended 31 March 2025

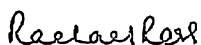
	<u>Notes</u>	<u>2025</u> <u>Unrestricted</u>	<u>2025</u> <u>Restricted</u>	<u>Total</u> <u>2025</u>	<u>Total</u> <u>2024</u>
Incoming Resources					
Donations and grants	3	272,192	41,404	313,596	249,394
Investment Income		1,632	-	1,632	2,070
Total Income		273,824	41,404	315,228	251,464
Resources Expended					
Raising Funds	4	16,803	-	16,803	7,553
Charitable Activities	5	188,223	39,120	227,343	219,520
Support Costs	6	151,816	11,174	162,990	168,600
Total Expenditure		356,842	50,294	407,136	395,673
Net Income / (Expenditure)		(83,018)	(8,890)	(91,908)	(144,209)
Net movement in funds		(83,108)	(8,890)	(91,908)	(144,209)
Reconciliation of funds					
Total funds brought forward		383,831	17,432	401,263	545,472
Total funds carried forward		300,813	8,542	309,355	401,263

Portsmouth Down Syndrome Association

Balance Sheet as at 31 March 2025

	<u>Notes</u>	<u>Total 2025</u>	<u>Total 2024</u>
Fixed assets	13	134,876	221,271
Current assets			
Debtors	10	46,981	19,142
Cash at bank and in hand		138,783	161,666
Total current assets		185,764	180,808
Creditors			
Amounts falling due within one year	11	(11,285)	(816)
Net current assets		174,479	179,992
Net assets		309,355	401,263
Funds of the charity			
Unrestricted funds		300,813	383,831
Restricted funds		8,542	17,432
Total charity funds		309,355	401,263

Approved by the trustees on 03 / 09 / 2025 and signed on behalf of all trustees



Mrs R Ross - TRUSTEE



Mr K Ross – TRUSTEE

Portsmouth Down Syndrome Association

Notes to the financial statements for the year ended 31 March 2025

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>2025</u>	<u>2024</u>
Donations and other income	240,592	217,156
Grants	<u>73,004</u>	<u>32,238</u>
	<u>313,596</u>	<u>249,394</u>

Portsmouth Down Syndrome Association

4. RAISING FUNDS

	<u>2025</u>	<u>2024</u>
Great South Run	12,123	7,553
Fundraising expenses	<u>4,680</u>	<u>-</u>
	<u>16,803</u>	<u>7,553</u>

5. CHARITABLE ACTIVITIES

	<u>2025</u>	<u>2024</u>
School Services	127,189	74,455
Communication Groups	12,444	7,558
Early Development Groups	11,421	14,260
Staff Costs	35,933	81,022
Social Events & Entertainment	26,654	26,262
General Expenses	5,922	9,434
Nursery Outreach Service	<u>7,780</u>	<u>6,529</u>
	<u>227,346</u>	<u>219,520</u>

6. SUPPORT COSTS

	<u>2025</u>	<u>2024</u>
Accountancy	852	828
Bookkeeping	574	415
Cleaning	1,772	1,003
Insurance	2,898	1,664
Bank charges	96	118
IT Costs	1,158	2,164
Service charges	36,885	33,654
Rates	4,541	4,254
Postage	241	287
Stationery & Printing	330	679
General	20	-
Venue Hire	2,249	1,914
Training	24,204	18,970
Legal costs	1,571	780
Repairs & Renewals	(1,664)	15,040
Telephone	868	435
Depreciation	<u>86,395</u>	<u>86,395</u>
	<u>162,990</u>	<u>168,600</u>

8. TRUSTEES REMUNERATION

There were no trustees' remuneration or benefits for the year ended 31 March 2025 nor for the year ended 31 March 2024.

Portsmouth Down Syndrome Association

9. STAFF COSTS

	<u>2025</u>	<u>2024</u>
Wages and Salaries	105,809	96,435
Social Security Costs	2,977	2,756
Pension Costs	1,901	1,861
Total wages Costs	<u>110,687</u>	<u>101,502</u>

No employee earned £60,000 pa or more.

The average number of employees during the year was 5, this consists of two full-time employees and four part-time employees.

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>2025</u>	<u>2024</u>
Trade debtors	-	300
Prepayments	46,981	18,842
	<u>46,981</u>	<u>19,142</u>

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>2025</u>	<u>2024</u>
Trade Creditors and Accruals	11,285	816
	<u>11,285</u>	<u>816</u>

12. ACCOUNTANCY FEE ANALYSIS

	<u>2025</u>	<u>2024</u>
Accountancy	275	270
Independent Examination	577	558
	<u>852</u>	<u>828</u>

13. TANGIBLE ASSETS

	Leasehold Improvements	Fixtures & Fittings	TOTAL
Cost			
Cost brought forward	318,282	16,589	334,871
Additions	-	-	-
Disposals	-	-	-
Cost carried forward	318,282	16,589	334,871
Depreciation			
Depreciation brought forward	109,929	3,671	113,600
Depreciation charge	83,074	3,321	86,395
Depreciation carried forward	193,003	6,992	199,995
Net book value brought forward	208,353	12,918	221,271
Net book value carried forward	125,279	9,597	134,876

Portsmouth Down Syndrome Association

14. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	<u>2025</u> <u>Unrestricted</u>	<u>2025</u> <u>Restricted</u>	<u>Total</u> <u>2025</u>	<u>Total</u> <u>2024</u>
Fixed Assets	134,876	-	134,876	221,271
Current Assets	177,222	8,542	185,764	180,808
Current Liabilities	(11,285)	-	(11,285)	(816)
	<u>300,813</u>	<u>8,542</u>	<u>309,355</u>	<u>401,263</u>

MOVEMENT IN FUNDS	<u>At 1.4.24</u>	<u>Incoming</u>	<u>Resources</u>	<u>At 31.3.25</u>
Unrestricted Funds				
General Fund	383,831	273,824	(356,842)	300,813
Restricted Funds				
Miscellaneous Funds	17,432	41,404	(50,294)	8,542
	<u>401,263</u>	<u>315,228</u>	<u>(407,136)</u>	<u>309,355</u>

24. OPERATING LEASE COMMITMENTS

	<u>2025</u>	<u>2024</u>
Within one year	25,000	13,750
Between two and five years	110,750	-
In over five years	<u>179,667</u>	<u>-</u>
	<u>315,417</u>	<u>13,750</u>

Portsmouth Down Syndrome Association

Registered Charity No. 1147355

Principal Office: Unit 1, Aspen House, Airport Service Road, Portsmouth, Hampshire, PO3 5RA

James Todd and Co
Furzehall Farm
110 Wickham Road
Fareham
Hampshire
PO16 7JH

Dear Sirs

During the course of your independent examination of the financial statements of the Charity for the period ended 31 March 2025, the following representations were made to you by management and trustees.

1. We have fulfilled our responsibilities as trustees under the Charities Act 2011, for preparing financial statements, in accordance with the applicable financial reporting framework (FRS102 Charity SORP), that give a true and fair view and for making accurate representations to you for the financial statements which you have prepared on our behalf for the Charity.
2. We confirm that all accounting records have been made available to you for the purpose of your independent examination, in accordance with your terms of engagement, and that all the transactions undertaken by the Charity have been properly reflected and recorded in the accounting records. All other records and related information, including minutes of all management, trustees' and members' meetings have been made available to you. We have given you unrestricted access to persons within the Charity in order to obtain your evidence and have provided any additional information that you have requested for the purposes of your examination.
3. We confirm that significant assumptions used by us in making accounting estimates, including those measured at fair value, are reasonable.
4. We confirm that all known actual or possible litigation and claims whose effects should be considered when preparing the financial statements have been disclosed to you and accounted for and disclosed in accordance with the applicable financial reporting framework.
5. We confirm there have been no events since the balance sheet date which require disclosure or which would materially affect the amounts in the financial statements, other than those already disclosed or included in the financial statements.
6. We confirm that we are aware that a related party of the Charity is a person or organisation with either (directly or indirectly) controls, has joint control of, or significantly influences the Charity or vice versa and as a result will include trustees, other key management, close family and other business interests of the previous. We confirm that the related party relationships and transactions set out below are a complete list of such relationships and transactions and that we are not aware of any further related parties or transactions.

<u>Party</u>	<u>Relationship</u>	<u>Nature of transaction</u>
R Ross	Trustee	None
K Ross	Trustee	None
A Osborne	Trustee	None
S Brock	Trustee	None
G Jones	Trustee	None
S Pitfield	Trustee	None

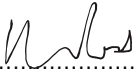
7. We confirm that all related party relationships and transactions have been accounted for and disclosed in accordance with the applicable financial reporting framework.
8. We confirm that the Charity has had, at no time during the year, any arrangement transaction or agreement to provide credit facilities (including advances and credits granted by the Charity) for trustees, nor to provide guarantees of any kind on behalf of the trustees.
9. We confirm that the Charity has not contracted for any capital expenditure other than as disclosed in the financial statements.
10. We confirm that we are not aware of any possible or actual instance of non-compliance with those laws and regulations which provide a legal framework within which the Charity conducts its activities and which are central to the Charity's ability to conduct its activities, except as explained to you in the financial statements.
11. We acknowledge our responsibility for the design and implementation of internal controls to prevent and detect fraud. We confirm that

we have disclosed to you the results of our own risk assessment that the financial statements may be misstated as a result of fraud.

12. We confirm that there have been no actual or suspected instances of fraud involving trustees, management or employees who have a significant role in internal control or that could have a material effect on the financial statements. We also confirm that we are not aware of any allegations of fraud by former trustees, employees, regulators or others.
13. We confirm that, having considered our expectations and intentions for the next 12 months and the availability of unrestricted reserves, the Charity is a going concern.
14. We confirm that all grants, donations and other income, including those subject to special terms or conditions or received for restricted purposes, have been notified to you. There have been no breaches of terms or conditions during the period regarding the application of such income.
15. We confirm that we are not aware of any matters of material significance that should be reported to the Charity Commission.

We confirm that the above representations are made on the basis of enquiries of management and staff with relevant knowledge and experience (and, where appropriate of supporting documentation) sufficient to satisfy us that we can properly make each of the above representations to you and that to the best of our knowledge and belief they accurately reflect the representations made to you by the trustees during the course of your audit.

Yours faithfully



.....
K Ross – Trustee
Signed on behalf of the Board of Trustees

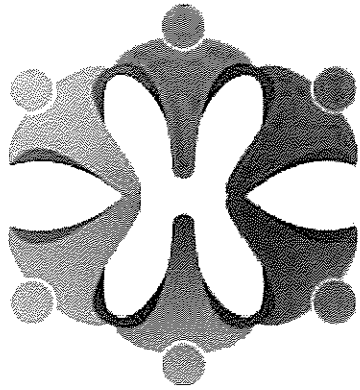
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PORTSMOUTH DOWN SYNDROME ASSOCIATION

England & Wales - Charity number 1147355

Accounts



**PORTSMOUTH
DOWN SYNDROME
ASSOCIATION**

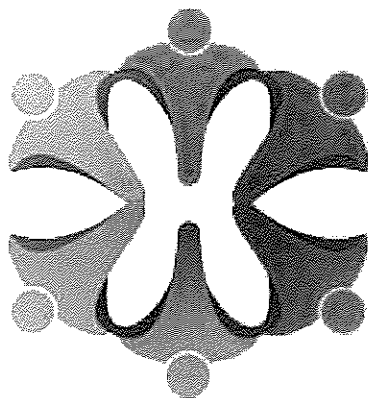
**Unaudited Financial Statements
Year ended 31 March 2024**

James Todd and Co. Limited

Portsmouth Down Syndrome Association

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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

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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*

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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.

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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.

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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

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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

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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.

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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

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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**

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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).

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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.

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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

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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.

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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

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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

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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.

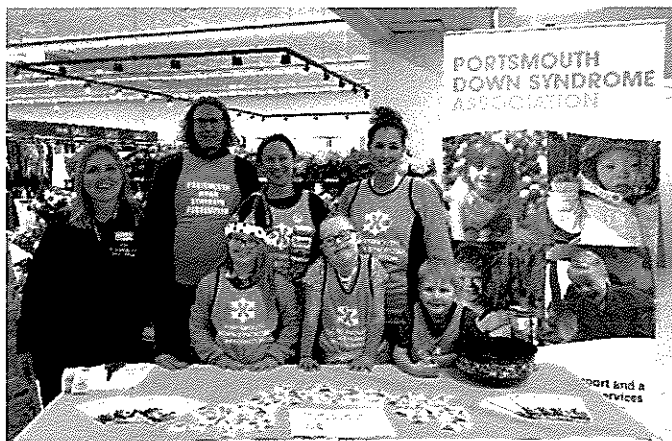
In particular, we were thrilled with the number of under 18s who turned out on the Saturday to support us, including many of our children, as well as athletes from the **SE Hants Special Olympic Team** who joined us for the 5k for the fourth year running. We also had a huge team of volunteers as usual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

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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

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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.

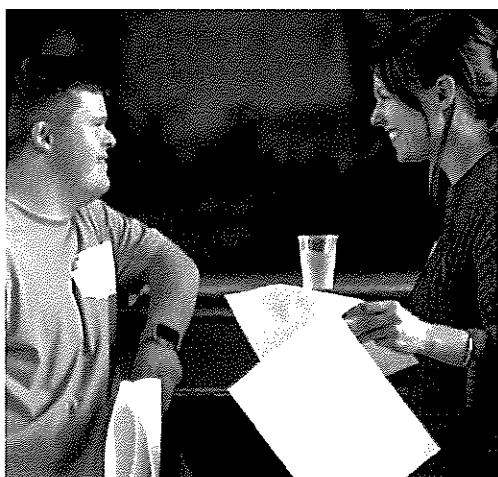
Over the past two years we worked with our contacts to ensure the refurbished **BAFTA** building was fully accessible for all. The report promotes a more inclusive media community, with increased opportunities for individuals with LD; an exciting prospect, and we are proud to have encouraged and contributed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

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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.

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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:

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- 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.

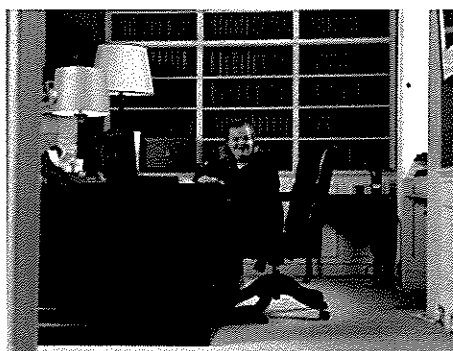
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Charity Ambassador Max Ross said, "Mrs Murty was very kind and put us all at ease. She told us to call her 'Ash' and she shared personal stories about herself, including her favourite colour is pink, and that she and her daughters love Taylor Swift's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



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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.**

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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

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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					
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
Total current assets		180,808	239,724
Creditors			
Amounts falling due within one year	11	(816)	(1,918)
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	-
		<u>401,263</u>	<u>545,472</u>

Approved by the trustees on 2/10/24

and signed on behalf of all trustees

Rosmarie Ross

Mrs R Ross - TRUSTEE

Helen Nelson

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
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
	<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
	<u>816</u>	<u>1,918</u>

12. ACCOUNTANCY FEE ANALYSIS

	<u>2024</u>	<u>2023</u>
Accountancy	270	270
Independent Examination	558	545
	<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	-	-	-
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
Depreciation carried forward	109,929	3,671	113,600
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>

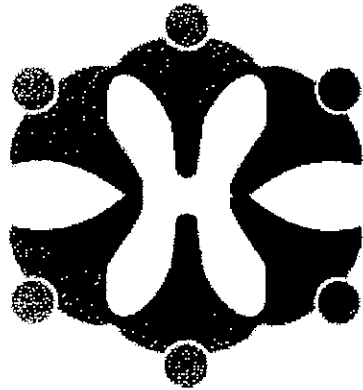
24. OPERATING LEASE COMMITMENTS

	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>

PORTSMOUTH DOWN SYNDROME ASSOCIATION

England & Wales - Charity number 1147355

Accounts



**PORTSMOUTH
DOWN SYNDROME
ASSOCIATION**

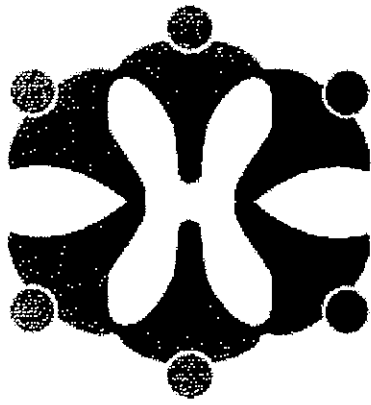
**Unaudited Financial Statements
Year ended 31 March 2023**

Leonard Gold Chartered Accountants

Portsmouth Down Syndrome Association

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PORTSMOUTH DOWN SYNDROME ASSOCIATION

Portsmouth Down Syndrome Association Trustees' Report and Financial Statements for the Year Ended 31 March 2023

The trustees submit their Annual Report and the Statement of Financial Activities and Balance Sheet for the year ended 31 March 2023.

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

Kate Allen – Charity Secretary

Simon Brock – Trustee

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

Independent Examiner: Mr A Chapman
Leonard Gold Chartered Accountants, 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 Alderman 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 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 in the UK supporting development and education and offers training to assist families and professionals in providing effective support from the point of diagnosis.

Our services are the only fully comprehensive and progressive services in the UK supporting the child's education and development from diagnosis through to young adulthood with training to assist families and professionals in providing direct 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 provided at no charge to the community as we want to remove all financial barriers to access.

Portsmouth DSA works hard to raise awareness, champion inclusion, and celebrate diversity in all areas. Life-expectancy and life in general is gradually improving for people with DS however, awareness in the community, provision and regulations have not kept pace with this progress due to lack of representation and interest at governmental levels and individuals continue to experience 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, 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, and as a first point of contact they have been put in touch with our excellent Family Liaison Team.

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 for over five years, as well as on additional 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, 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 educational and awareness articles have also been featured in national and regional education publications.

Rachael is also a Founding Officer for the **National Down Syndrome Policy Group** acting as Secretariat to the **All-Parliamentary Group on Down Syndrome**, and she is BAFTA's joint first Accessibility and Inclusion Patron.

In recognition of her sustained contribution to education and Down syndrome, Rachael was awarded The Points of Light Award in 2015, The Portsmouth Civic Award in 2018 and was honoured with an MBE for 'Services to Education and Down Syndrome' in 2019. Rachael was honoured by HM the Queen, with a Platinum Champions Award in 2022 and was selected as one of the top 68 exemplary volunteers in the UK.

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** is the charity's **Development Officer**. He has worked as an entrepreneur predominantly in the real estate and film sectors. He is also 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 South East 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.

Portsmouth Down Syndrome Association

Helen Nelson is the charity 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 knowledge and expertise to the role.

Kate Allen is Charity Secretary. Kate was a former trustee with Down Syndrome Education International. She comes from a marketing background and has a wealth of experience of being a part of a wide range of committees and is also chair and trustee of her local village hall. She is also a committee member for Down Syndrome Swimming GB. Kate has a daughter with Down syndrome Lizzie, who has been a member of Portsmouth DSA since inception, and who swims for the Down Syndrome Swimming GB squad achieving world record holder status, as well as winning multiple medals.

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 Team

Charity Manager **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**. She continues to manage our membership, welcome new families and lead our community liaison team, in particular educating health professionals to effectively support new families.

At Portsmouth DSA we fully recognise the positive impact regular social opportunities have on our families. Our 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 co-ordinating the junior social activity evenings.

Catherine Crook, co-founder of Portsmouth DSA, has been actively volunteering for the charity since inception. She is also the charity's **Social Communication Group Manager**, making sure that our communication sessions run seamlessly throughout the year.

Lucy Field, co-founder of Portsmouth DSA, has been actively volunteering for the charity since inception. She is also the charity's **Centre Admin Manager**, ensuring our centre runs smoothly.

The board and management team is 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.

Portsmouth Down Syndrome Association

Awards and Acknowledgements

Freedom of the City of Portsmouth

We were delighted to have been awarded 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'

Three of our members also 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 recognised as a **Coronation Champion** this year by Queen Camilla. Charity ambassador Max also received the Portsmouth Inspirational Men's '**Inspiring Young Man Award**'.

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 let us know that we were selected from thousands of organisations, and the national judges were immensely impressed with our 'exceptional' work.

Charity Chairperson Rachael Ross MBE says, *"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 our brilliant team of trustees, 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 furthered 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.

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 also 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.

Portsmouth Down Syndrome Association

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. Portsmouth DSA was also a runner up in the **National Diversity Awards**.

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

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 and health professionals in Hampshire and the surrounding counties of Dorset, West Sussex and Wiltshire, and we have continued 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 PDSA services model and have asked for advice from our trustees and practitioners, and some have attended our sessions and training for guidance.

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.

Portsmouth Down Syndrome Association

This year we were once again been approached to support a family 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.

Our social activities include coffee and information mornings, 'Learn and Play' sessions, 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 New Family Support Services, Baby Support Groups, Early Development Groups, Communication Groups, Social Communication Groups 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.

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 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 offer support and information from the point of diagnosis for families and professionals.

Down Syndrome Specific Maternity Pathways

After many years of campaigning, we were thrilled when 2 regional hospitals contacted us for advice about creating their first Down syndrome specific maternity pathways. We continue to work in positive partnership with these hospitals, and we are delighted that one of these pathways has now been approved and is ready to launch. We hope that these specific pathways will raise awareness in the medical community, combat measurably poorer

Portsmouth Down Syndrome Association

maternity outcomes and higher rates of stillbirth for babies with Down syndrome, improve services for families, enhance the quality of care and help ensure clear and consistent support for families, with better life outcomes.

Parent and Community Liaison Initiative



We are very proud of the links we 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. 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 is also regularly working with midwives, nurses, paediatricians, GPs, social workers, portage workers and other relevant health

professionals to ensure they have the information 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. World leading toy manufacturers **Jellycat** are also impressed with the pack and continue to support the initiative by donating a soft toy for each new family.

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.

The programme also enables us to offer 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.

The initiative continues to be a big success, families are now automatically sign-posted/referred to us by professionals, and 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 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)*

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"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, 2023)

"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

"The 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

Baby Support Groups

We continue to offer support from birth, at what can be a difficult time for new parents. The **Baby Support Groups** are delivered by our expert practitioners and provide advice and information for parents with infants aged up to 18 months. Parents are advised of the services and checks they should be receiving, what benefits to which they are entitled and support to complete application forms, they receive advice in all areas of development, and learn activities to practise at home to aid their child's development.



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 supported by volunteers, meaning that our staff are free to chat with parents, offer advice and answer any questions they might have.

We received generous grants from the **Zurich Community Team** of £500 and a £500 **British Science Week** Grant for sensory equipment and educational and cause and effect toys.

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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.

We received two grants to help fund our EDGs this year. One for £2,500 from the **St James Place Foundation**, £2,500 from the RHS Spugin Charitable Trust and a further grant from the **Hants and Isle of Wight Community Foundation** for £5,000.

Communication Groups

After struggling for the previous year to find a replacement Communication Group Speech and Language Therapist due to a shortage in the field, we were delighted to welcome Emily Harnett to deliver our monthly groups. Emily is Highly Specialist *Speech and Language* Therapist, working for Cognus Ltd with experience in supporting children with Down syndrome, and she proved very popular with our members. These groups are for school age children aged 4 – 11 on Saturdays delivered by an experienced Speech and Language Therapist. 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.

After just a few months, Emily was forced to step down from the position due to family issues, and we were very sorry to see her go.

Unfortunately, due to the continuing shortage of therapists, we have once again been unable to find a replacement to deliver these invaluable sessions. Our search continues.

Social Communication Groups

The format for our **Social Communication 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

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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 groups are now led by our co-worker **Tracy Leason** after our speech and language therapist Grace Anstey stepped down to spend more time with her new family. Tracy has an abundance of experience delivering SALT programmes and has worked with children with DS and SEND in an educational setting.

This year we welcomed our new co-worker **Danni Francis** who works alongside Tracy. Danni 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. Danni has settled well into her new role, and both Danni and Tracy are well liked by the teenagers. The groups are still overseen by Leela Baksi (Symbol UK) specialist Speech and Language Therapist. The young people enjoy attending and the sessions and they have been a big success.

Special Partnership with King Edward VI School – Our Buddy Initiative

We have developed strong links with many schools in the region including **King Edward VI School** who have been active supporters of our charity over past years, and who often take part 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. We have been delighted to continue our exciting **buddying partnership** 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 so far, and the students and our teenagers have embraced the opportunity to engage with massive benefits to all taking part.

Outings have included swimming, donutting at the ski slope and a barn dance. It has been wonderful to watch the friendships developing throughout the year.

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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.

New Junior Age Buddy Initiative

We were delighted this year to be able to offer this same 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, particularly while our Communication Sessions are out of action.

We would like to thank Mark Miller and 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

We would like to thank Jody and **Percussion Play** for generously sponsoring our social communication group outings with their generous donation of £3,000, and for providing their lovely instruments for our summer party.

The School, College and Nursery Education Advisory Service

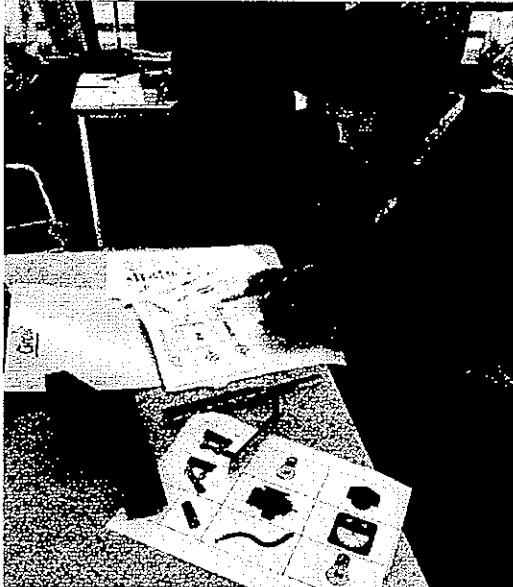
Portsmouth Down Syndrome Association has worked hard to establish and develop our flagship **School, College and Nursery Advisory Service**, which we believe it is now the best and most comprehensive example of its kind in the UK.

We currently support the successful inclusion of our members in over 100 educational establishments. 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,

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assessment, development and inclusion, individualised to meet the needs of the child and school. The child 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 child'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 problems which might arise over the year.

As more of our children 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 is largely a new area for many 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 very pleased to say that our training evaluation sheets continue to be 100% positive.

This year, we made the decision to review our training model, and fully open up 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.

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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.

The charity has previously invested time into exploring alternative accreditations and exam courses which are more suitable for our young people, will offer more choice and opportunities, and will allow them to achieve meaningful, recognised qualifications. In particular, we identified 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.

We were delighted to receive a donation of £2,200 from **Little Lives UK** to help us fund our school advisory service, and we are very grateful for their interest in our charity and their support.

Our Practitioners

Our services are all delivered by experienced and highly qualified experts in the field of Down syndrome. This year we welcomed **Kate Milford** to take on the role of our new 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, is a recognised authority on the education of children with DS, formerly working with Ups and Downs, Southwest. Allison has worked hard to develop a training programme and supporting literature to advise schools and parents on

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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 20 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 45 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 attended safeguarding training and shared information with charity workers. Key charity staff and volunteers have also attended relevant 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 families with a child with a disability can feel isolated, so our social events and parties remain of key importance to provide families with opportunities to come together, have fun make friends and share experiences.

Events over the past financial year have included 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 and a very successful outdoor event at Fairthorne Manor where children were 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. Thank you to the representatives from the **Zurich** team who very generously donated £500 towards the gifts for the children which were hugely popular with our children, a to **One Stop** who once again donated £500 towards our celebrations.

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The **Events Team** once again excelled themselves with this event, making an amazing Santa's Grotto and hosting a fantastic party for the children.

The highlight of the year was without doubt our Summer Party. Hundreds of our members gathered at Jenny's farm to celebrate the Queen's Platinum Jubilee. After featuring on live TV on the Morning Live Show, our members enjoyed our 1950s themed celebrations with live music, stalls, fancy dress, bake off, races, Percussion Play instruments and barbecue in a beautiful farm setting. It was another great example of our wonderful community spirit. Thank you to Jenny Toomer at **Venthams Farm** for donating her wonderful venue, **Asda** and **One Stop** for their grants of £500 to help fund a superb celebration, and of course thank you to our fabulous volunteers.

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, and families and the Events Team regularly volunteer to support collections and other charity activities. We have core volunteers who support regularly, but it would be lovely to see some new faces supporting our activities.

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 and fundraising events. These teams have 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 run by volunteers, and we are very grateful to everyone for their support.

We were delighted when Portsmouth DSA received the **Queen's Award for Voluntary Service** this year academic year, and it is credit to our inspirational leadership team, many of whom are full and 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 received an individual Queen's Award certificate and a social covid recognition certificate, and this number included some of our teenagers with Down syndrome and their older siblings.

Fundraising, Awareness and Community Support

We have been very successful in meeting our targets for fundraising once again this year due to our successful fundraising programme, and we have continued to maintain healthy reserves.

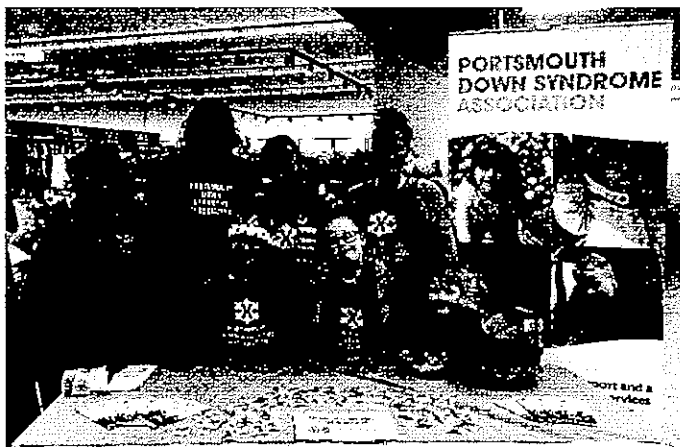
We have organised several fundraising events, including the **Great South Run** in October. The run takes place annually in Portsmouth, and we continue to take advantage of its location to make it one of our largest annual fundraisers. Numbers have not yet recovered to pre-COVID levels, but we had a large team of entrants in all runs totaling 222, and £52,198.88 was raised in sponsorship. 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 so many of our green charity vests, and

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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 certainly the best represented charity there on the day once again. The weekend was a huge success and saw sponsorship funds generated **£52,000** in gross sponsorship.

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.



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, **STS Defence** and **One Stop Stores**, as well as continuing our long-term partnership with **Warner Goodman Solicitors**, who generously sponsored our Down Syndrome Week Awareness celebrations for the 12th consecutive year, as well as supporting our fundraising events.

Community and business donations included donations from the **Keay family** who have been active fundraisers, raising over £10,000 which we have used to help fund our new sensory room, **BCBN** who donated £2,892 for our new centre, **Portchester Pétanque**, **Morrisons** who granted £21,624 for our new kitchens at the centre and a Community Inclusion Grant of £1,000 from **Portsmouth City Council**, and a further Grant of £15,000 from **Portsmouth City Council** to support our move to our new premises.

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 twelfth 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.

Local businesses have continued to offer the charity their expertise and support for which we

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are very grateful, including our web designers **Design Image** who provide invaluable support in all areas and John and the team at **Progression Signage** who have donated free signage to us for many years.

Our parents 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 parents **Steve Birch** who took part in a boxing challenge and **Claire Manson** who abseiled down the Spinnaker Tower. Special thanks to supporter **Nathan Tracy** who completed a 24-hour non-stop run raising £3,428, and event which was incredibly well supported by our members, many of whom kept him company at various stages of the run, and through the night.

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

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 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 and we are proud to have co-commissioned a review into inclusion policy and subsequent report. We also 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. This 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 feature length 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.

We were delighted to join forces with the **Lily and Lime** team in Portsmouth, to offer some of our older teenagers valuable work experience in hospitality and catering over the summer holidays. The initiative was a big success, with participants each receiving a certificate, and we hope to repeat the opportunity again this summer.

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Portsmouth University Eye Clinic

We were proud to train staff and to have been instrumental in the establishment of the Portsmouth Eye Clinic – the first eye clinic in England to offer highly specialist services for people with Down syndrome. The clinic was in high demand, with families travelling from counties cross the south of England to access these services.

We heard earlier in the year that the University has failed to secure funding, and sadly the clinic was forced to close its doors leaving staff and families devastated. Some of the former staff are in the process of establishing a smaller optician centre in Portsmouth offering some of the same specialist care, and we will liaise with them about further support and access for our members.

PR

Successful PR is important as it not only helps parents to know where they can find support, 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 (18,431 likes), **Twitter** page (2,597 followers), **Instagram** (1,397 followers) and our new **LinkedIn** (414 followers) pages 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. **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

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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 also 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. Many of them 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.

Paving the Way for 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 co-found the **Down Syndrome Policy Group**. 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 and Down Syndrome Education International, as well as over 120 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 joins

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together 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:

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

We 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.

We teamed up with the **National Down Syndrome Policy Group** once again on 21st March to organise a celebration in **Westminster** of World Down Syndrome Day, and the progress of the Down Syndrome Act 2022. We were joined by families and professionals from across the UK including PDSA members, as well as 150 MPs and Lords. We were honoured when three senior ministers joined us and made speeches about the importance of the Act, particularly as we were informed that it is unprecedented that 3 ministers to attend and speak at the same event, such is the support for our work.

Dr Liam Fox, the Bill's sponsor, was unable to join us as planned, as he was invited to speak in New York by the **United Nations** on World Down Syndrome Day about the world's first Down Syndrome Act.



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.

Portsmouth Down Syndrome Association

The All-Party Parliamentary Group on Down Syndrome

The **National Down Syndrome Policy Group** also provides the secretariat for the **All-Party Parliamentary Group on Down Syndrome (APPGDS)** and were instrumental in its re-establishment. The APPGDS aims to raise awareness of issues affecting people with Down syndrome, and the prospects for improving life outcomes, and to campaign for changes to government policy to improve the lives of people with Down syndrome. We were delighted when APPGDS MP members supported the Down Syndrome Bill on its journey through parliament.

Finances

The annual accounts are compiled by **Leonard Gold Accountants** and we are very grateful to Leonard Gold for their valued support.

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 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. We are therefore aware 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 in light of the cost-of-living crisis, as the future of the charity is wholly dependent on successful fundraising. 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 practitioners and staff, bespoke training for schools, SRE training, resources, social events, drama so the real cost is probably £30,000+). We have 126 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 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.

At the year end fund held were £238,958.

Portsmouth Down Syndrome Association

The Year Ahead

We look forward to fully furnishing and utilizing our new centre, as well as expanding our existing activities.

We would like to employ at least two new members of staff to help manage the increasing administrative load and to help manage the new centre but this is dependent on available funds.

We will continue working with our families and the local community over the forthcoming year, working towards a new future, and delivering a wide range of specialist services which we hope will continue to make a positive impact on the lives of children with Down syndrome and help enable them to develop the vital skills they need to become valued and productive members of their communities.

This report was approved by the Board of Trustees

Signed by order of the Board of Trustees



27/9/23
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 2023 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.

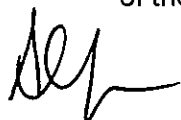
Independent examiner's statement

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.



Mr A Chapman FCA
Leonard Gold
Chartered Accountants
24 Landport Terrace
Portsmouth
Hampshire
PO1 2RG

Date: 16 OCTOBER 2023

Portsmouth Down Syndrome Association

Statement of Financial Activities for the year ended 31 March 2023

	<u>Notes</u>	<u>2023</u> <u>Unrestricted</u>	<u>2023</u> <u>Restricted</u>	<u>Total</u> <u>2023</u>	<u>Total</u> <u>2022</u>
Incoming Resources					
Donations	3	155,791	40,216	196,007	194,254
Government Grants	4	-	-	-	13,599
Investment Income		1,279	-	1,279	417
Total Income		157,070	40,216	197,286	208,270
Resources Expended					
Raising Funds	5	8,435	-	8,435	25,576
Charitable Activities	6	154,856	11,504	166,360	124,855
Support Costs	7	76,623	28,712	105,335	43,555
Total Expenditure		239,914	40,216	280,130	193,986
Net Income / (Expenditure)		(82,844)	-	(82,844)	14,284
Net movement in funds		(82,844)	-	(82,844)	14,284
Reconciliation of funds					
Total funds brought forward		628,316	-	628,316	614,032
Total funds carried forward		545,472	-	545,472	628,316

Portsmouth Down Syndrome Association

Balance Sheet as at 31 March 2023

	<u>Notes</u>	<u>Total 2023</u>	<u>Total 2022</u>
Fixed assets	13	307,666	-
Current assets			
Debtors	10	48,232	79,375
Cash at bank and in hand		191,492	549,679
Total current assets		239,724	629,054
Creditors			
Amounts falling due within one year	11	(1,918)	(738)
Net current assets		<u>545,472</u>	<u>628,316</u>
 Funds of the charity			
Unrestricted funds		545,472	628,316
Restricted funds		-	-
		<u>545,472</u>	<u>628,316</u>

Approved by the trustees on 27/9/23 and signed on behalf of all trustees

Richard Ross Ms R Ross - TRUSTEE

Helen Nelson Ms H Nelson – TRUSTEE

Portsmouth Down Syndrome Association

Notes to the financial statements for the year ended 31 March 2023

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>2023</u>	<u>2022</u>
Donations and other income	154,791	180,354
Grants	41,216	13,900
	<u>196,007</u>	<u>194,254</u>

Portsmouth Down Syndrome Association

4. GOVERNMENT GRANTS

	<u>2023</u>	<u>2022</u>
Coronavirus Job Retention Scheme	-	13,599
	<u>-</u>	<u>13,599</u>

5. RAISING FUNDS

	<u>2023</u>	<u>2022</u>
HMS Warrior Event	-	20,328
Great South Run	8,435	5,248
	<u>8,435</u>	<u>25,576</u>

6. CHARITABLE ACTIVITIES

	<u>2023</u>	<u>2022</u>
School Services	94,423	85,614
Communication Groups	8,113	6,994
Early Development Groups	9,747	7,275
Staff Costs	28,490	12,249
Social Events & Entertainment	19,373	5,512
General Expenses	2,226	2,568
Nursery Outreach Service	3,988	4,643
	<u>166,360</u>	<u>124,855</u>

7. SUPPORT COSTS

	<u>2023</u>	<u>2022</u>
Accountancy	815	720
Bookkeeping	411	905
Insurance	897	825
Bank charges	111	27
IT Costs	704	714
Service charges	40,923	9,560
Postage	304	60
Stationery & Printing	363	729
General	-	903
Venue Hire	2,478	1,416
Training	20,983	19,019
Legal costs	2,580	7,831
Repairs & Renewals	6,646	846
Telephone	915	-
Depreciation	27,205	-
	<u>105,335</u>	<u>43,555</u>

8. TRUSTEES REMUNERATION

There were no trustees' remuneration or benefits for the year ended 31 March 2023 nor for the year ended 31 March 2022.

Portsmouth Down Syndrome Association

9. STAFF COSTS

	<u>2023</u>	<u>2022</u>
Wages and Salaries	54,469	58,306
Social Security Costs	-	414
Pension Costs	957	1,116
Total wages Costs	<u>55,426</u>	<u>59,836</u>

No employee earned £60,000 pa or more.

The average number of employees during the year was 5, this consists of one full-time employee and four part-time employees.

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>2023</u>	<u>2022</u>
Prepayments	<u>48,232</u>	<u>79,375</u>
	<u>48,232</u>	<u>79,375</u>

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>2023</u>	<u>2022</u>
Accruals	<u>1,918</u>	<u>738</u>
	<u>1,918</u>	<u>738</u>

12. ACCOUNTANCY FEE ANALYSIS

	<u>2023</u>	<u>2022</u>
Accountancy	270	240
Independent Examination	<u>545</u>	<u>480</u>
	<u>815</u>	<u>720</u>

13. TANGIBLE ASSETS

	Leasehold Improvements	Fixtures & Fittings	TOTAL
Cost			
Cost brought forward	-	-	-
Additions	318,282	16,589	334,871
Disposals	<u>-</u>	<u>-</u>	<u>-</u>
Cost carried forward	<u>318,282</u>	<u>16,589</u>	<u>334,871</u>
Depreciation			
Depreciation brought forward	-	-	-
Depreciation charge	26,855	350	27,205
Depreciation carried forward	<u>26,855</u>	<u>350</u>	<u>27,205</u>
Net book value brought forward	<u>-</u>	<u>-</u>	<u>-</u>
Net book value carried forward	<u>291,427</u>	<u>16,239</u>	<u>307,666</u>

Portsmouth Down Syndrome Association

14. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	<u>2023</u> <u>Unrestricted</u>	<u>2023</u> <u>Restricted</u>	<u>Total</u> <u>2023</u>	<u>Total</u> <u>2022</u>
Fixed Assets	307,666	-	307,666	-
Current Assets	239,724	-	239,724	629,054
Current Liabilities	(766)	(1,152)	(1,918)	(738)
	<u>546,624</u>	<u>(1,152)</u>	<u>545,472</u>	<u>628,316</u>

MOVEMENT IN FUNDS	<u>At 1.4.22</u>	<u>Incoming</u>	<u>Resources</u>	<u>At</u> <u>31.3.23</u>
Unrestricted Funds				
General Fund	628,316	157,070	(239,914)	545,472
Restricted Funds				
Miscellaneous Funds	-	40,216	(40,216)	-
	<u>628,316</u>	<u>197,286</u>	<u>(280,130)</u>	<u>545,472</u>

PORTSMOUTH DOWN SYNDROME ASSOCIATION

England & Wales - Charity number 1147355

Accounts



**PORTSMOUTH
DOWN SYNDROME
ASSOCIATION**

Unaudited Financial Statements Year ended 31 March 2022

Leonard Gold Chartered Accountants

Portsmouth Down Syndrome Association

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PORTSMOUTH DOWN SYNDROME ASSOCIATION

Portsmouth Down Syndrome Association Trustees' Report and Financial Statements for the Year Ended 31 March 2022

The trustees submit their Annual Report and the Statement of Financial Activities and Balance Sheet for the year ended 31 March 2022.

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: The Sarah Duffen Centre, Belmont St Building, Cottage Grove School Campus, Chivers Close, Portsmouth PO5 1HG

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

Kate Allen - Charity Secretary

Simon Brock - Trustee

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

Independent Examiner: Mr A Chapman
Leonard Gold, 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 (Actress)

Portsmouth Down Syndrome Association

- Scott Heffield (Adventurer and TV Presenter)
- Tim Treloar (Adventurer and TV Presenter)
- Liam Bairstow (Actor)
- Tommy Jessop (Actor)
- Gregory Jones QC and Alderman 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 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 in the UK supporting development and education and offers training to assist families and professionals in providing effective support from the point of diagnosis.

Our services are the only fully comprehensive and progressive services in the UK supporting the child's education and development from diagnosis through to young adulthood with training to assist families and professionals in providing direct 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 provided at no charge to the community as we want to remove all financial barriers to access.

Portsmouth DSA works hard to raise awareness, champion inclusion, and celebrate diversity in all areas. Life-expectancy and life in general is gradually improving for people with DS however, awareness in the community, provision and regulations have not kept pace with this progress due to lack of representation and interest at governmental levels and individuals continue to experience 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, 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.

We are currently still based at the Sarah Duffen Centre which in normal times is well utilised and provides an invaluable base from which we can host our educational groups, coffee mornings and meetings. Membership has continued to steadily rise and with careful planning we have been able to cater for all our new families' needs. We have seen an increase in the number of prospective parents with a diagnosis making contact, and as a first point of contact they have been put in touch with our Family Liaison Team.

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, **Rachael Ross MBE**, previously served on the Board of Trustees for Down Syndrome Education International for over five years, as well as on additional 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, 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 educational and awareness articles have also been featured in national and regional publications, as well as county SEND publications for schools.

Rachael is also a Founding Officer 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.

In recognition of her sustained contribution to education and Down syndrome, Rachael was awarded The Points of Light Award in 2015, The Portsmouth Civic Award in 2018 and was honoured with an MBE for 'Services to Education and Down Syndrome' in 2019. This year Rachael was honoured by HM the Queen, with a Platinum Champions Award and was selected as one of the top 70 exemplary volunteers in the UK.

Rachael oversees the smooth running of the charity and is the Director of Educational Services. She manages the Schools Advisory and Training Service and is the charity's Director of Fundraising. She is also a 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** is the charity's Development Officer. He has worked predominantly as an entrepreneur predominantly in the real estate and film sectors. He is also a Founding Officer 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 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'. This year we are proud that Ken was honoured by HM the Queen, with a Platinum Champions Award and was selected as one of the 70 exemplary volunteers in the UK

Portsmouth Down Syndrome Association

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

This year we welcomed **Kate Allen** to the trustee board in the role of Charity Secretary. Kate was a former trustee with Down Syndrome Education International. She comes from a marketing background and has wealth of experience of being a part of a wide range of committees and is also chair and trustee of her local village hall. She is also a committee member for Down Syndrome Swimming GB. Kate has a daughter with Down syndrome, and has been member of Portsmouth DSA for many years, actively supporting fundraisers and events.

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.

This year, long-standing board members **Lucy Field** and **Catherine Crook** stood down as trustees. Lucy and Catherine have been valued members of the board since the charity's inception. They have dedicated a huge amount of time and energy to their roles, helping to elevate the charity into one of the leading specialist charities in the UK. We would like to say a huge thank you to Lucy and Catherine for their 13 years of service, and we are pleased that Catherine will continue to support the charity through her role as Social Communication Group Manager and Lucy as Administration Manager.

Charity Manager **Alice Osborne** became a member of the charity five years ago after her son was born. She played an active role and worked as a key volunteer for several years managing our membership, welcoming new families and leading our community team, in particular educating health professionals to effectively support new families. Alice is a social worker by profession and has worked in the field of disability for over 17 years.

The board is actively supported by a strong team of charity administrators and 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.

New Patrons

We were delighted to welcome two new patrons to Portsmouth DSA.

Tommy Jessop was the first British actor with Down syndrome to star in a prime-time TV drama. He is a founding member of the award-winning integrated company Blue Apple Theatre, and the first person with Down syndrome to become a full-voting member of BAFTA, and the first to present an award at the BAFTA award ceremony. In 2021, Tommy was made a Doctor of Arts (honoris causa) by the University of Winchester.

Portsmouth Down Syndrome Association

Tommy is also an advocate and campaigner for people with Down syndrome. He is an ambassador for the national Down Syndrome Policy Group and played an active role in the campaign for the Down Syndrome Act. Tommy says, "I really am honoured and proud to be a patron of the Portsmouth Down Syndrome Association and will support all they do helping people living with Down syndrome to live their lives to the full."

Gregory Jones QC is a barrister and Alderman of the City of London. Greg's eldest cousin had Down syndrome and as children in 1970's, Gregory and his sister Angela joined in day trips organised by Mencap for youngsters with Down syndrome. Greg says, "I've been hugely impressed by the dynamic work of the PSDA in securing proper integration for young students with Down syndrome in schools. Their key role with the National Down Syndrome Policy Group has helped move things to a new level by securing the 'game changing' Down Syndrome Act 2022."

Portsmouth DSA Now Has Royal Approval

The Queen's Award

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 June last year. 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 let us

know that we were selected from thousands of organisations, and the national judges were immensely impressed with our 'exceptional' work.

Charity Chairperson Rachael Ross MBE says, *"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 our brilliant team of trustees, 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 received messages of congratulations from the community including the Lord-Lieutenant who conveyed, *"On behalf of HM the Queen....I am delighted that Portsmouth Down Syndrome Association has won the Queen's Award. This award is very richly deserved....Please convey my personal congratulations to everyone involved."*

Caroline Dinenage MP said, *"This prestigious award is well deserved recognition for your hard work over many years transforming lives and outcomes by promoting inclusion and providing outstanding specialist services and training. Many congratulations to the Portsmouth DSA team!"*

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 also 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.

Portsmouth Down Syndrome Association

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 spot lighted when Chairperson Rachael was made an **MBE** by the Queen for services to education and the field of Down syndrome.

This year we were delighted when the Charity Chairperson Rachael and Vice-chair Ken were once again recognised by HM the Queen and made Platinum Champions as two of 70 of the most exemplary volunteers in the UK.

Portsmouth DSA was also selected a **finalist for the National Diversity Awards** last year from over 52,000 entrants across the UK.

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

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 and health professionals in Hampshire and the surrounding counties of Dorset, West Sussex and Wiltshire, and we have continued 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 DS 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 PDSA 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.

This year we were once again been approached to support a family 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.

After the impact of the COVID pandemic on our activities, we were more than delighted to see our charity activities resume as usual. Our social activities include coffee and information mornings, 'Learn and Play' sessions, 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 include New Family Support Services, Baby Support Groups, Early Development Groups, Communication Groups, Social Communication Groups 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.

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 Support

We have found that developments in 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 offer support and information from the point of diagnosis for families and professionals

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Parent and Community Liaison Initiative



In 2018 we were excited to expand our existing support network for parents and health professionals by introducing our Parent and Community Liaison initiative, which was launched at **Queen Alexandra Hospital**, with

the Lord Mayor of Portsmouth in attendance. To accompany the launch, the charity produced a Parent Welcome Pack for new parents and supporting literature for NHS health professionals including advice on 'Delivering a Diagnosis of Down Syndrome' and 'Positive Language' written by Chairperson Rachael Ross. The pack was produced at cost price by local design company **Design Image** who have been loyal supporters of our charity. World leading toy manufacturers **Jellycat** were also impressed with the pack and were keen to support the initiative by donating a soft toy for each new family. We continue to distribute these packs to hospitals and maternity units across the region. This has been a big success and new parents are now regularly signposted to us.

The initiative includes a comprehensive support system for new parents from the point of diagnosis. 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 is also regularly working with midwives, nurses, paediatricians, GPs, social workers, portage workers and other relevant health professionals to ensure they have the information they need to effectively support families and colleagues.

The programme also enables us to offer bespoke training to health professionals including our '**Down Syndrome Today**' training and to date our team has had the pleasure of delivering training to over 300 trainee midwives at the Bournemouth University Midwives Conference, as well as hundreds more midwives, paediatricians, maternity nurses, social workers and other related professionals.

The team is led by **Alice Osborne** who comes from a social work background with experience of working with individuals with a learning disability. Alice continues to throw herself wholeheartedly into implementing our exciting initiative and has been busy meeting our lovely new families, developing and delivering training to health professionals and forging ever-stronger links with the health community. Last year we were pleased to welcome **Dr Anjali Hoyle GP** to our training team this year, who has helped organize training for GP surgeries.

We continue to receive excellent feedback from parents and health professionals about our initiative, and we look forward to expanding this further over forthcoming months.

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

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'The 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

“The 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

Baby Support Groups

We continue to offer support from birth, at what can be a difficult time for new parents. The Baby Support Groups are delivered by our expert practitioners and provide advice and information for parents with infants aged up to 18 months. Parents are advised of the services and checks they should be receiving, they receive advice in all areas of development, and learn activities to practise at home to aid their child's development.

Learn and Play Sessions



Our Learn and Play 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. The sessions are supported by volunteers, meaning that our staff are free to chat with parents, offer

advice and answer any questions they might have.

We received a generous grant from the **Hants and Isle of Wight Community Foundation** for £5,000 to help fund our EDGs and Learn and Play sessions.

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 developing early numeracy skills, social skills and behavior, and play and fine motor skills.

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.

We received two grants towards our EDGs this year. One for £1,000 from **Tesco Groundworks Fratton**, and a further grant from the **Hants and Isle of Wight Community Foundation** (as above) for £5,000 to help fund our EDGs and Learn and Play sessions.

Communication Groups

We run monthly Communication Groups for school age children aged 4 – 11 on Saturdays delivered by an experienced Speech and Language Therapist. 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.

After struggling to find a suitably qualified replacement speech and language therapist due to a shortage in the field, we were delighted to welcome Emily Harnett to the team. Emily is Highly Specialist *Speech and Language* Therapist working for Cognus Ltd with experience in supporting children with Down syndrome, and she has proved very popular with our members. This is unfortunately only a temporary measure and will provide a stop gap until we can hire an experienced permanent therapist, but nevertheless we are delighted to be able to continue to offer this invaluable service for our members.

Social Communication Groups

The format for our Social Communication 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.

These monthly groups are led by our new speech and language therapist Grace Anstey, who is suitably experienced in the field of DS, and supported by our new co-worker Tracy Leason who again has an abundance of experience delivering SALT programmes and has worked with children with DS and SEND in an educational setting. Both Grace and Tracy have settled into their new roles and are well liked by the teenagers. For now, the groups are still overseen by Leela Baksi (Symbol UK) specialist Speech and Language Therapist. The young people enjoy attending and the sessions they have been a big success.

We are aware that a good friendship network is particularly important for our young people, and an aim of the group is to encourage these friendships. To

further facilitate this, we have set up a closed WhatsApp Group so the young people can communicate with each other in a

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safe environment on social media. It is a work in progress! We also try to organise monthly outings for the teenagers where they can socialise and have fun with friends, and some groups also go out locally after their monthly session. It has been lovely to watch these groups mature and friendships develop.

Special Partnership with King Edward VI School



We have developed strong links with many schools in the region including **King Edward VI School** who have been active supporters of our charity over past years, and who often take part 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. This year we were thrilled to enter into an exciting new buddying partnership with some older students from King Edward VI School who join us for our Social Communication Group outings with the aim of developing friendships and social skills.

The partnership has been hugely successful so far, and the students and our teenagers have embraced the opportunity to engage with massive benefits to all taking part. Outings have included swimming, donutting at the ski slope and a barn dance. It has been wonderful to watch the friendships developing throughout the year.

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

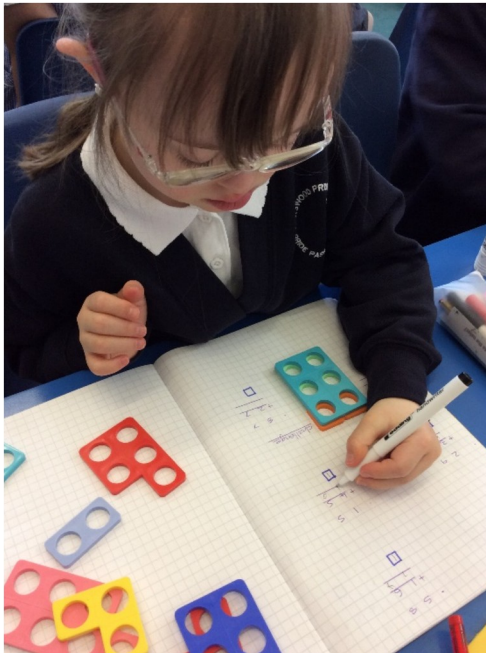
The School, College and Nursery Education Advisory Service

Portsmouth Down Syndrome Association has worked hard to establish and develop our flagship School, College and Nursery Service, which we believe it is now the best and most comprehensive example of its kind in the UK.

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In September 2012, we supported the successful inclusion of our children in over 21 mainstream schools in Portsmouth, Hampshire and surrounding counties. In March 2014, this figure rose to 40, and we currently now provide support for our members in 100+ nursery, primary, secondary and further education settings.



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 child and school. The child 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 child'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 problems which might arise over the year.

As more of our children 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 is largely a new area for many 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 free training session at the start of the term, or just prior to this. Our education manager Vik Ralfs is an expert in Relationships & Sex Education, and we invite schools to take advantage of her expertise to run sessions for children or staff when required, and we also offer an additional RSE training session or similar for all our Year 7 pupils.

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 'self-esteem and emotional well-being', 'relationships and sexual education', 'behaviour' and 'supporting literacy' and we have equipped schools with useful resources and toolkits to facilitate inclusion. We were also able to circulate our online training brochure featuring films to support successful inclusion made during COVID.

All training is relevant and based on up-to-date and evidence-based research, and we are very pleased to say that our training evaluation sheets continue to be 100% positive.

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

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was invited to contribute to the **Hampshire Inspection and Advisory Service SEND Publication** which was circulated to all schools in the county. Our guidance was then 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. Two new updated presentations about Down syndrome were prepared for schools specifically for awareness week.

The charity has previously invested time into exploring alternative accreditations and exam courses which are more suitable for our young people, will offer more choice and opportunities, and will allow them to achieve meaningful, recognised qualifications. In particular, we identified 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.

We were delighted to receive a donation of £7,000 from the **Wates Foundation** to help us fund our school advisory service, and we are very grateful for their interest in our charity and their continued support.

Our Practitioners

Our services are all delivered by experienced and highly qualified experts in the field of Down syndrome. **Vik Ralfs**, the charity's inhouse education manager, is an expert educationalist and authority in DS and Relationships and Sex Education (RSE). Vik has a wealth of experience and has worked for leading UK organisations such as MENCAP and Symbol UK, as well as taking on the role of National Training and Education Manager for eight years for the Down Syndrome Association, where she also co-wrote the original 'Tell it Right' Programme and worked with the Royal College of Midwives over 3 years to develop the accredited national midwifery training programme on supporting expectant and new families of children with Down syndrome which was rolled out nationally. Vik co-delivers our Junior and Senior School Advisory Service and training, our RSE training, and training for NHS health professionals. Vik has worked with Portsmouth DSA since 2013.

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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, is a recognised authority on the education of children with DS, formerly working with Ups and Downs, Southwest. Allison has worked hard 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 first cohort of 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 20 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.

Grace Anstey joined our team in 2019 to deliver our Social Communication Groups for our teenagers. Grace is a qualified speech and language therapist with experience of working with young people with additional needs. She is supported by co-worker **Tracy Leason** who joined us at the same time. Tracy is an experienced speech and language assistant with experience of supporting

children in schools with SEND. Tracy has also attended relevant co-worker training courses to enhance her skills and actively supports Grace in her role. Both Grace and Tracy are very popular with our teenagers and have been a welcome addition to the team.

Leela Baksi (Symbol UK) previously supervised the delivery of our senior Social Communication Groups (SCGs) and has remained in touch to offer advice. Leela is a qualified speech and language therapist with well over 20 years' experience of working with children with DS, and is a specialist in eating and drinking disorders, and was the author of the national paper 'How Much is Enough' giving guidance about speech and language therapy for children with Down syndrome. We are very fortunate to benefit from her expertise.

Emily Harnett

Emily joined our team this year to deliver our communication groups to our primary school-aged children. Emily is a highly specialist Speech and Language Therapist specialising in Down syndrome education and intervention. She has a wealth of experience working with children with Down syndrome and also works as part of the Cognus Therapies Team.

Alice Osborne joined our staff in September 2019 after volunteering with us for several years. Alice is now employed on a part-time basis for the charity in the capacity of Charity Manager. Alice also continues to regularly volunteer on a weekly basis. Alice is a qualified social worker with experience of working with individuals with a learning disability, and her knowledge and professionalism has been an asset to the charity.

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 40 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.

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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 Child Protection Officer who has attended safeguarding training and shared information with charity workers. Key charity staff and volunteers have also attended relevant training. We have a Child Protection 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 families with a child with a disability can feel isolated, so our social events and parties remain of key importance to provide families with opportunities to come together, have fun make friends and share experiences.

Given the importance of our social events for our families, we recruited a new **Events Manager** to our staff this year who takes responsibility for events management and fundraising, and also leads our amazing **Events Team**. Stacey Brooks had been a member of the volunteer events team herself for many years, so is experienced and familiar with our events and was able to jump straight into the role.



Events over the past financial year have included our very popular Easter party where children met their favourite 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 and a very successful outdoor event at Fairthorne Manor where children were given the opportunity to take part in activities such as kayaking, archery and climbing. All our events are extremely popular and well attended.

We would like to thank the **Portsmouth Carer's Centre** for their kind donation of £500 to help fund our Halloween party this year.

In December, we held a Christmas Party for pre-school children attended by the **Lord Mayor of Portsmouth** and also representatives from the **Zurich** team who very generously donated £500 towards the gifts for the children which were hugely popular with our children. The **Events Team** have been encouraged to take more responsibility for these activities over the year, and they excelled themselves with this event, making an amazing Santa's Grotto and hosting a fantastic party for the children.

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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 80 members formed part of our cheer teams or supported our event over the Great South Run weekend, and families and the Events Team regularly volunteer to support collections and other charity activities.

We have 5 volunteers who regularly help run our coffee mornings for parents and members of the community, and also a large events team of volunteers who help plan and organise our many social and fundraising events. These teams have 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 run by volunteers, and we are very grateful to everyone for their support.

We were delighted when Portsmouth DSA received the **Queen's Award for Voluntary Service** this year academic year, and it is credit to our inspirational leadership team, many of whom are full and 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 received an individual Queen's Award certificate and a social covid recognition certificate, and this number included some of our teenagers with Down syndrome and their older siblings.

Fundraising, Awareness and Community Support

We have been very successful in meeting our targets for fundraising once again this year due to our successful fundraising programme, and we have continued to maintain healthy reserves.

We have organised several fundraising events, 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. There was a drop in numbers as expected as the community emerged from COVID, but we still had a strong team of 165 runners who joined us for the tenth year running. 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 so many of our green 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 third year running. We also had a huge team of volunteers as usual who encouraged runners at various cheer points around the course. We were certainly the best represented charity there on the day once again. The weekend was a huge success and saw sponsorship funds generated of £37,186.79 clear profit.

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.

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Our annual black-tie dinner and auction on board HMS Warrior 1860 was well attended by 140 guests. Over £18,900 profit was raised from the proceeds of the evening. As well as raising awareness, the dinner also generated new contacts for the charity.



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 many businesses are giving COVID as a reason for not offering donations or support, and in March we received an email for a charity partner citing the invasion of Ukraine as a reason they were diverting funds.

Community and business donations included a donation of £500 from **Ineos**, £400 from the **Lord Mayor of Portsmouth Fund**, £1,000 from the **Arnold Clark Community Fund**, £1,500 from **CRBE Global**, as well as donations from local organisations like the **Hayling Legends Car Group** and local free mason lodges.

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

We started a new charity partnership with **Perfect Skin Solutions**, who have visited our centre and will be adding runners to our Great South Run team.

Local businesses have continued to offer the charity their expertise and support for which we are very grateful. Our web designers **Design Image** have continued to offer invaluable help and support in all areas, and we are particularly grateful for their continued support.

Our parents 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. We were very pleased to see lots of our families continuing to support the Warrior Dinner. We remain very grateful to our families for their support.

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 be fairly represented & included the media world. We have continued our work with **BAFTA** on their diversity board to advise about inclusion in the TV and film industry and we are proud to have co-commissioned a review into inclusion policy and subsequent report. We also worked with our contacts to ensure the refurbished **BAFTA** building was fully accessible for all. The report will promote 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, has been 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.

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 feature length 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.

Three years ago, we were invited to team up with celebrity signing duo '**Singing Hands**' for their newest 'Singing Hands Goes Pop' DVD. The charity is again acknowledged on the DVD.

PR

Successful PR is important as it not only helps parents to know where they can find support, 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 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 to **Hampshire County Council's HIAS SEND Publication**. 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 (17,857 likes and 54 five-star positive reviews), **Twitter** page (2,448 followers) and **Instagram** (1,230 followers) pages 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. 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.

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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 rewarded with a review and update of the eligibility criteria for the Blue Badge for individuals with DS.

Local councillors also receive a 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. Many of them 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 where we have had the opportunity to discuss with 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.

The National Down Syndrome Policy Group

Last year we were pleased to join forces with other key charity leaders to form the **Down Syndrome Policy Group**. 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 and Down Syndrome Education International, as well as over 100 Down Syndrome organisations.

The Down Syndrome Act 2022

The first undertaking of the **National Down Syndrome Policy Group** 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 producing 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 **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 joins together with one voice.

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We look forward to contributing to the Government consultation on Down syndrome and helping in the formation of guidelines in the areas of:

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

The All-Party Parliamentary Group on Down Syndrome

The **National Down Syndrome Policy Group** also provides the secretariat for the **All-Party Parliamentary Group on Down Syndrome (APPGDS)** and were instrumental in its re-establishment. The APPGDS aims to raise awareness of issues affecting people with Down syndrome, and the prospects for improving life outcomes, and to campaign for changes to government policy to improve the lives of people with Down syndrome. We were delighted when APPGDS MP members supported the Down Syndrome Bill on its journey through parliament.

Finances

The annual accounts are compiled by **Leonard Gold Accountants** and we are very grateful to Leonard Gold for their valued support.

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 slight rise in membership and members accessing services over the past year. It has become more evident that members living further afield are less active members as distance is an issue, and also our newer, younger families are not as engaged as previous families have been. We have membership criteria in place, and 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. We are therefore aware 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, as the future of the charity is wholly dependent on successful fundraising. We are also aware that more of our children are now reaching senior school age, and these are the costliest of our services. We support 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 £24,000 upwards per child (not including assessments, reports, training for parents and related professionals, trouble-shooting service, training for practitioners and staff, bespoke training for schools, SRE training, resources, social events, drama so the real cost is probably £30,000+). 120 families are members, and our aim is to support them from the point of diagnosis and throughout childhood.

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Portsmouth Down Syndrome Association

We also provide support and advice for non-member families, schools and organisations in the community, and 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.

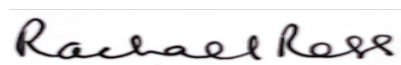
The Year Ahead

We have continued with our search for a new, larger venue, and were delighted to have finally found a suitable building. Unfortunately, COVID has hugely impacted every step of the legal and building process, and we are now several months behind with our plans through no fault of our own, but we are still very excited of the prospect of a new centre, and hope the increased space will enable us to increase our staff base and activities. We estimate we will be able to move to our new centre late in the Autumn term.

We very much look forward to working with our families and the local community over the forthcoming year, working towards a new future, and delivering a wide range of specialist services which we hope will continue to make a positive impact on the lives of children with Down syndrome and help enable them to develop the vital skills they need to become valued and productive members of their communities.

This report was approved by the Board of Trustees on 12 August 2022.

Signed by order of the Board of Trustees



Rachael Ross MBE

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 2022 set out on pages twenty to twenty five.

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.



Mr A Chapman FCA
Leonard Gold
Chartered Accountants
24 Landport Terrace
Portsmouth
Hampshire
PO1 2RG

Date: 1 September 2022

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Portsmouth Down Syndrome Association

Statement of Financial Activities for the year ended 31 March 2022

		<u>2022</u>	<u>2022</u>	<u>Total</u>	<u>Total</u>
	<u>Notes</u>	<u>Unrestric</u>	<u>Restric</u>	<u>2022</u>	<u>2021</u>
		<u>ted</u>	<u>ted</u>		
Incoming Resources					
Donations and other income	3	180,354	13,900	194,254	103,609
Government Grants	4	13,599	-	13,599	26,997
Investment Income		417	-	417	103
				7	
Total Income		194,370	13,900	208,270	130,709
Resources Expended					
Raising Funds	5	25,576	-	25,576	75
Charitable Activities	6	110,955	13,900	124,855	84,259
Support Costs	7	43,555	-	43,555	35,755

Total Expenditure	180,086	13,900	193,986	120,089
Net Income / (Expenditure)	14,284	-	14,284	10,620
Gain on sale of property	-	-	-	53,000
Net movement in funds	14,284	-	14,284	63,620
Reconciliation of funds				
Total funds brought forward	£614,032	-	£614,032	£550,412
Total funds carried forward	£628,316	-	£628,316	£614,032

Portsmouth Down Syndrome Association

Balance Sheet as at 31 March 2022

	<u>Notes</u>	<u>Total</u> <u>2022</u>	<u>Total</u> <u>2021</u>
Current Assets			
Debtors	10	-	378,00
Prepayments	10	79,37	0
Cash at bank and in hand		5	788
		549,6	235,83
Total current assets		79	2
Creditors	11	629,0	614,62
Amounts falling due within one year		54	0
		(738)	(588)
Net Current Assets		£628,3 16	£614,0 32
Funds of the charity			
Unrestricted funds		628,3	614,03
Restricted funds		16	2
		-	-
		628,3 16	614,03 2

Approved by the trustees on 12 August 2022 and signed on behalf of all trustees



Ms R Ross - TRUSTEE



Portsmouth Down Syndrome Association

Notes to the financial statements for the year ended 31 March 2022

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.

Change of Accounting Policy

In previous years the charity has prepared its accounts using the receipts and payments method. As the charity is looking to grow in the future the decision was made to now prepare the accounts using the accruals method. Therefore from the 1 April 2018 the accruals method has been used. The comparatives remain in the receipts and payments format, changing these to the accruals method would not make them materially different.

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.

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>2022</u>	<u>2021</u>
Donations and other income	180,35	133,209
Grants	4	(29,600
	<u>13,900</u>	<u>)</u>
	194,25	103,609
	<u>4</u>	<u></u>

Portsmouth Down Syndrome Association

4. GOVERNMENT GRANTS

	<u>2022</u>	<u>2021</u>
Coronavirus Job Retention Scheme	13,599	26,997
	<u>13,599</u>	<u>26,997</u>

5. RAISING FUNDS

	<u>2022</u>	<u>2021</u>
HMS Warrior Event	20,328	-
Great South Run	5,248	75
	<u>25,576</u>	<u>75</u>

6. CHARITABLE ACTIVITIES

	<u>2022</u>	<u>2021</u>
School Services	85,614	63,485
Communication Groups	6,994	2,190
Drama Groups	-	100
Early Development Groups	7,275	2,517
Staff Costs	12,249	10,394
Social Events & Entertainment	5,512	630
General Expenses	2,568	1,922
Nursery Outreach Service	4,643	3,021
	<u>124,855</u>	<u>84,259</u>

7. SUPPORT COSTS

	<u>2022</u>	<u>2021</u>
Accountancy	720	500
Bookkeeping	905	1,689
Insurance	825	778
Bank charges	27	-
IT Costs	714	739
Rent and Utilities	9,560	6,320
Postage	60	119
Stationery & Printing	729	630
General	903	475
Cleaning	-	-
Venue Hire	1,416	16
Training	19,019	12,797
Consulting	-	-
Legal costs	7,831	-
Repairs & Renewals	846	11,692
	<u>43,555</u>	<u>35,755</u>

8. TRUSTEES REMUNERATION

There were no trustees' remuneration or benefits for the year ended 31 March 2022 nor for the year ended 31 March 2021.

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Portsmouth Down Syndrome Association

9. STAFF COSTS

	<u>2022</u>	<u>2021</u>
Wages and Salaries	58,306	53,318
Social Security Costs	414	-
Pension Costs	1,116	898
Total wages Costs	<u>-</u>	<u>-</u>
	<u>59,836</u>	<u>54,216</u>

No employee earned £60,000 pa or more.

The average number of employees during the year was 3.

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>2022</u>	<u>2021</u>
Debtors	-	378,00
Prepayments	79,375	0
	<u>-</u>	<u>788</u>
	<u>79,375</u>	<u>378,788</u>

Included in prepayments is £39,250 that is due after more than one year.

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>2022</u>	<u>2021</u>
Accruals	<u>738</u>	<u>588</u>
	<u>738</u>	<u>588</u>

12. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	<u>2022</u> <u>Unrestrict</u> <u>ed</u>	<u>2022</u> <u>Restrict</u> <u>ed</u>	<u>Total</u> <u>2022</u>	<u>Total</u> <u>2021</u>
Current Assets	629,054	-	629,054	614,620
Current Liabilities	(738)	-	(738)	(588)
	<u>628,316</u>	<u>-</u>	<u>628,316</u>	<u>614,032</u>

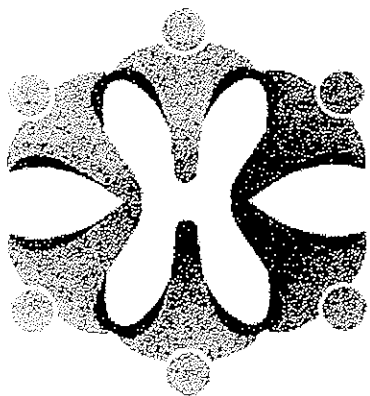
MOVEMENT IN FUNDS	<u>At 1.4.21</u>	<u>Incoming</u>	<u>Resourc</u> <u>es</u>	<u>At</u> <u>31.3.22</u>
Unrestricted Funds				

General Fund	614,032	194,370	(180,086)	628,316
Restricted Funds				
Miscellaneous Funds	-	13,900	(13,900)	-
	614,032	208,270	(193,986)	628,316

PORTSMOUTH DOWN SYNDROME ASSOCIATION

England & Wales - Charity number 1147355

Accounts



**PORTSMOUTH
DOWN SYNDROME
ASSOCIATION**

**Unaudited Financial Statements
Year ended 31 March 2021**

Leonard Gold Chartered Accountants

Portsmouth Down Syndrome Association (Portsmouth DSA)

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Portsmouth Down Syndrome Association (Portsmouth DSA)

Trustees' Report and Financial Statements year ended 31 March 2021

The trustees submit their Annual Report and the Statement of Financial Activities and Balance Sheet for the year ended 31 March 2021.

Previous names and working name

Also known by the working name Portsmouth DSA. Formerly known as Portsmouth Down Syndrome Support Group and Portsmouth Down Syndrome Association (Footprints).

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 (Actress)

Scott Hefffield (Adventurer and TV Presenter)

Tim Treloar (Adventurer and TV Presenter)

Liam Bairstow (Actor)

Board of Trustees

The trustees who served during the year were: -

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

Lucy Field – Secretary (Charity Centre Manager, Events & Drama Manager)

Helen Nelson - Treasurer

Catherine Crook – Trustee (Admin Manager, EDG/Communication Group Manager)

Ken Ross – Trustee (Development Officer, Fundraising Community Liaison)

Simon Brock – Trustee

The Constitution stipulates that there must be at least 3 trustees. Any future trustees must be appointed by a resolution of the trustees passed at a special meeting.

Charity Commission registered number: 1147355 – registered 21 May 2012

HMRC Charity registered number: XT32376 – registered 16 February 2012

Principal office: : The Sarah Duffen Centre, Belmont St Building, Cottage Grove School Campus, Chivers Close, Portsmouth PO5 1HG

Bank: HSBC, 118 Commercial Road, Portsmouth, Hampshire, PO1 1EP

Portsmouth Down Syndrome Association (Portsmouth DSA)

Independent Examiner:

Mr A Chapman FCA
Leonard Gold Chartered Accountants
24 Landport Terrace
Portsmouth
Hampshire
PO1 2RG

Introduction

Portsmouth Down Syndrome Association was formerly established in May 2009 to provide support, advice and social opportunities for families.

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 in the UK supporting development and education and offers training to assist families and professionals in providing effective support from the point of diagnosis.

Our services are the only fully comprehensive and progressive services in the UK supporting the child's education and development from diagnosis through to young adulthood with training to assist families and professionals in providing direct 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 provided at no charge to the community as we want to remove all financial barriers to access.

Portsmouth DSA works hard to raise awareness, champion inclusion, and celebrate diversity in all areas. Life-expectancy and life in general is gradually improving for people with DS however, awareness in the community, provision and regulations have not kept pace with this progress due to lack of representation and interest at governmental levels and individuals continue to experience 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, 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.

We are based at the Sarah Duffen Centre which in normal times is well utilised and provides an invaluable base from which we can host our educational groups, coffee mornings and meetings. Membership has continued to steadily rise and with careful planning we have been able to cater for all our new families' needs. We have seen an increase in the number of prospective parents with a diagnosis making contact, and as a first point of contact they have been put in touch with our Family Liaison Team.

Despite the restrictions of the COVID-19 pandemic, we have maintained and expanded services and our expert team has risen to the challenge of adapting services to deliver them in a remote format when necessary. We have managed to maintain our reserves and continued to forge even stronger links with our community.

Portsmouth Down Syndrome Association (Portsmouth DSA)

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 six dedicated and experienced trustees working either full time or part time on behalf of the charity, four of whom are parents of a child with Down syndrome.

The Chair of the Board, **Rachael Ross MBE**, previously served on the Board of Trustees for Down Syndrome Education International for over five years, as well as on additional 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, 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 educational and awareness articles have also been featured in national and regional publications, as well as county SEND publications for schools. In recognition of her sustained contribution, Rachael was awarded **The Points of Light Award** in 2015, **The Portsmouth Civic Award in 2018** and was honoured with an **MBE for 'Services to Education and Down Syndrome'** in 2019.

Rachael oversees the smooth running of the charity and is the Director of Educational Services. She manages the Schools Advisory and Training Service, and is the charity's Director of fundraising. She is also a 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** is the charity's Development Officer. He has worked as an entrepreneur predominantly in the real estate and film sectors. He is also a 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 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'.

This year **Simon Brock** stepped down as Treasurer, but we are very pleased that he will continue to serve as a Charity Trustee. Simon comes from a senior banking background and brings his expert knowledge of business and finance to the charity.

We were delighted to welcome **Helen Nelson** to the Portsmouth Down Syndrome Association Board in the role of Treasurer. Helen has been PDSA's bookkeeper for several years and has been an enthusiastic volunteer supporting our previous events and fundraisers. She comes from a senior banking background bringing knowledge and expertise to the role.

Lucy Field has served on the board since the charity's inception. She has a background in consumer and business publishing, working in a wide range of national and international publishing settings, and also has experience of marketing and budgeting. Lucy is the Sarah Duffen Centre/Administration Manager. Lucy was awarded **The Points of Light Award** in 2015 for her exemplary work with the charity.

Portsmouth Down Syndrome Association (Portsmouth DSA)

Catherine Crook has also served on the board of trustees since the charity's inception. Catherine has experience of working in educational settings supporting individuals with SEND and learning disability. Catherine manages our Communication Groups and Early Development Groups and helps to manage the charity's administration.

The board members carry out various managerial and administrative duties in addition to their trustee role. They are supported by the Primary and Early Years Manager, **Alice Osborne**, a strong team of charity administrators and practitioners, the Parent and Community Liaison Team and the Events Team as well as additional member volunteers and individuals from the community, all of whom provide valued support for the charity.

Portsmouth DSA Now Has Royal Approval

The Queen's Award

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 June 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 let us know that we were selected from thousands of organisations, and the national judges were immensely impressed with our 'exceptional' work.

Charity Chairperson Rachael Ross MBE says, *"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 our brilliant team of trustees, 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 received messages of congratulations from the community including the Lord-Lieutenant who conveyed, *"On behalf of HM the Queen....I am delighted that Portsmouth Down Syndrome Association has won the Queen's Award. This award is very richly deserved....Please convey my personal congratulations to everyone involved."*

Caroline Dinenage MP said, "This prestigious award is well deserved recognition for your hard work over many years transforming lives and outcomes by promoting inclusion and providing outstanding specialist services and training. Many congratulations to the Portsmouth DSA team!"

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 also 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.



Trustees Rachael and 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 spot lighted when Chairperson Rachael was made an **MBE** by the Queen for services to education and the field of Down syndrome.

Portsmouth Down Syndrome Association (Portsmouth DSA)

We have just received the fantastic news that we have been selected as one of a handful of **finalists for the National Diversity Award** from over 52,000 entrants across the UK. The winner will be announced in February 2022.

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 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

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 and health professionals in Hampshire and the surrounding counties of Dorset, West Sussex and Wiltshire, and we have continued 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 DS 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 PDSA services model and have asked for advice from our trustees and practitioners, and some have attended our sessions and training for guidance. 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.

This year we were once again been approached to support a family seeking asylum in the UK, and our volunteers have risen to the challenge, going above and beyond to ensure that individuals were warmly welcomed into our community and continue to have the necessary resources and support they need.

Our social activities usually include coffee and information mornings, 'Stay and Play' sessions, social events, information sessions and our very popular seasonal parties however these have been severely impacted by the COVID pandemic. Where possible we have provided remote alternatives mainly via zoom including a successful quiz evening for families, and a Singing Hands session which replaced our annual Easter party.

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 include New Family Support Services, Baby Support Groups, Early Development Groups, Social Communication Groups 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

Portsmouth Down Syndrome Association (Portsmouth DSA)

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. In response to the COVID-19 pandemic, our practitioners have delivered some of these services and training via zoom when it has not been possible to offer support in person, and they have worked hard to produce supporting online videos and resources. As to be expected during the pandemic, there was a huge rise in families and related professionals contacting us to ask for specific support and advice and a mark increase in telephone and virtual platform communications.

Frustratingly we have been unable to provide our usual Communication Groups for 4–11-year-old members. Despite an extensive ongoing search, we have struggled to find a suitable replacement Speech and Language Therapist to deliver these groups due to a national shortage of qualified therapists and a reluctance for practitioners to work on Saturdays. The COVID pandemic has also provided a further barrier to recruitment. We are continuing our search so that this vital support can resume as soon as possible.

Our services are all delivered by experienced and highly qualified experts in the field of Down syndrome. **Vik Ralfs**, the charity's inhouse education manager, is an expert educationalist and authority in DS and Relationships and Sex Education (RSE). Vik has a wealth of experience and has worked for leading UK organisations such as MENCAP and Symbol UK, as well as taking on the role of National Training and Education Manager for eight years for the Down Syndrome Association, where she also co-wrote the original 'Tell it Right' Programme and worked with the Royal College of Midwives over 3 years to develop the accredited national midwifery training programme on supporting expectant and new families of children with Down syndrome which was rolled out nationally. Vik co-delivers our Junior and Senior School Advisory Service and training, our RSE training, and training for NHS health professionals. Vik has worked with Portsmouth DSA since 2013.

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, is a recognised authority on the education of children with DS, formerly working with Ups and Downs, Southwest. Allison has worked hard 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 first cohort of 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 20 years' experience of working with children with Down syndrome. She is also a qualified speech and language therapist, specialising in Down syndrome. Becky co-delivers our Early Development Groups, Nursery and Infant School Advisory Service along with practitioners **Sam Wood, Millie Pollard and Sarah Holton**. Becky and her team have been working with Portsmouth DSA since 2009.

Grace Anstey joined our team in 2019 to deliver our Social Communication Groups for our teenagers. Grace is a qualified speech and language therapist with experience of working with young people with additional needs. She is supported by co-worker **Tracy Leason** who joined us at the same time. Tracy is an experienced speech and language assistant with experience of supporting children in schools with SEND. Tracy has also attended relevant co-worker training courses to enhance her skills and actively supports Grace in her role. Both Grace and Tracy are very popular with our teenagers and have been a welcome addition to the team.

Portsmouth Down Syndrome Association (Portsmouth DSA)

Leela Baksi (Symbol UK) previously supervised the delivery of our senior Social Communication Groups (SCGs) and has remained in touch to offer advice. Leela is a qualified speech and language therapist with well over 20 years' experience of working with children with DS, and is a specialist in eating and drinking disorders, and was the author of the national paper 'How Much is Enough' giving guidance about speech and language therapy for children with Down syndrome. We are very fortunate to benefit from her expertise.

We said a fond farewell this year to Speech and Language Therapist **Hilary Platt** who delivered our Communication Therapy Groups for our 4–11-year-old members. Unfortunately, despite a concerted effort, we have not been able to secure a suitably qualified replacement due to a national shortage of qualified therapists and a reluctance for some practitioners with families to work on Saturdays. The COVID pandemic has also provided a further barrier to recruitment. We will continue our search as a matter of priority.

Alice Osborne joined our staff in September 2019 after volunteering with us for several years. Alice is now employed on a part-time basis for the charity in the capacity of Primary and Early Years Manager as well as helping with the management of some of the charity's wider activities. Alice has continued to regularly volunteer on a weekly basis. Alice is a qualified social worker with experience of working with individuals with a learning disability, and her knowledge and professionalism has been an asset to the charity.

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 40 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 Child Protection Officer who has attended safeguarding training and shared information with charity workers. Two further Trustees have completed safeguarding courses. We have a Child Protection 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.

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 Support

We have found that developments in 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 offer support and information from the point of diagnosis for families and professionals.

Portsmouth Down Syndrome Association (Portsmouth DSA)

Parent and Community Liaison Initiative



In 2018 we were excited to expand our existing support network for parents and health professionals by introducing our Parent and Community Liaison initiative, which was launched at **Queen Alexandra Hospital**, with the Lord Mayor of Portsmouth in attendance. To accompany the launch, the charity produced a Parent Welcome Pack for new parents and supporting literature for NHS health professionals including advice on 'Delivering a Diagnosis of Down Syndrome' and 'Positive Language' written by Chairperson Rachael Ross. The pack was produced at cost price by local design company **Design Image** who have been loyal supporters of our charity. World

leading toy manufacturers **Jellycat** were also impressed with the pack and were keen to support the initiative by donating a soft toy for each new family. We continue to distribute these packs to hospitals and maternity units across the region. This has been a big success and new parents are now regularly signposted to us.

The initiative includes a comprehensive support system for new parents from the point of diagnosis. 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 is also regularly working with midwives, nurses, paediatricians, GPs, social workers, portage workers and other relevant health professionals to ensure they have the information they need to effectively support families and colleagues.

The programme also enables us to offer bespoke training to health professionals examining '**Down Syndrome Today**', and to date our team has had the pleasure of delivering training to over 300 trainee midwives at the Bournemouth University Midwives Conference, as well as paediatricians, midwives and maternity nurses, social workers and other related professionals.

The team is led by **Alice Osborne** who comes from a social work background with experience of working with individuals with a learning disability. Alice continues to throw herself wholeheartedly into implementing our exciting initiative and has been busy meeting our lovely new families, developing and delivering training to health professionals and forging ever-stronger links with the health community. We were pleased to welcome parent **Dr Angela Hoyle GP** to our training team this year, who has helped organize training for GP surgeries. Due to COVID, much of our training has taken place virtually or in smaller groups.

We continue to receive excellent feedback from parents and health professionals about our initiative, and we look forward to expanding this further over forthcoming months.

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

"The 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

Portsmouth Down Syndrome Association (Portsmouth DSA)

"The 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

Baby Support Groups

We continue to offer support from birth, at what can be a difficult time for new parents. The Baby Support Groups are delivered by our expert practitioners and provide advice and information for parents with infants aged up to 18 months. Parents are advised of the services and checks they should be receiving, they receive advice in all areas of development, and learn activities to practise at home to aid their child's development.

Last year we began offering 'stay and play' sessions once again to parents, led by Alice and parent volunteers which have been well received and provide a quieter environment for our parents to chat and socialise, and share advice. This has been impacted by COVID, but we have run sessions when possible, and the PDSA team have been available at all times to offer support.

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 speech, play and fine motor and transition to school.

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.

This year activities have been impacted by COVID. Sessions have been delivered at our centre when permitted, Government COVID policy has been followed and all health, safety and risk assessment measures have been adhered to. When it was not possible to deliver the groups in person, **Becky Baxter** and the EDG team worked hard to adapt the service, so it could be delivered virtually, supported by online training sessions and resources.

Communication Groups

Our Communication Groups have been on hold whilst we try to find a replacement therapist to deliver these groups.

Social Communication Groups

The format for our Social Communication 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.

Portsmouth Down Syndrome Association (Portsmouth DSA)



These monthly groups are led by our new speech and language therapist **Grace Anstey**, who is suitably experienced in the field of DS, and supported by our new co-worker **Tracy Leason** who again has an abundance of experience delivering SALT programmes and has worked with children with DS and SEND in an educational setting. Both Grace and Tracy are well settled into their roles and are well liked by the teenagers. For now, the groups are still overseen by Leela Baksi (Symbol UK) specialist Speech and Language Therapist. The young people enjoy attending and the sessions they have been a big success.

We are aware that a good friendship network is particularly important for our young people, and an aim of the group is to encourage these friendships. To further facilitate this, we have set up a closed WhatsApp Group so the young people can communicate with each other in a safe environment on social media. It is a work in progress! We also try to organise monthly outings for the teenagers where they can socialise and have fun with friends, and some groups also go out locally after their monthly session. It has been lovely to watch these groups mature and friendships develop.

Again, our SCGs have been impacted by COVID, and when meeting in person was not possible, the sessions have been successfully delivered on a virtual platform. The young people have risen to the challenge, and enjoyed these sessions and relished staying in touch during the difficult last year.

Special Partnership with King Edward VI School

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

Last year we were thrilled to enter into an exciting new budding partnership with some older students from King Edward VI School who join us for our Social Communication Group outings with the aim of developing friendships and social skills. The partnership has been hugely successful so far, and the students and our teenagers have embraced the opportunity to engage with massive benefits to all taking part.

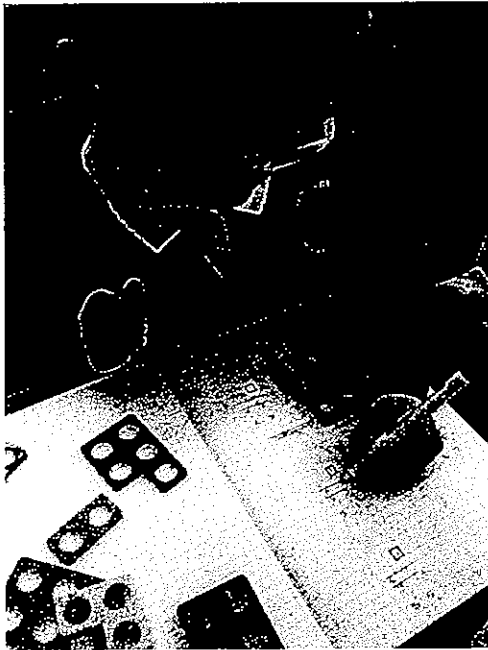


Unfortunately, COVID has impacted on our usual monthly outings which previously included swimming and climbing, and the KES students attending PDSA activities. The young people have stayed in touch via Zoom, and KES students have been busy fundraising in the hope that the summer camp at the end of August hosted by KES will still be able to proceed. We would like to thank Mark Miller and everyone at KES for providing such an exciting and unique opportunity for our teenagers.

Portsmouth Down Syndrome Association (Portsmouth DSA)

The School, College and Nursery Advisory Service

Portsmouth Down Syndrome Association has worked hard to establish and develop our flagship School, College and Nursery Service, which we believe it is now the best example of its kind in the UK.



In September 2012, we supported the successful inclusion of our children in over 21 mainstream schools in Portsmouth, Hampshire 7 surrounding counties. In March 2014, this figure rose to 40, and we currently now provide support for our members in 100+ nursery, primary, secondary and further education settings.

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 child and school. The child 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 child's educational needs in their Annual Review.

As more of our children 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 is largely a new area for many 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 free training session at the start of the term, or just prior to this. Our education manager Vik Ralfs is an expert in Relationships & Sex Education, and we invite schools to take advantage of her expertise to run sessions for children or staff when required.

Several termly training sessions are also included in the outreach programme on a variety of relevant topics, delivered by a variety of UK experts. This year, as well as our annual DS overview and learning profile training, we have highlighted topics such as school transition, successful inclusion and developed new online resources for further education settings. Pre-school training has included topics such as school transition, speech and language and the value of using print.

We have continued to offer training and bespoke advice specifically for parents and schools on issues such as RSE and exam options and alternative accreditations. All training is relevant and based on up-to-date and evidence-based research, and we are very pleased to say that our training evaluation sheets continue to be 100% positive.

Portsmouth Down Syndrome Association (Portsmouth DSA)

COVID has seriously impacted all of our services, the school service included. However, our team worked hard to ensure that the quality of our service didn't suffer. When it wasn't possible to deliver training and visits in person, the team delivered virtual training and advice, as well as developing online resources and training films which could be accessed by schools and parents. They also developed specialist resources to help support the student's return to school after the long COVID break, and to help them adapt to the new COVID procedures such as social distancing, masks and hygiene.

Our work has been featured in various publications. Last year our chairperson and director of education was invited contribute to the **Hampshire Inspection and Advisory Service SEND Publication** which was circulated to all schools in the county. Our guidance was then 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 was 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.

The charity has recently invested time into exploring alternative accreditations and exam courses which are more suitable for our young people, will offer more choice and opportunities, and will allow them to achieve meaningful, recognised qualifications. In particular, we identified 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. One school hosted an information evening at their school so they could disseminate information and training. These alternative options have revolutionised exam possibilities for our teenagers and can also be of benefit to other pupils in the school community.

In addition to our services we also support members (and non-members) with applications for their Education and Health Care Plans and Disability Living Allowance and other benefits, as well as giving specialist advice when applications are refused or issues arise with provision.

Rachael Ross MBE, Chair, would like to thank all the practitioners and service managers and volunteers for their hard work and excellent efforts during the pandemic to ensure that services continued for our families and service users.

Portsmouth Down Syndrome Association (Portsmouth DSA)

Social Events and Parties



Many families with a child with a disability can feel isolated, so our social events and parties remain of key importance to provide families with opportunities to come together, have fun make friends and share experiences.

Sadly COVID-19 had a big impact on our face-to-face events. Activities were replaced with virtual activities where possible. At Christmas time, the **Zurich Community Team** donated vouchers for our pre-school children, which were posted to their address along with an accompanying letter from Father Christmas. Families were invited to take part in our charity online quiz, organized by our events team and IT team. The evening was a big

success and helped to raise spirits during lockdown. Instead of our usual Easter Party we held a virtual gathering with entertainment from **Singing Hands** which was enjoyed by our families.

VOLUNTEERS

Our charity is largely managed by full and part time volunteers, some of whom are our young ambassadors who make themselves available for PR and photoshoots, cheque collections and fundraisers. Our charity is a cooperative, and we encourage a community spirit within our membership. There are many volunteer opportunities, and in usual times we estimate that around 80% of our members volunteer either on a regular basis or ad hoc when needed for events and fundraisers.

The charity would simply not exist without this volunteer support, and we are very grateful to all our volunteers.

Over lockdown, volunteer opportunities were reduced, but a core number of trustees and volunteers were vital in insuring that the charity could continue to function. Rachael Ross MBE, Chair, would like to thank the Trustees, Events, Fundraising and IT Teams and individuals for their hard work and dedication during lockdown.

Fundraising, Awareness and Community Support

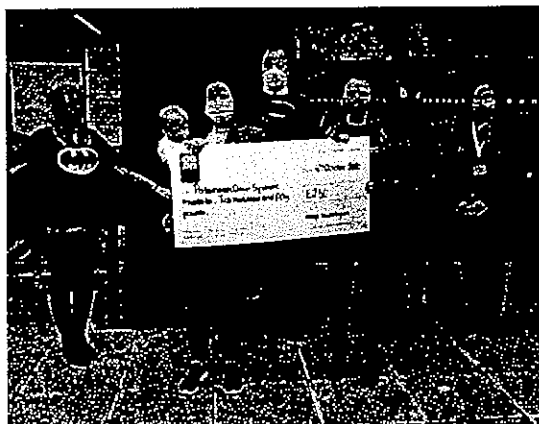
Despite the restrictions of the pandemic, we have managed to keep our accounts on an even keel. Plans to move to our new Commercial Road building were abandoned during COVID. There has been an offer on the property of £372,000 which leaves a small profit after works and expenses.

Our two largest sources of annual income, The Warrior Dinner and The Great South Run, were both cancelled, and valuable potential funds were lost. The Events Team led by Alice Osborne created a virtual T21 Challenge to replace these events. Members and supporters completed various challenges involving the number 21 (in recognition of the 21st chromosome) which ranged from baking, jigsaw and sewing challenges to cycling, cold water swimming and running. The event was a huge success, galvanizing our community in a challenging time, and raising an incredible £45,599 (plus Gift Aid). The event also raised awareness with radio and TV coverage. Alice and the team should be commended for their efforts, and we are very grateful to our families and our community for their support.

Again, our Down Syndrome Awareness Week celebrations were severely impacted by COVID, so we focused on social media to stage our usual awareness week campaign. The campaign included photo competitions judged by the Lord Mayor of Portsmouth and the sharing of facts about the condition. A handful of schools and organisations managed to hold awareness events and fundraisers in support, and our Events Team organized a fantastic Mega March Draw, with an abundance of prizes donated by our generous community, raising £2,831.

Portsmouth Down Syndrome Association (Portsmouth DSA)

The campaign was very successful reaching a very large audience, and was well supported by the community, MPs and councillors. **Warner Goodman Solicitors** generously sponsored our campaign for the 8th consecutive year, and donated £2,000 to our charity. We very much appreciate their valued support.



We have worked hard over the years to nurture strong links with our community,

We have the honour of being elected the first civilian charity of the **WO & SR Mess on board HMS Queen Elizabeth**, and the crew held a fundraiser raising £300.82.

Business donations included **Airbus** (£5,001.65) rolled over due to COVID, **INEOS** (£1,000), £400 the **Lord Mayor's Fund**, **CBRE Global Investors** (£1,000), **Glowsure** (£4,000), **AJ Bell Trust** (£1,000) as well as generous donations from the **COOP**, **Waitrose** and **Sainsbury's**, as well as **Hampshire Free Masons** and **Cosham Free Masons**.

A donation was made in memory of Daphne Nicholson of £2,000. We are always very touched when families think of us at this difficult time.

Local businesses have continued to offer the charity their expertise and support for which we are very grateful. Our web designers **Design Image** have continued to offer invaluable help and support in all areas, and we are particularly grateful for their continued support.

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 be fairly represented & included the media world. We have continued our work with **BAFTA** on their diversity board to advise about inclusion in the TV and film industry, and a draft inclusion policy is due to be completed imminently which we look forward to promoting. As a result of this work, many other media organisations are following suit, and we are already seeing 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.

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) 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 feature length 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.

Portsmouth Down Syndrome Association (Portsmouth DSA)

Our links with BAFTA enabled us to nominate our lead actor in Innocence, Tommy Jessop to be considered for the BAFTA Elevate Programme this year. We were delighted when Tommy was selected for the programme, and his first meeting was with none other than Martin Scorsese and he is currently working with Stephen Spielberg. He has also starred in popular TV dramas such as 'Line of Duty'. We look forward to seeing much more of Tommy on our screens.

As a result of our work with BAFTA, they have invited Chair Rachael Ross MBE and Vice-Chair Ken Ross to be their first ever Accessibility and inclusion Patrons. We hope that this will open new opportunities for our charity and also people with DS in general.

Two years ago, we were invited to team up with celebrity signing duo '**Singing Hands**' for their newest 'Singing Hands Goes Pop' DVD. The charity is again acknowledged on the DVD.

PR

Successful PR is important as it not only helps parents to know where they can find support, 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 worked with key national policy makers and service providers including the **NSPCC**, **MENCAP**, the **Paralympics** and the **Special Olympics** to help further services and opportunities specifically for people with Down syndrome.

Portsmouth DSA has always lobbied hard against discrimination and actively advocates for equality, playing a leading role in the review of **Blue Badge** criteria. This year, we helped lead the '**No Place for Hate**' campaign against discriminatory slogans on clothing sold on **Amazon**. We were also proud to lead the '**Emmerdale Campaign**' campaigning against the discriminatory storyline in the prime-time TV soap. This was picked up by the local and national media on TV, radio and newspapers, with our charity being extensively featured.

Charity Vice-Chair Ken Ross was featured in **The Guardian** newspaper highlighting the need for better opportunities for people with Down syndrome in the film and TV industry, and showcasing the incredible work of the professionals already making their mark in this industry.

Social media

Social media played a very important role during the last year, enabling the charity to stay in touch with our members and our community during the pandemic, and all our platforms were very well supported.

The charity **Facebook** page (17,207 likes and a number of positive five star reviews) and **Twitter** page (2,219 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. The members' only Facebook Page is also regularly utilized. Our **Instagram** account is steadily growing (988 followers).

We have recently set up a **LinkedIn Page** for the charity, which we hope will improve networking within our community.

We actively encourage our members to support our social media pages, as it is vitally important for raising awareness and 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.

Portsmouth Down Syndrome Association (Portsmouth DSA)

We think it is very important to liaise regularly with those in positions of authority, our local councillors and MPs to highlight issues surrounding DS. These issues have included service provision, screening and abuse. Local councillors and MPs receive a 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, and they are also invited along to key events. This year our DS Awareness Week was very well supported by local politicians.

We have regularly attended think tanks and also visited the Houses of Parliament where we have had the opportunity to discuss with 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.

Finances

The annual accounts compiled by **Leonard Gold Accountants** are currently being collated for the year April 2020 to March 2021 and will be available for viewing later in the year. We are very grateful to Leonard Gold for their valued support.

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 and Treasurer who meticulously maintains the charity's books.

There has been a slight rise in membership and members accessing services over the past year. It has become more evident that families living further afield are less active members as distance is an issue, and also our newer, younger families are not as engaged as previous families have been. We have membership criteria in place, and 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. We are therefore aware 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, as the future of the charity is wholly dependent on successful fundraising. We are also aware that more of our children are now reaching senior school age, and these are the costliest of our services. We support 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 upwards of £24,000 per child (not including assessments, reports, training for parents and related professionals, trouble-shooting service, training for practitioners and staff, bespoke training for schools, SRE training, resources, social events, drama so the real cost is probably £30,000+). Over 100 families are 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 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.

Portsmouth Down Syndrome Association (Portsmouth DSA)

The Year Ahead

We very much look forward to working with our families and the local community over the forthcoming year, working towards a new future, and delivering a wide range of specialist services which we hope will continue to make a positive impact on the lives of children with Down syndrome and help enable them to develop the vital skills they need to become valued and productive members of their communities.

This report was approved by the Board of Trustees on 18 October 2021

Signed by order of the Board of Trustees

Rachael Ross

R Ross - Chair, Portsmouth Down Syndrome Association's Board of Trustees

Portsmouth Down Syndrome Association (Portsmouth DSA)

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 2021 set out on pages twenty to twenty five.

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.



Mr A Chapman FCA
Leonard Gold
Chartered Accountants
24 Landport Terrace
Portsmouth
Hampshire
PO1 2RG

Date: 29/10/21

Portsmouth Down Syndrome Association (Portsmouth DSA)

Statement of Financial Activities for the year ended 31 March 2021

	Notes	<u>2021</u> <u>Unrestricted</u>	<u>2021</u> <u>Restricted</u>	<u>Total</u> <u>2021</u>	<u>2020</u>
Incoming Resources					
Donations	3	133,209	(29,600)	103,609	429,157
Government Grants	4	26,997	-	26,997	-
Investment Income		103	-	103	838
Total Income		<u>160,309</u>	<u>(29,600)</u>	<u>130,709</u>	<u>429,995</u>
Resources Expended					
Raising Funds	5	75	-	75	40,435
Charitable Activities	6	83,859	400	84,259	144,636
Support Costs	7	24,063	11,692	35,755	56,374
Total Expenditure		<u>107,997</u>	<u>12,092</u>	<u>120,089</u>	<u>241,445</u>
Net Income / (Expenditure)		52,312	(41,692)	10,620	188,550
Gain on sale of property		53,000	-	53,000	-
Transfer between funds		140,596	(140,596)	-	-
Net movement in funds		<u>245,908</u>	<u>(182,288)</u>	<u>63,320</u>	<u>188,550</u>
Reconciliation of funds					
Total funds brought forward		368,124	182,288	550,412	361,862
Total funds carried forward		<u>614,032</u>	<u>-</u>	<u>614,032</u>	<u>550,412</u>

Portsmouth Down Syndrome Association (Portsmouth DSA)

Balance Sheet as at 31 March 2021

	<u>Notes</u>	<u>Total</u> <u>2021</u>	<u>2020</u>
Current Assets			
Tangible Fixed Assets	10	-	325,000
Debtors	11	378,788	4,360
Cash at bank and in hand		<u>235,832</u>	<u>221,183</u>
Total current assets		614,620	550,543
Creditors			
Amounts falling due within one year	12	<u>(588)</u>	<u>(131)</u>
Net Current Assets		<u>614,032</u>	<u>550,412</u>
 Funds of the charity			
Unrestricted funds		614,032	368,124
Restricted funds		-	182,288
		<u>614,032</u>	<u>550,412</u>

Approved by the trustees on 18 October 2021 and signed on behalf of all trustees

Rachael Ross Ms R Ross - TRUSTEE

H Nelson Ms H Nelson - TRUSTEE

Portsmouth Down Syndrome Association (Portsmouth DSA)

Notes to the financial statements for the year ended 31 March 2021

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.

Change of Accounting Policy

In previous years the charity has prepared its accounts using the receipts and payments method. As the charity is looking to grow in the future the decision was made to now prepare the accounts using the accruals method. Therefore from the 1 April 2018 the accruals method has been used. The comparatives remain in the receipts and payments format, changing these to the accruals method would not make them materially different.

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.

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 INCOME

	<u>2021</u>	<u>2020</u>
Donations	133,209	255,522
Grants	(29,600)	173,635
	<u>103,609</u>	<u>429,157</u>

Portsmouth Down Syndrome Association (Portsmouth DSA)

4. GOVERNMENT GRANTS

	<u>2021</u>	<u>2020</u>
Coronavirus Job Retention Scheme	26,997	-
	<u>26,997</u>	<u>-</u>

5. RAISING FUNDS

	<u>2021</u>	<u>2020</u>
HMS Warrior Event	-	30,867
Great South Run	75	9,568
	<u>75</u>	<u>40,435</u>

6. CHARITABLE ACTIVITIES

	<u>2021</u>	<u>2020</u>
School Services	63,485	45,698
Communication Groups	2,190	14,251
Drama Groups	100	688
Early Development Groups	2,517	16,085
Staff Costs	10,394	46,796
Social Events & Entertainment	630	8,826
General exp	1,922	1,388
Nursery Outreach Service	3,021	10,904
	<u>84,259</u>	<u>144,636</u>

7. SUPPORT COSTS

	<u>2021</u>	<u>2020</u>
Accountancy	500	-
Bookkeeping	1,689	508
Insurance	778	720
Bank charges	-	30
IT Costs	739	598
Service Charges	6,320	6,315
Postage	119	30
Stationery & Printing	630	551
General	475	1,460
Cleaning	-	110
Venue Hire	16	2,318
Training	12,797	7,877
Consulting	-	14,606
Legal costs	-	3,749
Repairs & Renewals	11,692	17,501
	<u>35,755</u>	<u>56,374</u>

Portsmouth Down Syndrome Association (Portsmouth DSA)

8. TRUSTEES REMUNERATION

There were no trustees' remuneration or benefits for the year ended 31 March 2021 nor for the year ended 31 March 2020.

9. STAFF COSTS

	<u>2021</u>	<u>2020</u>
Wages and Salaries	53,318	45,795
Social Security Costs	-	225
Pension Costs	898	776
Total wages Costs	<u>-</u>	<u>-</u>
	<u>54,216</u>	<u>46,796</u>

No employee earned £60,000 pa or more.

The average number of employees during the year was 3.

10. TANGIBLE FIXED ASSETS

	Freehold Property	Total
	£	£
COST		
At 1 April 2020	325,000	325,000
Additions	-	-
Disposals	<u>(325,000)</u>	<u>-</u>
At 31 March 2021	<u>-</u>	<u>325,000</u>
DEPRECIATION		
At 1 April 2020	-	-
Charge for year	-	-
Elimination on disposal	<u>-</u>	<u>-</u>
At 31 March 2021	<u>-</u>	<u>-</u>
NET BOOK VALUE		
At 31 March 2021	<u>-</u>	<u>325,000</u>
At 31 March 2020	<u>325,000</u>	<u>325,000</u>

11. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>2021</u>	<u>2020</u>
Debtors	378,000	-
Prepayments	<u>788</u>	<u>4,360</u>
	<u>378,788</u>	<u>4,360</u>

Portsmouth Down Syndrome Association (Portsmouth DSA)

12. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	<u>2021</u>	<u>2020</u>
Accruals	588	131
	<u>588</u>	<u>131</u>

13. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	<u>2021</u> <u>Unrestricted</u>	<u>2021</u> <u>Restricted</u>	<u>Total</u> <u>2021</u>	<u>Total</u> <u>2020</u>
Current Assets	614,620	-	614,620	550,543
Current Liabilities	(588)	-	(588)	(131)
	<u>614,032</u>	<u>-</u>	<u>614,032</u>	<u>550,412</u>

MOVEMENT IN FUNDS	<u>At 1.4.20</u>	<u>Incoming</u>	<u>Resources</u>	<u>Transfers</u>	<u>Total At</u> <u>31.3.21</u>
Unrestricted Funds					
General Fund	368,124	213,309	(107,997)	140,596	614,032
Restricted Funds					
New Building Fund	182,288	(30,000)	(11,692)	(140,596)	-
Miscellaneous Funds	-	400	(400)	-	-
	<u>550,412</u>	<u>183,709</u>	<u>(121,345)</u>	<u>-</u>	<u>614,032</u>