

FUNDRAISING EDITION

PSPA MATTERS

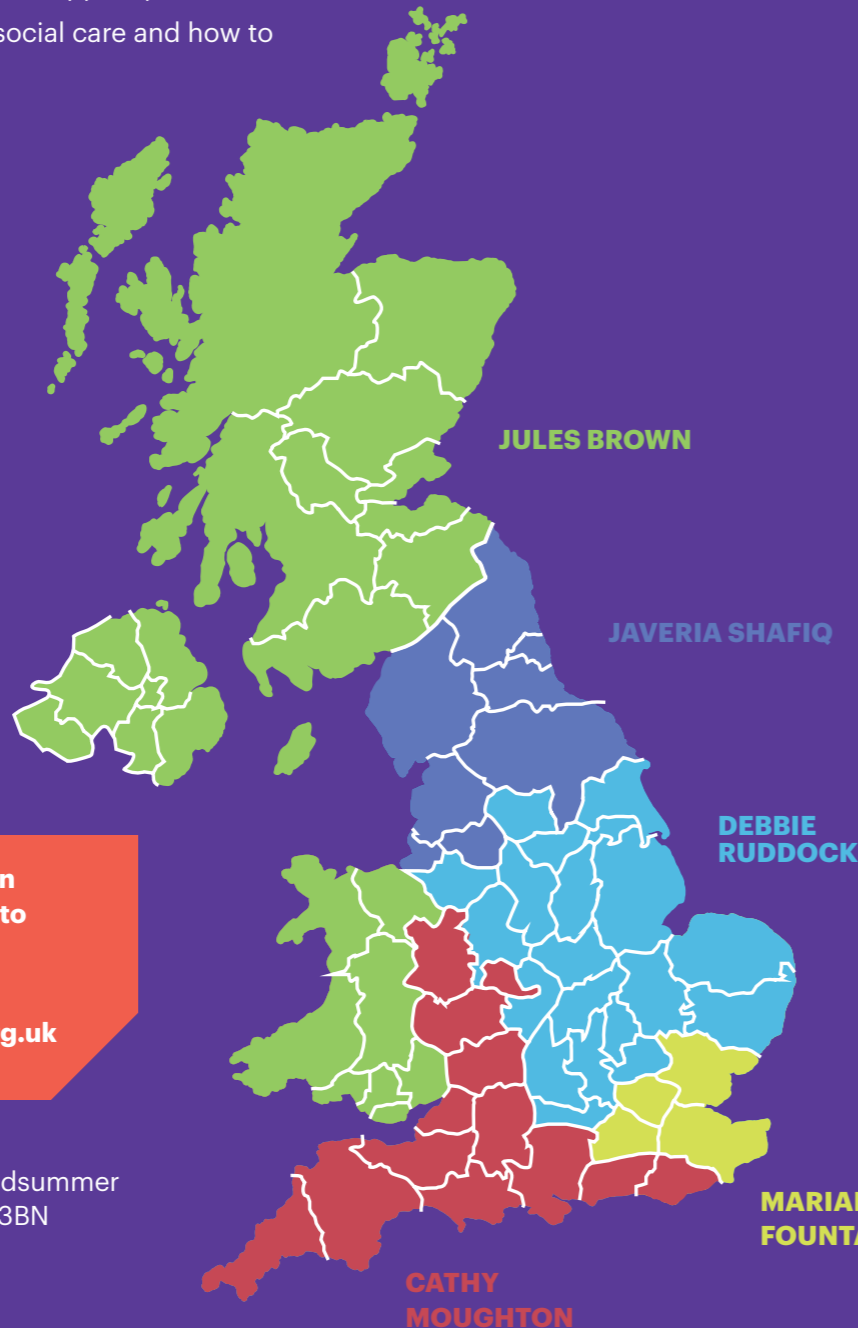


PSPA 30 YEARS
CREATING A BETTER FUTURE FOR
PEOPLE LIVING WITH PSP & CBD

HERE FOR YOU

Our Helpline Care Navigators are here to support everyone affected by PSP & CBD. Each Helpline Care Navigator has a designated area (see map) where they provide proactive support, including:

- Information on all aspects of living with PSP & CBD, such as symptom management, benefits and entitlements and everyday living
- Emotional and practical support
- Contact details for local support, which may include Support Groups
- Information about how PSPA can support you
- Information about health and social care and how to access these services
- Signposting to other sources of information
- Referral for non-means tested benefits applications via Department of Work and Pensions (DWP) home visiting service
- Supporting evidence about PSP & CBD for Blue Badge applications and Continuing Healthcare applications
- Provide specific information written for health and social care professionals and access to Education Volunteers.



Our Helpline and information service is available Monday to Friday 9am to 9pm.

Tel: 0300 0110 122 or email helpline@pspassociation.org.uk

PSPA
Margaret Powell House, 415a Midsummer Boulevard, Milton Keynes, MK9 3BN

Registered charity number England and Wales 1037087 and Scotland SCO41199.



WELCOME

The New Year kicks off PSPA's 30th Anniversary. Since the inception of the charity 30 years ago, running from Micheal Koe's kitchen table, the charity has grown to support thousands of people living with PSP & CBD, their carers and families, and provided information to health and social care professionals. We want 2024 to mark the start of a new drive to raise awareness of PSP & CBD, to search for treatments and to get earlier diagnosis. For people who turn 30 this year, we want to make sure the future will be different if they receive a diagnosis in later life.

In 2024, we have budgeted to increase our investment in research by 40% and will have seven research grants and one fellowship in operation supporting researchers in their search to understand more about PSP & CBD. We have recruited a Director of Policy and Influencing to raise awareness and campaign for better services and care across the UK. Thanks to the National Lottery Community Fund we will be launching two new services as part of our Mind, Body and Soul project focusing on mental and physical health through counselling and on-line exercise.

Our 30 for 30 campaign is designed to involve the wider PSPA family in our 30th anniversary year. You can find out more about how you can get involved in pages 19 to 21. Personally, I have signed up to do the Thames Path Ultra and will be walking 100km over two days in September 2024, it would be great if anyone wants to join me on the walk.

2024 is set to be a busy year full of potential for making a big step forward. The whole team at PSPA is excited for what the year can bring. You can read about our plans in this and three forthcoming magazines. Each one will be themed, starting with fundraising. Thank you to everyone who has supported us through the years and we hope to meet many of you in the months ahead.

Rebecca Packwood
PSPA CEO

P.S
You can sign up to the Thames Path Ultra Challenge, here: www.pspassociation.org.uk/events-list/thames-path-challenge-14-and-15-september-2024



CONTENTS

- 04 PSPA NEWS
- 06 WELCOME TO #TEAMPSPA
- 07 NEW TRUSTEES
- 08 OUR RESEARCH COMMITTEE
- 10 30 YEARS OF PSPA
- 12 WHERE IT ALL BEGAN
- 14 HOW FUNDRAISING CAN HELP SHAPE THE FUTURE OF PSPA
- 16 30 YEARS OF TRUSTS SUPPORT
- 19 30 FOR 30 CHALLENGE
- 22 PSPA 30TH ANNIVERSARY AWARDS
- 25 PSPA WALK OF HOPE
- 27 PEDALLING FOR PSPA
- 30 FAMILY FUNDRAISING
- 33 CELEBRATING 30 YEARS OF AMAZING SUPPORT
- 36 30TH ANNIVERSARY ACTIVITIES

The views expressed in PSPA Matters are not necessarily those of PSPA. The advertisement of third party products or services does not in any way imply endorsement by PSPA nor that those products or services will be provided, funded or available via PSPA. All content © PSPA 2024.

- USEFUL CONTACTS**
- Main contact **01327 322410**
info@pspassociation.org.uk
 - Helpline **0300 0110 122**
helpline@pspassociation.org.uk
 - Fundraising **01327 322414**
fundraising@pspassociation.org.uk
 - Volunteering **01327 368597**
volunteering@pspassociation.org.uk
 - Rebecca Packwood, CEO
01327 322413
rebecca.packwood@pspassociation.org.uk
 - Helen Chapman, PSPA Matters Editor
helen.chapman@pspassociation.org.uk
 - Megan Hodgson, Research Coordinator
01327 322418
research@pspassociation.org.uk




PSPA NEWS

MARK PSPA'S 30TH ANNIVERSARY WITH OUR NEW SHOP PRODUCTS

Pick up a memento for PSPA's 30th Anniversary from our new shop range.

Choose from a selection of thoughtfully picked items which make ideal gifts or a treat for yourself:

- 30th Anniversary pin badge
- 30th Anniversary tote bag
- Limited edition t-shirt
- Lots more.

You can buy items from our shop to help raise awareness of PSP & CBD in your community, here: www.pspassociation.org.uk/fundraising/shop/



INSIDE NEUROLOGY: OUR UNIQUE BRAIN

PSPA is excited to be involved in a news style programme called Inside Neurology: Our Unique Brain.

The programme was produced by ITN Business in partnership with The Brain Charity to highlight the positive efforts being made to support people living with neurological conditions.

Bruce and Neda kindly share their experience of living with CBD. PSPA CEO Rebecca Packwood and PSPA Trustee and Consultant Neurologist, Dr Boyd Ghosh, also feature to provide insight into symptoms, diagnosis and the care people living with PSP & CBD need, which doesn't currently exist.

The programme launched on 10 January and is available to watch on the ITV Business Hub: www.business.itn.co.uk/programmes/inside-neurology-our-unique-brain/



DATE FOR YOUR DIARY! PSP & CBD AWARENESS WEEK

This year, we are pleased to confirm PSP & CBD Awareness Week will take place 17 to 23 June 2024.

Each year, we garner your enthusiasm and support during PSP & CBD Awareness Week to help spread the word about the two conditions.

Last year, you kindly helped share Eye Red Flag posters to opticians in your area to aid early diagnosis. This year we will be focusing on improving support for carers.

Keep a look out for more information in Edition 2 of PSPA Matters, due out in May.



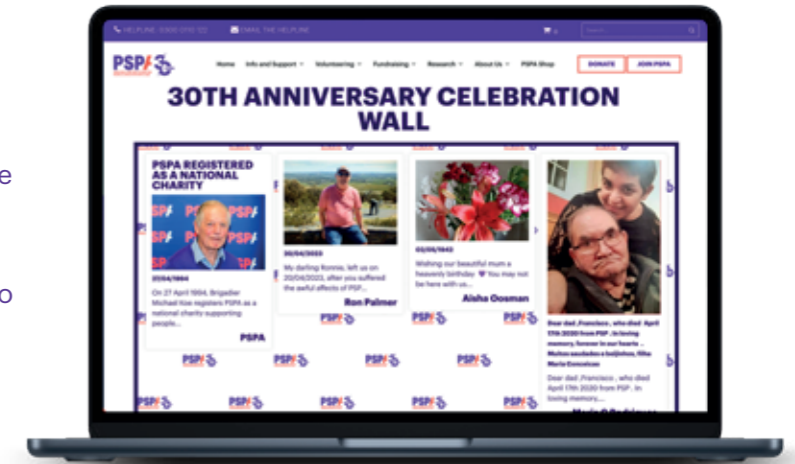
MARK A SPECIAL OCCASION ON THE PSPA CELEBRATION WALL

You can mark a special occasion on our website.

Whether you would like to mark a birthday, anniversary or in-memory date, you can do so on the PSPA Celebration Wall if you donate £30 or more.

Each brick on the Celebration Wall enables you to upload a photo and share a special message of up to 250 words.

Mark your special occasion here: www.pspassociation.org.uk/30th-anniversary-celebration-wall/



RECORD YOUR FUTURE WISHES USING THE PSPA FREE WILL SCHEME

Everyone needs a Will; it is important because it ensures your intentions are known, that you protect your family, and just when your loved ones are missing you most, you have ensured all the finer details are taken care of them, so they can grieve.

You can now write a simple Will for free with PSPA.

There is no obligation to leave a gift to PSPA in your Will, however after considering your friends and family, you may wish to gift an amount, part of your estate or an item to the charity – it will help support the future of PSPA.

To make a free Will, please visit: www.farewill.com/pspa-30 or email fundraising@pspassociation.org.uk

ANNIVERSARY CAKE COMPETITION

To kick off our anniversary year, we are inviting you to design a PSPA Anniversary Cake; and share your design on social media to mark the day we were registered as a charity – 27 April 1994.

What would it be? A purple chocolate bomb? A mandarin segment cake, or something completely different representing what PSPA has meant to you over the years.

Share your cake designs with us on Facebook or Instagram by tagging [@PSPAAssociation](https://www.facebook.com/PSPAAssociation) and using the hashtag [#PSPA30](https://www.instagram.com/PSPAAssociation) by 29 February 2024. Alternatively, email your photos to fundraising@pspassociation.org.uk

The winning design will be used as our 30th Anniversary cake.





WELCOME TO #TEAMPSPA

Since our last edition of PSPA Matters, we have welcomed a number of new team members who are all eager to help the charity reach its goals. Here we say a quick hello to two of them.



CLAIRE AYLING, SENIOR FUNDRAISING MANAGER - TRUSTS

I joined PSPA's fundraising team at the end of summer 2023. After a short stint working for a transportation and engineering consultancy, I moved into the charity sector in 2000 and have never looked back!

I have worked for a range of local and national charities with my roles initially focusing on volunteer recruitment and support, as well as promotion of good practice in volunteering. Whilst volunteering as a Trustee for a local Home-Start scheme, I supported the manager with researching and applying to charitable trusts. I found my new passion and in 2015, I moved into trust fundraising as a career.

It's very competitive in trust fundraising, but I'm looking forward to the challenge and opportunities ahead. It's a privilege to share the breadth of our work, as well as share your stories and our impact in order to inspire charitable trusts so that, together, we can create a better future for everyone affected by PSP & CBD.



MEGAN HODGSON, RESEARCH COORDINATOR

I'm really excited to join PSPA as the new Research Coordinator.

The last two years I've been working in the NHS as a research associate, primarily on the PROSPECT study at UCL. I've also worked on two other projects focused on young on-set and familial Parkinson's (The Parkinson's and Movement Disorders Families Project) and the Vision in Parkinson's study. Before this while I was studying for my master's degree in Genomic Medicine I was working as a care assistant in a neurological care centre for Sue Ryder.

I'm very much looking forward to getting stuck in, meeting people who use our services and finding out the research priorities of people living with PSP & CBD along with their carers and families.

I'm also looking forward to working with some brilliant academics and researchers as they try to improve the lives of people with PSP & CBD.

In my free time I love being outdoors walking with my dog Scout, baking and am spending more and more of my time running which I have a love/hate relationship with as I begin my training for the London Marathon 2024 for PSPA.

NEW TRUSTEES JOINING THE PSPA BOARD

This year we are excited to welcome three new members to the Board of Trustees. Here each new Trustee shares an insight into their background and what they are looking forward to helping PSPA achieve during their four-year term.



ANDREW

ANDREW HARRINGTON

Andrew is delighted to become a Trustee of PSPA.

He is a retired registered nurse with over 35 years of experience of healthcare clinical and operational management. His clinical field of nursing was cancer and palliative care.

Andrew has worked across many fields of health and social care, both in England and abroad.

Andrew is now the managing partner of a large GP practice in Hertfordshire. He has previously held the positions of Director of Commissioning, Chief Nurse and CEO in healthcare.

As part of his Trustee role, Andrew aims to work with colleagues, members, and the wider community to enhance knowledge and understanding of PSP & CBD, and provide as much support as he can.

MARIA TENNANT

Dr Maria Tennant is a senior communications professional and chartered PR practitioner with several years' experience working in PR and communications across many sectors, including charities, universities, local government and healthcare.



MARIA

As a research engagement and communications specialist, Maria is passionate about bringing research to life and telling the stories of the science and the people behind it.

A research scientist by training, Maria has also worked as a post doc in academia following her PhD in Neuroscience. Maria's mum has advanced CBD.

GREG RICHARDSON

Greg is the Head of Orthoptics at The Royal Berkshire Hospital in Reading and Prince Charles Eye Unit in Windsor. His clinical interest is in eye movement disorders, in particular neurological disorders affecting eye movement.

Greg's interest in PSP stems from seeing patients with eye movement disorders and helping them regain a better quality of life by managing the symptoms associated with abnormal eye movement.

Greg is looking forward to supporting PSPA to raise awareness of PSP & CBD amongst clinicians, in particular ophthalmic and allied health professionals, in order to promote earlier diagnosis for patients, enabling them and their families to access support earlier.



GREG



THANK YOU TO OUR RESEARCH COMMITTEE

The PSPA Research Committee was established in 2020 as a Sub-Committee reporting to the Board of Trustees, making recommendations to the Board in relation to the research programme.

Following three successful years, which has seen the introduction of initiatives such as the Small Research Grant and Research Project Grants, we want to say a huge thank you to all the researchers involved for their commitment and expertise.

Sadly, the three years does mark a time of change as we say goodbye to Professor Siddharthan Chandran, Dr Alistair Church, Professor Diane Hanger and Professor Michele Hu. Thank you for your continued contribution to PSPA.

WE ALSO WELCOME FIVE NEW MEMBERS TO THE COMMITTEE:



PROFESSOR PETER GARRARD

Peter Garrard is a Professor of Neurology and Honorary Consultant Neurologist at St George's University Hospitals NHS Foundation Trust.

Professor Garrard graduated from the University of Oxford in 1985, proceeding to earn an MD ChB in 1990 from the University of Bristol and a PhD in 1999 from the University of Cambridge.

He has worked as a Consultant Neurologist at the National Hospital for Neurology and Neurosurgery in 2001, then to a similar post at the Royal Free Hospital from 2005 to 2007. He then became a consultant neurologist at Southampton General Hospital in 2007 for three years.

Professor Garrard has also been involved in academic roles as a senior lecturer in clinical neuroscience at UCL from 2001 to 2007 then as a Reader in neurology at the University of Southampton from 2007 to 2010. Since 2010 Dr Garrard has been a Reader and then Professor in neurology at St George's, University of London.

Professor Garrard directs the dementia research group in the St George's, University of London Neuroscience Research Centre (Molecular and Clinical Sciences Research Institute). His research focuses on the effects of neurodegenerative disorders on spoken and written language.



DR VICTORIA MARSHALL

Dr Vicky Marshall is a Consultant Neurologist at the Queen Elizabeth University Hospital in Glasgow. She is Lead for the Movement Disorders Service and Lead for the Neurology Atypical Parkinsonism Clinic which was set up in 2021. Mainly being involved in the clinical side, she has had recent involvement in facilitating research studies for those with Atypical Parkinsonism.



PROFESSOR WENDY NOBLE

Wendy is Professor of Molecular Neurobiology at the University of Exeter. Her work is focused on understanding the molecular mechanisms underlying neurodegenerative diseases, with a particular interest in tau.

Wendy graduated with a BSc Honours degree in Anatomy from the University of Edinburgh in 1996. Following a spell as a research assistant at the National Heart and Lung Institute, Wendy undertook a PhD at University College London, 1998 to 2001.

It was during her first postdoctoral position at the Nathan Kline Institute/New York University, starting in 2001, that Wendy first began to work in dementia research. Wendy's work examined some of the tau changes important for disease development, and this was expanded in an Alzheimer's Society fellowship at King's College London that Wendy started upon returning to the UK in 2004. This was followed by an MRC New Investigator Award in 2007 after which Wendy was appointed as Lecturer at King's College London in 2010, becoming a senior Lecturer in 2015, Reader in 2018 and Professor in 2021.



DR MAURA MALPETTI

Dr Maura Malpetti is the Race Against Dementia Alzheimer's Research UK Fellow in the Department of Clinical Neurosciences at the University of Cambridge. She originally trained in Italy for a BSc in Psychology and an MSc in Cognitive Neurosciences, where she worked with brain scanning techniques, such as positron emission tomography (PET).

After obtaining her PhD in Clinical Neurosciences in Cambridge, she further trained as a visiting researcher at the University of California in San Francisco, and the Ludwig Maximilian University of Munich. Her research focuses on the application of brain scans and blood tests to measure early brain changes, like signs of inflammation, that can forecast clinical outcomes in people with PSP, CBD and frontotemporal dementia. Her work aims to identify clinically relevant biomarkers and targets for early detection, more accurate prognosis and effective treatments in people living with these conditions.



PROFESSOR HUW MORRIS

Huw Morris is Professor of Clinical Neuroscience at UCL Queen Square Institute of Neurology, and honorary consultant neurologist at the Royal Free Hospital and the National Hospital, Queen Square. He was senior lecturer and then Professor in Neurology and Neurogenetics at Cardiff University, the Royal Gwent Hospital and the University Hospital of Wales from 2003 to 2013. His clinical and research

training took place at the National Hospital, the Mayo Clinic and the Western Pacific island of Guam. He began research in PSP and related disorders as a PSPA and MRC Clinical Research Fellow in 1997. His main interests are neurogenetics, movement disorders and dementia.

He is leading a UK-wide research study in PSP & CBD (PROSPECT-M-UK) and a UK-wide research project in genetic Parkinson's disease (Parkinson's Families Project). He leads the cohort group of the Global Parkinson's genetics program (gp2.org). He also studies genetic determinants of progression and variation in Parkinsonian disorders to help define new treatments.

30 YEARS

30 YEARS

30 YEARS OF PSPA



1994



PSPA is registered with the charity commission following Sara Koe's diagnosis in 1993

2002



HRH The Duchess of Gloucester opens the Sara Koe PSP Research Centre, London

2008



PSPA Matters is developed to provide information to people with PSP & CBD

2019



£25,000 is secured from The Scottish Government to fund a role to raise awareness and improve care

2019



PSPA Fellow Dr Ed Jabbari research suggests there are 10,000 people living with PSP & CBD in the UK

2023



A carers Guide to PSP & CBD is launched during Carers' Week

1994

The charity forms the first PSP Medical Advisory Panel chaired by Professor Andrew Lees

2002



One of PSPA's first employees, Debbie Benadie, is hired

2010



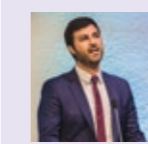
We publish A Guide to PSP & CBD for Occupational Therapists

2018

The charity develops first professional guide to CBD



2020



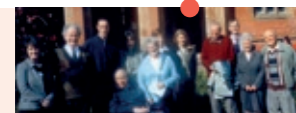
PSPA Fellow Dr Ed Jabbari research establishes genetic variant which determines speed of PSP progression

2023

PSPA Eye Red Flag campaign launched to raise awareness with opticians



1995



The first PSPA-led Local Support Groups are set up in Liverpool, Northern Ireland, Merseyside and Kent

2001



The Magnolia Ball raises £25,000 and is attended by the Royal Patron the Duchess of Gloucester

2012



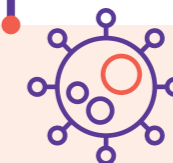
The charity launches the Helpline and online forum Health Unlocked

2018



PSPA and CurePSP organise the world largest research symposium on PSP & CBD

2020



Adapting to COVID-19 lockdown, PSPA develops online Support Groups

2023



The charity publishes A guide to PSP & CBD for physiotherapists

1996



We host the first research workshop

1999



PSPA funds research by Dr Nath which establishes there are more than 5,000 people living with PSP in the UK

2013



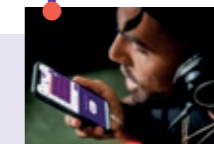
We host our first Family and Friends Day

2016

We launch our GP red flag awareness campaign



2021



PSPA Support Grants launched and a voice banking service is developed in partnership with SpeakUnique

2023

PSPA Link Volunteer Scheme launched following a generous grant from Global Make Some Noise

1997

PSPA supporter Sebastian Coe, whose mother lived with PSP, presents a Radio 4 appeal



1997



Professor Huw Morris becomes the charity's first funded research fellow

2015



PSPA agrees £1.3 million funding for PROSPECT the most ambitious PSP & CBD research study to date

2016



Our survey discovers 50% of people living with PSP & CBD are misdiagnosed

2021



The PSPA Podcast takes to the airwaves thanks to the support of Pavers

2022



Regional Carers Support Group established to support family and friends of people living with PSP & CBD



WHERE IT ALL BEGAN

Motivated by his family's own experience of PSP, Brigadier Michael Koe established PSPA in April 1994, driving forward the ambition to create a better future. Here we look back at key PSPA moments.



Michael's wife, Sara, was diagnosed with PSP in 1993 after developing worrying symptoms including problems with balance, speech, swallowing and looking up and down. Local neurologists were unable to determine what was wrong.

A CHARITY ESTABLISHED FROM PERSONAL EXPERIENCE

Undeterred, the family continued investigations into Sara's symptoms. This led to a week's stay at the National Hospital for Neurology at Queen's Square, London, under the care of Professor Martin Rossor and Professor Andrew Lees. During this stay, Sara received a diagnosis of PSP.

Driven by the bleak prognosis, Michael began to research what help was available.

He visited the American PSP Association, where he heard that one specialist, Dr Irene Litvan, may be close to a cure. Unfortunately, this was incorrect.

The trip planted a seed in Michael's mind. Setting up a charity in the UK to help other people affected by the condition.

When discussing the decision to establish PSPA, Michael said: "Sara and I were upset that no one knew, or seemed to care much about PSP. We were

keen to do something to draw public attention to this particularly nasty brain disease and help others living with PSP. We also were determined to raise awareness and funds for research."

So, in 1994 Michael joined forces with local MP, Michael Morris and friends; Sir Michael Carleton Smith, Baron Nasby - James Stanford and Sir John Greenaway to establish the PSP Association for the UK.

PROGRESSING RESEARCH AND UNDERSTANDING

Sadly, less than a year after the charity was registered, in January 1995, Sara died aged 56 years old.

Like many of our supporters, Michael found solace in PSPA. Michael said: "Following Sara's death was a miserable time. During those dark days, PSPA saved me. Running the charity took a huge amount of my time and effort, and was something positive to focus on."

Professor Andrew Lees and Professor Martin Rossor joined the PSPA team, as Chief Medical Advisers. The latter also aided the development of PSPA's Medical Advisory Panel, with a view of developing research and setting up the Sara Koe Research Centre.

Two of the early research developments included funding PSPA's first research fellow, Professor Huw Morris, as well as Dr Uma Nath's study into prevalence of the condition.

Professor Morris said: "I was interviewed for the PSPA Fellowship by Michael Carleton Smith, and successfully took up the position in 1997. The first time I met Michael Koe, I was taken aback by his tenacity and drive to progress research, and make a difference. It was from the fellowship that my interest in PSP and relationship with PSPA grew, leading to the development of the largest PSP & CBD study PROSPECT."

FUNDRAISING AND RAISING AWARENESS

Fundraising has been key to the growth of PSPA. Not only in terms of raising funds, but also vital awareness too. From Radio 4 Appeals, to Magnolia Balls and Golf Days, all have served as key events through the years funding core aims of research, awareness and support.

Michael's four sons, Simon, Jamie, Richard and Digby had been involved in Sara's care and initial investigations into PSP. Naturally, their support to Michael's growing charity continued through the years.

All four completed more than 40 marathons to raise funds for PSPA. These included running the London and New York Marathons. Richard ran the Marathon des Sables, raising £70,000.

The Koe family, said: "At the time of mum's diagnosis, our parents didn't know where to get support. Very few had heard of PSP. Alongside his friends and the connections he had built through our mum's illness, dad set about establishing PSPA, determined to make a difference so others didn't face a similar fate.

As a family, we take great pride in seeing the charity grow, year on year. It is wonderful to see the core aims dad first set out, are still visible within the charity and new service developments.

Although the brothers have hung up their running shoes in recent years, family support of PSPA continues. Simon served as Chair of PSPA Trustees from 2016 until 2020. And Michael's grandsons have taken over the family fundraising reins. Orlando and Max have run the London Marathon for PSPA, and Hamilton helps dad run the annual PSPA Golf Days which are a lot of fun and raise great awareness."

DEVELOPING ESSENTIAL SUPPORT SERVICES

As the only UK charity supporting people living with PSP & CBD, fundraising helps maintain and develop the support offered. We receive no government funding, which means income is generated from voluntary donations from our supporters.

Funds are used to connect families affected by PSP & CBD, nationally and locally. Support Groups were set up in Liverpool, Northern Ireland and Kent initially. There are now more than 30 Support Groups across the UK meeting regularly in person and online, and annual Family and Friends' days extend the opportunities for people to meet and receive updates.

Ongoing support from Trusts and Foundations, has also aided service development including the launch of the PSPA Helpline and HealthUnlocked in 2012, and more recently the Volunteer Link Service in 2023.

Debbie Benadie, an early PSPA employee, said: "My journey with PSPA began in 2002 when Michael was the driving force behind the organisation. He was the voice on the other end of the phone, diligently building connections and ensuring families received vital support following their diagnosis.

In those initial stages, my role involved assisting Michael with letter typing and administrative tasks.

Over the 22 years at PSPA, I've witnessed numerous transformations and progress. I am proud of the collective efforts to shape PSPA into the remarkable charity it is today."

In 2024, developments in PSPA will continue. Policy and influencing work will gain pace, helping us to make all important changes at central government and healthcare levels. Our Mind; Body; Soul project will begin in the spring, extending support for peoples' mental and physical health.

PSPA Chair of Trustees, Rowena Ironside, said: "As we mark PSPA's 30th Anniversary and look forward to what the next 30 years could bring, we are always mindful of Michael's legacy.

As well as a time for reflection about the charity's past achievements, this milestone year provides opportunity to set out ambitions for the future. We know diagnosis remains problematic, and there are currently no standards of care for people living with PSP & CBD. We want this to change. We want a better future for anyone diagnosed in 30 years' time, for treatments to become available and a clear pathway of care established. As a charity, it is our mission to step forward and make these changes happen."

HOW FUNDRAISING CAN HELP SHAPE THE FUTURE OF PSPA

We understand fundraising for PSPA is a very personal and emotive venture. Our supporters are driven by their own devastating experiences and thus determined to raise awareness and facilitate a greater understanding around PSP & CBD.

This makes our fundraising family very precious; we hope you feel valued; as a group you hold an unspeakable awareness of the difficulties families living with PSP & CBD face, and yet you have still been so amazing. Thank you for your committed and loyal support which has helped us deliver services for 30 years.

As a charity PSPA is totally voluntarily funded; this means we do not receive any government grants and are not part of the NHS. So, what we have then is a careful balancing act; to raise income, to provide enough services, to ensure we make a difference, to ensure we care for you, our fundraisers, and the families we are supporting, to make a change that has greatest impact.

What holds this careful balance together is our vision.

Rebecca Packwood, our CEO, explains how she sees this unfolding; "Our work at PSPA is important because people with PSP & CBD do not receive a timely diagnosis, there are no national standards of care and no treatments or a cure. We want to create a future that has better outcomes; better standards of care that people are able to access when they need to and treatments to slow the progression of the disease or alleviate symptoms. To do this we need to be ambitious, we need to invest more in research, raise awareness of the conditions, alongside developing new services to support people living with a diagnosis now. That ambition has to be matched by raising more funds and creating a stable future for the charity.

2024 offers a fantastic opportunity to push our ambition for improved diagnosis and better care forward as PSPA celebrates its 30th Anniversary. In recognition we have set a bold vision to continue to grow the impact of PSPA, creating a better future for everyone affected by PSP & CBD, and honouring the vision that Michael Koe set out in memory of his late wife Sara."

FINANCIALLY THE EXPECTATION IS THAT WE RAISE £1.5M IN 2024, OUR ANNIVERSARY YEAR. THIS WILL BE AN INCREASE IN INCOME OF 12%.

This is matched by an increased investment in research of 40%, and investment in our policy and awareness raising work by recruiting a Director of Policy and Influencing to take a more strategic approach to how we get improved standards of care and increased knowledge of the two conditions.

We plan to drive this growth through awareness raising and fundraising.

Our growth as an organisation is linked to two factors. First, we need to increase our support and reach out to a wider network of people. This is linked to our renewed focus on awareness raising to a wider group of people who we hope will become supporters. PSP & CBD do not currently have the profile of some other neurological conditions which can garner support from the public. Secondly, we need to improve our performance in fundraising with corporates, trusts, and community fundraising so we are less dependent on a small number of income streams such as legacies and in-memory donations.

Building on our current core income streams and making sure we are developing new initiatives for new audiences is our long-term aim to make income at PSPA more sustainable.



THE CHALLENGES

We know this won't be easy and already the current cost of living crisis is having an impact on charities. At PSPA we have seen this impact for example with our raffles. Costs of printing and postage have risen, making it harder to make a good return on investment, despite supporters working harder than ever to sell tickets.

Also we recognise that you, our key supporters, feel under increased pressure every year.

Our financial target for 2024 will be an organisational challenge, but we know by working together, and working outwards into and across our community we can get others involved.

PSPA has worked hard to provide lots of opportunities to get involved in 2024, and if you feel you are not able to get involved; do "Pass it on", and take up the challenge, to tell those around you what PSP & CBD have meant to you and your family.

We have some great events in the plan for 2024, which you can read about in more detail across these pages.

- We want our Walk of Hope to be bigger and better than ever in 2024
- Share and like our social media posts – encouraging others to get involved!
- Sign up to give through a regular gift – an easy way to support a favourite charity!
- Take advantage of our free Will scheme – we have 10 Free Wills to give away
- Put a company forward to get involved with us – if PSPA is to grow we need more corporate support.

DO JOIN US AND SHARE YOUR IDEAS

This year, we'd like to set up an online Fundraising Forum. This would be a place where we develop ideas and talk about opportunities. Would you like to join us and be part of this? All are welcome, with your enthusiasm, skills, and knowledge.

If you would like to join the forum, please email Julie Line at fundraising@pspassociation.org.uk



30 YEARS OF SUPPORT FROM TRUSTS

We have a long history of partnering with charitable trusts of all different sizes and we are extremely grateful to all the trusts that have supported us over the last 30 years. From small beginnings in 1995 with our first two grants totalling £1,500, we have since been granted a total of £3.4 million from charitable trusts.



Whilst some trusts are happy to give unrestricted grants which enable us to direct the funds to where they are most needed, others prefer to fund a specific area of work or project that relates to their objectives. The Sir Samuel Scott of Yews Trust has a particular interest in supporting medical research. In April 1997 the trust awarded us our first five figure grant of £10,000 restricted towards our research programme. Subsequent grants from the trust have supported specific research projects including a genetic study into PSP (1998), a study into use of MRI scanning as a diagnostic tool (2002), and an investigation into the link between tau protein and PSP (2004). More recent grants have seen the trust continue to support research.

Multi-year grant pledges help with our sustainability and planning. We have been fortunate to receive such funding on three separate occasions from The Band Trust, with each pledge covering a three-year period, with a grant of £15,000 per year. The trust supported the development of our Support Groups between 2002 and 2004, Regional Development Officers between 2006 and 2008, and between 2013 and 2015, the trust supported our Helpline and Information service.

After our first 10 years operating on a shoestring, the Trustees of the Garfield Weston Foundation generously supported our 2005 to 2007 growth plan with a grant of £50,000 awarded in 2005. This significant funding boost helped us as we worked towards becoming a larger, more mature organisation with a stronger voice nationally and internationally. We have since received a further three grants totalling £60,000 from the Garfield Weston Foundation - £30,000 of which was used to help set up our Helpline, Advisory and Volunteer Services project in 2012, and volunteer development was supported in 2015 and 2017 with grants of £20,000 and £10,000 respectively.

Not only do charitable trusts support us to continue to do the work we do, they also enable us to springboard or pilot new areas of work. Global's Make Some Noise generously provided £45,000 of funding to launch our new Link Volunteer service in 2022.

Whilst larger grants play a substantial part in our ability to fund our work, we can't ignore the importance of the smaller grants which, when added up, make a significant contribution to our income. 797 grants received over the last 30 years (61% of all grants), have been for £1,000 or less and we are very grateful for the trusts that support us in this way.

As we celebrate our 30th year and focus on the future, we will continue to build and consolidate our relationships with charitable trusts, identify new opportunities, and raise the next £3.4 million!

WHAT IS A CHARITABLE TRUST?

A Charitable Trust is a trust where the Trustees can use the income or capital to benefit charities or charitable purposes. There are approximately 8,000 active grant-making charitable trusts in the UK, giving away around £8 billion each year. Many trusts support general charitable purposes, however others will have a particular area of focus – this could be geographical, or subject. Trustees meet to discuss applications submitted by charities and make decisions on grant awards.

HOW CAN YOU HELP?

Do you know a Trustee of a Charitable Trust? Do you, your friends or family members, work for a company that has a Charitable Foundation? Personal introductions can really make a difference, so please do get in touch if you are able to introduce us to any Trustees.

Contact Claire Ayling, Senior Fundraising Manager – Trusts, on **01327 640921** or email claire.ayling@pspassociation.org.uk

“HAVING SEEN AT FIRST HAND THE DIFFICULTIES THAT PEOPLE WITH PSP & CBD FACE IN EVERYDAY LIFE, WE ARE DELIGHTED TO SUPPORT PSPA AND HELP MAKE A DIFFERENCE FOR OTHER FAMILIES AFFECTED BY PSP & CBD.”

Houghton Dunn Charitable Trust



30 YEARS OF SUPPORT FROM TRUSTS CONTINUED

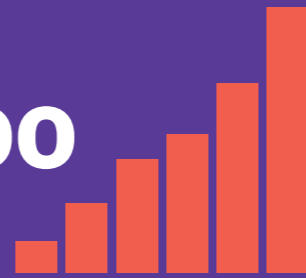
1,305 grants

totalling £3.4 million from 387 Charitable Trusts



Grants range from

£50 to £50,000



243 Charitable Trusts

(63%) have given two or more grants



101 Charitable Trusts

(26%) have given five or more grants



838 grants

(64%) were unrestricted – enabling us to direct the funds to where they are most needed



467 grants

(36%) restricted towards a particular area of our work



30 FOR 30

A 30 themed challenge for 2024 to help create a better future for everyone affected by PSP & CBD.



"TURNING 30 IS A MONUMENTAL MILESTONE FOR THE CHARITY AND IT FEELS LIKE A GREAT TIME TO SHOW PSPA JUST HOW MUCH THEIR SUPPORT PERSONALLY MEANT TO ME AND MY FAMILY."

THIS YEAR, PSPA TURNS 30!

This milestone year is an opportunity to mark PSPA's achievements over the years but also sets out our ambitions.

Rebecca Packwood, CEO of PSPA said, "The build up to the anniversary has been a time of acknowledging how far we have come, and the amazing job Michael Koe did in setting up the charity in memory of his wife Sara 30 years ago".

However, thinking about others turning 30 this year, it has also made us think about what we want to be ambitious for.

Take a 30-year-old now, if you were given a diagnosis in another 30 years how could we make sure things are better? This got us thinking and reflecting on what we need to achieve next, and as part of this we are launching a new anniversary fundraising campaign.

WHAT IS 30 FOR 30?

30 for 30 is a fun, themed challenge, cultivated by PSPA supporter Kelly Hooper.

Kelly's mum died from PSP in 2015 and since her mum's diagnosis she has been doing everything she can to raise awareness and much needed funds for PSPA. Previously, Kelly has run the London Marathon, held a tea party and successfully nominated PSPA to be her employer's charity of the year in 2021 and 2022. And now Kelly has her eye on her next pursuit!

Keen to help PSPA mark its 30th Anniversary, Kelly is challenging herself to take on 30 different activities throughout the year. All to raise awareness and funds!

PSPA is encouraging all members of the PSP & CBD community to get behind Kelly and join her by taking on a 30 themed challenge of your own.

The opportunities are endless in terms of the challenges you can take. From walking 30 steps once a month on the 30th day, to hosting a bake-off competition with 30 friends and colleagues, to cycling 30km locally or at your favourite spot or hosting a 30-hour dance-a-thon.

If you are a person who prefers to coordinate your world from your armchair, you can still make a real difference. This could be done through setting up a regular gift for 30 months, leaving a gift in your Will, or simply donating £30 on our website Celebration Wall.

HOW TO GET INVOLVED IN 30 FOR 30



If Kelly's 30 for 30 challenge has inspired you to organise a 30 themed activity of your own, we can help!

The poster at the back of this magazine, lists a few ideas for how you can get involved as well as our inspiration list to the right. As you can see there is something for everyone so have a think about what you might like to do and watch out for our final list of fresh and inspiring challenge ideas which will be posted on the website by the end of January 2024.

We've also developed a fundraising kit to help kick start your 30 for 30 challenge.

Visit our website to download the tools:
www.pspassociation.org.uk/30-for-30/



30 FOR 30 INSPIRATION

A 30-day challenge



A 30 themed event
(such as walking 30 miles or cycling 30km)

Inviting 30 friends and family to attend an event or take part in a challenge
(such as a Walk of Hope or baking competition)



Host a 30-hour non-stop event



Visit 30 places or destinations in 2024

Swim 30 lengths every day for a month



Play golf at 30 different courses



Wear a PSPA t-shirt for 30 days in a row



Read 30 books in a year



Give up your favourite thing for 30 days



Host a quiz with 30 friends



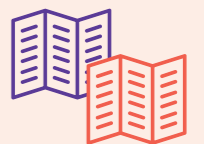
Share 30 PSPA social media posts



Tell 30 new people about PSPA



Distribute 30 PSPA leaflets in your area



Introduce PSPA to 30 companies



Donate £30 to PSPA on our Celebration Wall



Ask 30 people to sign up to give regularly to PSPA



CONTACT US

If you need any support cultivating your own 30 for 30 challenge during 2024, get in touch! Our team will be on hand to help you shape your ideas into real-time events and challenges. Email us at fundraising@pspassociation.org.uk



NOMINATE SOMEONE YOU KNOW FOR A PSPA 30TH ANNIVERSARY AWARD

As part of our 30th Anniversary activities, we want to take the opportunity to celebrate members of the PSP & CBD Community.

PSPA 30 YEARS AWARDS

The awards will recognise all people living within the community, including people diagnosed with the conditions, carers, volunteers, fundraisers and past loved-ones. Help to shine a light on the people who you know from the PSP & CBD community by nominating them for one of our awards.

THE SIX AWARD CATEGORIES ARE:

- 1 ALWAYS AMAZING AWARD FOR SOMEONE LIVING WITH PSP**

The Always Amazing Award will be given to someone who has shown courage and determination whilst living with PSP. As a positive role model, they may have shared their experience to provide inspiration and support as they help to improve the lives of people living with PSP & CBD.
- 2 ALWAYS AMAZING AWARD FOR SOMEONE LIVING WITH CBD**

The Always Amazing Award will be given to someone who has shown courage and determination whilst living with CBD. As a positive role model, they may have shared their experience to provide inspiration and support as they help to improve the lives of people living with PSP & CBD.
- 3 CARING AWARD**

This award will be given to an unpaid carer, a family member or friend, who has been looking after someone they know who is living with PSP & CBD, helping them to live the best life they can.
- 4 VOLUNTEERING AWARD**

The Volunteering Award will be given to an individual who has volunteered time to support other members of the PSP & CBD community. This could be by organising Support Group Meetings, helping out at PSPA events, educating health professionals or by providing Link Support.
- 5 FUNDRAISING AWARD**

This award is for a fundraiser who has shown creativity and determination in raising awareness and funds, big or small, for PSPA.
- IN-MEMORY AWARD**

6 This award will be given in memory of the courage and achievements of a family's loved one. The person being honoured will have lived with PSP or CBD themselves, and through their determination to live life to the fullest, have created legacy within the PSP & CBD community.



NOMINATION FORM

NOMINEE DETAILS

Name:

Address:

Tel number: Email:

What Award are you nominating your nominee for?

What is their connection to the PSP & CBD community?

In no more than 500 words, please tell us why you think your nominee deserves the award (please use a separate piece of paper if required). Please pay close attention to the award criteria and refer to this in your description. Please provide any photos, articles or evidence that may support your nomination.

NOMINATORS DETAILS

Name:

Address:

Tel number: Email:

Is the nominee aware that you have made this nomination? Yes No

PLEASE SEND THIS COMPLETED FORM BACK TO US BY SUNDAY 23 JUNE 2024
 Email it to: communications@pspassociation.org.uk Post it to: **FREEPOST PSPA** or fill in the online form www.pspassociation.org.uk/information-and-support/pspas-30th-anniversary/30th-anniversary-awards

WALKING TO PROVIDE HOPE TO THE PSP & CBD COMMUNITY

Although only a few years old, the annual PSPA Walk of Hope is already a regular fixture in the PSPA calendar. We created this activity as both a fundraising and awareness opportunity. It's all about getting outside, talking to others about PSP & CBD, raising funds and giving hope to the PSP & CBD community.



DAVID CARTER



VAL AND ALAN

At its core, the Walk of Hope is a 5km walk. However, how people complete theirs is completely up to the individual – supporters can do what they want with this idea. And the real driver of this activity is to get outside, have fun, raise awareness and be a part of the PSPA community.

It is an opportunity to take this activity to do what you want from it, with support from the charity.

If 2022 laid the path for this activity, summer 2023 was the biggest and most successful Walk of Hope yet. Even PSPA staff completed one!

One of the most wonderful things that happened with this year's Walk of Hope was that supporters took the activity and did it in a way that worked for them.

One example of getting the community involved in a walk was undertaken by Val.

"We saw PSPA was organising events to raise funds for research, care and support for people with the conditions of PSP & CBD. Alan had been diagnosed with PSP in June 2022.

"PSPA'S WALK FOR HOPE EVENTS SOUNDED LIKE AN IDEAL WAY FOR US 'TO DO OUR BIT' TO RAISE FUNDS AND AWARENESS AND SOMETHING WE COULD GET THE FAMILY INVOLVED WITH."

Please turn over ►



We arranged to do our Walk of Hope in August; we chose a beautiful 5km route along the Tees Barrage, close to where we live. We thought close family members would take part and decided a £1,000 target would be do-able for us to reach.

Our JustGiving page invited us to have team members and we were overwhelmed with family members and friends who wanted to join Alan's team and gain sponsorship from their own kind friends and colleagues. We had 13 team members who each gained generous sponsorship and we soon realised our £1,000 target was going to be smashed.

It was the best day; Alan's big smile and being surrounded by so much love from family and friends made it a great experience, whilst raising essential funds for PSPA."

"LOTS OF FRIENDS WANTED TO COME ALONG AND WALK THE 5KM WITH US. WE HAD 74 PEOPLE AND 12 DOGS ON THE DAY. WE EVEN MET TWO PEOPLE LIVING WITH PSP WHILE ON OUR WALK. IN TOTAL WE RAISED £4,412.37. WHICH WAS BEYOND OUR WILDEST EXPECTATIONS. "



NRL GROUP LTD'S WALK OF HOPE



VAL AND ALAN WITH THEIR FRIENDS AND FAMILY WHO TOOK PART IN THE WALK

A BIGGER AND BETTER EVENT FOR 2024

Alongside the wonderful story of Alan and Val's Walk of Hope, many other supporters joined in, with different variants, from families, to daily dog walks, to organisations. One organisation even completing a walk in fancy dress! There was also supporter David, who was inspired by our promotion to complete a walk between 17 June and 31 August and decided to do a 5km walk on each of those days – a total of 75 walks! That just happened to be the equivalent distance of walking from his home in Oxfordshire to Land's End. He even completed an extra walk, his 76th consecutive, backwards as the grand finale!

As incredible as our supporters who completed the Walk of Hope in 2023, there is still so much room for this activity to be built on and grow. We would love to see supporters all over the UK getting involved, creating or joining a walk, and this year, our 30th Anniversary year, is the perfect opportunity to do just that.

HELP RAISE £60,000 WITH A WALK OF HOPE

Another reason to take part in our 2024 Walk of Hope is to help us raise £60,000 with the event.

A generous donor has offered to match fund our Walk of Hope total. So, if we can raise £30,000 as a community, the donor will donate another £30,000! Which would be amazing.

REGISTER YOUR WALK OF HOPE

The Walk of Hope promises to continue to help PSPA raise funds and awareness throughout 2024, and beyond. Would you like to take part? If so, please contact fundraising@pspassociation.org.uk

WE WOULD LOVE TO SEE SUPPORTERS ALL OVER THE UK GETTING INVOLVED, CREATING OR JOINING A WALK



PEDALLING FOR PSPA: STORIES OF DETERMINATION AND COMPASSION

Cycling is often seen as a personal challenge, a way to push one's physical limits and embrace the thrill of the open road. However, for some individuals, it becomes a powerful tool to make a difference in the lives of families affected by PSP & CBD.



TOTAL RAISED DURING THE CHALLENGE: £3,811

STEFAN'S JOURNEY OF REFLECTION AND RESILIENCE

Stefan, a novice cyclist, took on the monumental 100-mile Ride London in May 2023. Having never cycled a distance like that before, and being assigned a later start time near the back of the pack, the apprehension and anxiety set in.

Stefan chose to support PSPA because of his dear friend, Earl, who has PSP. Watching Earl's movement and mobility be affected, as well as his vision, and the impact this has had on Earl's family, drove Stefan to use his Ride London ballot place as a means for awareness and fundraising. With the support and adrenaline on race day, Stefan finished the ride in under seven hours, exceeding his expectations. With his original fundraising goal surpassed more than three times over, Stefan's dedication highlights the power of cycling as a force for good.

"WEARING A PSPA JERSEY WAS VERY INSPIRING, AND ON THE RIDE, I REFLECTED ON WHY I WAS HERE, DOING WHAT I WAS. THERE WAS NO WAY I WASN'T GOING TO FINISH!"



TOTAL RAISED DURING THE CHALLENGE: £2,320

ANN'S TRIBUTE RIDE FOR HER DAD

For Ann, cycling became a healing journey after losing her father in 2022. Ann's father, initially diagnosed with Parkinson's in 2015, and then PSP, had always prided himself on keeping fit and healthy, and on the many walks he and Ann went on over the years, he spoke about his desire to go to Vietnam. Her father's dream of visiting Vietnam remained unfulfilled due to his health issues; however, Ann was able to carry his spirit forward in 2023.

"Just after Dad died, I struggled to find a purpose to carry on. The total devastation was drowning me, and then an advert popped up on my Facebook about 10-day cycle from Vietnam to Cambodia. I felt like Dad's guiding hand was helping me find something positive to focus on."

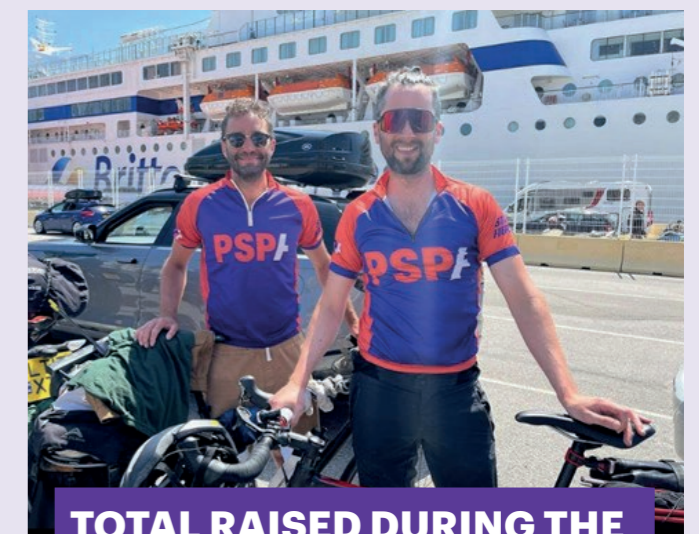
"I decided I would do it to raise money and awareness for PSP. The horrible disease that took him from us. The training was difficult and those who followed my journey would know I fell off the bike a few times and ate numerous flies (unintentionally). I have never travelled anywhere on my own in my life so that alone was going to be a challenge!"

Ann found purpose and a positive focus through cycling, creating a lasting tribute to her hero, Reuben Davison. At time of writing, Ann has just returned from her 264 mile, six-day adventure, and more than doubled her original fundraising target.

Ann says "Crossing the finish line was such a proud but emotional moment for me. I know dad would have been with me celebrating the end."

DEWI'S 600-MILE CHALLENGE - ROSCOFF TO SANTANDER

With motivation coming from his own mother's battle with PSP, Dewi and friend Tim, embarked on a very unique cycling challenge in June 2023. A challenge that would cover around 600 miles, from the top of France to the top of Spain. The journey, spanning two weeks, was not a traditional event, but more a personal challenge with a heartfelt purpose. The pair camped on-route and carried everything they would need on their bikes with no additional support. Dewi and Tim did not just cycle for the physical feat, but to raise awareness and funds for PSPA.



TOTAL RAISED DURING THE CHALLENGE: £1,450



TOTAL RAISED DURING THE CHALLENGE: £2,155

FREDDIE'S 100 MILE - CHALLENGE FOR NANNY

Freddie, age 14, rode 100-miles from Basingstoke to, and around, the Isle of Wight over the course of two days in August.

Freddie says "My Nanny had been poorly for quite a while, she used to have fuzzy blurred vision which no one could help her with. She went from doctor to doctor, hospital to hospital even the optician but no one could help her, COVID then happened, and she appeared to fall off everyone's radar and she's not one to make a fuss, so she didn't."

At the beginning of 2023, Freddie's Nanny had a couple of falls and found herself in hospital. Fortunately or not, while she was in hospital, there was a doctor doing his routine checks and he recognised the tell-tale signs and symptoms and immediately went and organised some scans. After a lengthy stay, many tears and just as many worries from the family, Nanny came home, and not long after they had the diagnosis of PSP.

Freddie said "I felt so sad and angry, my Dad said we had to be strong for Nanny and we were going to make some amazing memories, Nanny wouldn't want us to be sad."

The family were soon blown away with people's kind donations and messages of support on their fundraising page. The original target of £1,000 was reached on the day Freddie departed Basingstoke and headed for the ferry terminal. The route took him through the lush Hampshire countryside and the

weather was perfect. Arriving on the Isle of Wight around 4pm and determined to cover as much distance as possible.

"I was soon met with "hellish hills" that got me questioning what I was doing! I kept going thinking of all the sponsorship and support I couldn't let anyone down- not finishing was not an option."

The family rallied together for a finish to remember with all the emotion and elation you can imagine. In the end the original fundraising target was more than doubled and Freddie now has set himself a goal of cycling from London to Amsterdam!

COULD YOU PEDAL FOR PSPA IN 2024?

These stories showcase the diverse ways individuals are using cycling as a platform to support PSPA.

Whether it's reflecting on a friend's battle, honouring a loved one's unfulfilled dream, or facing a personal challenge for a cause, each pedal is a symbol of hope. As these cyclists' journey through miles and memories, they carry the mission to create a better future for everyone affected by PSP & CBD.

Interested in taking on your own cycling challenge? Let us know by writing to fundraising@pspassociation.org.uk



FAMILY FUNDRAISING IN MEMORY OF MUM

Music, families and fundraising were the key notes of Charlotte and Molly Chapman-Boyle's recent fundraising for PSPA, after their much-loved mum and grandma died of PSP in April 2023.



"SINCE MUM'S DEATH, WE HAVE BEEN KEEN TO RAISE AWARENESS OF THIS AWFUL DISEASE. NOT JUST TO HELP IMPROVE THE LIVES OF EVERYONE AFFECTED BY PSP BUT ALSO TO FUND RESEARCH TO FIND A CURE."

"Mum's PSP diagnosis literally stopped her in her tracks. Her mobility was the first indication something was wrong, and the most affected throughout. She had been falling frequently. Some really bad falls too, one caused her to break her back. We attributed many of her other mobility issues to this particularly bad fall, which resulted in her needing support from a rollator to get about.

Around three years ago, mum's health was getting worse. She was referred to a neurologist to investigate mini strokes. But it was during these investigations, mum was diagnosed with PSP.

Before mum's diagnosis, we had never heard of the condition. Following the appointment, mum and dad were sent home with just one post-it note that had 'Parkinsonism - PSP' written on it. It was my Google search which unravelled what this mystery illness was. It was also where I learned about PSPA. They were so helpful after we reached out, sending us lots of information to help us better understand the condition and how it would affect mum.



Over the last three years, I watched my mum deteriorate before my eyes. Mentally my mum was fine which somehow made it worse as she was aware of how she had become.

My wonderful mum lost her battle with PSP on Wednesday 19 April 2023. We are devastated and our world will never be the same.

Since mum's death, we have been keen to raise awareness of this awful disease. Not just to help improve the lives of everyone affected by PSP but also to fund research to find a cure.

My mum's funeral took place on 11 May, and many people asked beforehand whether they should buy flowers or donate to a charity. This seemed like a good time to start fundraising for PSPA. I sent up a Tribute Fund for mum via PSPA's website and then posted about it on Facebook.

It was thanks to that Facebook post, that the fundraising music concert came about.



"WE RAISED AN AMAZING £867 AT THE CONCERT, AND AN ADDITIONAL £421 IN DONATIONS ON MY MUM'S TRIBUTE FUND PAGE."

Molly has been playing the accordion since she was five. She started at primary school and then joined the Junior Accordion Orchestra last summer.

The orchestra was a large group, so they got together as much as they could but they needed a focus. They decided to hold a concert at St Peter's church hall, where the weekly practice sessions also took place.

The music teacher, Harry, spotted my Facebook post and married the concert and my fundraising idea together - deciding to hold the concert in memory of my mum and also to raise funds for PSPA.

This was perfect, as mum was a big music fan. She loved the Rolling Stones and every Christmas she would encourage Molly to get the accordion out and play carols.

The week before the concert, Molly and myself spoke on our local radio station to promote the event and talk about why we were fundraising for PSPA.

The concert took place on Saturday 11 November at 7pm. It was a real community effort. The hall was packed full of families and local residents. Many had contributed to the event in some way, whether it was

helping to set the hall up, baking cakes to be sold at the event, or businesses donating prizes to our raffle. The raffle prizes were really wonderful, I couldn't believe how generous some of the businesses were, prizes included sparkling afternoon tea, tickets to local attractions, vouchers for restaurants and bakeries and treats like chocolates and wine.

Entrance to the concert was free, so it was the raffle, cake sale and Molly's idea of hosting a 'Guess the number of sweets' competition, which helped raise funds.

I spoke at the event, to promote the raffle, cake sale and sweet competition, and it gave me a good opportunity to talk about PSPA and how PSP has impacted our family. It was good to know I was helping to raise awareness of PSP as well as much needed funds.

In total, we raised an amazing £867 at the concert, and an additional £421 in donations on my mum's Tribute Fund page.

Both Molly and I were really pleased with the fundraising total. It just goes to show what can be done by organising just one event!"



CELEBRATING 30 YEARS OF AMAZING SUPPORT

From way back, when PSPA started at Michael’s kitchen table, and right up to the present day, we have been fortunate to attract the most committed and loyal supporters in the charity sector.

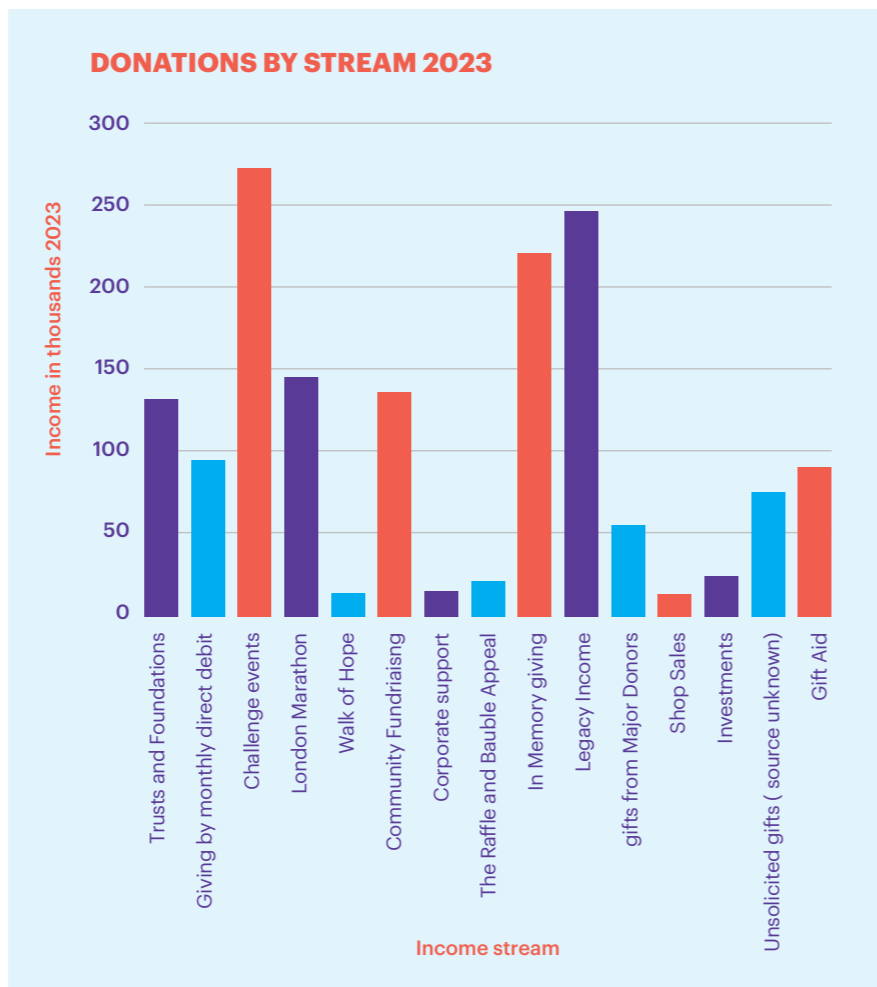


The main reason for this is PSPA is the only charity in the UK creating a better future for everyone affected by PSP & CBD. As such we draw on a small, and passionate group of fundraisers driven by their own personal experiences, to make a difference for others, even whilst they also carry the huge challenges the conditions can bring.

Take our London Marathon runners. Per runner we know you are raising more, and some of our precious supporters just can’t seem to stop running. Steven Watson is an amazing example, in 2024 he will complete his 6th marathon for PSPA. A challenge he set himself to raise funds and mark the six years his mum lived with PSP.

The annual PSPA raffle is another example. Our supporters who do get involved have increased their activity by 25%, which during the cost-of-living crisis is phenomenal.

PSPA's work is reliant on voluntary donations and is totally voluntary funded, and in 2023, you our supporters ensured we were able to raise over £1.3 million. The bar chart shows you how you did it.



Over the past 30 years, you have been raising money to support the PSP & CBD community and to do this you have been doing some amazing, ridiculous, simple, generous, challenging feats to ensure our services continue to support those who need us and allow us to grow.

THANK YOU TO ALL OF YOU!

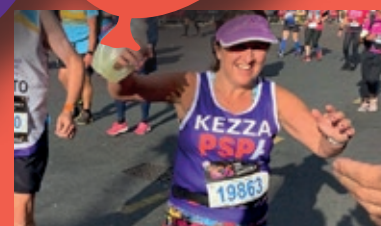


WE WANT TO TAKE THIS OPPORTUNITY TO CELEBRATE YOU ALL AND EVERYTHING YOU DO – SO FAR IT HAS BEEN AN AMAZING RIDE, AND WE KNOW THERE IS STILL SO MUCH MORE TO COME.

JOIN IN OUR 30TH ANNIVERSARY ACTIVITIES

PSPA 30 YEARS
CREATING A BETTER FUTURE FOR PEOPLE LIVING WITH PSP & CBD

Help mark PSPA's 30th Anniversary in 2024 and raise funds to help improve diagnosis and access to appropriate care. Join us and get involved in one of more of our anniversary activities.



- | | |
|------------------------------|---|
| 2 January | Listen to our 30th Anniversary podcast |
| 8 January | Write out your wishes using the PSPA free Will scheme |
| 15 January | Visit our interactive timeline to learn about PSPA's history |
| 22 January | Pledge to take on a 30 for 30 challenge |
| 27 & 28 January | Take a Winter Walk in London for PSPA |
| 5 February | Nominate a loved one for a 30th Anniversary Award |
| 12 February | Enter of 30th Anniversary Cake Competition |
| 29 February | Get involved in Rare Disease Day |
| 4 March | Share a special date on our Celebration Wall |
| 11 to 17 March | Post PSP & CBD facts on social media this Brain Awareness Week |
| 18 March | Host a 30th Anniversary tea party with your friends |
| 27 March | PSPA hosts a 30th Anniversary Party |
| 7 April | Join our cheer squad at the London Landmarks Half Marathon |
| 20 April | Meet families at our Awareness Event in Scotland |
| 21 April | Help cheer our team of nearly 100 runners at the London Marathon |
| May | Connect with others at our Family and Friends Day North |
| 26 May | Pedal 100 miles for PSPA at RideLondon |
| June | Spread awareness by hosting a Walk of Hope |
| 15 June | Meet families at our Awareness Event in Wales |
| 17 June | Get involved this PSP & CBD Awareness Week |
| 7 July | Take part in Parallel London for PSPA |
| 27 August | Tee off at the annual PSPA Golf Day |
| September | Connect with others at our Family and Friends Day South |
| 8 September | Run or cheer our team at the Great North Run |
| 14 & 15 September | Hike the Thames Path Ultra Challenge with PSPA CEO Rebecca Packwood |
| October | Get PSPA updates at our Volunteer Development Day |
| October | Get the family together for a Power of the Brain Quiz |
| October | Expand your knowledge at our Study Day for Healthcare Professionals |
| 29 November | Remember a loved one with the PSPA Bauble Appeal |
| 2 December | Learn something new with our interactive advent calendar |

For more information on our 30 for 30 challenge just visit www.pspassociation.org.uk/30-for-30